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MIE2014 Preface

On behalf of the European Federation for Medical Informatics and the Turkish Medical Informatics Association, we are proud and happy to invite you to the 25th European Medical Informatics Conference in Istanbul.

The 25th edition of our conference – this is an important anniversary!

Twenty-five is the age of youth, but also the beginning of maturity; it is a time of transition. What better place to celebrate this anniversary than in Istanbul, with its unique history and its fascinating mixture of past and present, of old and new, of religions and cultures.

Information technology and the information sciences have also reached the age of maturity. They are revolutionizing the healthcare system and deeply changing the whole health landscape, as well as health culture. Boundaries are becoming less clear. There is no less well-defined state than the 'patient' state. We are sometimes healthy and sometimes sick, but most of the time we are somewhere in between – not so healthy. We should all care about staying healthy. The boundary between health and ill-health is becoming harder to draw. A similar situation exists between prevention and care. While the healthcare system has always predominantly been involved in the management of disease and care, a new trend has appeared, with citizens increasingly involved in wellness and the prevention of ill-health. The quantified self provides the necessary tools to accompany this societal transformation.

The most recent impacts of the emerging field of biomedical informatics will be presented during the MIE 2014 conference. New phenotypical data sources, especially those arising from the 'healthy world', which is not usual for the medical sciences, are becoming an important pillar of health determinants, together with genetics, environment and lifestyle. New devices, new sources of data, new roles for all the actors involved are being invented. This point is well illustrated by several reports on Google Glass. The difference between Second Sight glasses, which were available as early as 2002, and Google Glass in 2014 is aesthetic, connectivity and information. The technology was already there, but only the added value derived from connectivity and information have made the glasses an attractive device. Environmental data, lifestyle, bio-captors, phenotypes extracted from EHRs, not to mention all the -omics, constitute the 'holy grail' of life science research: a data coverage of the major health determinants. Will we be able to transform the incredibly large amounts of data currently being made available into a clever and smart "Big data". There are numerous challenges to be dealt with: technological challenges concerning the vast distributed volumes; semantic challenges concerning sources which are heterogeneous over time, of varying quality and reliability, and different contexts; ethical challenges when it comes to balancing public and individual benefits; and legal and societal challenges. All in all, the challenge of Big data questions the whole of society; its values, and its goals – not to mention the results. While this immature technology is promised a bright future, there are already enough reports stating that we need a more reliable methodology, especially when looking at preliminary work such as Google Flu Trends, which were demonstrated to be fast, inexpensive and *wrong* (Lazer et al., Science. 2014 Mar 14;343(6176):1203–5. doi: 10.1126/science.1248506).

Care process reengineering, the involvement of citizens and patients, continuity of care and health: these are only some of the numerous revolutions taking place. This dynamic is characterized by combined advances in technology and sciences, deep socio-cultural changes, and wide global adoption. And this is precisely the heart of the challenge.

We do not have the option to be spectators; we are actors. Thus, it is necessary to move forward while building an evidence base; making sure that knowledge can be shared and that experiences are reproducible. Amassing evidence and using standards are thus important aspects of our work. It is necessary to keep the ultimate goal of improved healthcare in mind, all the time directing projects and activities towards this goal. The building up of evidence has to be done while retaining some room for disruptive ideas, non-acceptable hypotheses and non-demonstrable theories. It is also our challenge to allow room to all those who think differently, for those who don't respect the evidence, for those transgressing truth; because truth is a contextual reality, only valid in a certain time and context.

Finally, because health determinants are local, because most health threats are local, and because the process of globalisation tends to lose sight of the personal, we must also be sure to balance truly global science with local experience. To quote Ilias Iakovidis: "Medicine is a global science, and a local art".

We would also like to acknowledge all our colleagues who devoted their time to the careful review of submissions. They have made it possible for the SPC to select the best papers and posters for inclusion in the proceedings. All submissions are Medline indexed and made available as open access through IOS Press homepage.

Istanbul, July 2014

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1. Decision Support Systems and Clinical Practice Guidelines

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Embracing case management for computerization of care pathways

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Abstract. The computerization of care pathways (CPs) has drawn considerable attention, for improving quality of health care and reducing costs. A well-known big challenge of implementing CPs is their flexibility and ad hoc variations in execution of clinical tasks. We observe that case management suits well to address this problem, and this paper proposes a CMMN-based CP model, where CMMN (Case Management Model and Notation) is becoming an industry standard. Via an experimental experience on modelling CHF (congestive heart failure) ambulatory CP, we illustrate that the usage of case management paves the way to popularize CPs, particularly for its quick deployment and execution in industrial products.

Keywords. Care pathway, CMMN, vMR, GELLO, clinical decision support

Introduction

A care pathway (CP) is a complex intervention for the mutual decision-making and organisation of care processes for a well-defined group of patients during a well-defined period [1]. In literature, there are a variety of methods for computerization of CPs, such as [2] used process/workflow technologies, and [3] adopted guideline-modelling languages. However, there is still a big barrier for implementing CPs due to their flexibility and ad hoc variations in execution of clinical tasks. In order to address this issue, we advocate adopting the case management-modelling standard, namely Case Management Model and Notation (CMMN) [5], to implement CPs.

Taking congestive heart failure (CHF) ambulatory CP [4] as an example, activities in the initial assessment phase are not predefined sequences – e.g. to complete physical examination can be done before, after, even parallel to consult a clinical nutrition. That is, a process definition for a CP will definitely have many variations in reality. Case is introduced to address the flexibility problem of process modelling, and planning at run-time is a fundamental characteristic of case management, especially for run-time planning for the selection of tasks for a case, run-time ordering of the sequence in which the tasks are executed, and ad-hoc collaboration with others on the tasks [5]. Thus, clinical activities such as "complete physical examination" and "consult a clinical nutrition" will be defined as case tasks at design time, and any run-time ordering (before/after/parallel) is legal in the case perspective.

Compared to the traditional process modelling standards, e.g. BPMN, BPEL, etc. which restrict the sequences of activities with predefined decision logics, a case is a proceeding that involves actions taken regarding a subject in a particular situation to

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achieve a desired outcome, and it can inherently model flexible execution of activities that depend on evolving circumstances and ad hoc decisions. A typical example is a medical case, which involves the care of a patient with medical history and problems.

Nevertheless, computerization of CPs using CMMN is not straightforward. First, terminologies of CPs and case management are different. Key elements of CP are phase, goal, criterion, activity, etc., while model elements in CMMN are stage, milestone, sentry, task, etc. Second, CMMN is defined for general purposes, and we need to customize them in the clinical context. For example, the case files in CPs will be specified as clinical documents, aka., virtual medical record (vMR) [6]. Accordingly, CMMN does not specify any expression language for conditions, while following HL7 standards, we choose GELLO (guideline expression language) [7] to express them in CPs. Last but not least, decision-making is quite complicated in CPs, such as diagnosis, which may result from a Markov decision process. Obviously, CMMN is not designed for making complex decisions, and we propose to extend CMMN with decision tasks, leveraging well-developed predictive models to provide decision support for diagnosis, prognosis, and treatment, etc. That is, we propose a CMMN-based CP model, with customization of vMR/GELLO and extension of decision tasks.

1. Methods

First, we define a conceptual model for CPs, and then a CP logical model is specified, on basis of CMMN with customization of vMR/GELLO and extension of decision tasks. Finally, we implement it as a physical model used in IBM Case Manager [8].

1.1. A conceptual model for care pathways

As shown in Figure 1, there are a variety of concepts in CPs. A CP consists of phases (e.g. Initial Assessment), and each phase has its goal (e.g. weight decreased since admission). In a phase, activities are grouped, e.g. "complete history" is an activity in the group of "clinical assessments", and roles are assigned to activities, e.g. the role of "nurse" is assigned to the activity "complete physical examination including weight". Besides, the conceptual model also includes activity specification, patient data and criterion. The relationships of these elements are illustrated in Figure 2.

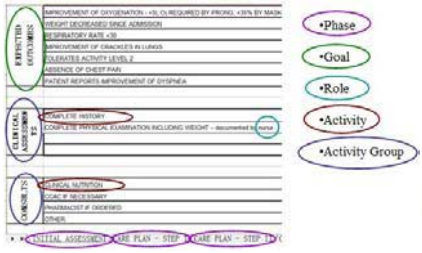


Figure 1. A conceptual model for CHF ambulatory CP.

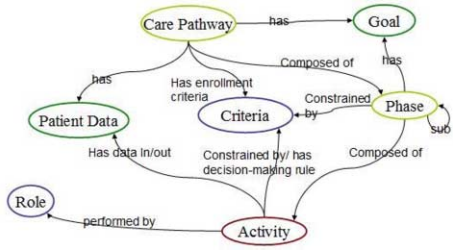


Figure 2. The relationships of CP key elements.

1.2. A logical model for care pathways

According to the CMMN specification [5], we define a logical model for CPs, and Table 1 shows the model elements with customization.

Table 1. A logical model for care pathways

Concepts in care pathway	Elements in CMMN	Customization in CMMN
care pathway	Case	/
phase	Stage	/
role	Role	/
goal	description of stage	vMR goal
activity	Task	/
activity group	sub stage	/
activity specification	description of task	vMR observation order, etc.
	description of decision tasks	PMML definition
patient data	case file	vMR observation result, etc.
criterion	Expression	GELLO expression

Specially, the CP goal is a clinical outcome or aim towards which effort is directed, and unfortunately, there is no such model element in CMMN. Therefore, we leverage the description of a stage to present the goal of a phase. Considering that description in CMMN is a string, we customize it as a vMR goal.

Next, we strictly distinguish activities and activity specifications in CPs. For example, blood pressure monitoring is an activity, and we define it as a task in CMMN, but we also need its clinical description, such that the observation focus is blood pressure finding, the observation method is direct measurement, and the target body site is cuff. In this respect, description of a task can be used to present the activity specification. Again, description in CMMN is a string, and we customize it as a choice of vMR observation order, procedure order, substance administration order, etc.

Besides, we notice that complicated decision making plays an important role in CPs, outside of the CMMN scope. In particular, we expect to use various predictive models to provide decision support for diagnosis, prognosis, and treatment etc., where such predictive models may be produced by data mining and machine learning algorithms. For instance, Markov decision process could be used for sequential decision making under uncertainty, special for a sequential clinical treatment problem [14]. As a result, we propose to extend CMMN with decision tasks – a decision task is a task which description will be specified using the Predicative Model Markup Language (PMML) [9]. Thus, a variety of well-developed data mining and machine learning tools can be used to implement the decision tasks.

In CMMN, all information or references to information (required as context for managing a case) are defined by a case file. Intuitively, patient data in CPs can be specified as the case file, but considering our clinical context, we customize it as a choice of vMR observation result, procedure event, substance administration event, etc.

For criteria in CPs, they may involve expressive knowledge, such as an abnormal blood pressure finding, which means systolic is higher than 120 mmHg or diastolic is higher than 80 mmHg. While CMMN expressions are strings, we restrict its specified language as GELLO – the HL7 standard for clinical expressions.

1.3. A physical model for care pathways

A CP will be used to create care plans (instances of CPs) for individual patients to improve care quality. The IBM Case Manager (ICM) [8] is a good candidate to put CMMN-based CPs into practice. First, the Case Manager Builder is used to implement them, and after their deployment, instances of CPs will run in the Case Manager Client.

As shown in Figure 3, the ICM object model consists of case type, task, external process, document type, role, etc., which are correspondingly mapped to care pathway, phase (activity group, activity), decision task, patient data, role, etc. Particularly, tasks

in ICM are embeddable, and we specify the top level tasks as phases, the sub-tasks as activity groups, and the sub-sub-tasks as activities. With the mappings, we developed a transformer to automatically transform a CMMN-based CP into a case type in ICM.

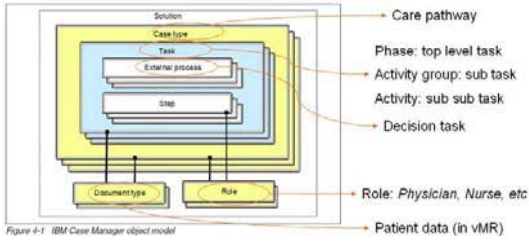


Figure 3. A physical model for care pathways.

2. Results

At the pilot phase, given a conceptual model of CHF ambulatory care pathway, we designed its logical model and physical model in the perspective of case management. As shown in Figure 4 and Figure 5, the logical model includes 5 phases (e.g. initial assessment), 4 roles (e.g. physician and nurse), 17 goals (e.g. weight decreased since admission), 14 activity groups (e.g. consults, lifestyle changes), 90 activities (e.g. chest X-ray, renal function tests), 57 activity specifications (each activity has its activity specification, and the activity specification can be reused – that is why its count is less), 57 patient data (e.g. findings of chest X-ray, findings of renal function tests) and 10 criteria (e.g. the enrolment criterion). In particular, we adopt the HL7 standards of vMR and GELLO to describe the medical records and clinical expressions, resulting in 145 SNOMED CT codes used for the concept descriptors such as chest pain (finding) of ID 29857009. Besides, we define 4 decision tasks to provide support for drug choice. Its predictive model is a Markov Decision Process, which helps to generate an optimal policy, and given a patient state, it returns the best recommendation of treatment.

Figure 6 illustrates the physical model of CHF ambulatory CP in ICM, and Figure 7 is its run time client where a care plan is created for a case based on this pathway.

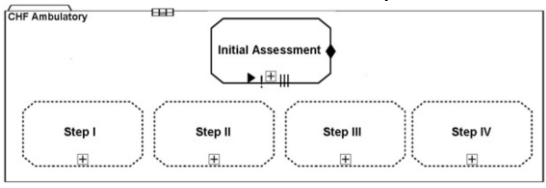


Figure 4. A logical model for CHF ambulatory CP.

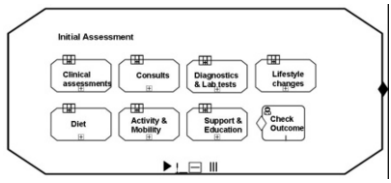


Figure 5. Initial assessment.

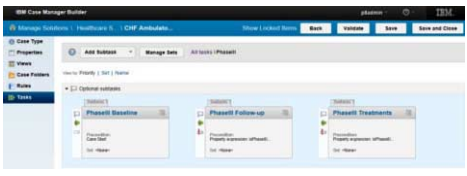


Figure 6. A physical model for CHF ambulatory in ICM.

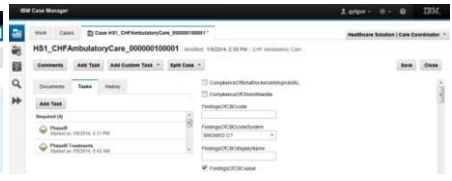


Figure 7. A run time client for CHF ambulatory.

It is remarkable that our computerization of care pathways has been integrated with a Care Pathway Workbench, which is a web-based platform to harmonize

evidences from knowledge and data driven insights [13]. This workbench is planned to be deployed to a clinical setting to evaluate its functionality and efficiency.

3. Discussion

It has been heavily debated about declarative and procedural approaches for modeling clinical guidelines [10]. Due to the flexibility of care pathways, we prefer using a declarative methodology. However, different from the declarative guideline language CIGDEC [10] which are grounded in Linear Temporal Logic (LTL) to define constraints, we adopt an industry standard (CMMN) to design the logic model of care pathways. Actually, the operational semantics of CMMN is based on a form of Event Condition Action (ECA) rules [11], and this ECA-like semantics is not a good candidate to do conformance checking (i.e., to verify whether the observed behavior recorded in an event log matches a modeled behavior). On the contrary, LTL-based semantics has been well investigated for conformance checking [12], where LTL formula will be translated into automata to verify constraints. However, the limitation of LTL is that numeric pre-conditions of activities, which may be represented in ECA rules, cannot be checked using LTL. Therefore, we are planning to give a first-order LTL semantics, which can be used to verify both temporal dependencies and numeric preconditions, to our CP models, towards integration with conformance checking.

References

[1] Vanhaecht K, De Witte K, Sermeus W. The impact of clinical pathways on the organisation of care processes. PhD dissertation, Belgium: KU Leuven; 2007.
[2] Burkle T, Baur T, Hoss N. Clinical pathways development and computer support in the EPR: lessons learned. *Studies in Health Technology and Informatics* 2006; 124:1025-1030.
[3] Patkar V, Fox J. Clinical guidelines and care pathways: a case study applying PROforma decision support technology to the breast cancer care pathway. *Stud Health Technol Inform* 2008; 139:233-242.
[4] Hunt SA, Abraham WT, Chin WH, et al. ACC/AHA 2005 guideline update for the diagnosis and management of chronic heart failure in the adult, *Circulation*, 2005; 112(12): 154-235.
[5] OMG Case Management Model and Notation (CMMN) 1.0 Beta Specification. [released 2013 Jan; cited 2014 Apr 24]. Available from: http://www.omg.org/spec/CMMN/.
[6] HL7 Version 3 Implementation Guide: Virtual Medical Record for Clinical Decision Support (vMR-CDS) for GELLO, Release 1. [cited 2014 Apr 24]. Available from: https://www.hl7.org/implement/standards/product_brief.cfm?product_id=271
[7] HL7 Version 3 Standard: Gello: A Common Expression Language, Release 2. [cited 2014 Apr 24]. Available from: http://www.hl7.org/implement/standards/product_brief.cfm?product_id=5
[8] IBM Redbooks: Advanced Case Management with IBM Case Manager, Third Edition. [released 2013 May; cited 2014 Apr 24]. Available from: www.redbooks.ibm.com/redbooks/pdfs/sg247929.pdf
[9] Predictive Model Markup Language, version 4.1. [cited 2014 Apr 24]. Available from: http://www.dmg.org/v4-1/GeneralStructure.html .
[10] Mulyar N, Pesic M, van der Aalst WMP, Peleg M. Declarative and Procedural Approaches for Modelling Clinical Guidelines: Addressing Flexibility Issues. *BPM Workshops* 2007: 335-346.
[11] Damaggio E, Hull R, Vaculín R. On the Equivalence of Incremental and Fixpoint Semantics for Business Artifacts with Guard-Stage-Milestone Lifecycles. *BPM* 2011: 396-412.
[12] de Leoni M, Maggi FM, van der Aalst WMP. Aligning Event Logs and Declarative Process Models for Conformance Checking. *BPM* 2012: 82-97.
[13] Yiqin Y, Haifeng L, Jing L, Xiang L, Jing M, Guotong X, Adam P, Fei W, and Jianying H. Care Pathway Workbench: Evidence Harmonization from Guideline and Data. *MIE* 2014.
[14] Alagoz O, Hsu H, Schaefer AJ, and Roberts MS. Markov decision processes: a tool for sequential decision making under uncertainty. Medical Decision Making 2010, 30(4):474-483.

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Using TimeML to Support the Modeling of Computerized Clinical Guidelines

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Abstract. The modeling of clinical guidelines in order to apply them in computerized medical tools is a challenging and laborious task. In this project we show that conditional subordination links – a temporal relation concept of TimeML – can be used to describe condition-based activities in a guideline. Therefore, we extend the specification of TimeML concerning events and subordination links. Subsequently, linguistic and semantic rules are developed to automatically generate annotations for these links and classify them as relevant for the clinical care path. Finally, the evaluation of the method shows that this categorization supports the task of the guideline modeling expert.

Keywords. computer-interpretable clinical guidelines; medical guideline modeling; TimeML; subordination links; Information Extraction (IE)

Introduction

Clinical Practice Guidelines (CPGs) are defined as "systematically developed statements to assist practitioners and patient decisions about appropriate health-care for specific circumstances" [1]. They are commonly published in a narrative format and have to be represented in specialized languages (see [2,3] for comparison and overview) in order to be used in computer supported medical systems. The modeling process is laborious and has to be done manually by experts in medicine and computer science. Thus, various approaches based on natural language processing (NLP) have been developed to automate this task [4,5]. The fact that guideline documents are often very extensive, contain complex sentence structures, and describe concepts rather vaguely or incompletely, limit the success of this methods to specific application areas.

As CPGs describe activities (corresponding to events in TimeML) and contain temporal expressions for arranging and relating them we propose the application of the TimeML specification language for our project. TimeML has become the de-facto standard for annotating events and temporal expressions in NLP and addresses the problems of (a) identifying an event and anchoring it in time, (b) chronologically arranging events, (c) reasoning with contextually incomplete temporal expressions (e.g., temporal functions such as "*post-dinner*" or "*fasting*"), and (d) reasoning about the duration of events [6]. Generally, the TimeML specification describes "events" as

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umbrella term for situations that *happen* or *occur (*which can be punctual or last for a period of time) [6].

Originally, TimeML was successfully implemented in the newswire domain but soon the capability of this formalism was also applied to other areas. In the medical domain TimeML has been applied to medical narratives and clinical discharge summaries [7] but these documents differ from clinical guidelines in many ways (e.g., in narratives the document creation time could be used for the time anchoring of the events, whereas in guidelines this is of no informative value). Therefore, the related results can only partially be re-used. Subordination links between events (TimeML distinguishes among temporal links, subordination links, and aspectual links) were not investigated in these projects but are of fundamental significance in the description of condition based activities in guidelines. Consequently, our project focuses on the identification of such links and possible consequences for an automatic modeling process of clinical guidelines.

1. Methods

The goal of this project is to show that the application of TimeML complying annotations on clinical guidelines (particularly on conditional sentences) can support the translation process of CPGs into their computer interpretable format. Therefore, we propose a rule-based, heuristic method using linguistic and semantic patterns to annotate subordination links in sentences and classify them as relevant for describing condition-based activities.

The TimeML specification for subordination links (SLINKs) distinguishes among different types of relations: *modal*, *factive*, *counter-factive*, *evidential*, *negative evidential*, and *conditional* [6]. Generally, the nature of SLINKs is either lexically-based (e.g., indicated by reporting verbs, perception verbs, intentional processes, etc.) or structurally-based (e.g., purpose clauses and conditional constructions) [8]. As condition-based activities play an important role in describing clinical care paths, we set our focus on structurally-based subordination links of the type *conditional*.

The automatic generation of SLINKs requires the correct identification and categorization of the underlying events within a sentence. Therefore, conforming to the TimeML specification, we manually annotated the events in conditional sentences from an Asthma guideline [9]. A few examples are illustrated below. The introducing event is marked "in bold" and the consequence is "underlined".

If there is no response to ***treatment*** *the drug should be* <u>*discontinued*</u>*.* (1)

They should be <u>*stopped*</u> *if no improvement in* ***steroid dose*** *is detected.* (2)

If both ***tests*** *meet diagnostic criteria for diabetes, then* <u>*diagnosis*</u> *of diabetes can be made.* (3)

To discover whether an event is subordinated or not, required a syntax analysis of the sentence in order to identify the antecedent (representing the condition) and the consequence clause (indicating the subordination). This segmentation was accomplished by structurally-based information extraction rules.

Subordination links are found all over the guideline document – not only in the descriptions of clinical care-paths (e.g., see sentence (3)). Consequently, a rule-based

algorithm was developed to exclude irrelevant sentences (see details in section 2.1). Hence, we analysed the events of our guideline concerning their workflow relatedness and developed a categorization scheme for representing this new feature. Finally, we manually annotated the events of condition-action sentences of six guidelines from different medical areas and evaluated our heuristic method.

2. Results

As we need additional semantic information for events in respect to our task, adaptations to TimeML were necessary.

2.1. Extensions to TimeML

TimeML specifies different types of events (e.g., *occurrence, state, reporting,* etc.) to enable temporal reasoning. However, these types did not prove sufficient for the annotation of control-flow related aspects in guidelines. Therefore, we analyzed our training sentences (from the Asthma guideline) and defined a new categorization type "workflow concept*"* called "wfcon" (see **Table 1**).

Table 1. Type "wfcon" (ant: category appears in the antecedent; cons: category appears in the consequence of a sentence)

type	wfcon	ant	cons	examples from the training sentences
treatment/therapy	trth	x	x	add-on therapy; add-on treatment; exercise
medication/pharmac. substance	meph	x	x	long-acting beta2 agonist; inhaled steroids
status	status	x		is established; is required
action	action		x	discontinue; stop; increase; continue

Based on that, we implemented rules which served as a filter mechanism to classify an SLINK as a control-flow related one. This is indicated by a new attribute in the SLINK specification called "relWF" (short for the "related to workflow") with its values "true" or "false".

The following example[2] (see **Figure 1**) shows the manual annotations of the events of sentence (1) and the automatically generated annotation for the SLINK by our method.

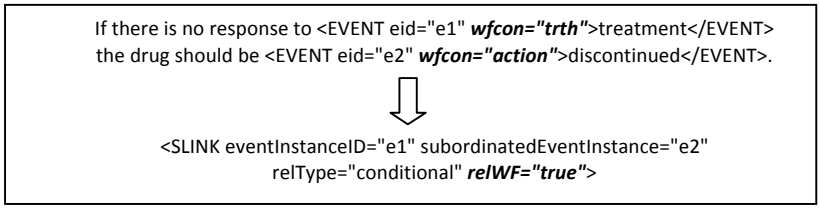


Figure 1. Generation of the SLINK annotation

2.2. Prototypical Implementation

The TARSQI Toolkit (TTK) was one of the first implementations which generated TimeML compliant annotations in order to enable temporally based questions about

[2] The EVENT-tags only show the attributes relevant to our method

events in news articles [10]. Due to the absence of structurally-based rules in the latest TTK version, we decided to implement our prototype built on the open source framework for text engineering GATE [11]. We extended the information extraction rules of a former project about the identification of condition-action sentences where we combined several text engineering components (ANNIE: a set of IE components, distributed within the GATE system, and the Apache OpenNLPChunker) [12]. Based on that, we implemented nine filter rules using the categories of the events in the antecedent and the consequence of a conditional sentence as described in section 2.1.

2.3. Evaluation

We manually annotated the events in a corpus of six different guidelines[3] according to the definition presented in subsection 2.1. As these guidelines were already used in a former project, the condition-action sentences were already annotated. The corpus contained 68 conditional sentences including 147 events. 34 of these sentences described conditional activities which should be identified by our method. 35 events which did not follow the categorization scheme were annotated as type "*other*". After applying our prototype to the corpus, the sentences were classified as shown in **Table 2**.

Table 2. Results of the classification process of the 68 conditional sentences

classification	true	false	total # of sentences
positive	22	10	32
negative	24	12	36
total	46	22	68

These values lead to a precision of 68,8%, a recall of 64,7%, and an accuracy of 67,6%.

3. Discussion

The precise identification of subordination links requires the identification of the antecedent and the consequence in a conditional sentence. Even though every if-sentence in the corpus was found, the segmentation of three sentences failed due to missing IE patterns.

The main reason why some subordinating clauses were not found was the fact that the events did not correspond to the defined categories. For example, in the sentence "*Consider referral if patient has **symptoms** of peripheral vascular disease such as loss of pulses and/or claudication*" a category for the event "symptoms" was not defined. The next sentence showed an equal problem: *"If two different **tests** are available …, then the test whose [sic] result is above the diagnostic threshold should be repeated"*. The event "tests" had no corresponding category.

Sometimes conditional activities were described repeatedly in a guideline. In such cases only the first appearance was modeled and the others were ignored. The sentence *"Use of statins if tolerated"* was correctly identified by our algorithm, so was the sentence "*Use of statins in all adult type 2 diabetes patients if tolerated*". However, the

[3] Guideline topics: Chronic Hypertension in Pregnancy; Diagnosis and Management of Type 2 Diabetes Mellitus in Adults; Hypertrophic Cardiomyopathy; Gestational Diabetes; Breast Cancer; Chronic Heart Failure

second one was not modeled in our corpus because the first one already contained the relevant information for the clinical care path.

The discussion shows that the improvement of the precision and recall values is possible if the pool of IE patterns for the segmentation of conditional clauses is extended and the coarse grained categories for events are adapted and expanded.

In this project we showed that our method automatically identified condition-based activities for control flow related aspects in a guideline document based on the temporal concept of subordination links (as shown in **Figure 1**) and therefore supports the modeling process of clinical guidelines.

Ongoing steps will be (1) the extension of the linguistic pattern set to improve the identification of the antecedent and the consequence in conditional clauses, (2) the refinement of the categories of events, and (3) the implementation of our algorithm in a model authoring tool.

Acknowledgement.

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References

[1] Field MJ, Lohr KN, editors. Clinical Practice Guidelines. Directions for a New Program. Washington DC: National Academies Press; 1990.

[2] Isern D, Moreno A. Computer-based execution of clinical guidelines: a review. Int. J. Med. Inform. Elsevier; 2008;77(12):787–808.

[3] Peleg M, Tu SW, Bury J, Ciccarese P, Fox J, Greenes RA, et al. Comparing Computer-Interpretable Guideline Models: A Case-Study Approach. J. Am. Med. Informatics Assoc. 2003;10(1):52–68.

[4] Kaiser K, Akkaya C, Miksch S. How can information extraction ease formalizing treatment processes in clinical practice guidelines? A method and its evaluation. Artif. Intell. Med. 2007 Feb;39(2):151–63.

[5] Kaiser K, Seyfang A, Miksch S. Identifying Treatment Activities for Modelling Computer-Interpretable Clinical Practice Guidelines. In: Riaño D, ten Teije A, Miksch S, Peleg M, editors. Knowl. Represent. Heal. Springer Verlag; 2011. page 115–27.

[6] Pustejovsky J, Ingria R, Setzer A, Katz G. TimeML: Robust Specification of Event and Temporal Expressions in Text. In: Bunt H, Van Der Sluis I, Morante R, editors. IWCS5 Fifth Int. Work. Comput. Semant. AAAI Press; 2003. page 1–12.

[7] Gooch P. A lightweight, pattern-based approach to identification and formalisation of TimeML expressions in clinical narratives. Proc. Sixth Informatics Integr. Biol. Bedside Nat. Lang. Process. Chall. Clin. Rec. Chicago, IL; 2012.

[8] Saurì R, Littman J, Knippen B, Gaizauskas R, Setzer A, Pustejovsky J. TimeML Annotation Guidelines Version 1.2.1. 2006.

[9] Scottish Intercollegiate Guidelines Network (SIGN), British Thoracic Society. British Guideline on the Management of Asthma. Edinburgh (Scotland); 2005 Nov.

[10] Verhagen M, Pustejovsky J. Temporal processing with the TARSQI toolkit. Proc. 22nd Int. Conf. Comput. Linguist. Association for Computational Linguistics; 2008. page 189–92.

[11] Cunningham H, Tablan V, Roberts A, Bontcheva K. Getting more out of biomedical documents with GATE's full lifecycle open source text analytics. Prlic A, editor. PLoS Comput. Biol. Public Library of Science; 2013 Jan;9(2):e1002854.

[12] Wenzina R, Kaiser K. Identifying Condition-Action Sentences Using a Heuristic-based Information Extraction Method. Proc. Jt. Int. Work. KR4HC/ProHealth 2013.

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Towards evidence-based CDSSs implementing the medical reasoning contained in CPGs: application to antibiotic prescription

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Abstract. Clinical practice guidelines (CPGs) are documents giving recommendations based on expert reasoning, weighing up the pros and cons of treatments on the basis of the available evidence. We propose a new approach to the construction of clinical decision support systems (CDSS), making use of the evidence-based medical reasoning used by experts in CPGs. In this study, we determined whether this approach could retrieve the recommendations for antibiotic prescription for empirical treatment in primary care. Methods: We manually extracted, from CPGs, all the properties of antibiotics underlying recommendations for their prescription or non-prescription. We then used these properties to establish an algorithm in the form of a sequence of conditions, leading to a list of recommended antibiotics. The optimal sequence was determined by studying, for each sequence, the degree of similarity between the list of antibiotics recommended in CPGs and the list obtained with the algorithm. Results: 12 antibiotic properties were used in the form of conditions in an algorithm. For 95% of clinical situations, 10 sequences retrieved the recommended treatment. Discussion: This algorithm could be used in a CDSS for antibiotic treatment and would be useful for experts drawing up CPGs.

Keywords: Clinical practice guidelines, knowledge-based reasoning, evidence-based medicine, antibiotic prescription, primary care.

Introduction

Many of the first clinical decision support systems (CDSSs) required cooperation between computer engineers and experts in the medical domain concerned [1]. These expert systems aimed to capture the knowledge of the expert, to reproduce his or her decision-making behavior (e.g. in the domain of infectious disease, the Mycin system [1] implemented expert knowledge in the form of production rules). In the 1990s, the concept of evidence-based medicine (EBM) emerged, leading to the diffusion of clinical practice guidelines (CPGs) textual documents generated by a group of experts. These CPGs were then implemented in CDSSs, mostly according to a set of rules or decision trees dealing with patient conditions and medical action [2,3].

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However, the use of CPGs in CDSSs raised two problems: (i) many clinical situations are not described [4]; (ii) CPGs are often updated at a pace slower than that of advances in medical knowledge [5]. We propose a new approach designed to overcome these limitations by implementing the evidence-based medical reasoning used by experts to recommend therapeutic strategies in CPGs. The use of such reasoning should make it possible to retrieve the therapeutic strategies recommended by experts, and to facilitate the updating of recommendations. We focus here on a case study: the empirical prescription of antibiotics in primary care. The updating problem is particularly serious in this domain, because rapid changes in resistance lead to equally rapid changes in available evidence [6].

In this study, we aimed to extract, from CPGs, the evidence-based medical reasoning used by experts in empirical antibiotic treatment, and to determine whether this approach could retrieve the antibiotics recommended by the experts.

1. Methods

We first identified the properties of antibiotics used by the experts to weigh up the pros and cons of their use. We studied seven CPGs (five French, and two from the US) relating to 21 clinical situations in the domain of urinary infections (cystitis, pyelonephritis, prostatitis), higher and lower respiratory tract infections (pharyngitis, otitis, sinusitis, pneumonia). For each clinical situation, we manually extracted all expressions relating to the properties of the antibiotics on which recommendations were based. We then grouped similar expressions into categories (e.g.: "prevalence of resistance", "frequency of acquired resistance" were grouped into the property "likely activity of the antibiotic").

We then determined how best to order these antibiotic properties to reproduce, as closely as possible, the reasoning used by experts in the construction of lists of recommended antibiotics. For each clinical situation, we analyzed the way in which these properties were used in medical reasoning. We established an algorithm, including a sequence of conditions that an antibiotic must satisfy to be recommended, leading to a list of recommended antibiotics.

We then obtained a generic algorithm, by identifying the optimal sequence of conditions satisfactory for the largest number of clinical situations. We implemented the algorithm and created a database containing all the antibiotic properties identified. We then tested all possible sequences of conditions for all clinical situations. A sequence was considered "satisfactory" if it retrieved the antibiotics recommended in the CPGs.

2. Results

2.1. Properties of antibiotics determining the choice of molecule

Twelve antibiotic properties were extracted from CPGs (Table 1). Six properties (A to F) were identified as "necessary" conditions for the prescription of an antibiotic in a given clinical situation. An antibiotic should only be prescribed if it is (i) usable, i.e. available in the country concerned and not contraindicated in the patient and (ii) potentially effective, i.e. active against wild-type strains of bacteria, probably active

against modified strains of bacteria, capable of achieving a sufficiently high concentration in the infected organ, and with proven clinical efficacy in the clinical situation concerned. Antibiotics that are usable and potentially effective are considered to be "appropriate antibiotics".

Six properties (G to L) were identified as conditions that should be met by the antibiotic for it to be chosen ahead of other molecules in a list of appropriate antibiotics. Such preferred antibiotics are referred to as "recommended antibiotics".

Table 1. Antibiotic properties determining the choice of antibiotic for empirical use in primary care

Antibiotic Properties		Conditions used in the algorithm Examples given in italics
Availability	A	Is the antibiotic available in the country? *No, pivmecillinam is not available in North America*
Natural activity	B	Is the antibiotic sufficiently active against wild-type strains of the bacteria? *Yes, cephalosporins are active against wild-type strains of E. coli*
Concentration	C	Does the antibiotic reach a sufficiently high concentration in the infected organ? *Yes, fluoroquinoles reach high concentrations in the prostate*
Evidence of efficacy	D	Has the clinical efficacy of the antibiotic been proven? *No, there is no evidence that fosfomycin is effective in complicated cystitis*
Likely activity	E	Is the antibiotic probably active against the etiologic bacteria? *No, S. pneumoniae has a rate of acquired resistance to erythromycin of 52%*
Contra indication	F	Can the antibiotic be used in the patient? *No, pristinamycin is contraindicated in children under the age of six years*
Protocol characteristics	G	Does the protocol promote higher levels of compliance than for the other antibiotics? *Yes, amoxicillin is prescribed for shorter periods for the treatment of pharyngitis*
Class characteristics	H	Does the antibiotic belong to a less precious class than the other antibiotics? *No, fluroquinolone use is restricted to severe conditions*
Side effects	I	Is the risk of side effects lower or are the side effects less serious than with the other antibiotics? *No, pefloxacin is associated with a higher risk of tendinopathy*
Level of efficacy	J	Is the antibiotic more effective than the other antibiotics? *No, Beta-Lactams are less effective than other antibiotics for the treatment of cystitis*
Activity spectrum	K	Does the antibiotic have a narrower spectrum of activity than the other antibiotics? *No, levofloxacin and moxifloxacin are newer, broad-spectrum antibiotics*
Ecological adverse effects	L	Is the antibiotic associated with a lower risk of collateral damage than the other antibiotics? *No, fluoroquinolone use promotes the acquisition of resistance in bacteria*

2.2. Algorithm for the choice of antibiotic for empirical use in primary care

We established a model reproducing expert reasoning, to weigh up the pro and cons of antibiotics for empirical antibiotic treatment. The resulting algorithm includes 12 conditions relating to 12 properties of antibiotics (Table 1) and generates a list of recommended antibiotics. The algorithm (Figure 1) begins with a list of antibiotics that are "potential candidates" for recommendation in a particular instance. Each question relating to antibiotic properties is asked in order, and with each successive question, none, one or several antibiotics may be removed from the list of potential candidates. Thus, the list gradually decreases in length, with each question. Once all 12 questions have been asked, the antibiotics remaining in the list should correspond to the list of recommended antibiotics from the CPGs.

2.3. The optimal sequences for retrieval of the recommended antibiotics

We investigated whether one or more sequences of conditions made it possible to retrieve the recommended antibiotics for all clinical situations. The six first conditions

(A to F, see Table 1) relate to essential properties of appropriate antibiotics. The order of these conditions in the sequence is unimportant, because all these individual conditions must be met for the antibiotic to be prescribed, regardless of the properties of the other antibiotics in the list.

The six next conditions (G to L, see Table 1) concern properties that are used to differentiate between molecules in the list of appropriate antibiotics. These conditions should generate the list of recommended antibiotics. However, the results obtained depend on the order in which the conditions are presented, because, at each step, antibiotics are excluded on the basis of comparison with other antibiotics in the list (Figure 1). We tested all 720 possible sequences for 21 clinical situations. For one clinical situation, none of the sequences retrieved the full list of recommended antibiotics. For the other 20 clinical situations, 10 sequences were considered "satisfactory", as they retrieved the full list of recommended antibiotics:

"H, G, J, I, L, K"--- "H, G, I, J, L, K"--- "H, I, G, J, L, K"--- "H, I, J, G, L, K" ---
"I, G, H, J, L, K"--- "I, H, G, J, L, K"--- "I, H, J, G, L, K"
"G, I, H, J, L, K"---"G, H, J, I, L, K"--- "G, H, I, J, L, K"

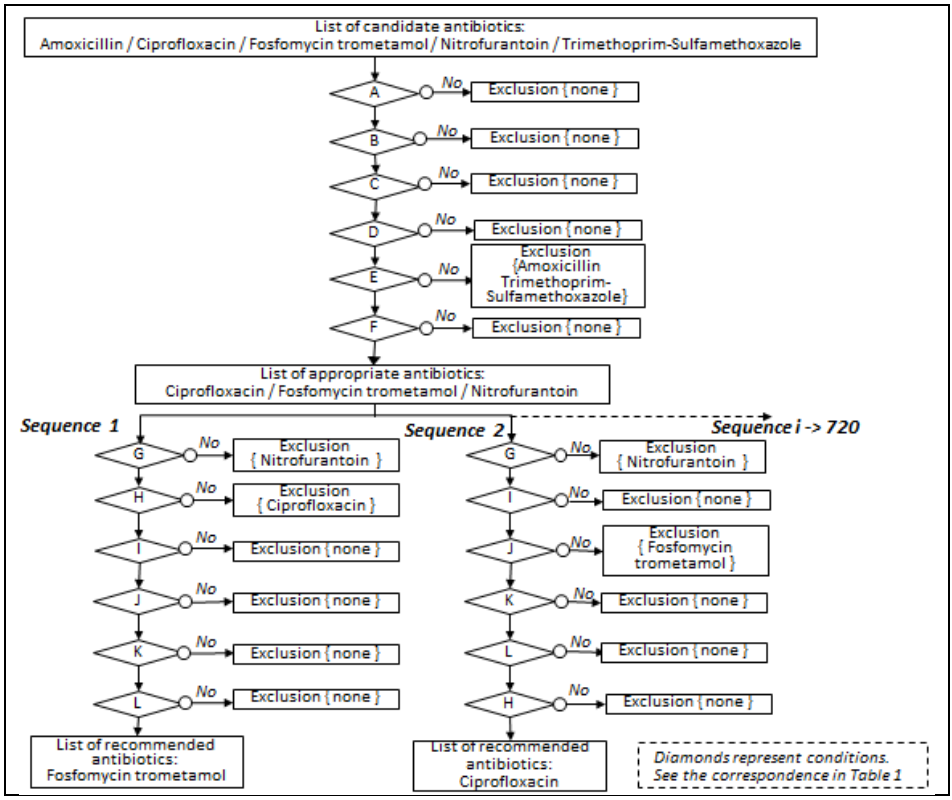


Figure 1. Example of 5 antibiotics for uncomplicated cystitis. At the beginning of the algorithm, all five antibiotics are candidates for recommendation. After the first six questions relating to essential conditions, the list of antibiotics is reduced to 3 (2 antibiotics being excluded by condition E). For the next six conditions, 720 sequences are possible and result in different lists of antibiotics (e.g.: fosfomycin for sequence 1 vs. ciprofloxacin for sequence 2).

3. Discussion

We propose a new approach based on the implementation of evidence-based medical reasoning, to generate a list of the antibiotics recommended in CPGs. We analyzed CPGs for empirical antibiotic treatment, to generate a set of 12 antibiotic properties accounting for the choices made by experts. These properties were included in an algorithm, which retrieved the recommended antibiotics in 95% of clinical situations. In one situation, the recommended antibiotics were not retrieved because the experts proposed a broader list of antibiotics, depending on the level of acquired resistance in the country of application of the CPG. This approach presents several advantages. First, it can be applied to all clinical situations, including those absent from CPGs (e.g. if the CPG does not deal with the case of renal impairment, drug properties relating to contraindications can be applied to exclude some antibiotics). Second, an explanation of the rationale for recommending a subset of antibiotics can easily be derived and given to the physician. This is an important feature for increasing confidence in the CDSS [7]. Third, this approach should facilitate the updating of knowledge, by making it possible to retrieve data concerning antibiotic properties from different resources [8] (e.g. drug databases, microbial observatories).

Further developments are required. For example, this algorithm was not assessed for all infectious diseases (e.g. sexually transmitted infections), or for all the antibiotics available on the market. The next step in this work will involve a more detailed evaluation of this formalization of expert reasoning, and its implementation in a CDSS for antibiotic treatment [9] to help experts drawing up CPGs.

References

[1] Shortliffe EH. Mycin: A Knowledge-Based Computer Program Applied to Infectious Diseases, *Proc Annu Symp Comput Appl Med Care* (1977), 66‑69.

[2] Lamy J-B, Ebrahiminia V, Riou C, Seroussi B, Bouaud J, Simon C, et al. How to translate therapeutic recommendations in clinical practice guidelines into rules for critiquing physician prescriptions? Methods and application to five guidelines, *BMC Med Inform Decis Mak* (2010), 10:31.

[3] Séroussi B, Bouaud J, Antoine EC. ONCODOC: a successful experiment of computer-supported guideline development and implementation in the treatment of breast cancer, *Artif Intell Med* **22(1)** (2001), 43‑64.

[4] Lugtenberg M, Zegers-van Schaick JM, Westert GP, Burgers JS. Why don't physicians adhere to guideline recommendations in practice? An analysis of barriers among Dutch general practitioners, *Implement Sci IS* (2009), 4:54.

[5] Shekelle PG, Ortiz E, Rhodes S, et al. Validity of the agency for healthcare research and quality clinical practice guidelines: How quickly do guidelines become outdated? *JAMA* **286(12)** (2001), 1461‑1467.

[6] Davies J, Davies D. Origins and evolution of antibiotic resistance, *Microbiol Mol Biol Rev MMBR* **74(3)** (2010), 417‑433.

[7] Schiff GD, Wisniewski M, Bult J, Parada JP, Aggarwal H, Schwartz DN. Improving inpatient antibiotic prescribing: insights from participation in a national collaborative, *Jt Comm J Qual Improv* **27(8)** (2001), 387‑402.

[8] Duclos C, Cartolano GL, Ghez M, Venot A. Structured representation of the pharmacodynamics section of the summary of product characteristics for antibiotics: application for automated extraction and visualization of their antimicrobial activity spectra, *J Am Med Inform Assoc JAMIA* **11(4)** (2004), 285‑293.

[9] Tsopra R, Jais J-P, Venot A, Duclos C. Comparison of two kinds of interface, based on guided navigation or usability principles, for improving the adoption of computerized decision support systems: application to the prescription of antibiotics, *J Am Med Inform Assoc JAMIA* **21(e1)** (2014), e107‑116.

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Clinical Guideline-Driven Personalized Self-Management Diary for Paediatric Cancer Survivors

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Abstract. Shared Decision Making (SDM) is the process of patients and clinicians working together to manage medical treatment using the existing knowledge base. This paper presents the *YouCan* framework, a system for summarizing and presenting the necessary knowledge for SDM related to pediatric cancer follow-up management. Knowledge modelling of a Clinical Practice Guideline produced a customized ontology, which was then passed through a pellet reasoned to produce a customized patient diary that summarizes a patient's oncological history as well as the potential issues they may face in follow-up.

Keywords. Patient Education as Topic, Clinical Practice Guideline, Knowledge Management, Pediatrics, Medical Oncology

Introduction

Pediatric cancer survivors face a lifetime of follow-up care that involves monitoring the patient's psychological and behavioral parameters in response to a regime of therapeutic interventions. Upon leaving a cancer care facility, cancer survivors are provided with a self-management program with information on how to interpret and manage symptoms, how to make healthy lifestyle choices, how to deal with specific situations and most importantly how to manage their therapy plan. To ensure sufficient uptake of their recommended self-management program, it is important to engage them in the design of their program, and personalize it with respect to their conditions and preferences, as this will improve overall satisfaction [1, 2].

Shared Decision Making (SDM) is a patient-centered care paradigm where clinicians and patients leverage the best available evidence to make decisions together about the best management of their care [3]. Engaging patients in the care process has been shown to lead to better communication, better task orientation and improvement of quality of life [4]. A key aspect of SDM is the incorporation of evidence in the design of a patient-specific (i.e. personalized) self-management program. In a SDM setting the pertinent aspects of the relevant Clinical Practice Guidelines (CPG) are

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discussed with the patient and through their understanding, consent and participation an evidence-informed and personalized self-management program is formulated, with the expectation that personalized educational content is more likely to be read, followed and experienced. Health informatics technologies can be exploited to develop evidence-based personalized self-management programs that deliver on-demand, individualized educational content in a private learning environment. Personalized educational interventions are more likely to be read, remembered and experienced as relevant [5, 6, 7], thus enabling patients to become active agents in their care activities.

In this paper we present a Youth Cancer management framework - called *YouCan* - to facilitate the long-term follow-up care of survivors of childhood, adolescent and youth adults cancers. The *YouCan* framework is designed to provide pediatric cancer survivors leaving the cancer treatment center at the IWK Health Center (in Halifax, Canada), with a personalized self-management diary based on their specific disease condition and care needs, to help them safely manage their condition in a home-based setting.

The *YouCan* framework is based on the concept of SDM and it uses a computerized version of the "Guideline for Long Term Follow-Up for Survivors of Childhood, Adolescent, and Youth Adult Cancers" [8] to personalize the self-management activities and care options based on the patient's current therapeutic agents, health and psychosocial behavior; and to recommend relevant evidence-informed self-management activities that are safe and effective as per the patient's condition. *YouCan* is a prototype patient self-management system, used by cancer follow-up care providers, to compose a personalized self-management diary in a SDM session between the care provider and cancer survivor.

1. Methods

We have taken a healthcare knowledge management approach to the design of the *YouCan* framework [9], where semantic web based technologies have been developed to (i) establish an evidence-informed SDM session, (ii) computerize the CPG on Long Term Follow-Up for Youth Adult Cancers [8]; and (iii) dynamically compose a personalized patient diary. Figure 1 presents the functional components of the *YouCan* framework: CPG computerization, CPG execution and diary composition.

1.1. CPG Computerization

To leverage the cancer follow-up CPG [8], the first step is the computerization of the CPG in terms of a semantically expressive and executable knowledge model. We used our own ontology [10] to computerize the follow-up CPG, resulting in the *YouCan* Ontology (in OWL-DL).

The *YouCan* Ontology serves as the basis for the formalization of the SDM rules that guide the SDM session in selection of the pertinent self-management recommendations. The premise of the SDM rule includes a specific therapeutic agent (i.e. a drug) together with a set of patient attributes and preferences, while the body of the rule contains corresponding CPG-based follow-up recommendations for the patient. The recommendations are classified into three types: (i) disease information that

patients need to know (such as negative outcomes), (ii) what actions to take in specific situations, and (iii) specific issues to discuss with the GP.

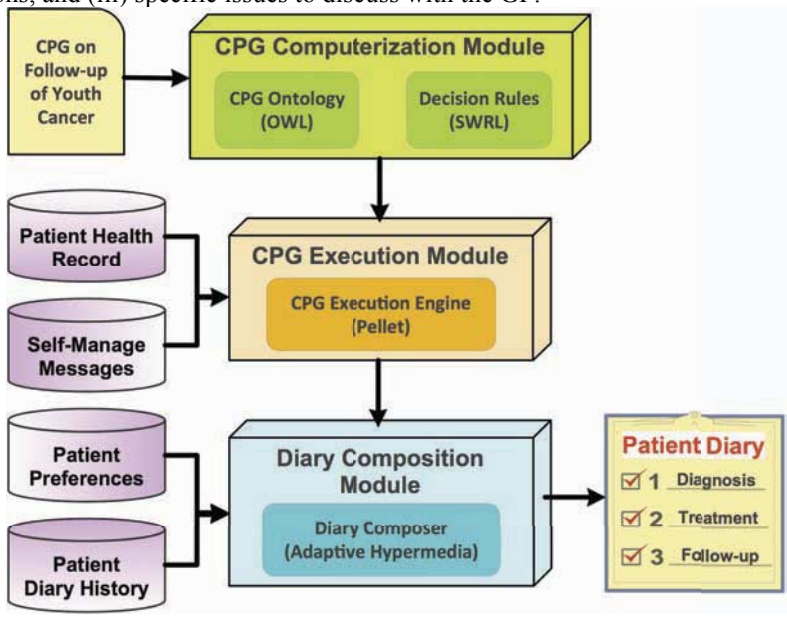


Figure 1. The system diagram for the *YouCan* framework

1.2. CPG Execution

To select the content for the diary, the SDM rules are executed based on the survivor's profile: Therapeutic agents currently being used, personal attributes and preferences. Survivor information (including disease condition, past and current therapeutic agents, age, risk factors, etc) is retrieved from the survivor's medical record. A Pellet reasoner is used to execute the SDM rules: survivor data is injected into the CPG execution engine such that matching rules are fired, thus producing a series of recommendations matching the patient's particulars. Inter rule consistency is established by a consistency checking algorithm to ensure that all the recommendations are mutually consistent and safe.

1.3. Patient Diary Composition

The preparation of the personalized patient diary is achieved by using an adaptive hypermedia approach. We have prepared a template for the patient diary, stratified into the following key sections: Introductory information, diagnosis summary, treatment summary, self-management recommendations, information about conditions and potential complications and next steps in the care plan. The proposed recommendations are discussed by the patient through the SDM model, and are further personalized as per the survivor's preferences. The educational material is then embedded within the predefined diary templates.

1.4. Evaluation

The evaluation of the diary requires three phases. In phase 1, domain experts evaluated the SDM rules for their clinical validity. In phase 2, the execution of the rules was evaluated to ensure completeness and consistency of the execution results. Sample clinical cases were used as input to the CPG execution engine and the resulting diaries were evaluated. In phase 3, the composed patient diary was field tested by practicing oncologists and nurses to evaluate the message content and diary layout.

As a final evaluation step, we plan a pilot study involving cancer survivors from the IWK who will be provided their personalized diary and we will evaluate the diary's impact on their self-management.

2. Results

The knowledge modeling for the CPG computerization was done by two domain experts who worked closely with the knowledge engineers to computerize the CPG and create the *YouCan* Ontology. The *YouCan* Ontology covers therapeutic agents, risk factors, patient condition evaluations, therapeutic actions, therapy outcomes, potential complications and a range of corresponding recommendations covering drug administration, lifestyle choices, side effects, symptom monitoring and psychosocial support.

Using the *YouCan* Ontology we derived over 600 SDM rules relating to 110 drug side-effect interactions for 22 different therapeutic agents. The SDM rules were represented in SWRL (a W3C standard) and are decidable. Table 1 presents a SDM rule for the drug Bleomycin and the associated risk of pulmonary fibrosis.

Table 1: A sample of the rules extracted for the drug Bleomycin related to pulmonary fibrosis

Things to Know	Bleomycin can affect lung function by causing pulmonary fibrosis (scarring)
What you need to do	Keep your lungs as healthy as possible
	Don't smoke
	Avoid dusty and fumey places
	Tell your doctor if you develop a cough or wheeze that lasts more than a week or if you feel short of breath or breathless when exercising
Decision Points	
IF age > 10 yrs at treatment AND dose <400 units/m^2	Ask your doctor to check your lung symptoms (cough, wheeze, shortness of breath) and do a physical exam every year.
IF age < 10 years at treatment OR dose > 400 units/m^2 OR received chest irradiation OR received Busulfan, BCNU or CCNU	Ask your doctor to do a baseline breathing test (including peak flow, diffusion capacity and spirometry)
	Ask your doctor to check your lung symptoms (cough, wheeze, shortness of breath) and do a physical exam every year.

Using the SDM rules and the patient diary template, the system produces a 5-10 page personalized self-management diary that would then be handed to patients.

The 3-phase evaluation of the diary has been completed. In phase 1 the rules were reviewed and found to be consistent and compliant to the CPG content. In phase 2 the domain experts helped review the tone of the recommendations being proposed, and

ultimately were in line with the CPG and were safe for the said patient. In phase 3 the diary content was deemed to be sufficient, relevant and usable. The diaries are now past the testing phase, and are ready to be evaluated with the patient population.

3. Discussion

Home-based management of pediatric cancer survivors is a challenging undertaking, as it demands adherence to the follow-up plan by young patients. The use of SDM principles allows opportunities to engage youth survivors in their care plan. In this project, we have presented a semantic web based *YouCan* framework that facilitates the formulation of a personalized self-management diary based on the theory of SDM and evidence derived from a cancer follow-up CPG. Our *YouCan* framework enables the engagement of youth cancer survivors through a self-management diary that assists them in managing their condition on a daily basis in a home-based setting. The survivor diary is being embedded within the CYP-C portal (an electronic health record for the clinical management of all pediatric cancer cases in Canada) so that the SDM based and CPG-guided self-management service can be extended to youth survivors from other provinces. We plan to deliver the survivor's self-management diary through a secure web app that will be accessible to survivors by mobile devices.

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References

[1] W.W. Weston, Informed and shared decision-making: the crux of patient-centered care, *Canadian Medical Association Journal* **165** (2009), 438–439

[2] D.J. Kiesler, S.M. Auerbach, Optimal matches of patient preferences for information, decision-making and interpersonal behaviour: evidence, models and interventions. *Patient Education and Counseling* **61** (2006), 319–341

[3] G Elwyn et al. Shared Decision Making: A Model For Clinical Practice. *Journal of Internal Medicine* **27** (2012), 1361-1367.

[4] R Grilli, C Ramsay, S Minozzi, Mass media interventions: effects on health services utilisation. *Cochrane Database Systematic Reviews* **1** (2002), CD000389.

[5] E Murray, J Burns, T.S. See, R Lai, I Nazareth, Interactive health communication applications for people with chronic disease, *Cochrane Database Systematic Reviews* **4** (2005), CD004274.

[6] J Brug, M Campbell, P van Assema, The application and impact of computer-generated personalized nutrition education: A review of the literature. *Patient Education and Counseling* **36** (1999), 145-156.

[7] S Davis, SSR Abidi, SA Stewart, A compositional personalization approach for designing personalized patient educational interventions for cardiovascular risk management. *Studies in Health Technology and Informatics*. **160(pt 1)** (2010), 629-633

[8] Children's Oncology Group, Long-term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers. Version 3.0. Arcadia, CA: Children's Oncology Group; 2008

[9] SSR. ABIDI, S. Abidi. An Ontology-Driven Personalization Framework for Designing Theory-driven Self-Management Interventions. *Knowledge Representation for Health Care and Process-oriented Information Systems in Healthcare (KR4HC'13 / ProHealth'13)*, Murcia, June 1 - June 1, 2013. Springer.

[10] S.S.R. Abidi, S. Shayegani. Modeling the Form and Function of Clinical Practice Guidelines: An Ontological Model to Computerize Clinical Practice Guidelines. *Knowledge Management for Health Care Procedures, LNCS* **5626**, pp. 81-91.

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Care Pathway Workbench: Evidence Harmonization from Guideline and Data

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Abstract. Care pathways (CPs) as a means of healthcare quality control are getting increasing attention due to widespread recognition in the healthcare industry of the need for well coordinated, evidence based and personalized care. To keep the promise, CPs require continuous refinement in order to stay up to date with regard to both clinical guidelines and data-driven insights from real world practices. There is therefore a strong demand for a unified platform that allows harmonization of evidence coming from multiple sources. In this paper we describe Care Pathway Workbench, a web-based platform that enables users to build and continuously improve Case Management Model and Notation based CPs by harmonizing evidences from guidelines and patient data. To illustrate the functionalities, we describe how a CHF (Congestive Heart Failure) Ambulatory Care Pathway can be developed using this workbench by first extracting key elements from widely accepted guidelines for CHF management, then incorporating evidence mined from clinical practice data, and finally transforming and exporting the resulting CP model to a care management product.

Keywords. Care pathway, evidence synthesis, clinical guidelines, patient data

Introduction

In recent years, care pathways (CPs) [1] (also known as integrated care pathways, clinical pathways, critical pathways, critical paths or care paths) have became increasingly important and more widely used in healthcare industry as a means of healthcare quality control for well coordinated, evidence based and personalized care.

Despite the increasing popularity of CPs, significant efforts are still needed to enable their continuous development. One of the most significant obstacles is to keep a CP up to date with evidence of best practices to allow effective decision support [1,2]. Traditionally, CPs are derived from clinical guidelines. However, extracting evidence from guidelines alone is not enough because guidelines often capture abstract clinical recommendations rather than regional characteristics and may lack implementation details such as concrete medications [1]. To complement guideline-based approaches, researchers have been using process mining techniques to identify real practice evidence for CPs from local electronic patient records [3,4]. Unfortunately, there still remains a deficiency of integrating evidences both from guidelines and data-driven

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insights from real world practice. Therefore, there is strong demand for a unified platform that allows harmonization of evidence coming from multiple sources to support computer assisted CP development.

This work aims to fill the above gap by developing a Care Pathway Workbench (CPW) that allows users to create CPs with synthesized evidence from guidelines and patient data and conforming to Case Management Model and Notation (CMMN) [5] which is an emerging OMG (Object Management Group) standard for supporting flexible and knowledge intensive business processes. In CPW, users can build and continuously improve CPs by first extracting key elements from guidelines, then incorporating evidence discovered from clinical practice data, and finally transforming and exporting the resulting CPs to a care management tool for execution. We evaluate CPW by working on a widely accepted CHF Ambulatory Care Pathway and a real clinical data set. The derived pathway is also reviewed by clinical professionals and used in a product for care management.

1. Methods

Care Plan Workbench is an end-to-end web-based platform for care pathway development whose architecture is shown in Figure 1. The platform consists of two parts: (1) CP management components (surrounded by long dashed line) allow the user to manage CPs by creation, editing, saving and transformation; and (2) analytics components (surrounded by square dotted line) include extracting elements from clinical guidelines, variation analysis and outcome driven CP pattern mining and exploration from Electronic Medical Records (EMR) data. These evidences are then fed to CP management components for further harmonization.

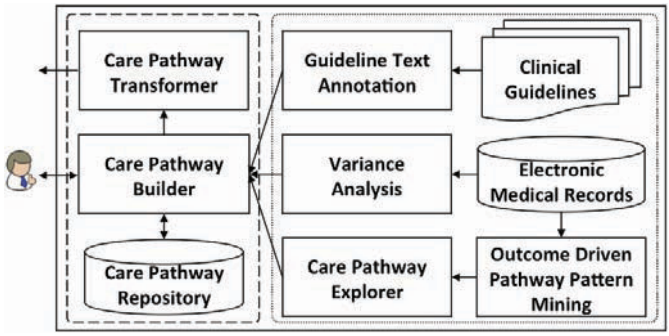


Figure 1. Architecture of CPW.

1.1. CP Model

Before we introduce CPW's components, let us describe our computerized CP model first as it lays the foundation for CPW. One challenging task in modeling CP is that the model should support rich flexibility to allow ad hoc variation in execution of clinical tasks [1] for individual patients. Hence we adopt an approach of extending CMMN to enable the flexibility of CPs and fit to industrial use by 1) using CMMN model schema to keep case management design paradigm, 2) extending case data model via HL7 vMR [6] for data item definition, 3) enriching care activity description via vMR for its

encoded semantic meaning, 4) expressing clinical criteria via HL7 GELLO [7], and 5) adding new elements required by a CP, e.g., clinical goals achieved in a care phase. Table 1 summarizes the elements of the CP model.

Table 1. Elements of CP model

Elements	Description	CMMN Elements (Extension)	Example
Care Pathway	Top-level element.	Case (entryCriteriaRef: enrollment criteria)	CHF Ambulatory Care
Phase	Groups sub-phases/activities with same goals.	Stage (goalRef: reference to Goal(s))	Clinical assessments, Phase I treatments
Activity	An atomic unit of work during the care process.	Task (activitySpecification: semantic definition in vMR	Weight monitoring, Electrolytes measurement
Data Item	Input and output of an Activity/trigger of a criterion.	Case file (patientData: vMR specified)	Body weight measure, Electrolytes normal
Goal	Expected outcome of certain phase.	(goal: specified by GoalProposal in vMR)	Improving oxygenation, Decreasing weight
Criterion	Watches out for important situations to occur.	Expression (GELLO specified expression)	Phase I Treatments should be started after Phase I Baseline starts

1.2. CP Management Components

Care Pathway Builder As the core component in CPW, it is responsible for two main tasks: (1) managing pathways including their creation, editing, saving and transformation, and (2) synthesizing evidence by drag–and-dropping (DnD) from multiple analysis components to the existing CP model.

Care Pathway Transformer This component is introduced to adaptively transform and export CPs to various care management tools in order to create individual care plans based on the defined pathways. As a pilot, transformation from our CP model to care plan template in IBM Patient Care and Insights [8] has been implemented and proven to be beneficial for health care management.

1.3. Analytics Components

Analytics components are developed to retrieve evidence from guidelines and patient data, and then convert to CP elements that can be consumed by Care Pathway Builder.

Guideline Text Annotation retrieves evidence from guidelines by annotating guideline text. With the imported guideline text, a user can go through the guideline text and select whatever he or she thinks can be part of the CP. Currently, this component supports annotation of phases and activities from a piece of text. The annotated pathway elements are created and placed appropriately in the pathway according to the selected source text's positions in the guideline.

Variance Analysis is the process to identify the variations between clinical practice data and existing CPs. The analysis results can be used to further amend the CPs. Given a CP model and EMR traces, variance analysis component first aligns every trace with the model by using the technique of Hidden Markov Models, with the purpose of mapping every care event onto a correct activity. Then, three categories of variations can be identified from the aligned patient traces: (1) Additional activities, which are not defined in the CP model but often occur in the patient traces; (2) Absent activities, which are defined in the CP model but seldom/never occur in the patient traces; and (3) Violated criteria, which are defined in the CP model but often violated

in the patient traces. The violated criteria are detected by applying the technique of linear temporal logic.

The goal of **Care Pathway Explorer** and **Outcome Driven Pathway Pattern Mining** is to utilize historical clinical practice data to extract common sequences of clinical events such as diagnoses and treatments that are present, and perform statistical analysis on how each of these sequences corresponds to patient outcome. They mine frequent event sequences from EMR data of patients by (1) constructing an EMR trace for each patient, (2) adopting a data mining method to mine a set of frequent subsequences from those patient traces, and (3) constructing a bag-of-pattern representation for each patient. By understanding patterns of CPs that lead to healthy outcomes can help users refine the pathway for dealing with the patients with more complex conditions. Some of the mining and visualization capabilities are described in further detail in [9].

After the **Care Pathway Explorer** sends selected patterns back to CPW, they need to be converted to CP elements according to the following rules: (1) each event e in the pattern is transformed as an activity a; (2) if event e_2 is temporally subsequent of event e_1, then their temporal relationship is transformed to the entry criteria: activity a_2's entry criterion is a_1. For example, results of transforming "Diuretics → Heart Failure → Electrolyte" include Diuretics, Heart Failure and Electrolyte as activities; Heart Failure's entry criterion is Diuretics, and Electrolyte's entry criterion is Heart Failure.

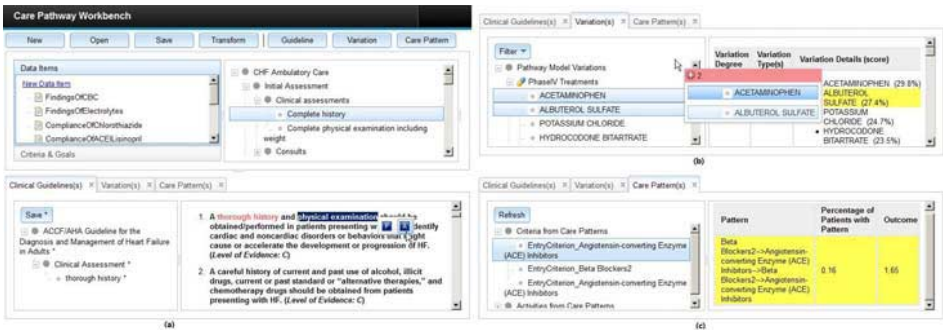


Figure 2. (a) User interface of CPW with CHF Care Pathway (in upper half) and evidence (totally three tabs in bottom half) from clinical guidelines; (b) Evidence from variation analysis and drag-and-drop operation; (c) Evidence from care pattern mining and exploration.

2. Results

Here we describe how a CHF Ambulatory Care Pathway is developed using CPW. First, based on a widely accepted guideline for CHF management [10], the base CHF pathway is created which includes 5 phases at first level and about one hundred activities as shown in Figure 2 (a). The bottom part of Figure 2(a) shows an example of guideline text annotation, where titles such as "Clinical Assessment" are annotated as "Phase" and plain text "thorough history" are annotated as "Activity".

Subsequently, variation analysis is performed by inspecting the base CP against a local data set. This result is shown in Figure 2 (b) where "Acetaminophen" is an additional activity for "PhaseIV Treatments" with 29.8% data support. Together with "Albuterol Sulfate", they are added to the pathway by drag-and-drop. Care pathway

patterns in Figure 2 (c) are also mined from the local data set, in which two patterns with better outcome (>=0.5) and reasonable frequency support (>=0.3) are received from Care Pathway Explorer and then converted to CP elements.

After completing the pathway in need, the user can export it to practical care management systems. As a validation, we have exported the pathway as a care plan template into IBM Patient Care and Insights. Users can then review it and create new care plans from it for patients with CHF.

3. Discussion

We have developed a Care Pathway Workbench to harmonize evidence from clinical guidelines and data-driven insights from real world practices. For now, users need to manually do evidence synthesis. The advantage is that users have sufficient freedom to decide whether to integrate these evidences. One potential shortcoming is once CP models become large and complex, and multiple evidences from different analysis sources are available, it may become a burden for users to make decisions. Thus, our planned future work is to design proper model integration methods to make the process of evidence harmonization more efficient.

Evidence analytics components can be improved too. For example, in Guideline Text Annotation, extracting evidence from guideline text can be automated by employing text analytics. Furthermore, the CP model we defined is not restricted to clinical CPs, and it would not be difficult to apply the model in other areas of case management. For example, IBM Cúram [11] is our next target platform which uses outcome plans to manage social care for citizens.

References

[1] Gooch P, Rousdari A. Computerization of workflows, guidelines, and care pathways: a review of implementation challenges for process-oriented health information systems. J Am Med Infom Assoc. 2011;18(6):738-48.
[2] Schrijvers G, Van Hoorn A, Huiskes N. The care pathway: concepts and theories: an introduction. Int J Integr Care. 2012 Sep 18;12:e192.
[3] Mans, R. S., Schonenberg, M. H., Song, M., van der Aalst, W. M., & Bakker, P. J. Application of process mining in healthcare–a case study in a Dutch hospital. Biomedical Engineering Systems and Technologies. 2009; 425-438.
[4] van der Aalst, Wil MP. Business alignment: using process mining as a tool for Delta analysis and conformance testing. Requirements Engineering 2005; 10(3):198-211.
[5] Object Management Group. Case Management Model and Notation (CMMN) 1.0 Beta 1. [released 2013 Jan. cited 2014 Apr 21]. Available from: http://www.omg.org/spec/CMMN/
[6] HL7 Version 3 Implementation Guide. Virtual Medical Record for Clinical Decision Support. [cited 2014 Apr]. Available from: https://www.hl7.org/implement/standards/product_brief.cfm?product_id=271
[7] HL7 Version 3 Standard: Gello: A Common Expression Language, Release 2. [cited 2014 Apr 21]. Available from: http://www.hl7.org/implement/standards/product_brief.cfm?product_id=5
[8] IBM. IBM Patient Care and Insights. [cited 2014 Apr 21]. Available from: http://www-01.ibm.com/software/ecm/patient-care/
[9] Perer A, Wang F. Frequence: Interactive Mining and Visualization of Temporal Frequent Event Sequences. ACM Intelligent User Interfaces (IUI); 2014; Haifa: Israel.
[10] Hunt S A, Abraham W T, Chin M H, et al. ACC/AHA 2005 guideline update for the diagnosis and management of chronic heart failure in the adult, Circulation. 2005; 112(12):154-235.
[11] IBM. IBM Cúram. [cited 2014 Apr 21]. Available from: http://www-01.ibm.com/software/info/curam/

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Online Dissemination of Clinical Practice Guidelines as Narrative Texts and Structured Pathways: a Case Study with the Treatment of Type 2 Diabetes

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Abstract. Recently, National agencies in charge of the development of clinical practice guidelines (CPGs) have started to improve the usual narrative CPGs to provide guidance for different clinical pathways. In France, in conjunction with the development of the type 2 diabetes National CPGs, we have developed the system RecosDoc-Diabète which allows to interactively build a patient-centred pathway and get the appropriate recommendations. National narrative CPGs and RecosDoc-Diabète were published and made available online at the same time (February 2013). A questionnaire was provided to collect visitors' judgement about the system. Between February 12th and December 31st, 2013, 55,203 visitors accessed the narrative CPGs whereas 10,565 accessed the system. Among them, 186 (2%) responded to the questionnaire. One third of the comments were criticisms towards the CPG content. The system was globally positively evaluated although assessments were mixed illustrating that users' needs may be contradictory.

Keywords. Practice Guidelines as Topic, Guideline publication, Clinical Decision Support Systems, Type 2 Diabetes Mellitus

Introduction

Developed by health professional societies or National health agencies, clinical practice guidelines (CPGs) are usually textual documents expected to improve care quality and promote cost-effective practices. CPGs are widely disseminated and easily accessible through public web-based portals like the National Guideline Clearinghouse (NGC) of

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the Agency for Healthcare Research and Quality in the United States, the Canadian Medical Association or CMA infobase, the National Institute for Health and Care Excellence (NICE) in the UK, or the "Haute Autorité de Santé" (HAS) in France. Because of state regulations newly formulated in most developed countries to guaranty patient safety and assure that high quality care is delivered, private companies have also started to penetrate the CPG market (UpToDate®, MD Consult, Vidal, etc).

However, many barriers to the widespread adherence of clinicians with CPGs have been reported [1]. Despite they should theoretically support clinician decisions, CPGs are indeed extremely criticised and considered abstract, ambiguous, always incomplete, often out of date, and too simple or too complex to be applied to actual patients. Moreover, the sole dissemination of narrative CPGs has proven to have nearly no impact on physician behaviour. Indeed, when querying NGC, CMA, NICE, MD Consult, with the keyword "Diabetes", we got 609, 71, 821, and 86 results respectively[2]. All returns were narrative except the NICE guidance, which provides structured pathways similar to the scenarios of EON [3]. With UpToDate®, the synthesis entitled "Overview of medical care in adults with diabetes mellitus" is about 20 pages long. Thus, finding which CPGs or which parts of CPGs are relevant for a patient condition may take a time often judged incompatible with the length of a medical consultation.

Several reviews [2] have suggested that since clinical decision support systems (CDSSs) are patient-centred, they are appropriate tools to promote CPG use. However, this requires that narrative CPGs be translated into formalized knowledge bases. This complex task is usually carried on once CPGs are published, thus with a delay and with no solution to correctly address the steps of "atomization", "deabstraction", "disambiguation" and "verification of completeness" [4] that knowledge modelling would require. Many authors have claimed that CPGs and their computerized counterpart should be developed as a unique process. In the same way, target CPG users require computerized supporting tools to be delivered at the same time [5,6].

In collaboration with the HAS, we have conducted an experiment to develop the structured formalization of CPG content while its authoring was still in progress [7]. This experiment has been handled on the development of the French CPGs for the therapeutic management of type 2 diabetes (T2D-CPGs). During this process, information exchanges have been made possible between knowledge modellers and CPG authors, improving the quality of both textual and structured versions of CPGs. The structured version of CPGs constitutes the knowledge base of a system named RecosDoc-Diabète, which provides pathways that can be interactively browsed online.

The aim of this paper is to present the results of the simultaneous diffusion of French T2D-CPGs both as narrative documents and structured pathways.

1. Material and Methods

Following the document-based paradigm first developed with OncoDoc [8], the content of HAS T2D-CPGs [9] was modelled and structured as a decision tree. Nodes represent patient criteria and are displayed along with the set of their possible values. Paths are clinical patient profiles for which recommended treatments are proposed at the leaf level. The decision tree is interactively browsed. While clicking at each step on the right value of criteria, the user dynamically selects the right pathway. When the leaf is

[2] Ressources accessed online on January 31, 2014

reached, the summary of the clinical condition (the list of all instantiated criteria) and the therapeutic advices associated to this pathway are displayed. Citations of the recommendations given in textual HAS CPGs are also provided. The RecosDoc-Diabète system is not a full CDSS since the verification of completion has not been performed in order to stick to the content of textual CPGs. In this way, the system is only a re-writing of HAS T2D-CPGs as a structured patient-centred version.

The publication of the new version of French T2D-CPGs was announced during a press conference by the CEO of the HAS accompanied by the head of the CPG department of HAS and the three project leaders. The HAS portal has been updated to integrate a page introducing the new CPGs[3] and presenting the experiment with RecosDoc-Diabète with a link to the system[4]. On the home page of the system, instructions were given with a link to a tutorial. Some warnings were displayed, telling in particular that RecosDoc-Diabète is not a full CDSS and that the gaps existing in the narrative CPGs were reported in the knowledge base of the system. An open anonymous questionnaire was proposed, asking visitors to identify their profile (GPs, diabetologists, other specialists, other health care professionals), specify their type of practice (healthcare facilities, individual practice, group practice, health centers, coordinated care structures), characterize the context of their use of the system, assess its perceived utility and intent to use it, and, finally, collect their comments.

Visits were recorded through the servers' web logs and analysed with awstats v 0.7. Answers to the online questionnaire were stored from PHP scripts on the server, and exported to MS Excel for analysis. Free comments were analysed by the authors.

2. Results

Online traffic was observed for the T2D-CPG page of the HAS site and for the RecosDoc-Diabète system. Figure 1 provides the distribution of visits from the publication date on February 12th, 2013, to December 31st, 2013. The 10,565 system's visits correspond to 19% of the 55,203 CPG page visits. They ranged from 37% of CPG page access at the beginning of the period to around 10% at the end of the year. Most connections to the system (68%) originated directly from the HAS web site.

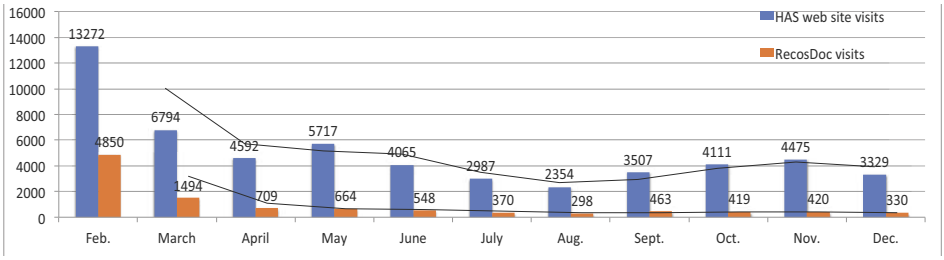


Figure 1. Monthly online visits of the T2D-CPG page and accesses to RecosDoc-Diabète (Feb.-Dec. 2013).

A total of 186 visitors (2% of the visits to RecosDoc-Diabète) responded to the online questionnaire. Table 1 characterizes respondents in terms of profession, years of practice, and type of practice. Many respondents were GPs (64%), most were

[3] http://www.has-sante.fr/portail/jcms/c_1022476/fr/strategie-medicamenteuse-du-controle-glycemique-du-diabete-de-type-2

[4] RecosDoc-Diabète is available online at http://ics.upmc.fr/RecosDoc/diabete/ (in French)

healthcare professionals, and few were patients. One third declared an individual practice. Nearly half of respondents had more than 20 years of professional practice.

Table 1. Profiles of questionnaire respondents

Professions (n=184)	(%)	**Years of practice** (n=179)	(%)	**Types of practice** (n=178)	(%)
GPs	64%	*< 5 y*	21%	*Healthcare facilities*	21%
Diabetologists	6%	*5–10 y*	13%	*Individual practice*	30%
Other specialists	11%	*10–20 y*	18%	*Group practice*	26%
Other HC prof.	12%	*> 20 y*	47%	*Health centers*	4%
Diabetic patients	2%	—		*Coordinated care structures*	3%
Other	5%	—		*Other*	15%

Table 2 reports the answers obtained for the questionnaire. Most visitors (55%) used the system to consult CPG recommendations. It was used to get support for a given patient in 21% of the visits (synchronous: 9% ; asynchronous: 12%). Visitors' judgments were rather positive about the ease of use (87%), and usefulness for routine practice (88%). They also evaluate positively the structuration in pathways to understand narrative CPGs (86%). Most visitors (93%) declared they would use the system sometimes, often, or always. Considering the answers of the 147 physicians, there was no significant statistical association (Fisher's exact test) either with the professional category (GPs vs specialists), or with the years of practice (< 10 vs > 10).

Table 2. Distribution of answers to the questionnaire for the 186 respondents

Questions	**(n)**	**Answers**				
1. Context of use		*CPG knowledge*	*Training*	*Consultation*	*Case*	*Other*
	185	55%	22%	9%	12%	3%
2. Easy to use		*Disagree*	*Tend to disagree*	*Tend to agree*	*Agree*	—
	182	2%	12%	54%	33%	
3. Useful for practice		*Disagree*	*Tend to disagree*	*Tend to agree*	*Agree*	—
	183	3%	9%	50%	38%	
4. Intent to use		*Never*	*Sometimes*	*Often*	*Always*	—
	182	7%	45%	38%	11%	
5. Useful for understanding		*Disagree*	*Tend to disagree*	*Tend to agree*	*Agree*	—
	180	3%	11%	50%	36%	

Among the respondents, 36% (n=67) entered free text comments. Ten could not be interpreted and 3 reported technical problems. On the remaining 54 comments, 17 were about CPGs content, among which 15 were criticisms. The other 37 comments were related to the RecosDoc-Diabète system: 9 were positive, 12 were negative, and 16 were suggestions of developments. Negative comments were: "the decision tree is too complex" (7), "it would be better if the decision tree was totally visualized" (3), "the method is not didactic" (1), and "medicine is an art and cannot be computerized" (1).

3. Discussion

Numerous studies have reported that guideline-based decision support may have an impact on practices when it is provided at the time and location of decision-making and as part of clinician workflow. However bodies in charge of the development of CPGs can only provide a synthesis of the state of the art as narrative documents with the poor impact on practices we know. The development of RecosDoc-Diabète is the first

experience handled by the HAS to provide CPGs in a structured format. Since the publication of CPGs, RecosDoc-Diabète has been accessed less frequently than the narrative CPGs. This can be explained by the poor visibility of the system on the web (badly Google-indexed, scarcely noticeable on the T2D-CPG HAS web page, new service not known by the regular visitors of the HAS website). However, accesses remained at a steady rate, which is an encouraging result. The analysis of the comments posted shows that about 30% of respondents (17/54) took advantage of the space offered to criticize HAS CPGs, found to be poorly evidence-based, essentially made of professional agreements, drug-centred, incomplete, and expressed at a high level of abstraction (using drug classes where commercial names were expected). Comments about the system were contradictory, some respondents found it too complex, others too simple which underlined that "One size does not fit all" with decision support, and that a given static system may not be suitable for both simple and complex patients, or to both expert and novice practitioners. Other respondents proposed to enrich the system with links to pedagogical documentation for patients, students or physicians. A few respondents ask to have RecosDoc-Diabète integrated within their EMR software, or developed as a smartphone application. Since few visitors, less than 1%, responded to the online questionnaire, this may not reflect the position of all visitors, which is a known bias of this kind of voluntary polling. Additional experiences of this kind should be carried on to help structuring clinical pathways and promote CPG implementation.

References

[1] Flottorp S, Oxman A, Krause J, Musila N, Wensing M, Godycki-Cwirko M, et al., A checklist for identifying determinants of practice: A systematic review and synthesis of frameworks and taxonomies of factors that prevent or enable improvements in healthcare professional practice, *Implement Sci.* 2013;8(1):35.

[2] Jaspers MW, Smeulers M, Vermeulen H, Peute LW, Effects of clinical decision-support systems on practitioner performance and patient outcomes: a synthesis of high-quality systematic review findings, *J Am Med Inform Assoc*. 2011;18(3):327–34.

[3] Peleg M, Tu S, Bury J, Ciccarese P, Fox J, Greenes RA, et al., Comparing computer-interpretable guideline models: a case-study approach, *J Am Med Inform Assoc*. 2003;10(1):52–68.

[4] Shiffman RN, Michel G, Essaihi A, and Thornquist E, Bridging the guideline implementation gap: a systematic, document-centered approach to guideline implementation. *J Am Med Inform Assoc*. 2004;11(5):418–26.

[5] Goud R, Hasman A, Strijbis AM, Peek N, A parallel guideline development and formalization strategy to improve the quality of clinical practice guidelines, *Int J Med Inform*. 2009;78(8):513–20.

[6] Shiffman RN, Michel G, Rosenfeld RM, Davidson C, Building better guidelines with BRIDGE-Wiz: development and evaluation of a software assistant to promote clarity, transparency, and implementability, *J Am Med Inform Assoc*. 2012;19(1):94–101.

[7] Bouaud J, Falcoff H, Séroussi B, Simultaneously authoring and modeling clinical practice guidelines: a case study in the therapeutic management of type 2 diabetes in France, *Stud Health Technol Inform*. 2013;186:108–12.

[8] Séroussi B, Bouaud J, and Antoine ÉC, OncoDoc, a successful experiment of computer-supported guide- line development and implementation in the treatment of breast cancer, *Artif Intell Med*. 2001;22(1):43– 64.

[9] Haute Autorité de Santé, *Recommandation de bonne pratique - Stratégie médicamenteuse du contrôle glycémique du diabète de type 2*, January 2013. [Available at http://www.has-sante.fr/portail/upload/docs/application/pdf/2013-02/10irp04_reco_diabete_type_2.pdf - accessed Apr. 11th, 2014].

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Arranging ISO 13606 Archetypes into a Knowledge Base

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Abstract. To enable the efficient reuse of standard based medical data we propose to develop a higher level information model that will complement the archetype model of ISO 13606. This model will make use of the relationships that are specified in UML to connect medical archetypes into a knowledge base within a repository. UML connectors were analyzed for their ability to be applied in the implementation of a higher level model that will establish relationships between archetypes. An information model was developed using XML Schema notation. The model allows linking different archetypes of one repository into a knowledge base. Presently it supports several relationships and will be advanced in future.

Keywords. Archetype, UML, Knowledge base

Introduction

Many of modern electronic health record (EHR) standards make use of the dual model architecture (i.e. ISO 13606). However, the impact of such standards is biased by the limited availability of tools that facilitate their usage and practical implementation. Clinical archetypes provide a means for health professionals to design what should be communicated as part of an electronic health record. The semantic of archetype data fields can be defined by linking these fields to the registers through an "ontology section" [1, 2]. However, a generally accepted method to semantically connect different data fields or archetypes is still missing and it cannot be resolved within the Archetype model of ISO 13606. Development of a higher level model that will enable semantic linking of archetypes and certain archetype data fields within a repository can advance the application of archetype based EHR systems and facilitate for example decision support [3] or medical data visualization [4] where the context of knowledge is very important. This can be further enhanced with semantics if the archetype is linked to knowledge representations, that might, for example, enable the system to act on the information directly e.g., by triggering an alert or notification if the value contained in the Blood test instance is above normal reference suggest some action or provide other existing information. The system that receives an instance of the Blood Test observation should be also able to deliver it to a specialist, who will proceed with its assessment. Archetypes connected to business process stages will allow semantic interoperability on the process level. Classification and categorization of archetypes will reduce the entropy of knowledge.

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Archetypes are defined by Archetype Definition Language (ADL) [5] that currently supports neither inference nor rules to form a knowledge base. One approach to connect archetypes into a knowledge base is the semantic web [6, 7]. Semantic web methods of domain description may be redundant and not specific for the limited applications that use archetyped medical data at the moment.

Transforming archetypes to widely accepted formats simplifies their processing by EHR systems. Several methods were developed to transform ADL archetypes to XML [8]. This allows processing of archetypes and archetyped medical data by electronic health records and facilitates the development of higher level models to organize archetypes into knowledge bases. To develop the information model it is necessary to define the relationships between archetypes that the model will support.

1. Materials and methods

To develop an information model and a method to connect archetypes we analyzed the existing connectors' types that are used to link domain concepts. Existing UML connectors' types were analyzed to find out which of them can be applied to connect different archetypes or archetype data fields and to set up the semantically meaningful relations. ISO 13606 archetype model allows definition of different relationships between archetypes connection. So the structure of the ISO 13606 archetype model was studied to find out which relationships are already implemented in the model and which are missing. The examples of weaknesses and advantages of ISO 13606 models were studied and presented in the paper. Some of UML connectors [9] were implemented in the model. XML Schema approach [10] was used to specify the information model. A web-application was developed to prove the concept and test the feasibility of the developed approach. The "Association" connector was implemented to bind [value]-[Normal interval] association for laboratory results archetypes. The application was implemented in Microsoft Visual Studio using asp.net and XSL templates that process XML visual medical concept files to present EHR content to users.

2. Results

The following UML connectors' [9] were analyzed for the possibility to be applied to organize an archetype based knowledge base.

Abstraction

An abstraction relationship is a dependency between model elements that represent the same concept at different levels of abstraction or from different viewpoints. You can add abstraction relationships to a model in several diagrams, including use case, class, and component diagrams. Archetypes of one type i.e. blood test may be attributed to a different level of abstraction depending on the requirements of a certain specialist. It can be focused i.e. to a diabetologist emphasizing the parameters special for diabetes or can be a general blood test.

Aggregation

An aggregation relationship depicts a classifier as a part of, or as a subordinate to, another classifier. This is already implemented in the ISO 13606 archetype model. Archetypes are extensible formal constraint definitions of object structures. In common with object model classes, they can be specialized, as well as composed (i.e.

aggregated). An archetype may have a container for another archetype. This can be used to define complex medical documents that consist of several concepts. However, the model implemented as including of one archetype into another while modeling and does not imply consistency if one of the archetypes is changed later.

Composition

A composition relationship represents a whole–part relationship and is a type of aggregation. A composition relationship specifies that the lifetime of the part classifier is dependent on the lifetime of the whole classifier. In archetype model there exist a composition type of relationship. This is used to form whole Compositions in the EHR, e.g. for "discharge summary", "antenatal exam" and so on. However, this corresponds to the aggregation connector in UML.

Association

An association relationship is a structural relationship between two model elements that shows that objects of one classifier (actor, use case, class, interface, node, or component) can connect and can navigate to objects of another classifier. This is a very important relationship for medical concepts. There exist several types of associations that are used on the daily basis by the doctors and cannot be implemented within the archetype model of ISO 13606. For example [value]-[Normal Interval] or [Secondary diagnosis]-[Primary diagnosis] especially when this relationship is one to many.

Directed association

A directed association relationship is an association that is navigable in only one direction and in which the control flows from one classifier to another (for example, from an actor to a use case). Only one of the association ends specifies navigability.

Dependency

A dependency relationship indicates that changes to a one model element (the supplier or independent model element) can cause changes in another model element (the client or dependent model element). The supplier model element is independent because a change in the client does not affect it. The client model element depends on the supplier because a change to the supplier affects the client.

Generalization

A generalization relationship indicates that a specialized (child) model element is based on a general (parent) model element. Although the parent model element can have one or more children, and any child model element can have one or more parents, typically a single parent has multiple children. Generalization is used in several archetype modeling tools e.g. LinkEHR [5]. One generic archetype can be specialized by adding specific names and values to the generic archetype. For example a generic laboratory test archetype becomes a basis for a Blood sugar archetype.

Realization

A realization relationship exists between two model elements when one of them must realize, or implement, the behavior that the other specifies. This relationship is implemented by the openEHR Template model where a user can specify localization properties of an archetype. For example reference interval, data fields names, language properties and so on. However, there exist no mechanism to maintain consistency of the [archetype]-[template] relationship when the archetype is changed.

A possible archetype repository is presented in Figure 1. Archetypes are connected by the proposed UML connectors.

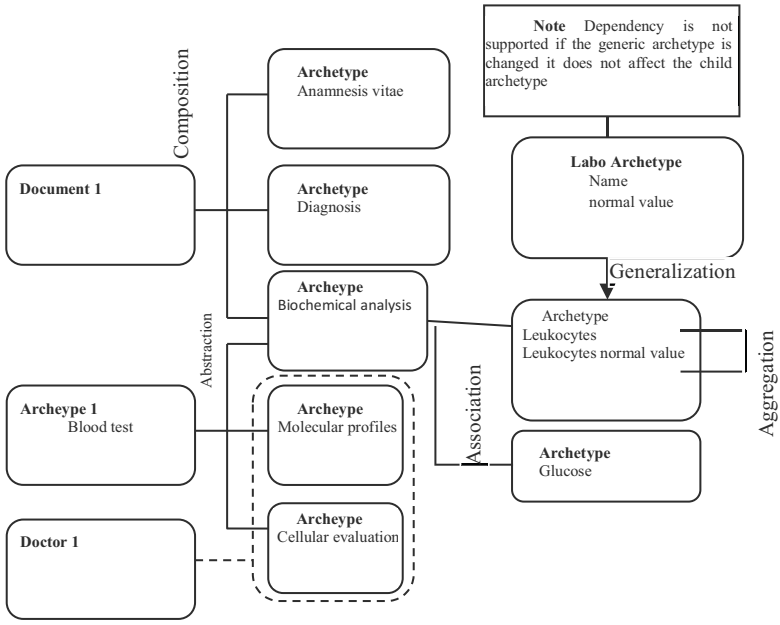


Figure 1. Application of UML connectors in an archetype repository

To demonstrate the example of how the archetypes can be connected within a repository we can have a look at a group of archetypes for Blood tests (figure 1). There can exist several abstractions for a blood test: cellular test, molecular profiles and biochemical analysis. Archetypes can be combined to fulfill different needs. For example each doctor can use his/her own set of archetypes, or archetypes with different level of abstraction, e.g. blood test can be more or less detailed for different specialists.

Archetypes are hierarchical structures and support an XPath-like definition to access substructures. An information model that allows building a knowledge base was developed considering the archetype model of ISO 13606 in form of XML schema to ensure a full compatibility with archetypes. Each information model entity (ME) is stored as XML file, which can be generated manually or partially automatically. An instance is logically divided into two main sections: metadata and medical content. The metadata section specifies the properties of the ME. The data fields are derived from different archetypes and combined into groups. The groups allow specifying the user context for each element. This allows not only connecting different archetype and archetype data fields but enables more specified description of each medical document. The developed information model is based on the archetype model of ISO 13606. The archetypes and information model instances that contain relationships between archetypes and archetype data fields are placed on the instance level. On the data level ME files with specified content and properties are associated with corresponding XML medical data files.

3. Discussion

Connecting archetypes within a domain model will expand the application of archetype based electronic health records. The methods to connect archetypes that are available in the ISO 13606 archetype model are not sufficient and consistent. This can

be advanced by implementing a higher level information model. The model must support at least the relationships that are defined in UML. The information model complementing the archetype layer must be able to provide different semantic for connectors. For example “Association” connector may have different meanings such as [value]-[normal interval], [primary diagnosis-secondary diagnosis]. Modification of existing UML connectors in order to apply different logical mechanisms, e.g. fuzzy logic [11], modal logic [12] will enable expressing knowledge more explicitly and closed to the reality.

4. Conclusion

The UML connectors were analyzed for their ability to be applied in the implementation of a higher-level model that will establish relationships between archetypes. An information model was developed using XML Schema notation. The model allows linking different archetypes of one repository into a knowledge base. Presently it supports several relation-ships and will be advanced in future. The introduced information model allows semantic connection of different archetypes or archetype data fields. The implemented web-application shows a high potential of the developed models and specifications.

References

[1] S. Yu, D. Berry, J. Bisbal, Clinical coverage of an archetype repository over SNOMED-CT, *Journal of biomedical informatics*, **45** (2012) 408-418.
[2] M. Menarguez-Tortosa, C. Martinez-Costa, J.T. Fernandez-Breis, A generative tool for building health applications driven by ISO 13606 archetypes, *Journal of medical systems*, **36** (2012) 3063-3075.
[3] S. Garde, R. Chen, H. Leslie, T. Beale, I. McNicoll, S. Heard, Archetype-based knowledge management for semantic interoperability of electronic health records, *Studies in health technology and informatics*, **150** (2009) 1007-1011.
[4] G. Kopanitsa, Standard based multiclient medical data visualization, *Studies in health technology and informatics*, **180** (2012) 199-203.
[5] J.A. Maldonado, D. Moner, D. Bosca, J.T. Fernandez-Breis, C. Angulo, M. Robles, LinkEHR-Ed: a multi-reference model archetype editor based on formal semantics, *International journal of medical informatics*, **78** (2009) 559-570.
[6] M. Arg, #252, e. Casteleiro, J.J.D. Diz, Clinical practice guidelines: A case study of combining OWL-S, OWL, and SWRL, *Know.-Based Syst.*, **21** (2008) 247-255.
[7] C. Martinez-Costa, M. Menarguez-Tortosa, J.T. Fernandez-Breis, J.A. Maldonado, A model-driven approach for representing clinical archetypes for Semantic Web environments, *Journal of biomedical informatics*, **42** (2009) 150-164.
[8] C. Rinner, S. Janzek-Hawlat, S. Sibinovic, G. Duftschmid, Semantic validation of standard-based electronic health record documents with W3C XML schema, *Methods of information in medicine*, **49** (2010) 271-280.
[9] IBM, Designing a software application using models, in, 2005.
[10] J.A. Maldonado, D. Moner, D. Bosca, J.T. Fernandez, C. Angulo, M. Robles, Semantic upgrade and normalization of existing EHR extracts, *Conference proceedings : ... Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE Engineering in Medicine and Biology Society. Conference*, **2008** (2008) 1466-1469.
[11] B. Prados-Suarez, C. Molina, C. Pena Yanez, M. Prados de Reyes, Contextualized access to electronical health records in cardiology, *IEEE transactions on information technology in biomedicine : a publication of the IEEE Engineering in Medicine and Biology Society*, **16** (2012) 401-412.
[12] [J. Feldman, Symbolic representation of probabilistic worlds, *Cognition*, **123** (2012) 61-83.

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Using an Ontological Modeling to Evaluate the Consistency of Clinical Practice Guidelines: Application to the Comparison of Three Guidelines on the Management of Adult Hypertension

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Abstract. Every year, numerous clinical practice guidelines (CPGs) are published on a same topic. They may be conflicting, thus infringing clinicians' confidence in adhering to them. In order to build a clinical decision support system to assist GPs in the management of hypertension, we have considered three recent CPGs written in French. We developed a methodological framework to evaluate how consistent the three CPGs were. After a manual extraction of recommendation rules, all patient profiles covered by the CPGs have been identified. Then, ontological modeling and reasoning were used to build a subsumption graph of all profiles. This graph allows the retrieval of recommendations that could be conflicting. Results show that if rules are different in the three CPGs according to a document-based approach, many profiles are related through subsumption, and no critical inconsistencies were discovered when implementing an ontological modeling.

Keywords. Practice guidelines as topic, Medication therapy management, Knowledge comparison, Ontology, Hypertension

Introduction

Clinical practice guidelines (CPGs) are recommendations on the appropriate treatment for patients with specific diseases and conditions. Relying on the scientific literature, and a priori evidence-based, CPGs are intended to optimize patient care. However, CPGs published on a same given topic are usually inconsistent which is recognized as a barrier to guideline adherence [1]. Numerous reasons can explain this inconsistency, including the fact that CPGs are developed at different dates and by different

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institutional bodies. Indeed, since evidence is often missing, CPGs are mostly based on consensus statements made among the members of the guideline development group. Thus, choosing relevant CPGs for a given patient is a practical issue for clinicians [2]. In the domain of hypertension management, results are mixed with studies retrieving significant differences between CPGs (*e.g.* [3]) and a recent survey reporting consistent recommended practices across different countries [4].

Because they operate in a patient-centred approach, clinical decision support systems (CDSSs) are considered efficient tools to promote guideline-based care [5]. They usually rely on the CPGs developed by the national agency in charge of CPG development. In France, the last CPGs on the management of hypertension (HT) have been published in 2005 and there is no updated version. Thus, in order to build a CDSS to support GPs in the management of HT, we needed first to choose the CPGs to be used as knowledge resources, and then perform a knowledge modeling step to translate the narrative CPGs into a formalized representation. We conducted a literature search and got three CPGs published in French on the management of HT in 2013. A preliminary comparison of the conceptual coverage of these CPGs showed an overlap of more than 50% of the concepts used, but also highlighted some specificities [6].

However, the fact that CPGs share concepts does neither mean they share the same set of patient profiles for which recommendations are given nor that the recommendations provided are identical. Thus, a deeper analysis was necessary to assess how consistent the recommendations issued from the three different CPGs on HT were. We first represented CPGs as rules to compare them. In order to go beyond the strict comparison of texts and take into account the different levels of abstraction of rules, we performed an ontological modeling. The aim of this work was to use subsumption on rule conditions representing patient profiles to identify how the different recommendations may be related and to assess CPGs' inconsistencies.

1. Materials and Methods

The three CPGs we worked with were (i) SFHTA guidelines, developed for GPs by the French society on hypertension, (ii) Vidal Recos HTA (VR-HTA), published and updated continuously by Vidal, a French company that markets the drug database namesake, and (iii) CHEP guidelines, edited by Hypertension Canada, a learned society which aims at covering all aspects of HT management. To perform an ontological reasoning, we used the ontology OntolUrgences, developed in our research laboratory for the LERUDI project [7]. This ontology organizes approximately 10,000 concepts mainly related to common signs, symptoms and pathologies of patients admitted in an emergency department. We implemented the following steps to compare the CPGs:

1. *Rule extraction.* A rule is classically made of a condition part and of an action part. Each of the three CPGs was manually processed by different persons (AG, JB, BS) working independently, in order to identify the decision rules related to the therapeutic management of HT. Then, the three sets of rules were shared and consolidated in a unique list of rules. Criteria of the condition parts were normalised to avoid variants. When a criterion was aligned with a concept of OntolUrgences, this concept was used. The condition part is a conjunction of concepts C_i that describes a patient condition, or patient profile noted P_n:"$C_1 \wedge C_2 \wedge \ldots \wedge C_p$" (*e.g.* P:"HT∧Bradycardia"). The action part was standardised, but not formalized, and included the recommendations, its location within the text,

and the level of evidence. It must be noted that several rules, possibly from distinct CPGs, could have the same profile although their actions could be concurrently applied.

2. *Ontology enhancement.* Since all concepts used in patient profiles did not exist in OntolUrgences, new concepts were added within the existing subsumption hierarchy. For instance, HT had no subclass and SystolicHT and DiastolicHT were added as sibling subclasses of HT. Categorical data have been treated as standard classes (*i.e.* not data properties). Protégé was used as the ontology editor.
3. *Profiles classification*. Since profiles are expressed as conjunctions of concepts, they are implicitly organized in a subsumption hierarchy. For instance, a profile P_1:"C_a" subsumes P_2:"$C_a \wedge C_b$", and P_3:"C_c" if C_a subsumes C_c. This implies that all rules subsuming another rule through their profiles also apply on the subsumed profile. All profiles extracted from CPGs were represented as new concepts and classified with an OWL reasoner yielding a subsumption graph of profiles.
4. *Assessment of recommended actions*. All actions issued from a given patient profile's subsuming rules were collected and categorized with respect to their consistency as follows:
   a) No inconsistency: all actions are similar or redundant (*e.g.* "modify treatment" and "change treatment").
   b) Potential inconsistency: actions may lead to a decisional conflict depending on the nature and origin of the inconsistency:
      - Action extension: An action is extended by a new action. For instance, a more specific situation requires that a new action is added to what is done in the general case (*e.g.* "add aspirin to current treatment").
      - Action restriction: An action is restricted by a new action. The restriction between actions can be explained by the specialization of associated profiles. For instance, a criterion specializing a given profile (*e.g.* "ACEi contraindication") restricts the possible actions for this profile (*e.g.* ACEi can no more be indicated and should be substituted by ARBs).
   c) Inconsistency: Actions are contradictory (*e.g.* "prescribe BBs" and "do not prescribe BBs"). These conflicting situations may come from rules of different CPGs, or from very specific profiles within the same CPGs.

2. Results

The modeling process of the three CPGs led to the identification of 205 decision rules (28 for SFHTA, 62 for VR-HTA, and 115 for CHEP) among which 165 rules, specifically dedicated to the therapeutic management of HT, were analysed. Table 1 provides examples of these rules. The 165 rules correspond to 138 different patient profiles (profiles have been initially numbered according to rules number, from P1 to P205, before common profiles belonging to multiple rules were taken into account). When comparing patient profiles, only two profiles were identically found in the three CPGs (P1:"HT" and P11:"HT ∧ GoalNotReached ∧ CurrentBitherapy"), one profile was shared by VR-HTA and CHEP, one profile was shared by VR-HTA and SFHTA, and 21, 35, and 78 profiles were specific to SFHTA, VR-HTA, and CHEP respectively.

Table 1. Examples of rules extracted from the 3 CPGs with their patient profiles

	Rules		
CPGs	**Id**	**Patient Profiles (Condition part of rules)**	**Actions**
SFHTA	R1	P1:HT	ACEi, ARBs, CCBs, TDs, BBs recommended ; ACEi +ARBs contraindicated ...
SFHTA	R11	P11:HT ∧ GoalNotReached ∧ CurrentBitherapy	Adjust dose or modify bitherapy or prescribe tritherapy
VR-HTA	R49	P11:HT ∧ GoalNotReached ∧ CurrentBitherapy	Adjust dose or prescribe tritherapy
VR-HTA	R78	P78:HT ∧ Bradycardia	BBs contraindicated
CHEP	R113	P11:HT ∧ GoalNotReached ∧ CurrentBitherapy	Prescribe tritherapy
CHEP	R162	P162:HT ∧ CardiacFailure ∧ GoalNotReached	Prescribe ACEi+ARBs

A total of 121 concepts were used to represent all rule profiles. Sixteen of these concepts (13%) were found in OntolUrgences (*e.g.* HT, Systolic BP, Bradycardia…). The remaining 105 concepts were added (*e.g.* GoalNotReached, CurrentTreatment, etc).

The 138 patient profiles were then classified using an OWL reasoner, yielding a profile subsumption graph. Figure 1 shows an excerpt of this graph starting with P1:"HT" which subsumes all other profiles. We observed 36 isolated profiles (only subprofiles of P1) that corresponded to particular conditions, *e.g.* P78:"HT ∧ Bradycardia". We also observed 10 different groups of profiles connected by subsumption links (*e.g.* P134:"HT and age>50" subsumes P27:"HT and age≥80").

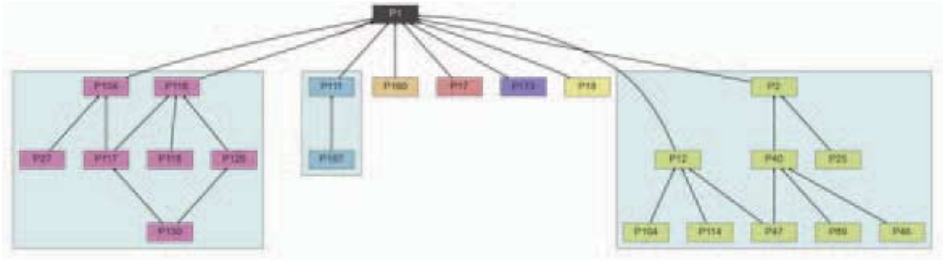


Figure 1. Excerpt of the subsumption graph for the 138 profiles extracted from the rules of the 3 CPGs.

When subsumption relationships are taken into account, we found that each profile was subsumed by at least one rule of each CPGs. This is due to the fact that the root profile P1:"HT" is used by the rules of the 3 CPGs. However, when P1 is not considered since it provides very general recommendations, 10 profiles were covered by the 3 CPGs, 44 by only 2 CPGs, and 83 by only one CPGs.

Regarding the consistency of conclusions provided by all the rules that subsume a given profile, we observed the following distribution: 38 cases of no inconsistency, 95 cases of potential inconsistency (15 cases of extension, and 80 cases of restriction), and 6 cases of inconsistency *(*for example, P162:"HT ∧ CardiacFailure ∧ GoalNot Reached" recommends the combination of ACEi and ARB which is contraindicated by P1:"HT", a more general profile).

3. Discussion

The method we developed was designed to assess the consistency of several CPGs covering the same topic. It was applied to three CPGs on the therapeutic management of hypertension. Usual CPG modeling showed that the patient profiles considered by CPGs were mainly distinct with only 2 profiles shared by the 3 CPGs over a total of 138. CPGs are indeed not written with the same level of abstraction and do not focus on the same particular conditions. However, when performing an ontological reasoning, it appears that many profiles are linked and organized by subsumption relationships.

The analysis of the different profiles and of their associated recommended actions, obtained through the subsumption graph of profiles, showed that for the majority of profiles (100/138) the recommended actions might appear as potentially inconsistent. This could explain why CPGs are considered conflicting. However, the elicitation of the subsumption order between rules provides an explanation of these apparent conflicts. Most often, the more specific rule superseded more general rules as expected, but this is not always the case. An improvement of the method would be an ontological representation of therapeutic actions. Thus, an automated and objective comparison of the recommended actions associated to patient profiles could be performed.

Finally, no critical inconsistencies were found between the recommended actions of the three hypertension CPGs. Therefore, we can assume that these CPGs would be good candidates for the building of a multiple guideline-based CDSS. Our approach also introduces the assets of ontological modeling for decision support. It would give a way for GPs to vary the abstraction and best match the profile of their patient within a set a decision rules. However, it should be noted that if CPGs can be considered consistent in abstracto, complex actual patients are represented by profiles not explicitly anticipated in CPGs that might trigger several rules, which would generate possible inconsistencies.

References

[1] Flottorp S, Oxman A, Krause J, Musila N, Wensing M, Godycki-Cwirko M, et al., A checklist for identifying determinants of practice: A systematic review and synthesis of frameworks and taxonomies of factors that prevent or enable improvements in healthcare professional practice, *Implement Sci.* 2013;8(1):35.

[2] Ferket BS, Colkesen EB, Visser JJ, Spronk S, Kraaijenhagen RA, Steyerberg EW, et al., Systematic review of guidelines on cardiovascular risk assessment: Which recommendations should clinicians follow for a cardiovascular health check? *Arch Intern Med*. 2010;170(1):27–40.

[3] Georg G, Colombet I, Durieux P, Ménard J, Meneton P. A comparative analysis of four CPGs for hypertension management. *J Hum Hypertens*. 2008;22(12):829–37.

[4] Chalmers J, Arima H, Harrap S, Touyz RM, Park JB, Global survey of current practice in management of hypertension as reported by societies affiliated with the International Society of Hypertension, *J Hypertens.* 2013;31(5):1043–8.

[5] Jaspers MW, Smeulers M, Vermeulen H, Peute LW. Effects of clinical decision-support systems on practitioner performance and patient outcomes: a synthesis of high-quality systematic review findings. *J Am Med Inform Assoc*. 2011;18(3):327–34.

[6] Galopin A, Bouaud J, Pereira S, Séroussi B, Comparison of clinical practice guidelines from a knowledge modeling perspective: a case study with the management of hypertension. EFMI Special Topic Conference (STC), 2014, Budapest, *To appear*.

[7] Charlet J, Declerck G, Dhombres F, Miroux P, Gayet P, Vandenbussche PY, Building a medical ontology to support information retrieval: terminological and metamodelization issues. Proc. of the10th International Conference on Terminology and Artificial Intelligence; 2013 Oct 28-30:171–178;. Villetaneuse, France

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A Service Oriented Approach for Guidelines-based Clinical Decision Support using BPMN

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Abstract. Evidence-based medical practice requires that clinical guidelines need to be documented in such a way that they represent a clinical workflow in its most accessible form. In order to optimize clinical processes to improve clinical outcomes, we propose a Service Oriented Architecture (SOA) based approach for implementing clinical guidelines that can be accessed from an Electronic Health Record (EHR) application with a Web Services enabled communication mechanism with the Enterprise Service Bus. We have used Business Process Modelling Notation (BPMN) for modelling and presenting the clinical pathway in the form of a workflow. The aim of this study is to produce spontaneous alerts in the healthcare workflow in the diagnosis of Chronic Obstructive Pulmonary Disease (COPD). The use of BPMN as a tool to automate clinical guidelines has not been previously employed for providing Clinical Decision Support (CDS).

Keywords. Clinical Guidelines, BPMN, Service Oriented Architecture, Clinical Decision Support

Introduction

The process of healthcare service delivery is composed of workflows. Dwivedi [1] presented a dynamic connection between healthcare, workflow and internet technologies, and proposed that workflow management systems can significantly influence the performance and outcome of a healthcare service. [2] identified that workflow tools have a potential to significantly improve healthcare delivery by augmenting the clinician's decision making in the form of alerts and reminders, a functionality of CDS. Healthcare workflows have been modelled using a number of techniques.[3] and BPMN has been relatively a new technology for this purpose. Several implementations exists[4][5] which are used to model the workflow in a diagnosis or treatment process using BPMN. "*BPMN is a graphical notation that depicts the end to end flow of a business process. It coordinates the sequence of processes and the messages that flow between different process participants in a related set of activities."*[6]

Clinical guidelines are recommendations on the appropriate treatment and care of people with specific diseases and conditions [7]. They are developed by research into the latest medical evidence base presented in a narrative manner. Clinical pathways

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visually represent a guideline, using process flow diagrams to guide a physician during patient-physician encounters.[4]. Clinical guidelines serve as strong evidence to facilitate a physician in making patient specific decisions[8]. Clinical decision support system (CDSs), assist a physician in making patient-specific inferences by utilizing patient data and clinical knowledge.

There is a need to integrate guidelines with the available information systems used by a physician like Electronic Health Record systems (EHRs). [9] show a mechanism for integrating guidelines within the EHR.[10] propose integrating clinical pathways into CDSs. To improve clinical outcome, there is a need for providing guidelines based CDS for physicians using different EHRs. To avoid complexity while designing such a system, the guidelines based decision rules need to be separated from the actual EHR or CDSs. By taking advantage of the potential of BPM and workflow technology in healthcare, we propose that using a workflow management system(WfMS) as a tool to automate clinical guidelines can be a novel approach for enabling CDS in a healthcare setting. To achieve this goal, the functionality needs to be distributed among various components participating in the healthcare workflow in order to allow maximum independence between the technologies thus enabling interoperability among EHR environments implemented using different software.

As healthcare processes continually evolve, there is a need to separate the business process functionality from technology infrastructure [11]. Service Oriented Architecture (SOA) is a widely adopted approach used for enterprise information systems to address this issue by sharing distributed services like clinical decision support as Web Services[12]. One approach popular with SOA use is the Service Component Architecture (SCA) [13].

1. Methods

Figure 1 shows a brief architecture overview of the project.

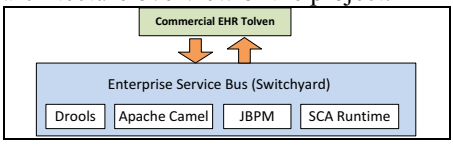


Figure 1: High level Architecture

In order to achieve the aim of providing CDS at the point of care, the architecture is designed using several open source components that allow developing services with different functionality that can work together. Commercial EHR Tolven [14] is used as a physician's interface for capturing patient data. This is also the interface where an alert will be received by the physician to facilitate clinical decision making. We use the enterprise service bus Switchyard [15] which is a "component-based development framework for building structured, maintainable services and applications based on best practices of SOA". jBPM, Drools and Apache Camel are accessed from within the ESB in order to keep our rules functionality easily accessible by EHRs. JBoss Drools is a java based open-source business logic integration platform based upon the RETE's algorithm [16]. jBPM is a java based workflow engine that allows for the execution of a business process using the BPMN 2.0 specification [17]. Apache Camel works as a message transformation and communication mechanism [18]. SCA Runtime is the Service Component Architecture specification supported by the ESB Switchyard.

For our methodology, we have followed BPM Process lifecycle[19]. This lifecycle is used for modeling, automating, and executing business processes and is similar to a software development process from defining requirements to deployment. Using the tools constituting the proposed architecture, the BPM process is divided in the following steps: **1)** ***Identify Business Process Workflow:*** We use the NICE Clinical Pathway for Chronic Obstructive Pulmonary Disease Diagnosis (COPD)[20]. We separate out the decision rules that govern the completion of each step in the workflow. e.g. checking for a patient age, problems and smoking assessment. 2) ***Model Process Visually***: We create a graphic model using Eclipse BPMN 2 Modeller. At this stage the rule logic is separated as tasks. Figure 2 shows a BPMN Model of the diagnosis scenario. A rule for checking the age of the patient is shown in the box.

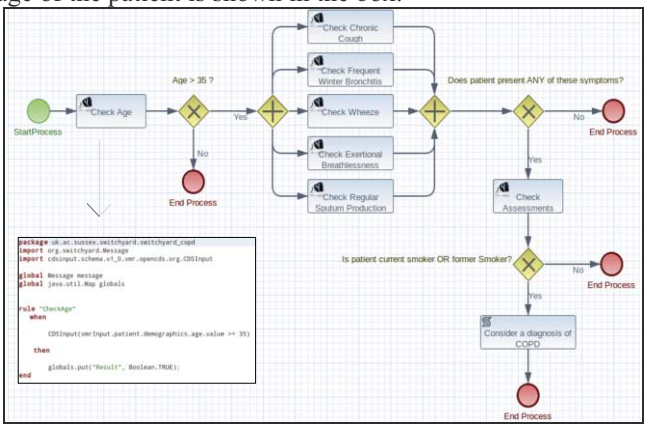


Figure 2: BPMN Representation of COPD Guideline

3)Develop Runtime Components: Develop tasks defined in the workflow as SCA Components. Each Task/component(e.g. check age etc.) can be wired together to a process "COPD Clinical Guideline" as shown in Figure 3.

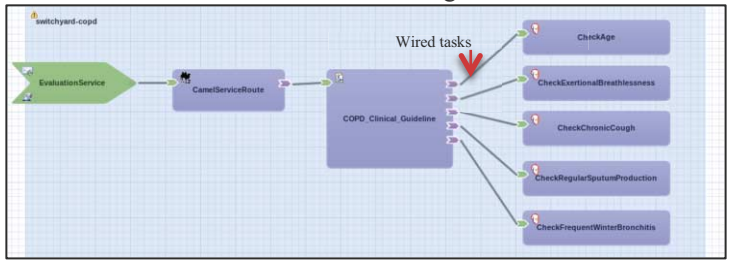


Figure 3: SCA Composite Service

4)Deploy Runtime Engine: This stage involves deploying the composite component to the SCA Runtime environment. The SCA component "Evaluation Service" is exposed as a reusable service for multiple EHRs.***5) Instantiate Runtime Instance:*** Execute Request and response process between SCA composite service and EHR. This is a sequence of five steps: **a)** A request is generated from the EHR to the SCA composite sending the problems list and patient demographics as recorded by the physician. This data is transferred as HL7/OMG CDSS [21] based SOAP message . Apache route service extracts the Base 64 encoded Payload based on HL7 Virtual Medical Record (vMR) [22] format. The vMR is transformed to java objects that are accessible by the

processes (e.g. check chronic cough, check wheeze etc).Here the medical terminology is specified according to the incoming semantic language systems like LOINC, SNOMED codes etc. b) Once the rule conditions are met, a response is sent from SCA composite to Tolven in the form of an alert, suggesting smoking assessment. **c)** The smoking assessment is recorded in Tolven by the physician and the results (patient demographics, problems list and smoking assessment) are sent as a request to SCA composite **d)** As a response, an alert is generated by the SCA composite stating "Consider diagnosis for COPD" for the physician at the Tolven interface as shown in figure 4.



Figure 4 EHR Interface showing Problems, Assessments and Alerts

2. Results

We have presented an implementation of the early stages of diagnosis in COPD Guidelines. We have shown that BPMN can be successfully used to model a clinical pathway. The architecture presented adheres to the SOA principles by using SCA composite web services, Drools, Apache Camel and jBPM deployed in the ESB. The ESB allows for robust message transformation and communication across EHRs. The combined functionality of these components enables a CDSS. The CDS capability was manifested in the Tolven interface resulting in alerts. We evaluated our system by recording the response time for CDS service for simultaneous requests by 20 users . The service response time was less than one second. The same results were recorded for requests by 40 and 50 users. The guidelines can be interacted with a number of different EHRs. This is possible because the clinical guideline is presented as a web service rather than being tied to a particular clinical decision support system or an EHR.

3. Discussion

The modelling approach we have used provides an alternate mechanism to model a clinical process. BPMN provides a visual interface to model the processes specified in the clinical guidelines. While basic clinical knowledge is represented using IF-THEN format as rules. This allows for the physicians and the domain experts to model the rules and processes in a guideline without looking at the implementation details. The clinical knowledge expressed in rules using Drools are human-readable and can be modified dynamically. The aim of automating clinical guidelines based decision support is to improve clinical outcome. This solution triggers alerts in the current workflow for the physician which facilitates the diagnostic process by saving time and improving patient safety. From a software development point of view ,SCA hides complexities such as web service security and policies, hence allowing the developers

to focus on business logic. One of the most promising characteristic of SCA is that it provides reusability. A decision Support system based on ESB as an architectural approach provides loose coupling for collaborating applications that can accept data formats from various sources and integrate data flows into the appropriate EHRs, thus ensuring interoperability and reusability An ESB separates the integration logic into manageable pieces and is highly scalable .The future directions for our work are two-fold: 1) Add a terminology web service to address semantic interoperability of data coming from systems using different terminology standards. 2) Integrate related guidelines for example: alternate diagnosis requests for guidelines on other diseases/conditions. The current implementation (SCA composite) is a relatively simple guideline but it can be utilized by more complex guideline implementations, hence promising reusability.

References

[1] Dwivedi A, Bali R, James A, and Naguib R. Workflow management systems: the healthcare technology of the future? In *the* 23rd Annual International Conference of the IEEE Engineering in Medicine and Biology Society. 2001; 4: 3887-90, 2001.

[2] Emanuele J, Koetter L. Workflow Opportunities and Challenges in Healthcare. In: Fischer L, editor. BPM & Workflow Handbook. 1st ed. Florida: Future Strategies Inc; 2007.p 157-66

[3] Gooch P, Roudsari A. Computerization of workflows, guidelines, and care pathways: J Am Med Inform Assoc. 2011 Nov-Dec;18(6):738-48.

[4] Kirchner K, Malessa Ch, Herzberg N, Krumnow S, Habrecht O, Scheuerlein H, Bauschke A, Settmacher U. Supporting liver transplantation by clinical pathway intelligence. Transplant Proc. 2013 Jun;45(5):1981-2.

[5] Rojo MC, Calahorra L, Ruiz F. BPMN in practice. Experiences of business modeling in the department of pathology. Diagnostic Pathology, 2010; 5(Suppl 1):S4

[6] OMG, Business Process Model And Notation (BPMN) Version 2.0, January 2011.

[7] Paleg M. Guidelines and Workflow Models. In: R. Greenes editor. Clinical Decision Support: The Road Ahead. 5th ed. Elsevier.2007 p.281-306.

[8] Sim I, Gorman P, Greenes RA, Haynes RB, Kaplan B, Lehmann H, et al. Clinical decision support systems for the practice of evidence-based medicine. J Am Med Inform Assoc. 2001 Nov-Dec;8(6):527-34

[9] Schadow G, Russler DC, McDonald CJ. Conceptual alignment of electronic health record data with guideline and workflow knowledge. Int J Med Inform. 2001 Dec;64(2-3):259-74

[10] Yao W, Kumar A. CONFlexFlow: Integrating Flexible Clinical Pathways into Clinical Decision Support Systems using Context and Rules, Decision Support Systems. 2013 May; 55(2): 499-515.

[11] Lenz R, Reichert M. IT support for healthcare processes - premises, challenges, perspectives. Data & Knowledge Engineering. 2007 April;61(1): 39-58

[12] Kawamoto K, Jacobs J, Welch BM, Huser V, Paterno MD, Del Fiol G et al. Clinical Information System Services and Capabilities Desired for Scalable, Standards-Based, Service-Oriented Decision Support. AMIA Annual Symposium Proceedings, 2012:446–55.

[13] Service Component Architecture Assembly Model Specification, Version 1.1, Available from http://docs.oasis-open.org/opencsa/sca-assembly/sca-assembly-spec-v1.1-csprd03.pdf.

[14] Tolven open source solutions, Tolven Inc. 2014 [Internet]Available from : http://home.tolven.org/

[15] JBoss Switchyard[Internet]. Available from: http://www.jboss.org/switchyard

[16] JBoss Drools [Internet]. Available from: http://www.jboss.org/drools

[17] JBoss jBPM [Internet]. Available from: https://www.jboss.org/jbpm

[18] Apache Camel [Internet]. Available from: http://camel.apache.org/

[19] Davis J. Introducing jBPM. In: Open Source SOA, Greenwich Manning Publications Co.2007. p. 125-56

[20] National Institute for Health and Care Excellence [Chronic obstructive pulmonary disease (updated)]. [CG101]. London: 2010. Available from: http://www.iasp-pain.org/am

[21] OMG Clinical Decision Support Service (CDSS) http://www.omg.org/spec/CDSS/1.0/

[22] HL7 Virtual Medical Record for Clinical Decision Support http://www.hl7.org/implement/standards/product_brief.cfm?product_id=271

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Towards a Web-Based Decision Support Tool for Selecting Appropriate Statistical Test in Medical and Biological Sciences

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Abstract. Statistical hypothesis testing is an essential component of biological and medical studies for making inferences and estimations from the collected data in the study; however, the misuse of statistical tests is widely common. In order to prevent possible errors in convenient statistical test selection, it is currently possible to consult available test selection algorithms developed for various purposes. However, the lack of an algorithm presenting the most common statistical tests used in biomedical research in a single flowchart causes several problems such as shifting users among the algorithms, poor decision support in test selection and lack of satisfaction of potential users. Herein, we demonstrated a unified flowchart; covers mostly used statistical tests in biomedical domain, to provide decision aid to non-statistician users while choosing the appropriate statistical test for testing their hypothesis. We also discuss some of the findings while we are integrating the flowcharts into each other to develop a single but more comprehensive decision algorithm.

Keywords. Statistical hypotesis testing, decision making, decision support, biostatistics

Introduction

Statistical hypothesis testing is an essential component of biological and medical studies for making inferences and estimations from the collected data in the study; however, the misuse of statistical tests is widely common [1-6]. Previous studies showed that researchers frequently made errors while deciding the selection of appropriate statistical tests and in sample size calculation, clinical trial planning, reporting and interpreting statistical results, selection of control group, use of figures and tables, and obtained false positive results due to multiple testing [6-9]. Among the statistical errors, inappropriate statistical test selection usually leads to obtaining inaccurate interpretations of results, wrong conclusions and wasting researcher's time

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[8].

In order to prevent possible errors in convenient statistical test selection, it is currently possible to consult available test selection algorithms developed for various purposes [1-5, 9-13]. In these decision algorithms, users are asked a series of questions regarding their data set such as sample size, normality assumption, scale type of variables, and dependent/independent samples and their aims as well. After answering all questions properly, the algorithms provide a suitable statistical hypothesis test, fitting user's demand. Some decision algorithms, for instance, UCLA's flowchart does not only provide decision support in the selection of appropriate statistical method but also introduce detailed documentation regarding how the statistical test suggested by the algorithm can be applied in distinct statistical packages such as SPSS and R [9]. However, none of the currently available algorithms covers and is designed for all parametric and nonparametric statistical tests commonly used in biomedical domain, and this situation causes several problems such as shifting users among the algorithms, poor decision support in test selection and lack of satisfaction of potential users. Therefore, in this study, we aimed at creating single and comprehensive decision algorithm by modifying and integrating distinct algorithms into each other. In addition to this, by creating descriptions for the concepts observed in simple decision questions of our unified algorithm, we created an initial framework of a decision support tool for appropriate test selection in hypothesis testing of biological and medical researches.

1. Methods

In order to seek out available decision algorithms for statistical test selection, we carried out a manual search in the literature and text books as well as on the Internet. After determining decision algorithms, we individually examined algorithms to identify for which statistical tests each algorithm was used to select. Furthermore, each algorithm was studied in terms of decision questions that comprised the algorithms and were answered for the selection of the most appropriate statistical test in the analysis of the data at hand. For this purpose, the number and attributes of decision questions in each algorithm were evaluated. Five statisticians ran the algorithms, expert in biostatistics, to clearly understand whether each of them works properly and provide accurate guidance. By this means, we determined possible potential shortages of each algorithm. For instance, if one wishes to compare non-normally distributed and paired two samples but the algorithm does not offer any non-parametric statistical tests, we noted this as a lack of algorithm. Later, we created a single but comprehensive algorithm for statistical test selection commonly used in biomedical researches by assembling algorithms currently in use. We selected Rosner's flowchart [13] as a base and integrated other algorithms into this flowchart. Additionally, we manually created descriptions for non-statistician users in each decision question of the unified algorithm. A list of fundamental statistical terms, concepts and their meaning was also built to provide user friendly and effective decision support in statistical test selection in biomedical domain.

2. Results

The manual screening of various sources revealed the presence of 10 distinct algorithms and decision tables, which facilitated the selection of the most appropriate statistical test according to data characteristics and researcher's purpose. Table 1 shows the decision algorithms found by manual search and statistical tests related to those algorithms.

Table 1. A list of decision algorithms, suggested statistical tests and number of tests used in these algorithms.

Decision Algorithm	Number of Tests	Suggested Statistical Tests
Rosner (2000)	36	Parametric, nonparametric and multivariate methods
UCLA (2014)	31	Parametric, nonparametric and multivariate methods
Nayak&Hazra (2011)	30	Parametric and nonparametric methods
Jaykaran (2010)	25	Parametric, nonparametric and multivariate methods
Mertler (2002)	17	Multivariate statistical methods
Gunawardena (2011)	14	Parametric and nonparametric methods
McCrum- Gardner (2008)	13	Parametric, nonparametric and multivariate methods
Marusteri&Bacarea (2010)	11	Parametric and nonparametric methods
Twycross&Shields (2004)	11	Parametric and nonparametric methods
Gaddis&Gaddis (1990)	9	Nonparametric methods

Rosner's flowchart is the most detailed one and it provides guidance for 36 different statistical tests used in biomedical research. The statistical tests, including, t-test, ANOVA, chi-square test, Kruskal-Wallis H test, Mann-Whitney U test, and Wilcoxon signed rank test were common in all 10 decision algorithms. The run of each algorithm by the experts showed that all algorithms included in the scope of this study worked properly and presented accurate guidance in test selection; however none of the algorithms covered the whole statistical test range frequently used in biomedical domain in a single decision flowchart. Therefore, the unification of all decision algorithms into a single algorithm resulted in the creation of a complete algorithm bearing 60 separate statistical tests.

Our unified algorithm also includes decision questions for potential users to help for determining the statistical test or tests which is appropriate for the user's aim and might be applied on the data set at user's hand. The questions basically cover the number of variables, number of samples, dependency of samples, normality assumption, and scale type of variables of the data as well as some additional questions for particular cases such as survival analysis and multivariate statistical techniques. All decision questions are in the form of yes/no questions. The longest path of our unified algorithm consists of 10 questions, and that path ends with suggestion of Cox proportional hazards model method. In addition to this, the shortest path ends with simple linear regression, and the path contains four yes/no questions.

Our unified statistical test selection algorithm is mainly built on Rosner's decision algorithm by revising and modifying of available other statistical test selection algorithms. In Figure 1, a sample branch of our decision algorithm for Repeated Measures ANOVA and Friedman tests is given. In this example, our statistical test selection algorithm offers 2 distinct statistical hypothesis tests in a case where the potential user is interested in one variable and would like to compare more than two paired samples. Depending on the normality assumption, one of the two suggested tests can be selected by the user. Additionally, our algorithm also informs the users how normality assumption of the data set can be checked.

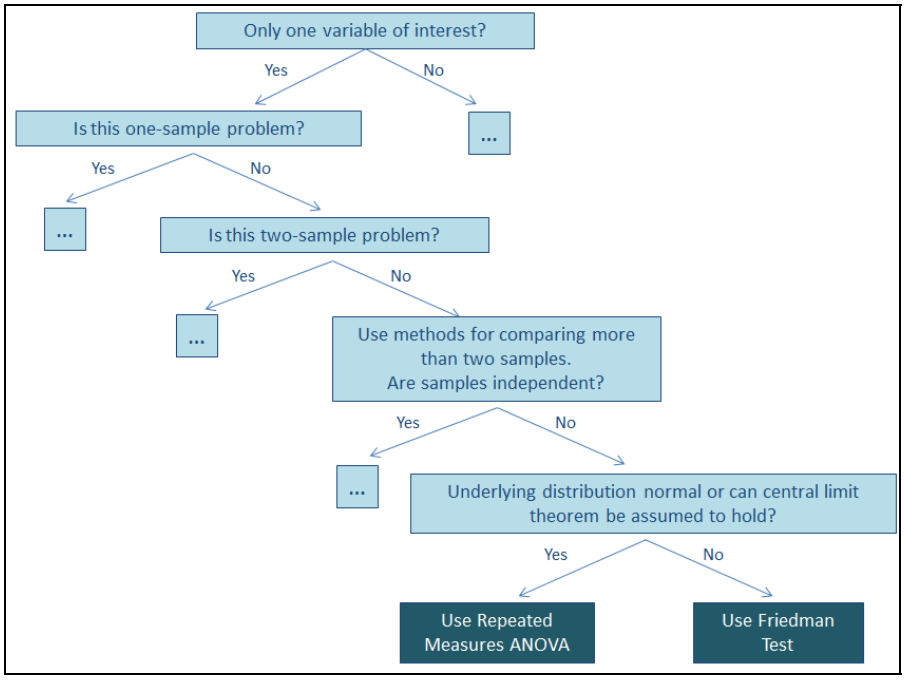


Figure 1. A sample branch of our unified algorithm for appropriate statistical test selection.

3. Discussion

The use of statistical hypothesis testing methods is essential for clarifying the meaning and significance of the collected data in biomedical research. Due to abundance of available statistical tests, the selection of the most appropriate statistical test is generally challenging among the non-statistician researchers. In addition to this, there is a lack of an algorithm presenting the most common statistical tests used in biomedical research in a single flowchart. Thus, this study described a unified algorithm; covers mostly used statistical tests in biomedical domain, to provide decision aid to non-statistician users while choosing the appropriate statistical test for testing their hypothesis.

In this study, Rosner's flowchart, the most comprehensive algorithm with regard to the number of statistical tests, has become the backbone of our unified algorithm, Rosner's flowchart consists of yes/no questions only and guides its users with relatively simple questions at each decision step; therefore we selected Rosner's approach as a base algorithm. On the other hand, Rosner's approach does not include multivariate statistical techniques such as Factor Analysis, Discriminant Analysis, and Principal Analysis. Not limited to these statistical tests however, Rosner's algorithm also does not provide decision support in the selection for multiple comparison methods, including, Mann Whitney U Test, Wilcoxon rank sum test, Dunn Test, Bonferonni's Test, Tukey's HSD Test, Scheffe's Test, and Dunnett's Test as well as nonparametric methods, such as Sign Test, Kendall W Test, Friedman Test and Cochran's Q Test. Thus we modified Rosner's flowchart by integrating other

algorithms and in this way we created a more comprehensive algorithm which could be used for different demands in statistical test selection.

To gain convenient and satisfactory results from the unified algorithm, it is essential to answer questions properly at each decision step. In addition to this, the main goal of this work was to develop a comprehensive decision support algorithm for non-statistician users. Therefore we also manually created descriptions of the statistical terms and concepts observed in the decision questions of our unified algorithm. By doing so, we aimed to simplify the questions asked to non-statistician potential users such as medical practitioners and inexperienced statisticians while determining the most appropriate tests in line with their purposes. Thus, we believe the creation of descriptions manually makes the algorithm as convenient as possible and easy to use.

Another issue regarding our unified algorithm to be discussed in detail is the accuracy of results generated by our unified algorithm. While each algorithm included in this study was manually controlled by experts, obtaining exact results from the flowchart completely depends on correctness of the user's answers at each decision step. Furthermore, we strongly recommend potential users to control the recommendations of the algorithm by referring to an expert statistician to prevent potential misuse of statistical tests.

In conclusion, here we created a framework algorithm of a potential computerized decision support tool, which enables users to select the correct statistical tests in their research. We are currently developing a web based decision support tool to practically apply the unified algorithm in this study. The decision support tool will make use of the structured algorithm proposed in this study and can be utilized while selecting the appropriate method for analyzing the data at hand.

References

[1] B.K. Nayak & A. Hazra, How to choose the right statistical test? *Indian Journal of Ophthalmology*, **59**(2) (2011), 85-86.

[2] Jaykaran, How to select appropriate statistical test? *Journal of Pharmaceutical Negative Results,* **1** (2010), 61-63.

[3] A. Twycross & L. Shields, Statistics made simple: part 4, Choosing the right statistical test. *Paediatric Nursing*, **16**(8) (2004), 24.

[4] N. Gunawardena, Choosing the correct statistical test in research. *Sri Lanka Journal of Child Health,* **40**(4) (2011), 149-153.

[5] E. McCrum-Gardner, Which is the correct statistical test to use? *British Journal of Oral and Maxillofacial Surgery*, **46**(1) (2008), 38-41.

[6] V.B. Nyirongo, M.M. Mukaka & L.V. Kalilani-Phiri, Statistical pitfalls in medical research. *Malawi Medical Journal*, **20**(1) (2008), 15-18.

[7] A.M. Strasak, Q. Zaman, K.P. Pfeiffer, G. Gobel & H. Ulmer, Statistical errors in medical research-a review of common pitfalls. *Swiss Medical Weekly*, **137** (2007), 44-49.

[8] T. Lang, Twenty statistical errors even you can find in biomedical research articles. *Croatian Medical Journal* **45** (2004), 361-370.

[9] What statistical analysis should I use? UCLA: Statistical Consulting Group. from http://www.ats.ucla.edu/stat/mult_pkg/whatstat/ (Last accessed: January 20, 2014).

[10] C.A. Mertler & R. A. Vannatta, *Advanced and Multivariate Statistical Methods*, Pyrczak, Los Angeles, 2002.

[11] M. Marusteri & V. Bacarea, Comparing groups for statistical differences: how to choose the right statistical test? *Biochemia Medica*, **20**(1) (2010), 15-32.

[12] G. M. Gaddis & M. L. Gaddis, Introduction to biostatistics: Part 5, Statistical inference techniques for hypothesis testing with nonparametric data. *Annals of Emergency Medicine*, **19**(9) (1990), 1054-1059.

[13] B.A. Rosner, *Fundamentals of Biostatistics*. (5th Ed), Duxbury Press, USA, 2000.

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Explicit Evidence for Prognostic Bayesian Network Models

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Abstract. Many prognostic models are not adopted in clinical practice regardless of their reported accuracy. Doubts about the basis of the model is considered to be a major reason for this as the evidence behind clinical models is often not clear to anyone other than their developers. We propose a framework for representing the evidence behind Bayesian networks (BN) developed for prognostic decision support. The aim of this evidence framework is to be able to present all the evidence alongside the BN itself. We illustrate this framework by a BN developed with clinical evidence to predict coagulation disorders in trauma care.

Keywords. Bayesian Networks, Clinical Evidence, Knowledge Engineering, Prognostic Models, Clinical Decision Support

Introduction

A large number of prognostic models are developed to support clinical decision making but many of them are not adopted into clinical practice [1]. The predominant reason for this are concerns regarding model accuracy. Accuracy alone, however, does not ensure use of a model: clinicians will be reluctant to use some prognostic models regardless of their accuracy [2] while some models with mediocre performance are widely used [3]. Clinicians tend to reject a prognostic model if they are not convinced that the model's performance, for their patients, will be similar to its published performance in validation studies [2,3]. Understanding the clinical evidence supporting the model is an important factor for clinicians to evaluate its prospective performance in their practice [2].

Bayesian networks (BN) offer a powerful framework for building evidence-based models as their graphical structure is well suited for representing causal relations. However, the current representation of BNs is not descriptive enough to show the details of clinical evidence behind a BN. In many clinical BNs, the names of variables are often short and ambiguous, the relations modelled by edges are not explained, and the corresponding evidence from the clinical literature and data is not presented. Consequently, domain knowledge and evidence behind these BNs are clear only to their developers. In this paper, we present an evidence framework that organises and presents the evidence behind clinical BN models. We illustrate the application of the evidence framework by a BN that has been developed to provide decision support in trauma care by predicting acute traumatic coagulopathy (ATC) [4]. In the remainder of this paper,

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Section 1 discusses the challenges of describing evidence behind BNs and presents our evidence framework, and Section 2 presents the conclusions.

1. Evidence Framework

The challenges of describing evidence behind a prognostic BN can be summarised in two points. The first challenge is to organise the evidence in a structured way. The evidence about a BN must be detailed enough to prevent ambiguities about its relevance, source and type. The evidence can be relevant to different parts of the BN: some can be relevant to a particular variable or relation whereas others can be relevant to an entire group of variables. Moreover, there may be different items of evidence. A part of the BN may have evidence from the data, and another part may be based on clinical publications. Conflicting evidence must also be taken into account in order to have a comprehensive description of the evidence. The evidence framework must contain all of the relevant evidence even if it belongs to something not modelled in the BN. The meaning of the modelled variables and relations must also be clear.

The second challenge is to present evidence in a user-friendly environment without losing any important information. The users do not necessarily need to see the technical details of the evidence structure when browsing the evidence. In order to overcome these challenges we propose an evidence framework composed of two elements: a structure for organising the evidence data (Section 1.1) and a web page generated from this structure for browsing the evidence (Section 1.2).

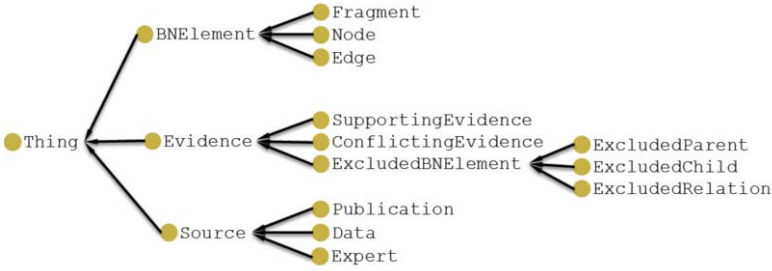


Figure 1. Class hierarchy for the evidence ontology

1.1. Evidence Ontology

We use the web ontology language (OWL) framework in the Protégé software (version 4.3.0) for organising the evidence data. Our primary reason for using ontologies is their flexibility in building and modifying a data structure. In the remainder of this paper, the classes, individuals, object and data properties of ontologies are represented by yellow circles, purple diamonds, blue and green rectangles respectively.

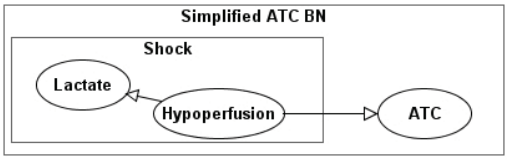


Figure 2. Simplified ATC BN

Our evidence structure is based on three main classes: BN element, evidence and source (Figure 1). We illustrate how data is entered to the evidence ontology by using a simplified version of the ATC BN that has 1 fragment, 3 variables and 2 edges (Figure 2). Evidence for the complete ATC BN can be found at [5].

Table 1. Defining the lactate variable in the evidence ontology

Lactate	
Type: BNElement Node	Object Properties: within Shock hasParent Hypoperfusion hasIncommingEdge HypoToLactate hasExcludedParent LactateExParEv1 Data Properties: description "The amount of lactate measured by…"

The BN element class has 3 subclasses: fragment, node and edge. A BN is composed of nodes representing variables and edges representing relations between those variables. It is necessary to clarify the meaning of these elements in order to describe knowledge behind the BN model. For example, a node named 'Heart Rate' may be sufficient to show that it represents a measurement of the patient's heart rate; but this name may not be descriptive enough if the time and location of this measurement is important for the use of the BN. Table 1 shows how the Lactate node in the ATC BN is defined in the evidence ontology. Associated fragments, edges, evidence and neighbor nodes are defined by object properties, and the node's description is recorded by a data property.

Table 2. Defining the 'Hypoperfusion → Lactate' edge in the evidence ontology

HypoToLactate	
Type: BNElement Edge	Object Properties: comesFrom Hypoperfusion pointsTo Lactate hasSupportingEvidence LactateSuppEv1 hasSupportingEvidence LactateSuppEv2

In order to include an edge in a BN model, the BN developers must have evidence that the relation represented by the edge exists. Therefore, all edges in a BN must have supporting evidence in an evidence-based BN. The meaning of a modelled relation is recorded in its associated evidence items. Conflicting evidence should also be taken into account. For example, one publication may claim that two variables are independent, whereas another publication may find correlation between those variables. Table 2 shows the data entered for the Hypoperfusion → Lactate edge in the evidence ontology. Its object properties define the variables connected by this edge, and relevant items of supporting evidence.

Table 3. Defining the shock fragment in the evidence ontology

Shock	
Type: BNElement Fragment MeasurementIdiom	Object Properties: contains Hypoperfusion contains Lactate Data Properties: description "This part of the model measure…"

A BN substructure represents a part of the BN that describes an important concept in its domain. Our ontology defines BN substructures in a general way as 'BN fragments'. The fragment class organises the information about description, evidence and member variables of a BN fragment. If the BN fragment has a specific type, such as idioms [6], this can be defined as a subclass of the fragment class. Table 3 shows the data about the Shock fragment recorded in the evidence ontology. This fragment contains 2 variables and its type is a measurement idiom.

Table 4. Supporting evidence item for the 'Hypoperfusion → Lactate' edge

LactateSuppEv1	
Type: Evidence SupportingEvidence	Object Properties: hasSource RixenEtAl2005 hasSource VanDrommeEtAl2010 Data Properties: statement "Lactate is produced in anaerobic…"

The evidence class organises the data about the type and statement of evidence related to the BN elements. There are three types of evidence in our evidence ontology: supporting evidence, conflicting evidence and evidence about relevant BN elements that are not included in the model. A BN element can have multiple items of evidence, and an item of evidence can have multiple sources. Table 4 shows one of the supporting evidence items for the Hypoperfusion → Lactate edge (Table 2). The evidence statement is recorded by a data property and publications related to this evidence are linked by the 'hasSource' object property. The source class describes the source of evidence; which can be a dataset, a domain expert or a scientific publication. Table 5 shows an example of a publication recorded in the source class. The evidence framework offers a convenient way to audit completeness of evidence by using SPARQL queries in OWL. For example, a user can review the edges without evidence by using the query below:

```
SELECT DISTINCT ?x
WHERE {?x a :Edge. MINUS {?x :hasSupportingEvidence ?evidence}}
```

1.2. Browsing Evidence

The evidence ontology is not a convenient tool to browse evidence especially if the user is not proficient with OWL. Therefore, our evidence framework generates a web page for browsing evidence after the data is entered to the evidence ontology using Protégé. The web page generated for the complete ATC BN can be found at [5].

Table 5. Details of a published evidence item stored in the source class

RixenEtAl2005	
Type:	Data Properties:
Source Publication	hasPMID 16277731 hasRefDetails "D. Rixen and J. H. Siegel (2005), Critical Care, vol. 9, no. 5, p. 441…"

2. Conclusion

This paper proposed an evidence framework that complements clinical BNs by representing relevant clinical evidence. The ATC BN is used as a case-study to illustrate the evidence framework [4,5]. Our evidence framework is able to organise and present the evidence in more detail than it is possible with the existing BN representation. The evidence framework can store various types of evidence, including evidence supporting or conflicting with the BN, and offers a convenient way to query completeness of evidence. It can store evidence related to different levels of BN representation including BN fragments, nodes and edges. Although the evidence is stored within a complicated ontology structure, users can browse the evidence in a web page that is automatically generated from the ontology, without dealing with any of the underlying technical details. The evidence framework is not specific to the ATC BN; it could be applied to other BN models in different clinical domains. The main challenge of applying it to other domains is to identify the relevant evidence from the clinical literature. This step requires significant amount of effort from domain experts but it is essential for building evidence-based models. Our next step is to run a qualitative evaluation session with a group of clinicians. The probability values from the BN could also be included in the evidence framework to allow it to be used as a standardised format for representing BN models, and the data could be matched with medical terminologies such as SNOMED to have universally consistent descriptions.

References

[1] Altman DG, Vergouwe Y, Royston P, Moons KG. Prognosis and prognostic research: validating a prognostic model. *BMJ.* 2009;338(7708):1432–5.
[2] Wyatt JC, Altman DG. Commentary: Prognostic models: clinically useful or quickly forgotten? *BMJ.* 1995;311(7019):1539–41.
[3] Moons KGM, Altman DG, Vergouwe Y, Royston P. Prognosis and prognostic research: application and impact of prognostic models in clinical practice. *BMJ.* 2009;338(7709):1487–90.
[4] Yet B, Perkins ZB, Fenton NE, Tai NR, Marsh DWR. Not just data: A method for improving prediction with knowledge. *J Biomed Inform.* 2014;48:28–37.
[5] Acute Traumatic Coagulopathy Bayesian Network Evidence Browser [Internet]. [updated 2014 Feb 22; cited 2014 Apr 14]. Available from: http://www.traumamodels.com/atcbn/ATC_EBase
[6] Neil M, Fenton NE, Nielsen L. Building large-scale Bayesian networks. *Knowl Eng Rev.* 2000;15(3):257–84.

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Towards a decision support system for hand dermatology

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Abstract. The complexity of the medical diagnosis is faced by practitioners relying mainly on their experiences. This can be acquired during daily practices and on-the-job training. Given the complexity and extensiveness of the subject, supporting tools that include knowledge extracted by highly specialized practitioners can be valuable. In the present work, a Decision Support System (DSS) for hand dermatology was developed based on data coming from a Visit Report Form (VRF). Using a Bayesian approach and factors significance difference over the population average for the case, we demonstrated the potentiality of creating an enhanced VRF that include a diagnoses distribution probability based on the DSS rules applied for the specific patient situation.

Keywords. Decision Support System (DSS), hand dermatology, differential diagnosis, diagnostic implicit knowledge, medical practices.

Introduction

In dermatology, hand skin pathologies often present similar signs and symptoms [1] that can be interpreted by highly experienced and trained specialists. Hence, inexperienced general practitioners (GPs) or non-specialized dermatologists need support in performing their diagnosis, and in timely recognizing the disease to refer the patient to an appropriate specialized centre. In fact, wrong diagnoses and thus inadequate therapies or treatments can worsen patients' conditions. Recently, the differential diagnostic process ([2], [3], [4]) has been applied to hand skin pathologies,

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but a systematic assessment in a multi-centre trial has not been performed yet. For this reason, the multi-centre study e-Dermatology - involving 16 Italian centres of excellence in the area of hand dermatology - was designed aimed at collecting information (enriched with implicit knowledge) regarding the practices of differential diagnosis by highly specialized dermatologists. The information collected in e-Dermatology can be used to develop a decision support system (DSS) for the hand dermatitis differential diagnosis devoted to non-specialized dermatologists and GPs, providing them with a simple tool for a first supported diagnosis of these diseases.

In this work, we present the e-Dermatology system for the collection of clinical diagnostic data in patients with hand skin pathologies and its use to define a preliminary set of decisional rules that can be used in a DSS aimed to support GPs and non-specialized dermatologists in their diagnostic process.

1. Methods

Sixteen Italian clinical centres specialized in hand skin pathologies participated in e-Dermatology, providing, in one year, data from 900 patients, in 1300 visits. The pathologies considered are divided in two classes: primary hand skin pathologies (Allergic Contact Dermatitis, ACD, Irritant Contact Dermatitis, ICD, ICD and ACD, Atopic eczema. Atopic eczema and ICD, Vescicular eczema, Hyperkeratosis eczema, Nummular eczema) and secondary hand skin pathologies in which the hand signs and symptoms are the epiphenomenon of another disease (Psoriasis, Palmoplantar keratoderma, Superficial cutaneous mycoses, Continuous acrodermatitis, Pityriasis rubra pilaris). As a first step, we designed and developed a specialized Visit Report Form (VRF) system [5], to support data collection. Then, we analysed the information collected through the shared VRF to disclose some possible rules for decision support.

VRF implementation: The VRF contents were designed together with trained specialists [6] belonging to the Italian reference centres involved in the study, to ensure its clinical correctness and usefulness. Then, the implemented VRF was re-assessed by specialists in the field who did not participate in its design, to prevent from possible biases introduced by personal experiences of the designers. The VRF comprised an explicit tracking system that recorded a personal score(in a 0-5 range) given to the collected information by the specialist during a patient encounter. The question underlying the scoring phase was: how much was this information (e.g. patient's gender, age, parts of the hand with altered skin) important/useful to diagnose patient's disease?

The web-based VRF was developed to ensure patient's anonymity and homogeneous data collection.

Data Analysis and rule definition: Data collected through the developed VRF system, after cleaning and scrubbing operations were analysed to obtain possible rules to suggest the diagnosis given an information dataset, and also the next possible diagnostic step (e.g., a test to be prescribed to reach a diagnosis, or a symptom to monitor).

Each field of the VRF was considered as a variable of the diagnostic process. The variables could have a binary value (e.g., yes/no, male/female), a categorical value (multi-choice field), or a numeric value (e.g., clinical scales). The distribution of each variable with respect to the diagnosed pathology was calculated in order to identify the most significant variables in the diagnostic process. Also, we evaluated the distribution

of the diagnoses among the combination of some variables selected following some clinical considerations.

Then, we calculated the conditional probability of a certain diagnosis provided a certain variable or a certain variable combination. To do so, we relied on a well-known statistical approach to estimate non-observable relationships and variables through the observation of depending events realization, called inferential statistic [7]. The output of this process is a Bayesian Network, an acyclic directed graph that encodes cumulated probabilities and that can be used to estimate the probability of depending events knowing the probabilities of the hidden factors [8].

Based on the results from the previous step, we calculated the conditional probabilities of being diagnosed of certain pathology, provided a certain attribute set. We then multiplied these probabilities obtained for each variable/combination of variables, and obtained a general probability for a variable set, that represent a binary flag of the possibility to observe the specific disease in the current case. Through this approach we found the diagnoses that should be excluded (total probability = 0). Then, to obtain a better discrimination amongst the non-excluded pathologies, we considered the difference between the conditional probability of single variables –or variable sets, based on medical considerations– within the current case and the average probability for the diagnosis in the population. In this way, we could estimate whether the current value of the single variable/variable set enhanced or not the population probability for a certain diagnosis. We used this information to apply a weighting factor that left untouched the variables supporting the diagnosis and weighted negatively the adverse ones. This means multiplying each factor for a discount value of +1 if the conditional probability was higher or equal than the population probability, and of -1 otherwise).

Eventually, by the combination of the conditional probabilities and a weighting process based on the sample size and on the significance of the variable in respect to its discriminatory capability, we created a possible set of rules able to suggest the most likely diagnosis, sorted by decreasing confidence.

2. Results

The Visit Report Form System: The VRF system was divided in 5 different sections: personal information, demographical information, physiological conditions, pathological conditions, and contact reaction tests [optional]. The VRF (Fig.1, *left side*) also included clinical scales such as the modified Total Lesion Symptom Score (mTLSS). A new VRF was created once a patient was visited in one of the clinical centres. Hence, each patient could have more than one VRF, each corresponding to a visit. The final diagnosis could be reached after one or more visits.

After the access by protected protocol to the website using the authentication codes provided, each centre could insert a new visit, retrieve the ones already executed, or insert an update for an already enrolled patient. To guarantee patient's privacy, the identification of the patient was achieved through an ID assigned by the centre, and by managing the association of the ID with the patient's name outside the system. Also, the system, to guarantee a secure identification of the patient, required inserting the patients code twice for crosschecking. In the case the patient code already existed, the persistent information (such as birth date, residence, gender) were preloaded in the VRF, making the filling out of new visit report form quicker.

Results and rules: Of the 1300 VRFs collected, 85% was error-free and considered for the subsequent analyses. In the other 15% either storage errors or errors during VRF filling-in occurred, and corresponding VRFs were excluded. The distribution of diagnoses was not homogenous: 38% of the population was affected by ACD, 20% by ICD, 19% by eczema, 20% by psoriasis, whereas the other pathologies covered the remaining 3%.

We considered as main diagnostic variables gender, contact with animals/pets, patient's job, family history, affected sites (palm, back, only hand, etc) and distribution of lesions, patient's reported factors that could have caused the pathology (e.g., contact with soaps other irritative substances), the mTLSS scale, and the results of the histology examination (if present). Their distribution among diagnoses showed that some factors were strongly correlated with some pathologies.

For instance, the superficial skin mycosis was the disease that had the highest percentage of positivity in the mycological test (70% of the population affected present a positive test result); the likelihood of developing the ACD in the case of family history of palmoplantar keratoderma, was quite high, summing up to 82% of the analysed cases; individuals having the combination of lesions on palms (site of infection at the time of visit) - erythema, desquamation (type of injury) - confluent in rashes (location to the injury) were affected by psoriasis with the rule confidence of almost 100%.

By applying then the weighting strategy presented in the previous section, we obtained a ranking of the probability associated to each pathology provided certain variable or combination of variables values for the specific patient. The validation of the system was then performed through the classification of some medical records extracted randomly from the same dataset (coming from the e-Dermatology multicentre study). The system gave satisfactory results as the first diagnosis was correctly indicated in the 70% of cases and, for the remaining 30%, the actual (real) diagnosis was ranked inside the possible ones, even if not as the most probable (primary).

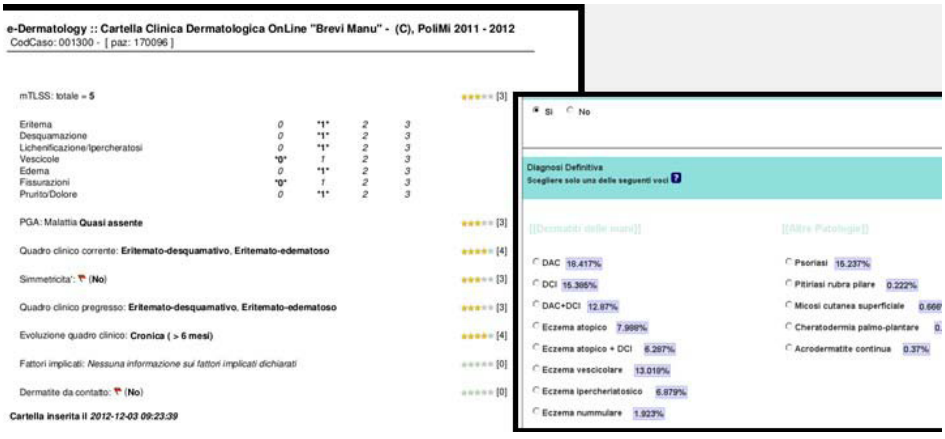


Figure 1. *Left side*: Representation of the mTLSS and PGA scales inside a compiled VRF. *Right side*: A possible VRF enrichment by the DSS rules: probability suggestion for each pathology.

Application to the VRF: The results obtained can be integrated in the implemented VRF (Fig.1, *right side*). The probability of each diagnosis, expressed as a percentage,

can be shown and updated each time the clinician fills-in one of the VRF fields. The probabilities are not presented as ranked by their order, to enforce the idea that the real choice is performed by the – human – medical professional. In fact, the percentages are indicative values from the data extracted, based on statistical and computational methods [7], in accordance with the clinical experience of the experts involved in the study.

3. Discussion

Our results provide the basis for a system able to support the GP or the non-specialized dermatologist in diagnosing hand-skin pathologies. This additional information can support the clinicians by allowing them to better target their diagnosis or to suggest a visit with a specialist, in case of doubt. The system is however still a prototype. In fact, despite being based on a large number of cases, the sample population was still biased by the incidence of the pathologies examined. The rules developed can be hence further optimized increasing the number of cases representing rare pathologies. Moreover, the proposed supportive system can be enhanced by providing the diagnosis probabilities while the clinician fills-in the VRF, instead of providing it at the end.

In conclusion, the significance of this work is twofold: first, this could help to increase the correctness rate of diagnosis performed by the GPs - or at least to make them aware of the need of a second specialized consultation. This decreases the risk of suggesting a wrong recovery path that could negatively impact on disease progression. Second, the collected information and the implicit diagnostic pathway (or rules) can lead to a better understanding of the usual way of reasoning followed by specialists for hand skin disease diagnosis.

References

[1] A. Svensson, M. Lindberg, B. Meding, et al, Self-reported hand eczema: symptom-based reports do not increase the validity of diagnosis. *Br J Dermatol*, 147 (2002): 281284.

[2] Weisshaar, E., Kallen, U., Weiss, M.: 'The itching hand"- important differential diagnoses and treatment. *J. Dtsch. Dermatol. Ges*. 11(1), 31–42 (2013), doi:10.1111/j.1610-0387.2012.08002.x.

[3] Jackson, S., Nesbitt, L.T.: Differential Diagnosis for the Dermatologist. Springer (2012) ISBN: 9783642280061

[4] Pesut, D.J., Herman, J.: Metacognitive Skills in Diagnostic Reasoning: Making the Implicit Explicit. *Int J Nurs Terminol and Classif* 3, 148–154 (1992), doi:10.1111/j.1744-618X.1992.tb00530.x

[5] L. Mazzola, S. Marceglia, S. Bonacina, et al 'Explicit tracking in the diagnostic process for hand dermatological practices'. In Digital Human Modeling and Applications in Health, Safety, Ergonomics, and Risk Management. Healthcare and Safety of the Environment and Transport (2013), Springer Berlin Heidelberg : pp. 248-257.

[6] F. Ayala, M. Nino, G. Fabbrocini, L. et al.: Quality of life and contact dermatitis: a disease-specific questionnaire. *Dermatitis* 21(2), 84–90 (2010); PubMed PMID: 20233546

[7] Cox D.R., Principles of Statistical Inferences. CUP (2006). ISBN: 0-521-68567-2

[8] Pearl J., Causality: Models, Reasoning, and Inference. Cambridge University Press (2000). ISBN: 0-521-77362-8

[9] D. Eynard, L. Mazzola, A. Dattolo, Exploiting tag similarities to discover synonyms and homonyms in folksonomies. In: Software: Practice and Experience. John Wiley & Sons, Ltd. (2012), doi: 10.1002/spe.2150

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A Preference-based framework for medical decision making

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Abstract. Medical decision making, such as choosing which drugs to prescribe, requires to consider mandatory constraints, *e.g.* absolute contraindications, but also preferences that may not be satisfiable, e.g. guideline recommendations or patient preferences. The major problem is that these preferences are complex, numerous and come from various sources. The considered criteria are often conflicting and the number of decisions is too large to be explicitly handled. In this paper, we propose a framework for encoding medical preferences using a new connective, called ordered disjunction symbolized by ~×. Intuitively, the preference "*Diuretic*~×*Betablocker* means: "Prescribe a *Diuretic* if possible, but if this is not possible, then prescribe a *Betablocker*". We give an inference method for reasoning about the preferences and we show how this framework can be applied to a part of a guideline for hypertension.

Keywords. Medical decision making, preferences, preferred solutions, inference, aggregation

Introduction

Medical decision making, such as choosing which drugs to prescribe, requires to consider various pieces of knowledge. Some of them are mandatory, *e.g.* indications and absolute contraindications, while others only express preferences that may not be satisfiable, *e.g.* recommendations from clinical practice guidelines (CPG) and relative contraindications. The integration of preferences in medicine is discussed in different works [1,2,3,4], and *preference* was defined as the desirability of a health-related outcome, process, or treatment choice [4]. Two approaches have been developed in the literature: 1) a quantitative approach [5,6] where preferences are expressed by means of a utility function, the option with the maximal utility is considered the best one, 2) a qualitative approach [7,8,9] where relative preferences are expressed by ordering the options. However, quantitative approaches are more complex because they require to express preferences with numerical values, which is often difficult in medicine. Our aim is to propose a qualitative framework that allows encoding medical knowledge including preferences and a method to select the best solution. This framework contains two types of formulas: 1) integrity constraints representing mandatory knowledge with usual connectives ($\Leftrightarrow$, $\Rightarrow$, $\wedge$, $\vee$, $\neg$) and 2) preferences, using usual connectives and a new connective called *ordered disjunction* ~×

where $A{\sim}{\times}B$ means: "if possible A, but if A is impossible, then at least B". Once integrity constraints and preferences are encoded, an inference relation method is given to rank order the options and determine which is the best one. In section 1 we present the proposed framework and in section 2 we show how this framework can be applied to a subset of a CPG mixing recommendations with absolute and relative contraindications and patient history. Section 3 concludes the paper.

1. Methods

Table 1 provides a simple example concerning the prescription of antihypertensive drugs, inspired by hypertension CPG [10]. In this example, three antihypertensive drugs are considered, and several pieces of knowledge must be taken into account, depending on comorbidities associated with hypertension and patient history. In the rest of this section, we propose a language for encoding these knowledge and reasoning about them.

Table 1. Some recommendations and contra-indications in hypertension CPG [10]. *LVH*: Left Ventricular Hypertrophy, ACI: Angiotensin Converting enzyme Inhibitor, CA: Calcium Antagonist, ARB: Angiotensin II Receptor Blocker, ADE: Adverse Drug Event.

Comorbidity / patient history	Recommendations and contraindications
LVH	Recommendation : ACI, CA, ARB
Heart failure	Relative contraindication: CA
Hyperkalemia	Absolute contraindication: ACI, ARB
History of ADE with ACI	Absolute contraindication: ACI

1.1. The proposed language

The language of the proposed framework is composed of two types of formulas: 1) Propositional formulas expressing integrity constraints and 2) Preference formulas offering a simple way to rank the various options.

Definition 1 *Let O be a set of propositional atoms that represent a set of options. If a_i are propositional atoms in O then each formula φ that is built using classical logical connectives ($\Leftrightarrow$, $\Rightarrow$ $\wedge$, $\vee$, $\neg$) over a_i is a propositional formula. If φ, ψ are propositional formulas then ($\varphi{\sim}{\times}\psi$) is a preference formula.*

Table 2 gives information of Table 1 encoded using the proposed language.

Table 2. Knowledge of Table 1 encoded using the proposed language.

Comorbidity	Preference formulas	Propositional formulas
LVH	$\varphi_1 = ACI{\sim}{\times}CA{\sim}{\times}ARB$	
Heart failure	$\varphi_2 = \neg CA{\sim}{\times}CA$	
Hyperkalemia		$\varphi_3 = \neg ACI \wedge \neg ARB$
History of ADE with ACI		$\varphi_4 = \neg ACI$

1.2. The inference relation

The semantics of formulas represented using our logic is based on the degree of satisfaction of each formula in a particular interpretation *I* (or solution). An interpretation *I* is an assignment of a truth value T (True) or F (False) to each atom. *I* will be represented by the set of its satisfied (True) atoms. An interpretation which satisfies a given formula is called a model. In Table 2, we have three options, thus there is 2^3=8 interpretations or possible solutions. For example, the interpretation *I*={*ARB*, *CA*} represents the solution where both *ARB* and *CA* are prescribed. The inference relation (symbolized by |=) is defined as follows:

Definition 2

1. *Let* $\varphi = a_1 \sim \times a_2 \sim \times ... \sim \times a_n$ *be a preference formula. Then* $I \models_k \varphi$ *iff* $I \models a_1 \vee a_2 \vee ... \vee a_n$, *and* $k = min(j \mid I \models a_j)$.

2. *Let* ψ *a propositional formula.* $I \models_1 \psi$ *iff* $I \models \psi$.

Namely, given a preference formula $a_1 \sim \times a_2 \sim \times ... \sim \times a_n$, an interpretation *I* satisfies φ to a degree *k* (formally, we write $I \models_k \varphi$), if it satisfies the kth proposition of φ (i.e. a_k) and does not satisfy the preceding ones (a_1, a_2,..., a_{k-1}). If no proposition a_k of φ is satisfied by *I*, the satisfaction degree is equal to 0. For propositional formulas, the satisfaction degree is 1 if they are satisfied, and 0 otherwise. For example, if we consider the interpretation *I*={*CA*, *ARB*}, then φ_1 is satisfied to degree 2 (we write $I \models_2 \varphi_1$). If *I*={Ø} (*i.e.* no drug prescription), then φ_1 is not satisfied.

1.3. Preferred solutions

If there is only one formula, best solutions are the ones which satisfy the formula with the smallest non-zero degree. However, in general many formulas should be considered (*e.g.* in case where the patient have several comorbidities). So, it is important to consider the different cases in order to give the best solution(s). In our framework, we use a lexicographic order, which is based on the number of formulas satisfied to a particular degree. To define the preferred solutions, let us consider *T* be a set of preference formulas, *K* a set of propositional formulas. The set of propositional and preference formulas is represented by $K \cup T$.

Definition 3 Let $I^k(T)$ denote the subset of formulas of T satisfied by an interpretation I to a degree k with respect to the patient cases. The cardinality of a set is denoted by |.|. An interpretation I_1 is K ∪T-preferred over an interpretation I_2 if there is k such that $|I_1^k(T)| > |I_2^k(T)|$ and for all $j < k$: $|I_1^j(T)| = |I_2^j(T)|$. I is a preferred solution of K ∪T if:

1. *I satisfies each formula of K, and satisfies each formula in T to some degree,*
2. *I is maximally preferred with respect to* $K \cup T$.

Intuitively, a preferred solution of $K \cup T$ is an interpretation which satisfies each formula in K and satisfies the maximal number of formulas in T with a non-zero smallest degree.

2. Results

In this section, we present reasoning example using the proposed framework and the knowledge pieces from Table 1. To do that, we apply the following algorithm: 1) determine the patient comorbidities, 2) for each comorbidity, represent the associated absolute contra-indications as propositional formulas and relative contradictions and recommendation as preference formulas, 3) compute the set of all possible interpretations, 4) compute the satisfaction degree of each formula for each interpretation, 5) compute the preferred solutions.

Table 3 shows the 8 possible interpretations for the example of Table 1, and for each, the satisfaction degrees for the 4 formulas we defined in Table 2. Using Table 3, the preferred solutions for various clinical situations can be determined (by applying Definition 3). For example, for a patient with hypertension and LVH, the best solutions are I_5 to I_8, *i.e.* ACI or any drug association including an ACI (with satisfaction degree 1). For a patient with two comorbidities, LVH and hyperkaliemia, the best solution is I_2, *i.e.* CA.

Table 3. The 8 possible interpretations for the example of Table 1, the corresponding drug prescriptions (ACI, ARB and/or CA) and the satisfaction degrees for the 4 formulas defined in Table 2. HF: heart failure, HK:hyperkaliemia, ADE-ACI: history of Adverse Drug Event with ACI.

Interpretations	***ACI***	***ARB***	***CA***	**has(*LVH*)** $\rightarrow\varphi_1$	**has(HF)** $\rightarrow\varphi_2$	**has(HK)** $\rightarrow\varphi_3$	**has(ADE-ACI)** $\rightarrow\varphi_4$
I_1	F	F	F	0	1	1	1
I_2	F	F	T	2	2	1	1
I_3	F	T	F	3	1	0	1
I_4	F	T	T	2	2	0	1
I_5	T	F	F	1	1	0	0
I_6	T	F	T	1	2	0	0
I_7	T	T	F	1	1	0	0
I_8	T	T	T	1	2	0	0

3. Discussion and conclusion

In this article, we have presented a qualitative framework for encoding medical knowledge including mandatory statements but also preferences, and for reasoning about them.

This framework is interesting since it can integrate preferences of different sources such as drug properties (*e.g.* contraindications), CPGs (*e.g.* recommendations) and patient history (*e.g.* history of adverse event with a given drug). In a previous work [7], we already successfully used a similar ordered disjunction on non-medical domain, particularly in alert

correlation. We applied our framework to a limited example on the hypertensive drugs where the formulas are manually formulated, we plan to extend this example by formalizing the hole CPG and implementing it in the ASTI clinical decision support system [11]. In addition, frequently, several preference formulas are available, based on different criteria, such as efficiency, tolerance or cost (*e.g.* ACI should be preferred to ARB due to their lower cost). In these situations, it would be interesting to define rules for combining several preference formulas into a single one. This would require to take into account the specificities of the criteria. For example, costs are additive, thus we can deduce from the previous cost-based preference that a bitherapy Diuretics+ACI should be preferred to Diuretics+ARB; this may not be true for other non-additive criteria. In our example (Table 1), we considered an order of preference between the 3 recommended drug class for LVH, although this is not clearly stated in the CPG. The order does exist between ACI and ARB (due to cost), but is less obvious for CA. Preferences elicitation is a difficult problem and we need to study how one can encode evidence and results obtained from reviews, meta-analyses or reports on clinical trials with respect to some factors.

References

[1] Ryan M, Scott DA, Reeves C, Bate A, van Teijlingen ER, Russell EM et al. Eliciting public preferences for healthcare: a systematic review of techniques. *Health Technol Assess*, 2001; 8:1-186.
[2] V-M Montori, MD, MSc, J-P Brito et al. The optimal practice of evidence-based medicine incorporating patient preferences in practice guidelines.
[3] Carmen D Dirksen, Cecile MA Utens, Manuela A Joore, Teus A van Barneveld, Bert Boer et al. Integrating evidence on patient preferences in healthcare policy decisions: protocol of the patient-vip study. *Implement Sci*, 2013; 8:64.
[4] Murray K, Gary N. The next step in guideline development: incorporating patient preferences. *JAMA*, 2008; 300(4):436-8.
[5] Von Neumann J, Morgenstern O. *Theory of games and economic behaviour*. Princeton University Press, 2nd edition, Princeton; 1947.
[6] J. Savage L. *The Foundations of Statistics*. New York; 1954.
[7] Benferhat S, Sedki K. Two alternatives for handling preferences in qualitative choice logic. *Fuzzy Sets and Systems*, 2008; **159**(15):1889-1912.
[8] Boutilier C, I. Brafman R, Domshlak C, H. Hoos H, Poole D. Cp-nets: A tool for representing and reasoning withconditional ceteris paribus preference statements. *CoRR*, abs/1107.0023; 2011.
[9] Dubois D, Fargier H, Prade H, Perny P. Qualitative decision theory: from savage's axioms to nonmonotonic reasoning. *Journal of the ACM (JACM)*, jul 2002; 49:4.
[10] Mancia G, Fagard R, Narkiewicz K et al. The Task Force Members. 2013 ESH/ESC Guidelines for the management of arterial hyprtension. *J Hypertens*, 2013; 31:1281-1357.
[11] Lamy J-B, Ebrahiminia V, Riou C, Seroussi B, Bouaud J, Simon C et al. How to translate therapeutic recommendations in clinical practice guidelines into rules for critiquing physician prescriptions? methods and application to five guidelines. *BMC Med. Inf. & Decision Making*, 2010; 31:10.

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Reporting of drug allergies for use in a national decision support system

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Abstract. In Denmark, there are plans for establishing a national decision support system, providing on-line support for physicians during drug prescribing. This includes establishment of a national database containing information about each patient's drug allergies. Allergy information already exists in medication modules in hospital systems and primary care systems and thus constitutes a potential source for the national allergy database. This paper reports an analysis of local data structure, content and registration policies with the aim to re-use existing allergy data. The result of the analysis is that due to lack of harmonisation most existing cannot be re-used in the national database. The paper propose a common dataset for allergy data where national and international standards were considered.

Keywords. Drug allergy, national database, data structure, decision support

Introduction

In Denmark, there are plans for establishing a national decision support system, providing on-line support for physicians during drug prescribing[1]. One of the decision support services provided is checking the drug against the patient's previously reported drug allergies. These drug allergy reports may arise from hospital care or primary care and originate from many different medication systems or EHR systems.

Denmark already has a shared medication record in place at a national level. Using this national service health care professionals can look up patients' complete and current medication information cross sectors. This service is integrated with the local medication systems. The new national decision support system will work seamlessly with the shared medication record. When the physician is in the process of prescribing a drug in a local system, the information will also be transmitted to the national decision support system – providing an instant advice about that prescription.

In order to provide reliable alerts towards previously reported drug allergies, the decision support system requires highly structured and standardised drug allergy reports. All hospital are already using medication systems and are obliged to register information about drug allergies. These data is unfortunately highly inconsistent, and the use of classifications varies. Furthermore, in primary care sector, the data is less structured that in the hospital sector.

The National eHealth Authority initiated an analysis in order to explore the possibility to re-use the existing local information on drug allergies for use in a national drug allergy database. This included suggestions for how the local information could be converted and securely uploaded to the national database. The analysis should also propose a standard dataset for the national drug allergy database. This paper reports the results of this analysis. However, The National Board of Health is responsible for making the final decision about which drug allergy data clinicians must register.

1. Methods

Since data on allergies already exists in the hospital systems and primary care systems, an in-depth analysis of the data structure and content was made – including the use of classifications.

Representatives from the five regional it-departments responsible for running the hospital systems were interviewed. The providers of the regional medication modules and EHR systems were also consulted. Material included database descriptions on the field level, screen dumps, and user guidelines. In addition, 250.000 free text allergy records from a region were analysed.

The seven largest system providers of primary care systems all responded to a questionnaire regarding data structure for allergies. Several responses were followed up by telephone interviews.

When using a national drug allergy database physicians have to rely on data reported by health care professionals from other institutions and regions. To establish a trustworthy information basis, it is necessary to ensure a common understanding of what is reported, and that the policies and procedures for data collection are transparent. Therefore, the regional guidelines from the five Danish regions regarding allergies were analysed.

In order to understand to what degree the existing data could be re-used for decision support, requirements from the decision support system were analysed. The aim was to identify the minimum of structured data needed for the system to work reliably.

Even the analyses should point out a pragmatic solution, an attempt was made to match the data structure in the local systems with national and international standards. Several standards were consulted, including HL7[2], openEHR[3], CEN[4], the national standard for the shared medication record[5], and the national standard for data exchange between primary care records[6].

2. Results

2.1. Analyses of regional guidelines

In the Nordic countries the term "CAVE" (= be aware) is used for alert information in broad terms, and allergy is considered a part of this concept. At the national level, the Danish Healthcare Quality Programme (DHQP) mentions "allergy and intolerance" and gives a general description of these. There is no detailed national guideline defining alert information nor a specification of what allergy data to register.

The regional guidelines describe alert information the same way as in DHQP, however it is recognised that allergy and intolerance cannot be distinguished clinically. The regional guidelines describe the *requirements* for allergy registration quite homogenously – i.e. in what situations data should be collected and what the responsibilities for the different professional groups are. In general, the guidelines state that allergy information should be registered at every admission and typically, a physician is responsible for the data quality. All regions requires information on both drug allergies and allergies due to other substances.

2.2. Analyses of existing data

When it comes to the actual data registered, there is large variation in the data content and data structure – including the use of classifications. The following information was included in the data analysis:

- Identification of the drug or substance resulting in the allergy
- Drug allergy reactions
- The certainty that the drug was the reason for the reaction
- Severity
- Other allergies
- Other allergy reactions
- Dates for start, updates and termination of the allergy
- The role of health care professional deciding to report the allergy

The drug or substance resulting in the allergy were identified using ATC codes[7] in three regions and the more specific "Drug ID" in two regions. In four regions structured entries was required. In the 5th region free text was also allowed. Regarding the allergy reactions, three regions used free text, and two regions required use of a classification. One of the regions used a restricted classification with 11 possible entries for allergy reactions; in the other region all diagnose codes were allowed.
Two regions provided classifications for certainty, and one region provided a classification for severity.

2.3. Proposal for a new dataset

Based on the input from the regional guidelines, the analyses of the existing data in the systems, taking into account requirements from the decision support system and considering the national and international standards and terminologies, the following minimum dataset and extended dataset for the national allergy database is proposed.

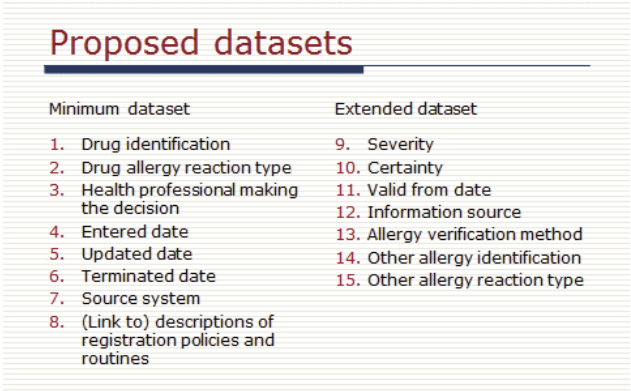


Figure 1. Proposed minimum dataset and extended dataset for the national allergy database

A description of the data items and the use of classification has been developed. Regarding the identification of the drug, an ATC code or a Drug ID is required. While the Drug ID is pointing to a unique drug, the ATC code may cover similar drugs, with different active ingredients. However, accurate information about the active ingredients is needed for the decision support system, and the National eHealth Authority is resolving this by developing a new drug terminology based on SNOMED CT. A classification of 11 entries is proposed for the allergy reaction. However, this shortlist must be supplemented with access to a complete diagnosis list.

It is important for the treating physician to know the source of the allergy information. Therefore, it is required to report the role of the health care professional who have taken the decision to report the allergy, including the organisational affiliation. This classification follows the one used in the shared medication record. In order to support the transparency towards the information sources, it is also required to provide information about the policies and procedures for data collection. The dataset also includes dates for entry, update and possible termination of the allergy (figure 1).

The minimum dataset is selected based upon what is needed to make the decision support system work in combination with the clinician's minimum requirements for understanding and trusting the information. The minimum dataset also takes into account which data actually are currently registered. However, when establishing such a national database, it should also be planned for improving the data quality compared with the existing situation. In the extended dataset, other information considered useful by the clinicians is included. Examples are severity and certainty, and a possibility to enter information about other allergies than drug allergy.

Comparing the proposed dataset with the data in the existing systems, the conclusion is that the drug identification is the only re-usable data item. Even this is cannot be used for all patients, since structured entry is not mandatory in one region. Data from primary care can be used for indicating penicillin allergies at a general level, but these data are not reported for all patients. For the remaining data, changes are needed in the local systems along with changes in the regional guidelines.

3. Discussion

The situation described in this paper regarding allergy data, illustrates a common challenge when trying to standardise datasets at a national level. The situation is of course more complex when many systems are already in use and considerable data already exists.

The aim of this analysis was to assess the possibility for re-using existing data. If data can be re-used, data entry work can be saved. On the other hand, if the data quality is so low that it threatens patient safety, new data must be generated. To improve quality of care, reliable, computable data is needed. In many cases, this implies more structured data entry by clinicians. Even data entry methods improve, it is important to restrict the requirements and only include the data clinicians consider useful.

For example, severity and certainty information was placed in the extended dataset (figure 1). These data items are not required for the decision support algorithm, and even some clinicians find them useful, there are indications of low use if this type of information. 250.000 free text allergy records from a region were analysed. Approximately 1% contained terms related to certainty, and only 0,2 could be related to severity. The most frequent term was "penicillin", mentioned 20% of the entries.

One of the challenges trying to standardise data cross sectors and professional groups, is that common definitions is often lacking. Even differences can be worked out in daily practice, strict concept delimitation and use of common terminology is necessary to re-use data in a secure way. SNOMED CT provides a great help in this area. However, the terminology is very extensive, and subset definitions are required for practical implementation.

The case reported in this paper shows that concept discussions are needed in Denmark. As mentioned, there is not a clear consensus regarding the alert information concept and how drug allergy and allergy subtypes is related to the broad concept.

Inspiration may come from the Swedish organisation *Sjukvårdsrådgivningen, which* made an analysis in the field of allergy information[8]. This work has given substantial input to CEN/ISO standards regarding alert information. The analysis reported in this paper used a modification of the dimensions described in the Swedish report (Figure 2). Drug allergies and other allergies are specified separately, and subtypes are included based on the openEHR adverse reaction archetype[3]. This structure seems to capture the "CAVE" concept used in Denmark, and at the same time clarifies the areas regarding allergies, where data collection is mandatory. It also shows the allergy subtypes, which clinicians find important.

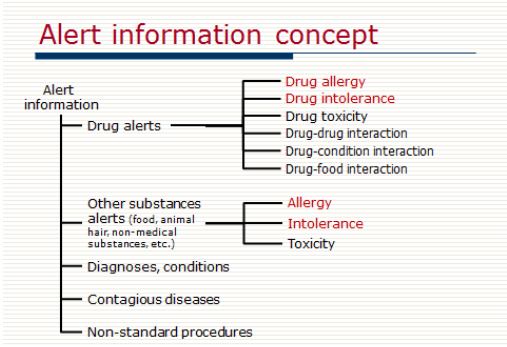


Figure 2. Overview over alert information. Drug allergy/intolerance is considered a part of this

In addition to the clarification of the concepts, a national guideline regarding data reporting for allergies and an agreement on the dataset is needed. This can be followed by an implementation process in the regions and in primary care systems using the already established infrastructure for the national shared medical record.

References

[1] Greibe K. *Development of a SNOMED CT based national medication decision support system*, Stud Health Technol Inform. 2013;192:1147.
[2] *Patient Administration,* Health Level Seven, v2.6. Chapter 3, 2011
[3] The archetype *Adverse reaction*, open EHR, 2013
[4] *Health informatics - Alert information in health records - Concepts, information model and visual presentation*, CEN/ISO TC 215, 2009.
[5] *Shared Medication record. Interface description. Version 1.4.0.5*. National eHealth Authority, 2013
[6] *PLO-format version 3.0 – OIO-XML*, MedCom 2009
[7] http://www.whocc.no/atc_ddd_index/
[8] *Varningsinformation Etapp 2.Slutrapport.* Sjukvårdsrådgivningen 2008. (in Swedish)

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A Causal Loop Approach to the Study of Diagnostic Errors

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Abstract. Missed, wrong or delayed diagnosis has a direct effect on patient safety. Diagnostic errors have been discussed at length, however it still lacks a systematic approach. This study proposed a more systematic way of studying diagnostic errors by using a causal loop diagram. A systematic review was used to find the key factors which may cause diagnostic errors and their interrelationships. A causal loop diagram, as a qualitative model at the first stage of system dynamics modeling, was produced to map all the factor and interrelationships. The diagram provides not only the direct and indirect factors affecting correct diagnosis, but also a clear view of how the change of one factor in the model triggers changes of other factors and then the change of the number of final diagnostic errors.

Keywords. Diagnostic errors, clinical diagnosis, causal loop diagram, system dynamics, patient safety

Introduction

Diagnostic errors cause severe harm to patient safety, as well as high payouts of extra medical cost [1]. However, it is widely believed this could be potentially reduced [2]. Current research findings are mostly limited to partial analysis, and the results are diverse and limited [3,4]. Errors which happen at any stage of the diagnostic process may lead to a diagnostic error directly or indirectly. [5] Thus, diagnostic errors need to be researched in a systemic way through the whole picture of diagnostic system instead of using piecemeal solutions. A Causal Loop Diagram (CLD) is the essential and fundamental model in the system dynamics approach, which maps the key factors affecting the problem, as well as how these interrelated factors affect each other [6]. It visualizes the interrelationships using loops with arrows. The aim of this study was to create a CLD model from a systematic study of diagnostic errors. The purpose of building a CLD model was to understand the diagnostic process, analyze root causes of diagnostic errors, map interrelations of relevant factors, and then provide a clear view of how relevant variables in the system are changed by the change of one variable. In this study, a systematic review was conducted to seek out the leading causes of diagnostic errors, and identifying the key inputs of the CLD model.

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1. Methods

A CLD was created based on the following steps: 1, identify the purpose of the model; 2, identify key variables; 3, developing the reference modes; 4 developing the causal map of the feedback processes. [7]

A systematic review was carried out to establish the key factors that affect correct diagnosis. Paper published in English between 2002 and 2012, using the following databases were covered in the search: PubMed, CINAHL with Full Text, EMbase, PsycINFO, Web of Science, IEEE Xplore, using search phrases: Diagnostic Error, Delayed Diagnosis, Misdiagnosis, Reduce diagnostic errors, Prevent diagnostic errors, Manage diagnostic errors. Papers were excluded if: 1, the paper was a commentary or general review paper; 2, the paper was used for medical disease study. Relevant papers were viewed and provided the information of possible factors affecting diagnosis.

An initial CLD was devloped to reflect on the factors collected from the systematic review and to map the important feedback loops or interrelationships among the factors which are responsible for the problem. The initial model was shown to 7 clinicians to increase model trustability and acceptability. After the model was explained in details, a number of semi-structured questions were asked in terms of the suitability of the variables in the model and the causal-effect interrelationships. Clinicians provided their feedback and suggestions based on their knowledge and experience. At last, the initial causal loop diagram was further refined based on the information collected from experts.

2. Results

57 papers were selected from the systematic review. There were 10 papers out of 57 focusing on diagnostic errors with possible suggestions to reduce errors. 26 out of 57 papers researched solutions by changing one or a few factors which affect diagnosis. 21 out of 57 papers related to specific diseases, but still focused on diagnostic errors instead of the medical disease point of view.

2.1. Key factors contributing to diagnostic errors

The main factors which affect a correct/incorrect diagnosis based on the selected papers, includes:

- Clinical disease features: This includes whether a disease is well researched [8] and the clarity of disease symptoms or presentations [9]**.**
- Education background of patients or doctors: Patient education background was shown it could affect patient health awareness in terms of whether proper actions could be carried out after a symptom was presented [10]. Doctor experience and knowledge and background cover doctor abilities to observe clinical signs, understand collected clinical information, reason clinical reasoning of the information and organizing treatment plans.[11]
- Clinical reasoning in retrieving key diagnostic clues [12]: Diagnostic clues are the evidential information used to make diagnostic decisions. Clinical reasoning involves using doctors' knowledge to retrieve key clues from

collected diagnostic information. This information could come from initial physical examinations, patient-doctor communication [13] and patient medical history [6], as well as further diagnostic information collected from tests [14] or consulting from other healthcare providers.

- Psychological factors: This mainly involves cognitive errors [15], bias[16] and doctor awareness of high risk cases.
- Follow-up after a diagnosis: Careful follow-up helps to discover and correct existing diagnostic errors before they can have a server affect on patients [17].

2.2. Causal loop diagram

Further to the systematic review, 7 clinicians reviewed the findings and gave suggestions about key factors and their inter-relations in terms of: continuity of care, workload for healthcare providers, easy access to medical services, and patient trust of the healthcare provider. The finial CLD is illustrated in Figure 1. Causal loop diagram of diagnostic errors after the initial model was refined.

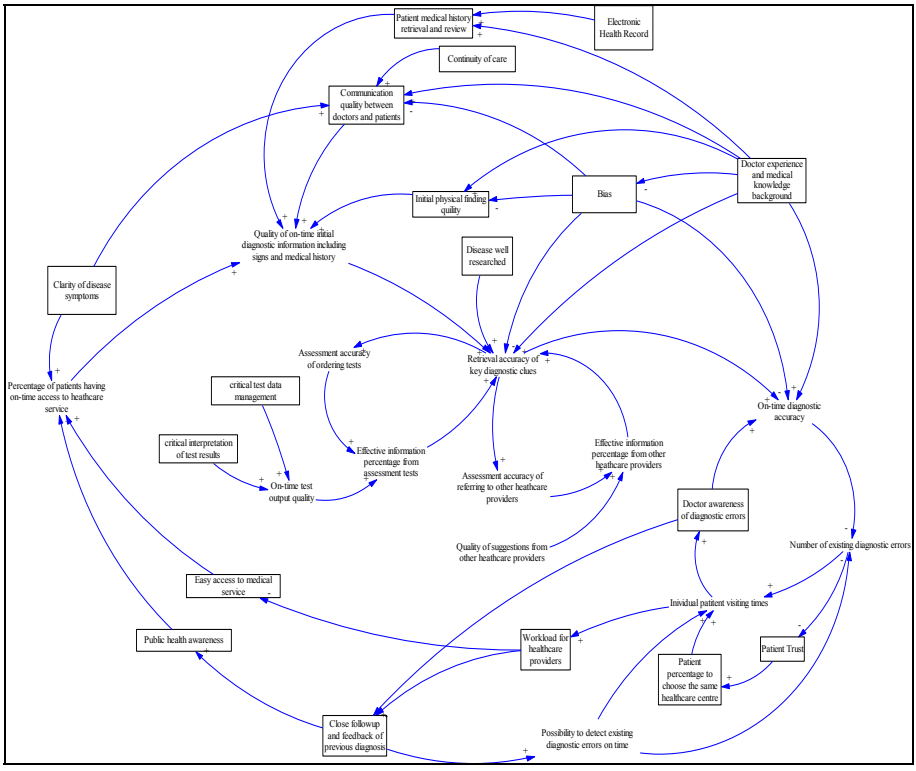


Figure 1. Causal loop diagram of diagnostic errors.

The CLD shows the research-level factors which affect diagnosis and their interrelationships. All factors and loops are based on the findings from the systematic review and the expert reviews.

The arrows in the diagram indicate a causal-effect interrelationship. The "effect variable" is the variable adjacent to the arrowhead, and the "cause variable" is at the opposite end of the arrowhead. Arrows with a positive polarity indicate the "effect variable" changes in the same direction with "cause variable"; while arrows with a negative polarity indicate the variables move in an opposite direction[7]. These arrows are linked into twelve loops in the diagram.

Each variable in the model has a clear view of different levels of causes by following its input arrows. The diagnostic errors are reflected as "Number of existing diagnostic errors" in the diagram, and its input arrows indicate the first-level factors which have direct causal effect on it. Additionally, a causes tree could be illustrated to show different level of factors. Figure 2 shows the first and the second level of factors of "Number of existing diagnostic errors" as an example.

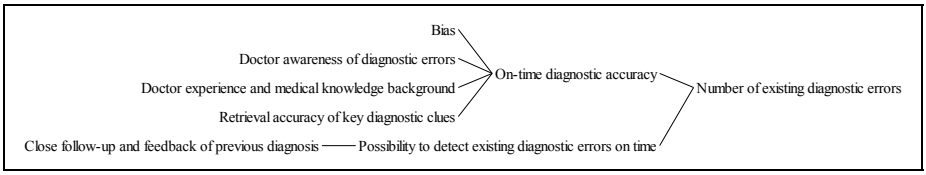


Figure 2. Causes tree of "Number of existing diagnostic errors".

Furthermore, following paths of loops, it is clear to see that a factor could pass one or more loops to affect the "Number of existing diagnostic errors". A change of a factor in the diagram triggers one or more changes of relevant variables, and then causes the change of "Number of existing diagnostic errors" directly or indirectly.

3. Discussion

The CLD shows many factors could potentially affect making a correct diagnosis and these multiple factors also have close interrelations with each other. A factor can appear to have a direct positive effect on diagnostics errors based on a partial view, but from a whole picture point of view in a CLD, it may actually produce negative outputs by affecting other factors essentially via other loops. It makes a CLD, as a systemic analysis, is important for the study of diagnostic errors. At the same time, the change of a factor could be caused by introducing an external intervention, thus a CLD also provides a potential way of visualizing the consequent influence of a new external intervention.

Current methods of reducing diagnostic errors can be divided into two groups, "Non-electronic methods" and "Electronic methods", based on whether individuals carrying out the diagnosis use computer technology to solve the problem. Non-electronic methods include improving education of patients or doctors, improving clinical guidelines and other creative ideas from other high-risk, high-reliability professions, like aviation. [18] Electronic methods work in the following two instances. The first is introducing advanced electronic laboratory equipments. The second is introducing other electronic interventions which work specifically in three ways: helping predict a diagnosis, providing information to doctors making a diagnosis, or helping to detect diagnostic errors in time after a diagnosis. [19]

A CLD is a qualitative analysis to understand what the key factors are and how they work from a systemic viewpoint. A quantitative model would be executed as a

next step in the future to transfer the CLD into a stock and flow diagram. This would provide a simulation of how much the output of diagnostic errors changes if one or more factors inside of the model are changed. as well as understanding the dominate factor(s) working inside of the model.

This model promotes patient safety in many ways. It gives suggestions of possible strategies to reduce diagnostic errors via finding how individual factors working inside of the model and discovering domain factors by performing sensitivity analysis. Also, it potentially provides a way of visualizing the consequent influence of a new external intervention. Furthermore, it could propose guidelines on how to reduce diagnostic errors.

References

[1] Weeks WB, Foster T, Wallace AE, Stalhandske E. Tort Claims Analysis in the Veterans Health Administration for Quality Improvement. J Law Med Ethics. 2001 Fall-Winter;29(3-4):335-45.

[2] Singh H, Graber M. Reducing Diagnostic Error Through Medical Home−Based Primary Care Reform. JAMA. 2010;304(4):463-464.

[3] Sibbald M, Cavalcanti RB. The biasing effect of clinical history on physical examination diagnostic accuracy. Med Educ. 2011 Aug;45(8):827-34.

[4] Kleit AN, Ruiz JF. False positive mammograms and detection controlled estimation. Health Serv Res. Aug 2003; 38(4): 1207–1228.

[5] Schiff GD, Kim S, Abrams R, Cosby K, Lambert B, Elstein AS, et al. Diagnosing Diagnosis Errors : Lessons from a Multi-institutional Collaborative Project. Advances in Patient Safety. [cited 2014 Apr] Available from: http://www.ahrq.gov/

[6] Wolstenholme EF. System enquiry: a system dynamics approach. Wiley; 1990

[7] Sterman JD. Business dynamics: systems thinking and modeling for a complex world. McGraw Hill; 2000

[8] Vaos G, Skondras C. Treves' field congenital hernias in children: an unsuspected rare cause of acute small bowel obstruction. Pediatric Surgery International. 2007 Apr;23(4):337-42.

[9] Hughes AJ, Ben-Shlomo Y, Daniel SE, Lees AJ. What features improve the accuracy of clinical diagnosis in Parkinson's disease: a clinicopathologic study. Neurology. 1992 Jun;42(6):1142-6.

[10] Parish LC. Hereditary angioedema: Diagnosis and management-a perspective for the dermatologist. J Am Acad Dermatol. 2011 Oct;65(4):843-50.

[11] Bertz RAS, First do no harm: A preliminary diagnostic error prevention case study conducted in the technical support department of an in vitro medical diagnostic instrumentation company. ProQuest, UMI Dissertation Publishing; 2011

[12] Arzy S, Brezis M, Khoury S, Simon SR, Ben-Hur T. Misleading one detail: a preventable mode of diagnostic error. J Eval Clin Pract. 2009 Oct;15(5):804-6.

[13] Wood DS, Tracey TJG. A brief feedback intervention for diagnostic overshadowing. Training and Education in Professional Psychology, Vol 3(4), Nov 2009, 218-225.

[14] Allen LK**,** Hatfield JM**,** DeVetten G**,** Ho JC**,** Manyama M. Reducing malaria misdiagnosis: the importance of correctly interpreting ParaCheck Pf (R) "faint test bands" in a low transmission area of Tanzania. BMC Infectious Diseases 2011, 11:308

[15] Sherbino J, Yip S, Dore KL, Siu E, Norman GR. The effectiveness of cognitive forcing strategies to decrease diagnostic error: an exploratory study. Teach Learn Med. 2011 Jan;23(1):78-84.

[16] Mendel R, Traut-Mattausch E, Jonas E, Leucht S, Kane JM, Maino K, et al. Confirmation bias: Why psychiatrists stick to wrong preliminary diagnose. Psychol Med. 2011 Dec;41(12):2651-9.

[17] Parnes B, Fernald D, Quintela J, Araya-Guerra R, Westfall J, Harris D, et al. Stopping the error cascade: a report on ameliorators from the ASIPS collaborative. Qual Saf Health Care. Feb 2007; 16(1): 12–16.

[18] Singh H, Petersen LA, Thomas EJ. Understanding diagnostic errors in medicine: a lesson from aviation. Qual Saf Health Care. 2006 Jun;15(3):159-64.

[19] Singh H, Giardina TD, Forjuoh SN, Reis MD, Kosmach S, Khan MM, et al. Electronic health record-based surveillance of diagnostic errors in primary care. BMJ Qual Saf. 2012 Feb;21(2):93-100.

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Ontology-based Diagnostic Decision Support in Radiology

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Abstract. The Radiology Gamuts Ontology (RGO) is a knowledge model of diseases, interventions, and imaging manifestations. RGO incorporates 16,822 terms with their synonyms and abbreviations and 55,393 relationships between terms. Subsumption defines the relationship between more general and more specific terms; causality relates disorders and their imaging manifestations. We explored the application of the RGO to build an interactive decision support system for radiological diagnosis. The Gamuts DDx system was created to apply the RGO's knowledge: it identifies a list of potential diagnoses in response to one or more user-specified imaging observations. The system also identifies a set of observations that allow one to narrow the diagnosis, and dynamically narrows or expands the list of diagnoses as imaging findings are selected or deselected. The functionality has been implemented as a web-based user interface and as a web service. The current work demonstrates the feasibility of exploiting the RGO's causal knowledge to provide interactive decision support for diagnosis of imaging findings. Ongoing efforts include the further development of the system's knowledge base and evaluation of the system in clinical use.

Keywords. Decision support, knowledge representation, ontology, radiology, diagnosis

Introduction

The Radiology Gamuts Ontology (RGO) is a large and growing knowledge model of diseases and their associated imaging observations [1]. It has been constructed from several sources of differential diagnosis information [2-5] to serve as a form of "computable knowledge" to aid in radiological diagnosis. RGO includes the names of disorders (e.g., "Aase-Smith syndrome"), interventions (e.g., "steroid therapy"), and observations (e.g., "hydrocephalus") with their synonyms and abbreviations. The subsumption ("is a") relation and its inverse ("has subtype") define a conventional hierarchy among more general and more specific concepts. The ontology incorporates knowledge across organ systems, patient populations (adults and children), and imaging modalities.

RGO is unique among current biomedical ontologies in that it specifies a causal relation ("may cause") and its inverse ("may be caused by") to relate entities to their imaging manifestations; for example, "hepatitis may cause cirrhosis," and "cirrhosis may cause portal venous hypertension." Unlike conventional "gamuts" listings, the representation of knowledge in the RGO model allows automated inference on that knowledge. This study describes the development of a platform for differential-

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diagnosis decision support using RGO's knowledge, called "Gamuts DDx." The platform has been applied to build an automated system for differential diagnosis of imaging observations.

1. Methods

As of January 2014, RGO included 16,822 terms, 1,755 subsumption relations, and 53,638 causal relations. A web-based user interface (*www.gamuts.net/ddx*) was developed to apply the RGO's knowledge. A web service using the Representational State Transfer (REST) architecture [6] and JavaScript Object Notation (JSON) was created to allow the system to be linked to other information systems.

Rather than using only direct links between entities, the Gamuts DDx system applied transitive closure over the ontology's subsumption relation,

$$\boldsymbol{isa}^{+}(X,Y) := \begin{cases} \boldsymbol{isa}\,(X,Y) \\ \boldsymbol{isa}\,(X,T),\ \boldsymbol{isa}^{+}(T,Y) \end{cases} \tag{1}$$

where **isa** (*X,Y*) means "*X* is a *Y*." Thus, if one knows "adenocarcinoma is a carcinoma" and "carcinoma is a neoplasm," the system can infer "adenocarcinoma is a neoplasm." Transitive closure over causality, where **causes** (*X,Y*) means "*X* may cause *Y*," incorporated transitive closure over subsumption:

$$\boldsymbol{causes}^{+}(X,Y) := \begin{cases} \boldsymbol{causes}\,(X,Y) \\ \boldsymbol{causes}\,(X,T),\ \boldsymbol{causes}^{+}(T,Y) \\ \boldsymbol{isa}^{+}(X,T),\ \boldsymbol{causes}^{+}(T,Y) \\ \boldsymbol{causes}^{+}(X,T),\ \boldsymbol{isa}^{+}(T,Y) \end{cases} \tag{2}$$

As a result, Gamuts DDx can follow chains of relations. For example, from the statements "hepatitis B is a viral hepatitis, which may cause cirrhosis, which may cause portal hypertension, which may cause splenomegaly, which is a splenic disease," the system can infer that hepatitis B may cause splenic disease.

For a given set of findings $F = \{ F_i \}$, the set of diagnoses is defined as the set of all entities X that satisfy **causes**$^{+}$ (X, F_i) for every finding F_i. We defined a "discriminator" as an observation that is caused by entities in a proper subset of the diagnoses. Thus, asserting the presence of a discriminator allows one to reduce the set of diagnoses.

2. Results

Gamuts DDx instantaneously and correctly identifies a list of potential diagnoses and a set of discriminators in response to user-specified imaging observations. Asserting the presence of a discriminator allowed users to refine the list of diagnoses. The lists of diagnoses and discriminators are narrowed or expanded dynamically as the user selects or deselects observations. The system accommodates an arbitrary number of specified findings.

Consider, for example, a patient in whom the initial finding is hypertelorism. Specifying the finding "hypertelorism" produces a list of 148 diagnoses, listed alphabetically from Aarskog syndrome to XXXXY syndrome. Among the 976 discriminators are observations such as acro-osteolysis, abnormal sternum, clubfoot, tracheomalacia, and Wormian bones. Selecting the additional observation "abnormal sternum" narrows the differential diagnosis to six entities: Brachmann-de Lange syndrome, cleidocranial dysostosis, Noonan syndrome, Rubinstein-Taybi syndrome, Seckel syndrome, and XXXXY syndrome. The list of discriminators is reduced to 278 possible observations. If the user then indicates that Wormian bones are present, the system identifies cleidocranial dysostosis as the only diagnosis in which all three of the observations are present.

On the web site, the user specifies an initial finding, such as "hypertelorism" (Figure 1). The discriminators are grouped by organ system and/or imaging modality, and are presented as a set of checkboxes. When checked, that finding is added to the list of the patient's findings. The lists of diagnoses and discriminators are updated accordingly. Selected findings can be unchecked. Additional information about each disorder is available through a hyperlink from the differential diagnosis listing. Figure 2 shows part of the web service response for hypertelorism and Wormian bones.

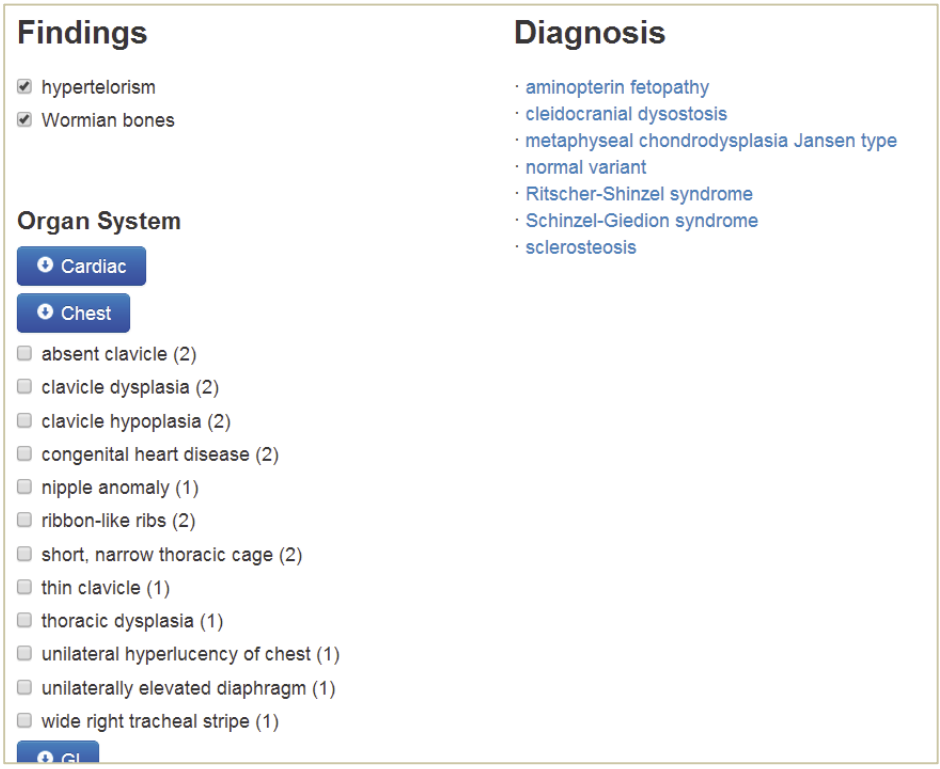


Figure 1. Screen shot of Gamuts DDx web-based user interface. Two observations (hypertelorism and Wormian bones) have been asserted. The seven diagnoses that exhibit both of these features are displayed at the right. Discriminators are grouped by organ system and imaging modality.

```
{
  "status": {
    "code": 200,
    "message": "Success",
    "createdAt": "2013-12-02T02:36:44Z"
  },
  "response": {
    "license": "Copyright (c) 2013 by the Authors. ALL RIGHTS RESERVED",
    "count": {
      "finding": 2,
      "diagnosis": 7,
      "discriminator": 258
    },
    "finding": [
      "hypertelorism",
      "Wormian bones"
    ],
    "diagnosis": [
      "aminopterin fetopathy",
      "cleidocranial dysostosis",
      "metaphyseal chondrodysplasia Jansen type",
      "normal variant",
      "Ritscher-Shinzel syndrome",
      "Schinzel-Giedion syndrome",
      "sclerosteosis"
    ],
    "discriminator": [
      {
        "name": "abnormal fibula",
        "n": "1"
      },
          . . .
      {
        "name": "widespread predominantly medullary osteosclerosis",
        "n": "1"
      }
    ]
  }
}
```


Figure 2. Example JavaScript Object Notation (JSON) output from differential diagnosis web service. For the two observations (hypertelorism and Wormian bones), seven diagnoses and 258 discriminators are identified.

3. Discussion

The Radiology Gamuts Ontology provides a large knowledge base of diseases and their imaging manifestations. The RGO incorporates information about a large number of rare diseases, such as metabolic disorders and skeletal dysplasias, including the Bone Dysplasia Ontology [7]. As defined by the U.S. National Institutes of Health, a rare disease is one whose prevalence is less than one in 1,500 (0.06%). There are 6,000 to 7,000 rare diseases, which in aggregate affect 25 to 30 million persons in the United States. The ontology is made available as a publically available web site (*www.gamuts.net*) and a web service [1]. Although useful for identifying potential causes of imaging findings, the original web site does not allow one to easily explore the intersection of more than one differential-diagnosis list.

One limitation of the Gamuts DDx system is the premise that a diagnosis must cause of all of the specified findings. As such, if the user asserts the presence of an imaging finding that is not linked a particular disease, that disease is eliminated from the differential diagnosis. The system also is limited by the extent of RGO's

knowledge of diseases and their associated imaging observations. Because the RGO currently lacks information about prevalence of the various disorders, it cannot rank diagnoses in order of likelihood, nor can it identify those imaging features that have the greatest discriminatory power.

One of the goals for the RGO is to incorporate the prior probability (prevalence) of each disorder in the knowledge model. The envisioned future work includes incorporating conditional probabilities into the RGO as well to express quantitatively the relationships between disorders and their imaging manifestations. Such information should allow better determination of the more likely diagnosis and more accurate ranking of the most informative imaging features. By linking to other biomedical ontologies and incorporating tools from platforms such as the National Center for Biomedical Ontology (NCBO), Gamuts DDx seeks to provide a sophisticated, semantically-aware platform for clinical decision support [8].

The current work demonstrates the feasibility of exploiting the RGO's causal knowledge to provide an interactive decision support tool for radiological diagnosis. Ongoing efforts include the further development of the system's knowledge base and evaluation of the system for clinical use.

References

[1] Budovec JJ, Lam CA, Kahn CE Jr. Radiology Gamuts Ontology: differential diagnosis for the Semantic Web. RadioGraphics. 2014;31(1):254-64.

[2] Reeder MM, Bradley WG, Merritt CB [Internet]. Gamuts in Radiology, 4.0 Web Edition: Comprehensive Lists of Imaging Differential Diagnoses. Reston, VA: International Society of Radiology; [updated 2003; cited 2013 Jul 24]. Available from: http://gamuts.isradiology.org/Gamuts.htm

[3] Reeder MM, Felson B, Bradley WG, Merritt CB. Reeder and Felson's gamuts in radiology: comprehensive lists of roentgen differential diagnosis. 4th ed. New York: Springer; 2003.

[4] Lachman RS, Taybi H. Taybi and Lachman's radiology of syndromes, metabolic disorders, and skeletal dysplasias. 5th ed. Philadelphia: Mosby Elsevier; 2007.

[5] Dähnert W. Radiology Review Manual, 7th ed. Philadelphia: Wolters Kluwer Health/Lippincott Williams Wilkins; 2011.

[6] Fielding RT, Taylor RN. Principled design of the modern Web architecture. ACM Trans Internet Technol. 2002;2(2):115-50.

[7] Groza T, Hunter J, Zankl A. The Bone Dysplasia Ontology: integrating genotype and phenotype information in the skeletal dysplasia domain. BMC Bioinformatics. 2012;13:50.

[8] Whetzel PL. NCBO Technology: Powering semantically aware applications. J Biomed Semantics. 2013;4 Suppl 1:S8.

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A novel personal health system with integrated decision support and guidance for the management of chronic liver disease

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Abstract. A personal health system platform for the management of patients with chronic liver disease that incorporates a novel approach to integrate decision support and guidance through care pathways for patients and their doctors is presented in this paper. The personal health system incorporates an integrated decision support engine that guides patients and doctors through the management of the disease by issuing tasks and providing recommendations to both the care team and the patient and by controlling the execution of a Care Flow Plan based on the results of tasks and the monitored health status of the patient. This Care Flow Plan represents a formal, business process based model of disease management designed off-line by domain experts on the basis of clinical guidelines, knowledge of care pathways and an organisational model for integrated, patient-centred care. In this way, remote monitoring and treatment are dynamically adapted to the patient's actual condition and clinical symptoms and allow flexible delivery of care with close integration of specialists, therapists and care-givers.

Keywords. Personal health system, integrated decision support, chronic liver diseases, patient management

Introduction

Personal Health Systems (PHS) are ICT enabled products and services that improve or preserve the health status of patients and healthy individuals outside institutional care. The penetration of healthcare systems with PHSs and associated services is still low for a variety of reasons, including a high demand for clinical resources and related financial costs. In addition, little support is provided by PHSs to doctors or patients to provide more efficient management of diseases and complications. In recent years progress has been made to incorporate informed clinical decision making in personal health services based on captured patient data [1]. However, integration of clinical

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decision support systems and health information systems used by healthcare providers with the PHSs used by patients lacks a clear strategy. Management aspects, such as triaging patients according to their clinical need, dynamic adaptation of therapy and system behaviour to patient condition and ensuring health professionals are involved only when necessary, are widely neglected.

In the context of chronic liver disease there is a clear, unmet need for an ICT-enabled system platform with associated monitoring and control for the remote management of patients outside the hospital. We chose to develop a personal health system for the outpatient management of chronic liver disease, incorporating a novel approach to integrated decision support and guidance through care pathways.

1. Methods

The core idea behind the system developed is that the formal disease management program for patients with chronic disease is designed off-line by domain experts on the basis of clinical guidelines, knowledge of care pathways and an organisational model for integrated patient-centred care. This patient management program is represented as a set of formal process models of the care flow including sub-processes for complication management following Business Process Modeling Notation BPMN 2.0. It is further personalised for a specific patient in an individual treatment plan (Care Flow Plan) that is executed by the central decision support unit of the system platform in the so-called Care Flow Engine. The Care Flow Engine will now guide the healthcare team and the patient through disease management by issuing tasks and presenting recommendations to the care team and the patient through their subsystems and by controlling the execution of the Care Flow Plan based on the results of tasks and monitored patient health status as shown in figure 1. The Care Flow Engine has well-defined interfaces to the subsystems based on a client-server like task-response concept. Tasks can be assigned to different users and roles but also to the subsystem itself. The Care Flow Engine can be enabled and disabled for individual patients. If disabled the system behaves like a conventional remote monitoring platform.

2. Results

A personal health system platform with integrated decision support, management and guidance through a Care Flow Engine has been developed for patients with chronic liver disease and their health professionals (figure 1). The knowledge base for the Care Flow Engine comprises process models with integrated clinical rules for the management of the complications of cirrhosis including ascites, hepatic encephalopathy, infection and cholestatic itch. The models focus on the modification of doses of drugs related to liver diseases and implement clinical guidelines where available, like those of the European Association for the Study of the Liver (EASL) for ascites management. An example of a process diagram for hepatic encephalopathy management is shown in figure 2. The diagram has been drafted by clinical liver experts from UK and Germany (the co-authors from (d) and (e)) in BPML2.0 notation and further translated to an executable Care Flow Plan that involves rules in a Rule Engine. In the design phase of the Care Flow Plan, the knowledge is modelled as a set of clinical rules that control execution of the plan. According to the plan, tasks are

issued by the Care Flow Engine for the patient and clinicians which are downloaded and processed by their subsystems and further executed with the help of the subsystem.

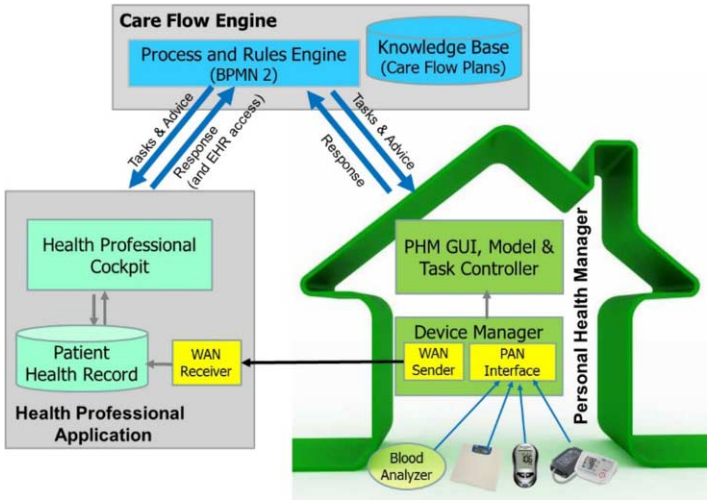


Figure 1. Architecture of the Personal Health System with integrated Care Flow Engine supporting informed clinical decisions, patient guidance and care pathways for the management of chronic liver disease.

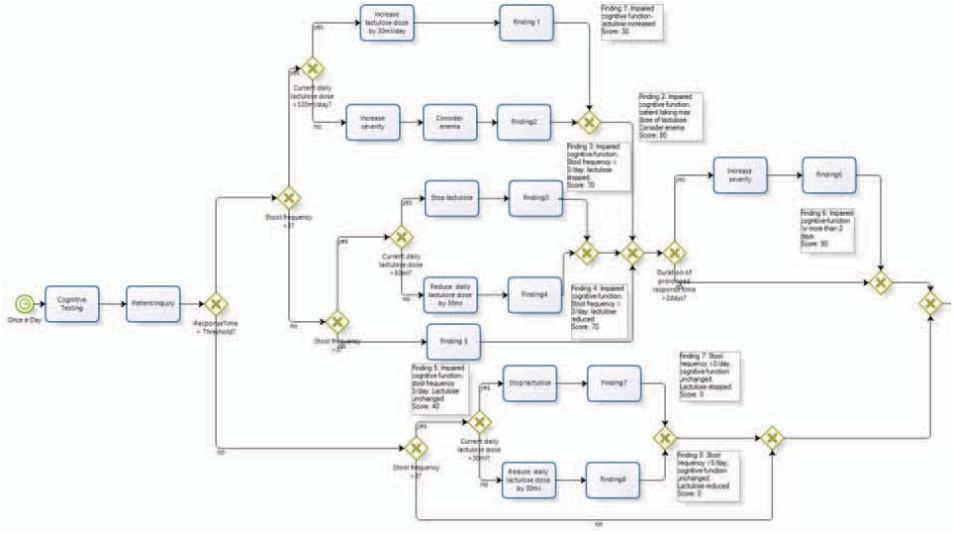


Figure 2. Excerpt of the process diagram for hepatic encephalopathy management.

Tasks for the patient typically include measurement tasks, medication intake tasks, execution of tests and clinical inquiries, exercising tasks, or simple recommendations. Results are sent back to the Care Flow Engine for further assessment and control. Tasks for doctors typically comprise acting upon warning messages and recommendations for interventions. Recommendations are based on findings obtained from the process models in the Care Flow Engine, with a focus on the semi-automated adaptation of medication doses in combination with reminders for medication intake. Findings are associated with a factor that quantifies the severity of the finding. The maximum of the

individual severity factors, along the process model, is used to quantify the overall disease severity of the patient, information which is used to rank patients in a list as an indicator for their need for medical attention. As a result, a flexible remote daily monitoring of the patient adapted to his/her actual conditions and clinical symptoms is achieved together with a strict and clear integration of specialists, therapists and caregivers according to a formal plan of the care process. This approach does not depend on the disease entity.



Figure 3. Personal Health Manager GUI.

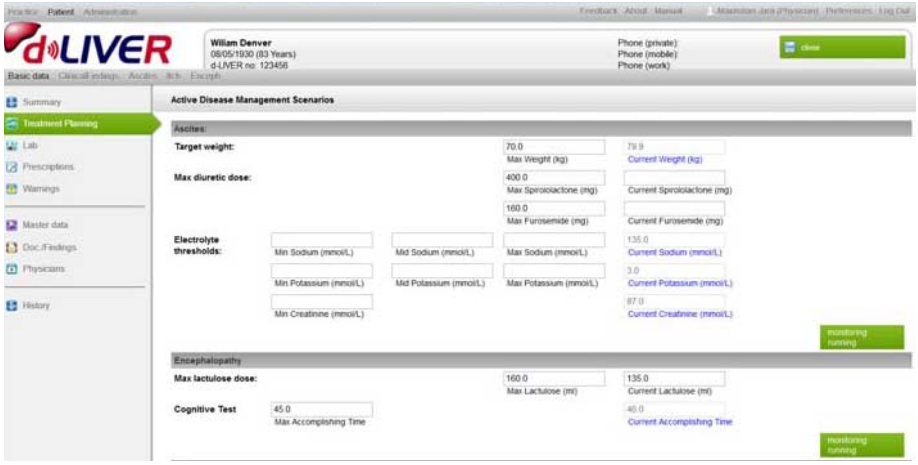


Figure 4. Health Professional Cockpit with interface for treatment planning for ascites and encephalopathy.

The Personal Health Manager, a Windows 8 App, is the Personal Health System of the patient (figure 3). Icons on the main screen indicate the functionality available to the patient. They start to flash and change their background colour when the corresponding tasks are issued by the Care Flow Engine and are received in the Personal Health Manager. Measurement tasks can be performed by the patient with the help of wireless devices like a weight scale, a blood pressure device, a blood glucose

meter and a blood analysis system for liver parameters. A device manager component inside the Personal Health Manager handles the communication interfaces with the devices. Communication interfaces follow when possible Continua Guidelines [2].

The Health Professional Cockpit is a web application that provides healthcare professionals access to a special electronic health record for the management of patients with liver diseases and allows them to personalize the Care Flow Plans for an individual patient (figure 4).

3. Discussion

An approach to integrate decision support for doctors with guidance for patients in Personal Health Systems has been presented and implemented for liver patient management. The flexibility behind this concept should provide better patient management in accordance with their health status while reducing the level of clinical contact required. Evidence for this assumption is subject to clinical validation of the implemented system in the context of the EU-FP7 d-LIVER project [3] as well as the designed Care Flow Plans for liver patient management. Patient safety aspects induced by risks associated with guiding patients through the therapy in combination with semi- or fully automated modification of treatment by the Care Flow Engine must be carefully analysed. Safety measures will need to be implemented both in the software and at service level to avoid patient harm through a malfunction of the system. As a future work, we plan to provide a design tool for formal process models of disease management that can be directly executed by the system platform. In this way, the solution could be easily adapted for the outpatient management of other chronic diseases.

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References

[1] Rigopoulou AV, Anthracopoulos MB, Katsardis CV, Lymberopoulos DK. An asthma management framework for the RespDoc clinical decision support system based on the combination of the official clinical guidelines, Bioinformatics and Bioengineering (BIBE), 2013 IEEE 13th International Conference on, (2013), 1-4.
[2] Continua Design Guidelines 2013 (Endorphin). November 23, 2012.
[3] d-LIVER - ICT-enabled, cellular artificial liver system incorporating personalized patient management and support, funded under FP7-ICT-2010-7, http://www.d-liver.eu (last accessed 29.01.2014).

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A new Multiple ANFIS model for classification of hemiplegic gait

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Abstract. Neuro-fuzzy system is a combination of neural network and fuzzy system in such a way that neural network learning algorithms, is used to determine parameters of the fuzzy system. This paper describes the application of multiple adaptive neuro-fuzzy inference system (MANFIS) model which has hybrid learning algorithm for classification of hemiplegic gait acceleration (HGA) signals. Decision making was performed in two stages: feature extraction using the wavelet transforms (WT) and the ANFIS trained with the backpropagation gradient descent method in combination with the least squares method. The performance of the ANFIS model was evaluated in terms of training performance and classification accuracies and the results confirmed that the proposed ANFIS model has potential in classifying the HGA signals.

Keywords. Adaptive neuro-fuzzy inference system; Fuzzy logic; Hemiplegic, Gait analysis

Introduction

Human gait analysis is particularly attractive to model because of its importance in everyday life and its complexity as a total body movement. In particular, pathological gait in humans following disease or injury is the subject of much contemporary research. For the rehabilitation process, quantification of gait is necessary for monitoring of functional recovery. The process of motor system recovery is qualitatively classified into stages by the Brunnstrom method [1]. The accelerometry technique is widely used clinically to investigate body motion of gait in healthy and post-stroke hemiplegic patients. The study of gait analysis through the accelerometric records is one of the most important tools for the diagnosis of locomotion defects. Sekine and co-authors demonstrated that the wavelet transform method was effective for classifying walking types for young subjects but not for elderly subjects, since gait changes with age [2,3]. In particular, locomotion is slower for elderly people than for young people. The amplitude of impact acceleration at heel-strike decreases with age. Elderly people also shuffle during locomotion and complexity of acceleration increases. Therefore, it is difficult to classify the post-stroke hemiplegic patient's walking type by using the former methods. The techniques have been used to classify gait and diagnosis to gait disorders using the, frequency domain features, time frequency analysis, and WT [2, 4-7]. The wavelet based approach has been found to be a useful tool for analysis of nonstationary biological signals and the results of the studies in the literature have demonstrated that the WT is the most promising method to

extract features from the gait signals [8-12]. In this respect, in the present study the WT was used for feature extraction from the HGA signals.

This study aims an assessment of gait after stroke that is useful as a support of diagnosis and therapy considerations. Our previous study on classification of HGA signals has been done by using fuzzy logic approach [13]. That study showed us the possibility of discrimination of subjects as healthy or patient using fuzzy logic. Fuzzy set theory plays an important role in dealing with uncertainty when making decisions in medical applications. Neuro-fuzzy systems are fuzzy systems, which use artificial neural networks (ANNs) theory in order to determine their properties by processing data samples. A specific approach in neuro-fuzzy development is the ANFIS, which has shown significant results in modeling nonlinear functions. In ANFIS, the membership function parameters are extracted from a data set that describes the system behavior. The ANFIS learns features in the data set and adjusts the system parameters according to a given error criterion [14,15]. Successful implementations of ANFIS in biomedical engineering have been reported, for classification [16,17]. Successful classification of patients to correct Brunnstrom stages, because of unstable signal behavior, was found extremely difficult. Classifying patients becomes increasingly difficult linearly according to hemiplegia's severity. Our results suggested that combination of artificial intelligence techniques may be suitable to assess the hemiplegic gate. In this article we try to explain an ANFIS classification application for hemiplegic gate to correct Brunstromm stages by using WT coefficients.

1. Materials and Method

Decision making was performed in two stages: feature extraction of HGA signals using the WT (28 extracted features as ANFIS inputs) and classification using the ANFIS classifier trained with the hybrid learning algorithm. In this section we restrict ourselves to explain how the HGA data collected for the datasets. For description of the used datasets and further details please refer to reference [18]. The complete dataset consist of five sets (denoted H, STVI, STV, STIV, STIII) each of them contains three subject's anteroposterior (×) acceleration signals. After the accelerometer device had been calibrated it was fixed on an acrylic plate that had two slits for a waist belt. It was fastened by an elastic waist belt to the subject's back in the lumbosacral region of the vertebral column, close to the subject's center of gravity while standing. Set H have been taken from recordings of healty elderly volunteers. Sets STVI, V, IV and III have been taken form post-stroke hemiplegic patient recordings.

2. MANFIS

2.1. Neuro-fuzzy system

Neuro-fuzzy system is a combination of neural network and fuzzy system in such a way that neural network learning algorithms, is used to determine parameters of the fuzzy system. ANFIS is a neuro-fuzzy model proposed by Jang [11]. The structure of ANFIS with five layers is shown in Fig. 1. x and y are the inputs for ANFIS. Note that the input layer is not calculated as an ANFIS layer.

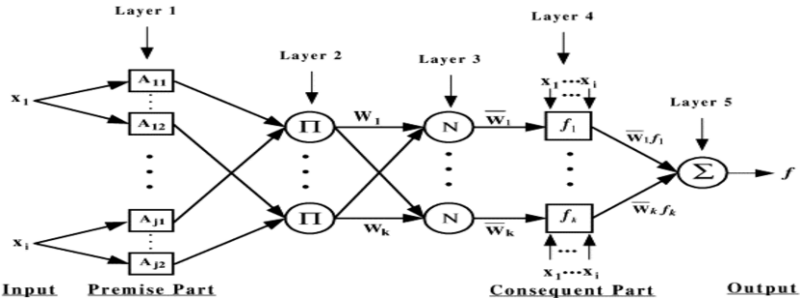


Figure 1. ANFIS Architecture

For learning rule of ANFIS, hybrid learning algorithm which combines the gradient descent and least-squares method is used to find a feasible set of parameters. Table 1 shows the hybrid learning procedure for ANFIS.

Table 1. Two passes in the hybrid learning procedure for ANFIS

	Forward Pass	Backward pass
Premise Parameters	Fixed	Gradient Descent
Consequest Parameters	Leastsquares estimate	Fixed

However, ANFIS itself only suitable for single output system. For a system with multiple outputs, ANFIS will be placed side by side to produce a Multiple ANFIS (MANFIS). The number of ANFIS required depends on the number of required output.

3. Results and Discussion

Spectral analysis of the HGA signals was performed using the WT. The number of decomposition levels is chosen based on the dominant frequency components of the signal. The levels are chosen such that those parts of the signal that correlate well with the frequencies required for classification of the signal are retained in the wavelet coefficients. The frequency band of normal gait signals is approximately 4-512 Hz. It is generally accepted that the frequency corresponding to step cycle is approximately 2 Hz, and almost all variance of the signal is in the band below 17 Hz. Sekine and co-authors suggested to use scales 6 and 7 for discrimination of walking patterns of healty subjects since these scales closely related to the impact acceleration, and the rest can accepted as a noise [8]. In this study, because the complexity of HGA signals we used the scales 7 to 1 instead of 6 and 7. The HGA signals were decomposed into details D1-D7. Generally, tests are performed with different types of wavelets and one which gives maximum efficiency is selected for the particular application. The smoothing feature of the Daubechies wavelet of order 4 (db4) madeit more suitable to detect changes of the HGA signals. Therefore, the wavelet coefficients were computed using the db4 in the present study. A rectangular window, which was formed by 512 discrete

data, was selected so that the HGA signal considered being stationary in that interval. For each HGA segment, the detail wavelet coefficients (d^k k=1, 2, 3, 4, 5,6,7) at the first, second, third, fourth, fifth, sixth, seventh levels (259+133+70+38+22+14+10) and approximation wavelet coefficients (a^7) at the seventh level (10 coefficients) were calculated by using db4 wavelet. Then 556 wavelet coefficients were obtained for each HGA segment. Figure 2 illustrates details (D6-D7) of a healthy eldery gait signal. In order to reduce the dimensionality of the feature vectors, statistics over the set of the wavelet coefficients were used. The following statistical features were used to represent the time-frequency distribution of the HGA signals: Maximum of the wavelet coefficients in each sub-band, Minimum of the wavelet coefficients in each sub-band, Mean of the wavelet coefficients in each sub-band, Standard deviation of the wavelet coefficients in each sub-band. These feature vectors, which were calculated for D1-D7 and A7 frequency bands, were used in classifying the HGA signals. The MANFIS classifier were trained with hybrid learning algorithm when 28 features (dimensions of the extracted feature vectors) representing the HGA signals were used as inputs. The max, min, sd and mean features of signals for seven level accepted as inputs.

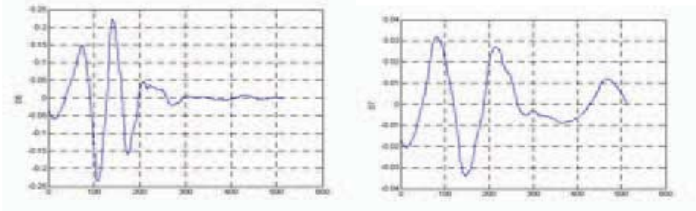


Figure 2. D6 and D7 coefficients of gait signal taken from healthy elderly subject

We prepared three sets each of them consists 20480 samples for each group. Then we wrote a short computer programme to produce 40 segments with 512 samples from these sets. After these steps 600x28 dimension matrix was obtained. MANFIS used 8400 traning data in 500 training epochs. At the end of the 500 training epochs average training error was found as 0.0079. After training period, 8400 testing data were used to validate the accuracy of the ANFIS model for classification of the HGA signals. In classification, the aim is to assign the input patterns to one of several classes, usually represented by outputs restricted to lie in the range from 0 to 1. In this application there were five classes as mentioned above: healthy elderly (H), Brunnstrom stage VI (STVI), Brunnstrom stage V (STV), Brunnstrom stage IV (STIV) and Brunnstrom stage III (STIII). The test performance of the classifiers can be determined by the computation of sensitivity, specificity and total classification accuracy. The ANFIS model's test performance was defined after comparing the real diagnosis results and FIS results. After our first attempts the avarage test error was found as 6.82. The training results were shown in Figure 3.

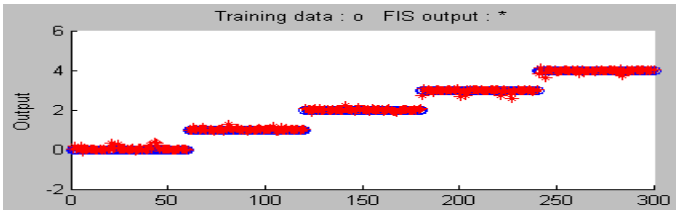


Figure 3. Training result of MANFIS

According to this test error point the classification of subjects to correct groups was not satisfactory. Finally the total classification accuracy was obtained as %84. As similar our previous study the main problem is here still to classify STIII patients. Successfull classification of this group patient to correct Brunnstrom stages, because of the complexity of signal is extremely difficult. Even the test result of system has not satisfactory yet, it is pleasent for us that this result belong to first attempt of study and it confirmed that the proposed ANFIS model has potential in classifying the HGA signals. We therefore have concluded that the proposed ANFIS model can be used in classifying the HGA signals by taking into consideration the misclassification rates. We believe that if we increase ANFIS moduls for each group the results will be better.

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References

[1] Baum HM and Robins M. The national survey of stroke. Survival and prevalence Stroke. 12, 159-68, (1981)
[2] Tamura T, Sekine M, Ogawa M, Togawa T and Fukui Y. Classification of acceleration waveforms during walking by wavelet transform. Meth. Inform. Med. Vol.36, 356-59, (1997)
[3] Sekine M, Tamura T, Togawa T and Fukui Y. Classification of waist acceleration signals in a continuous walking record. Med. Eng. Phys. Vol.22, 285-91 (2000)
[4] Sekine M, Akay M, Tamura T, Higashi Y, Fujimoto T. Fractal Dynamics of Body Motion in Patients with Parkinson's Disease. IEEE Transactions On Neural Systems and Rehabilitation Engineering. (2003)
[5] Sekine M, Akay M, Tamura T, Higashi Y, Fujimoto T. Investigating Body Motion Patterns in Patients with Parkinson's Disease using Matching Pursuit Algorithm. Med Bio Eng Comp. (2003)
[6] Akay M, Sekine M, Tamura T, Higashi Y, Fujimoto T. Time-Frequency Patterns of Body Motion in Post Stroke Hemiplegic Patients During Walking. IEEE EMB Mag. (2003)
[7] Akay M, Sekine M, Tamura T, Higashi Y, Fujimoto T. Unconstrained monitoring of body motion during walking. IEEE Eng Med Biol Mag. May-Jun;22(3):104-9. (2003)
[8] Sekine M, Tamura T, Akay M, Fujimoto T, Togawa T. Discrimination of walking patterns using wavelet-based Fractal Analysis. IEEE Tran. Neural Sys. Reh. Eng. Vol. 10, No.3, (2002)
[9] Fischer R, Akay M. Fractal analysis of hearth rate variability, in time frequency and wavelets in biomedical signal processing. M. Akay, Ed. Piscataway, NJ:IEEE, 719-28 (1998)
[10] Akay M. Wavelet applications in Medicine. IEEE Spectrum, 50-56, May (1997)
[11] Hazarika N, Chen JZ, Tsoi AC, Sergejew A. Classification EEG signals using wavelet transform. Signal process, 59(1), 61-72, (1997)
[12] Rosso OA, Figliolia A, Creso J, Serrano E. Analysis pf wavelet-filtered tonic-clonic electroencephalogram recordings. Med. Biol. Eng. Comput. 42(4), 516-23, (2004)
[13] Yardimci A. Fuzzy logic-based gait classification for hemiplegic patients. LNCS Lecture Notes in Computer Science Volume:4723, 344-354, (2007)
[14] Jang J-SR. ANFIS: Adaptive-network based fuzzy inference system. EEE Trans. Syst. Man Cybern. 23 (3), 665-685, (1993)
[15] Lang J-SR. Self-learning fuzzy controllers based on temporal backpropagation. IEEE Trans. Neural Network. 3 (5), 714-723, (1992)
[16] Belal SY, Taktak AFG, Nevill AJ, Spencer SA, Roden D, Bevan S. Automatic detection of distorted plethysmogram pulses in neonates and paediatric patients using an adaptive-network-based fuzzy inference system. Artif Intell Med, 24,149–65, (2002)
[17] Guler I, Ubeyli ED. Adaptive neuro-fuzzy inference system for classification of EEG signals using wavelet coefficients. J.Neuroscience Meth. 148, 113-121, (2005)
[18] Akay M, Sekine M, Tamura T, Higashi Y, Fujimoto T. Fractal Dynamics of Body Motion in post-stroke hemiplegic patients during walking. J. Neural Engineering 1, 111-16, (2004)

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ChronoQuery: Visual Modelling of Temporal Queries for Real-Time Decision Support

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Abstract. Clinical decision support systems are an important aspect of medical informatics. The increasing amount of available patient data requires physicians to rely on information technology for research and during their day by day work. In intensive care medicine, fast actions are especially important. One major step towards enabling direct interaction of medical staff with patient data was the development of clinical data repositories with easy query frontends. While clinical data repositories can be extended for the use of real-time data, the corresponding query frontends do not support the time concepts necessary for real-time queries and decision support. Aim of this project is the development of a user interface to give physicians visual understanding of propositional logic combined with time concepts. Thus, physicians should be able formulate simple time based queries on their own – and validate and quality check complex queries created by medical informatics experts.

Keywords. Clinical Decision Support Systems, Real-Time Systems, Intensive Care Units

1. Introduction

Clinical decision support systems (CDSS) are an important aspect of medical informatics. The increasing amount of available patient data requires physicians to rely on information technology for research and during their day by day work.

One major step towards enabling direct interaction of medical staff with patient data was the development of clinical data repositories with easy query frontends. Tools like i2b2 [1] and BTRIS [2] enable physicians to formulate queries from within a web browser. These query tools are commonly used for estimating study populations and answer simple research questions, but are limited to retrospective data and queries using simple propositional logic.

In intensive care medicine, fast actions are especially important. While we were able to extend clinical data repositories for the use of real-time data [3] the corresponding query frontends do not support the time concepts necessary for real-time queries and decision support.

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Aim of this project is the development of a user interface to give physicians visual understanding of propositional logic combined with time concepts. Thus, physicians should be able formulate simple time based queries on their own – and validate and quality check complex queries created by medical informatics experts.

This paper focuses on the technical implementation and the user interface. Evaluation results are not available at the time of publication.

1.1. Visualization of time oriented data

"The human perceptual system is highly sophisticated and specifically suited to spot visual patterns. […] Today, a variety of visualization methods exist and visualization is applied widely to present, explore, and analyze data. However many visualization techniques treat time just as a numeric parameter among other quantitative dimensions and neglect time's special character. In order to create visual representations that succeed in assisting people in reasoning about time and time-oriented data, visualization methods have to account for the special characteristics of time." [4]

In medical informatics, time-oriented visualization is mostly used to display patient data: Electronic health records are processed to visualize correlations (e.g. "Lifelines2" [5]). Yet, little work has been done on visualization of time based queries. A visual query tool "PatternFinder" was developed at the University of Maryland for searching patient histories [6]. A similar approach is described by Jin, using a comic strip metaphor for visual queries [7]. Our project aims to take these approaches one step further by allowing visual constructing of time-oriented rules for real-time decision support as well as retrospective data analysis.

2. Methods

2.1. Background and technical context

The university clinic in Giessen has a total of 1191 beds, treating 40,000 inpatients and 150,000 outpatients per year. In 2013, a total of 12,838 intensive and intermediate care episodes were counted. The intensive care information system stores around 3000 different structured concepts.

All information systems are connected via HL7 to an integration server, which is able to forward administrative data, diagnoses, procedures, laboratory results as well as all data from the intensive care system to our experimental decision support system HiStream[8] in real-time.

2.2. Medical Content

In order to enable physicians to construct decision support rules, a digital catalog with all concepts must be provided to the user. The catalog should include all concepts entered in the intensive care information system as well as diagnoses, procedures and laboratory results. Procedures and diagnoses are provided via OPS (German modification of the ICPM) and ICD-10. Proprietary laboratory result codes are imported from the software SwissLab. Intensive care concepts are imported from the

software ICU-Data. In a second step, all unused concepts (mostly procedures and diagnoses) are removed from the catalog.

2.3. Query interface and software architecture

Inspiration for the query interface was taken from several different projects. Similar to Fails[6] and Jin[7], time concepts are visualized horizontally from left to right. The remaining vertical dimension is used to build basic logic expressions, similar to BTRIS[2] and i2b2[1]. Following the recent success of touch screen interfaces, we envisioned the queries to be constructed using drag-drop gestures.

Targeting a broad target audience, the query interface should be usable from any computer or mobile device. As a web application, platform adaptions and deployment overhead would be minimal.

3. Results

3.1. Implementation

The query tool was implemented as a web application. It comprises a frontend part accessed from a web server but running in the user's web browser and backend part running on a web server. Communication between frontend and backend is done through representational state transfer (REST) over HTTP.

The frontend was developed as an interactive HTML5 web page using the JavaScript library jQuery 1.11.0[9]. JQuery Mobile was used for user interface dialogs and form elements.

The medical ontology is served by Apache Jena Fuseki ontology server. Diagnoses, procedures, lab results and intensive care documentation fields were converted to the Simple Knowledge Organization System [10] (SKOS) and loaded into the ontology server. The ontology is loaded into the frontend directly from the ontology server using a REST interface without involving the backend.

For the backend, PHP5 was chosen due to broad availability and simple installation. In its current implementation, the backend does only validate and store the queries. No execution is performed yet.

3.2. User Interface

The user interface is divided in two parts (Fig. 1): On the left hand side, a concept tree is rendered from the data received by the ontology server. Special concepts for time duration, time distance and prepositional logic are displayed on top of the concept tree.

The right hand side contains the query construction area. Queries can be constructed by dragging a concept from the concept tree to the construction area. This can be done either done with a finger gesture on a touch screen or by traditional means with a computer mouse. For each concept, a context menu can be opened (press+hold gesture or right click mouse) to specify additional options and constraints: Concept occurrence can be negated, as seen on Fig. 1 for pO2. Value ranges and search patterns can be specified for concepts with numeric or text values. For concepts with predefined values, a drop-down list is displayed (Fig. 2).

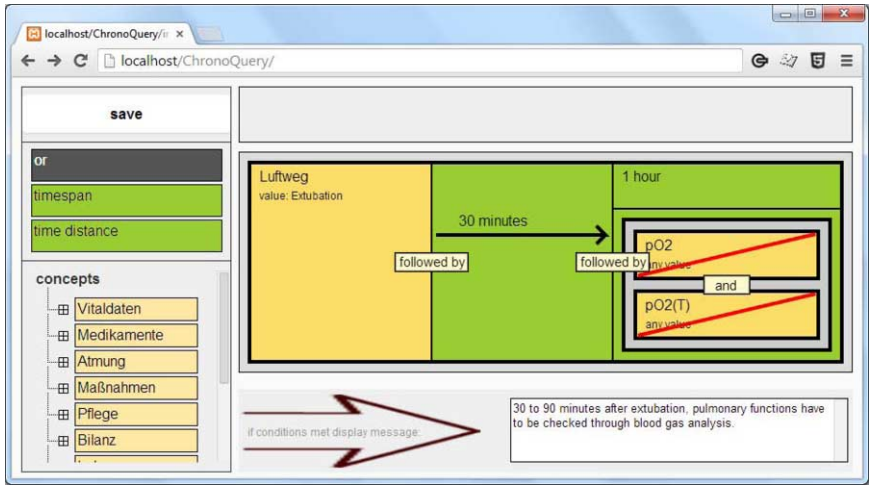


Figure 1. Visual modelling of an airway management SOP.

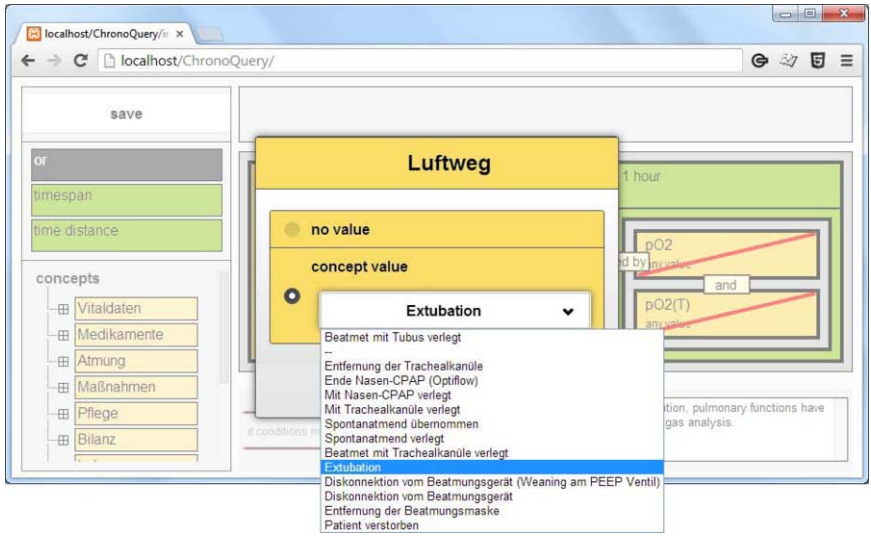


Figure 2. Restricting required values during airway management.

Figures 1 and 2 show the ChronoQuery interface displaying a standard operating procedure (SOP) for airway management: Pulmonary functions have to be checked via blood gas analysis 30 to 90 minutes after extubation. For notification purposes, the query is inverted: If there is no blood gas analysis 30-90 minutes after extubation, a message should be displayed to the responsible physician.

4. Discussion

We were able to design and implement a novel user interface to enable visual construction of real-time queries involving both time oriented concepts and

propositional logic. The drag-drop user interface can be used with touch screen devices as well as classical mouse input.

During the development process, the interface was shown to two senior physicians without background in information technology. Without specific instructions, the users were able to build simple queries and described the interface as intuitively usable. To test the limits of our interface, we asked a user to model SOPs from another intensive care unit. For complex SOPs, we encountered difficulties terms of self-descriptiveness: although the user was able to successfully construct the query, he would not agree with another user on what exactly the query meant.

We presume that self-descriptiveness is suffering especially for complex queries involving many concepts, due to large number of time and logic interactions. This might be solved by allowing queries to be reused as concepts themselves. Thus, a complex query could also be written as simple query comprised of simple sub queries. We are planning to investigate this issue through a systematic evaluation of the query interface.

Although the query interface was built for real-time decision support, we did not yet execute the visual queries yet. We are planning to integrate the query interface with our experimental CDSS[8] and automatically notify physicians through phone [11].

The query tool and all source code will be available through an open source license once evaluation is complete.

References

[1] Murphy SN, Weber G, Mendis M, Gainer V, Chueh HC, Churchill S et al. Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2). J Am Med Inform Assoc 2010; 17(2):124–30.

[2] Cimino JJ, Ayres EJ, Remennik L, Rath S, Freedman R, Beri A et al. The National Institutes of Health's Biomedical Translational Research Information System (BTRIS): Design, contents, functionality and experience to date. J Biomed Inform 2013.

[3] Majeed RW, Röhrig R. Automated realtime data import for the i2b2 clinical data warehouse: introducing the HL7 ETL cell. Stud Health Technol Inform 2012; 180:270–4.

[4] Aigner W, Miksch S, Schumann H, Tominski C. Visualization of time-oriented data. London, New York: Springer; 2011. (Human-computer interaction series).

[5] Manning JD, Marciano BE, Cimino JJ. Visualizing the data - using lifelines2 to gain insights from data drawn from a clinical data repository. AMIA Summits Transl Sci Proc 2013; 2013:168–72.

[6] Fails J, Karlson A, Shahamat L, Shneiderman B. A Visual Interface for Multivariate Temporal Data: Finding Patterns of Events across Multiple Histories. In: 2006 IEEE Symposium On Visual Analytics And Technology; 2006. p. 167–74.

[7] Jin J, Szekely P. Interactive querying of temporal data using a comic strip metaphor. In: MacEachren A, Miksch S, editors. 2010 IEEE Symposium on Visual Analytics Science and Technology (VAST); 2010. p. 163–70.

[8] Majeed, Raphael W. HIStream - A realtime HL7 stream based clinical decision support system; 2012 [cited 2013 Apr 15]. Available from: URL:https://sourceforge.net/projects/histream/.

[9] Resig, John. jQuery: The write less, do more, javascript library [cited 2014 Feb 7]. Available from: URL:http://jquery.com.

[10] Miles, Alistair; Bechhofer, Sean. SKOS simple knowledge organization system reference W3C; 2009 [cited 2014 Feb 7]. Available from: URL:http://www.w3.org/TR/skos-reference/.

[11] Majeed RW, Stöhr MR, Röhrig R. Proactive authenticated notifications for health practitioners: two way human computer interaction through phone. Stud Health Technol Inform 2012; 180:388–92.

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2. Health and Clinical Information Systems

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Plug-and-play Integration of dual-model based Knowledge Artefacts into an Open Source EHR System

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Abstract. In this paper we present our experiences with extending an existing approach for an archetype-compliant collection and export of data according to the *open*EHR specifications within the open source EHR system OpenMRS. It allows an automatic generation of forms from templates, which were introduced by *open*EHR as an extension of the dual-model approach. Data entered in these forms can be exported in form of standardized EHR extracts. The use of templates allowed us to solve problems reported for the original archetype-based version of the approach, which were caused by the high optionality within archetypes.

Keywords. EHR, Archetypes, Reference standards, Semantic interoperability

Introduction

Due to the great variety of medical treatments and the interdisciplinary cooperation among healthcare providers, patient-related data is often distributed amongst different EHR systems. For efficient and high-quality healthcare the exchange of this data is needed [1]. To achieve a semantically interoperable transmission of EHR data between systems with vendor-specific information models, it has to be implemented according to a standardized EHR specification [1] such as provided by the *open*EHR organization [2]. In this approach, data stored in one legacy EHR system is transformed into a standardized format and then sent to another EHR system, where it can again be transformed into a proprietary data format [3]. This standardized sharing of information can be eased by the usage of standard-compliant data entry forms, which directly enable the export of the entered data in standardized form [3].

The goal of the work presented here was to enable the archetype-compliant collection and export of data through entry forms in an open source EHR system. This should be achieved in a plug-and-play manner [4], without requiring manual effort for the creation of forms and mapping between the internal data model and the archetypes. Hereby we aimed to solve two problems reported in [3] when generating forms from archetypes. One problem was the existence of repeating archetype nodes in multiple hierarchical levels, which cannot be visualized with the form components that are

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commonly available in EHR systems. The other problem was the plethora of optional nodes within existing archetypes that affects the usability of generated forms.

1. Methods

We used the approach for plug-and-play integration of archetypes into legacy EHR systems presented in [3]. Therein the generation of entry forms from archetypes is based on a three-layered semantic mapping that was originally introduced by Chen et al. [5]. Structural constraints, data value constraints and terminology related constraints have to be mapped to the EHR system's data model. During the generation of the form, for each form component the path of the source archetype node is recorded. EHR extracts can then be created from data entered in the form without the need to access the underlying archetype.

To solve the two before-mentioned problems, we decided to adapt the approach presented in [3] in a way that it originates from *open*EHR templates instead of archetypes for the form generation. Templates represent an additional knowledge layer on top of archetypes and allow an aggregation of one or more archetypes and their customization to suit local clinical conditions [6]. This includes the option to constrain an archetype node's occurrence from *0..** to *0..1* and hereby remove multiple levels of repeating nodes. Further, optional nodes that are irrelevant for a particular clinical use case can be removed and nodes that should not be displayed on the form can be hidden. The final usable form of a template is called an operational template (OPT), which is intended to serve as basis for data entry forms in EHR systems according to [6].

In [3] a set of prerequisites for an EHR system's data model was introduced, that are required for applying the presented approach. In accordance with these requirements, we chose the "Open Medical Record System" (OpenMRS) as our test system from a list of open source EHR systems that were analyzed in [7].

OpenMRS is an open source EHR system designed to promote the provision of healthcare in developing countries [8]. It is built upon a *concept* dictionary, which defines the clinical concepts that are used in the system, e.g. diagnoses or procedures [9]. OpenMRS has a modular architecture, which allows functionality to be added to the core system. Besides modules supporting HTML and MS Infopath forms, a module is available for the creation of data entry forms based on the XForms mechanism. We chose this module for our prototype implementation.

XForms consist of an XForms Model, which defines a skeleton XML document, where data is inserted when the form is filled in, and an XForms User Interface, which describes how the form should be presented [10]. Every data entry field needs to be assigned to an OpenMRS *concept* in the XForms Model. In addition to the XForm, a Layout XML is necessary for a proper screen representation of the form in OpenMRS.

The semantic mapping underlying the form generation approach was defined as follows. The root node of the template is mapped to a new page on an OpenMRS form. A SECTION node is also mapped to a new form page, a CLUSTER node to a *GroupBox*. For labels, the local term of the node is used. If the node's type is not a descendant of LOCATABLE, the name of the attribute is used instead. Leaf nodes, i.e. nodes of type C_PRIMITIVE_OBJECT, are mapped to entry fields. Depending on the node type, suitable entry fields are used (e.g., *TextBox* or *DatePicker*). Intermediate nodes, i.e. nodes between the root node and leaf nodes in the hierarchical archetype structure, are mapped to labels. Repeating nodes are mapped to a *RepeatSection* on the

form. Entry fields inside a *RepeatSection* are placed next to each other, as shown in Figure 1 for the *Antibodies* segment. In this case the labels of intermediate nodes are concatenated and added to the label of the entry field that corresponds to the C_PRIMITIVE_OBJECT node.

In order to optimize the screen representation of the form, we hide the labels for some subtypes of DATA_VALUE. Further, for specified subnodes of the referenced DATA_VALUE object, the generated form fields are placed next to the label of the parent node instead of beneath it. This can be seen in Figure 1 for the ELEMENT *Oxygen flow rate*, which has a DV_QUANTITY *value* attribute, in comparison to the ELEMENT *FiO2*, which is displayed in the generic way.

C_DOMAIN_TYPE nodes and template-specific constraints, e.g. the "Hide on Form and HTML" option of the Template Designer, or *annotations* and *default values*, were also considered in the mapping. The *open*EHR primitive types and associated constraints, e.g. ranges of values, were mapped to the OpenMRS and the XForm data types. The descriptions provided in the *term definitions* section are shown as hints to entry fields. References to external terminologies were not yet considered. Predefined value lists were mapped to OpenMRS *ListBoxes*, as shown in Figure 1 for the *units* field.

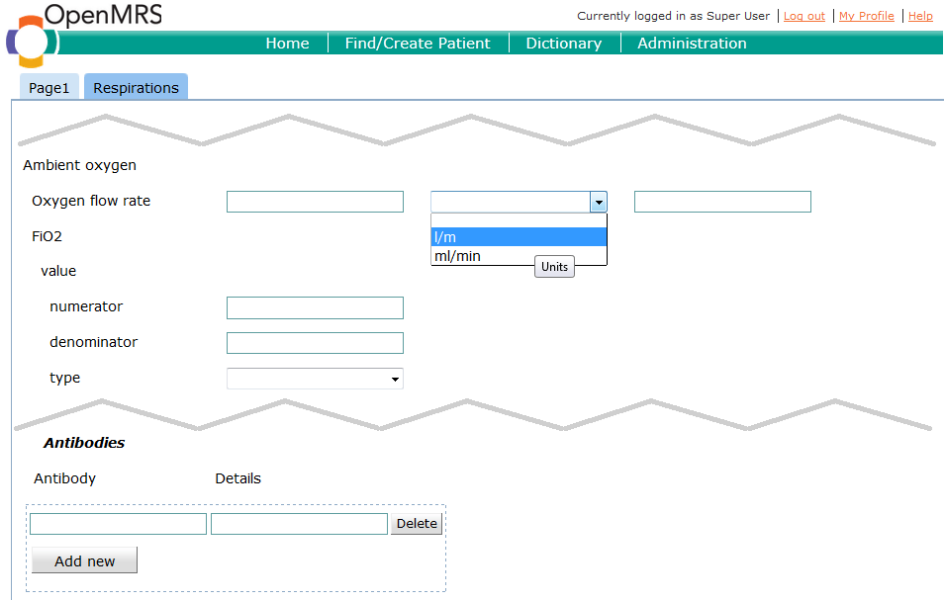


Figure 1. Excerpts of two OpenMRS forms generated from templates based on the "openEHR-EHR-OBSERVATION.respiration.v1" and "openEHR-EHR-OBSERVATION.blood_match.v1" archetypes.

The Ocean Template Designer [11] was used to define templates and generate OPTs from them. Using JAXB [12], OPTs were parsed into instances of Java classes generated from the *open*EHR release 1.0.2 XML schemas. Attributes, which are defined as mandatory in the *open*EHR reference model and are not constrained in the underlying archetypes, were added in order to obtain a comprehensive template. In case of an open archetype slot, the user has to choose from a list of all suitable archetypes from a specified directory. For the parsing of archetypes, the ADL parser of the *open*EHR Java Reference Implementation Project [13] was used. The necessary OpenMRS *concept*s, an XForm and a Layout XML were generated according to the

defined mapping. The hierarchical structure of the OPT was visualized in the form by appropriate form elements (*Pages*, *GroupBoxes*, and *RepeatSections*) as well as by means of indentation.

As preparatory step for the export of EHR extracts, for each node a metadata entry is recorded that contains the node's XPath, the ID of the form, the type of form element and optionally an associated OpenMRS *concept* and a default value. With the metadata, a document recorded by means of a generated OpenMRS form can then be directly translated into an archetype-compliant EHR extract. Generated EHR extracts were validated with the *open*EHR release 1.0.2 XML schemas.

2. Results

We tested our prototype with 27 templates. These templates were based on the same 27 archetypes used in [3] to examine whether the problems reported there could be solved by our adaptation of the approach. Additionally we created a test-template to check the prototype's ability to handle template-specific constraints.

In all cases of nested repeating nodes in the 27 archetypes, we were able to constrain the occurrence of these nodes within the templates in such a way that they could be represented with the *RepeatSection* on OpenMRS forms. All archetype slots were filled except for recursive slots (e.g., archetype "openEHR-EHR-CLUSTER.device.v1" contains a slot that refers to itself), which cannot be closed in the Template Designer.

3. Discussion

The method introduced in [3] could successfully be applied to the open source EHR system OpenMRS. The problem reported by Duftschmid et al. concerning nested repeating nodes could be solved by using *open*EHR templates instead of archetypes. Further, the usability of generated forms can be improved by removing irrelevant archetype nodes in the templates, respectively hiding nodes that must be present in the EHR extracts but should not be displayed in the form.

Analogous to the experiences made in [3] with the system ArchiMed, the OpenMRS data model is less expressive than the archetype model. So e.g. the *open*EHR *Real* and *Integer* primitive types both had to be mapped to the type *Numeric* in OpenMRS, resulting in information loss. Further, though C_DOMAIN_TYPES have been considered in the mapping, the dependencies between attributes defined through them couldn't be modeled with the available form elements.

Similar work in this area has been done by Atalag and Yang [14]. They created an application – GastrOS – for the recording of results from endoscopic examinations based on *open*EHR archetypes. Operational templates, including so-called GUI directives in the form of *annotations* for improvement of the visual appearance, were used as basis for the creation of data entry forms in this system. The main difference to our work is that GastrOS is already designed for the use of archetypes and templates, whereas we used an open source EHR system with a proprietary data model. In [15] Maldonado et al. present the software platform ResearchEHR, which, amongst others, includes the software ArchForms for the generation of web applications from archetypes, as well as a tool for the transformation of legacy data into standard-

compliant EHR extracts. In contrast to this work we focused on the creation of data input forms in one legacy EHR system and the usage of *open*EHR templates. The work done in [15] concerning the standardization of legacy EHR data is more comprehensive than our work, which is restricted to a specific EHR system.

We identified a probable bug in the Template Designer in the case of two slots occurring on the same hierarchy level, when both slots are filled with the same archetype. During the generation of the OPT by the Template Designer, the slot node itself is removed, resulting in identical XPaths of the plugged in archetypes. This subsequently causes problems during the creation of the EHR extract.

Our prototype does not yet support the reuse of existing OpenMRS *concept*s, i.e. it generates new OpenMRS *concept*s for every integrated OPT. To identify existing components that are semantically comparable to a new component and could thus be candidates for reuse, OpenMRS's ability to store *concept* mappings to other standard or non-standard vocabularies could be used in future. In the same way references to external terminologies from archetypes could be integrated into the system.

In future work, the optimization of the screen representation of forms generated from archetypes respectively templates will be an important part to increase the usability of the tested approach. In this context, the possibility to constrain reference model elements in a template, that are not included in the underlying archetype, has been missed in the Template Designer. We expect that this gap will be filled by the ADL 1.5 Workbench [11], which is planned to allow the editing of templates based on AOM 1.5 archetypes.

References

[1] Kalra D. Electronic health record standards. Yearb Med Inform. 2006:136-44.

[2] openEHR Specifications [cited 2014 Jan]. Available from: http://www.openehr.org/programs/specification/releases/currentbaseline.

[3] Duftschmid G, Chaloupka J, Rinner C. Towards plug-and-play integration of archetypes into legacy electronic health record systems: the ArchiMed experience. BMC Med Inform Decis Mak. 2013;13:11.

[4] Freriks G, de Moor G, Kalra D. White paper: archetype paradigm: an ICT revolution is needed. Available from: http://www.eurorec.org/files/filesPublic/ArchetypeParadigmFeb2007.pdf.

[5] Chen R, Klein GO, Sundvall E, Karlsson D, Ahlfeldt H. Archetype-based conversion of EHR content models: pilot experience with a regional EHR system. BMC Med Inform Decis Mak. 2009;9:33.

[6] Beale T. The openEHR Archetype Model - openEHR Templates 12 Jan 2012. Available from: www.openehr.org/releases/trunk/architecture/am/tom.pdf.

[7] Flores Zuniga AE, Win KT, Susilo W. Functionalities of free and open electronic health record systems. Int J Technol Assess Health Care. 2010;26(4):382-9.

[8] Mamlin BW, Biondich PG, Wolfe BA, Fraser H, Jazayeri D, Allen C, et al. Cooking up an open source EMR for developing countries: OpenMRS - a recipe for successful collaboration. AMIA Annu Symp Proc. 2006:529-33.

[9] OpenMRS [cited 2014 Jan]. Available from: http://openmrs.org/.

[10] XForms 1.1 [cited 2014 Jan]. Available from: http://www.w3.org/TR/xforms/.

[11] openEHR Modelling Tools [cited 2014 Jan]. Available from: http://www.openehr.org/downloads/modellingtools.

[12] Java Architecture for XML Binding (JAXB) [cited 2014 Jan]. Available from: https://jaxb.java.net/.

[13] openEHR Java Reference Implementation [cited 2014 Jan]. Available from: http://www.openehr.org/wiki/display/projects/Java+Project+Download.

[14] Atalag K, Yang HY. From openEHR domain models to advanced user interfaces: A case study in endoscopy. Health Informatics New Zealand Conference; Wellington 2010.

[15] Maldonado JA, Costa CM, Moner D, Menárguez-Tortosa M, Boscá D, Miñarro Giménez JA, et al. Using the ResearchEHR platform to facilitate the practical application of the EHR standards. J Biomed Inform. 2012;45(4):746-62.

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Development and evaluation of a memory clinic information system

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Abstract: Aim: To describe the requirements, development and evaluation of a cognitive disorders and older persons' clinical and research application, outlining the conceptual and practical challenges. **Methods**: A technology development methodology was used to develop a database of people being investigated for or diagnosed with cognitive disorders as well as their carers. The methodology involved phases of requirements gathering, modeling and prototype creation, and 'bench testing' the prototype with experts. **Results:** This case study suggests that construction and population of a memory clinic and research database is feasible, but initial development is complex. Its utility can be evaluated to some extent and was found to be acceptable to most users. **Discussion and Conclusions**: The development of a system needs to take in account existing data collection methods and other information systems used. The GreyMatters system can be considered a supplementary or complementary health record that sits alongside the main Trust information system. Integrating data from multiple systems enhances utility to clinical and research users.

Keywords. Mental health system, dementia, cognitive disorder, evaluation

Introduction

Memory clinics have become the most common way for adults who develop cognitive problems to be assessed, diagnosed and treated. Good memory clinics are multidisciplinary and holistic, integrating health and social care as well as the voluntary sector (National Audit Office 2007) to meet the needs of patients and their relatives and carers [1]. Standards for memory clinics are specified in the United Kingdom by the Memory Services National Accreditation Programme [2].

At its conception, much time was spent prescribing dementia drugs and monitoring their use and it was necessary to demonstrate to the Primary Care Trust that prescribing protocols were adhered to. It was also recognized that valuable clinical data could be used for service development, research recruitment and primary research purposes. Recently, the importance of research has been a key component of the G8 Dementia Summit pledge to find a cure or disease modifying treatment by 2025 [3].

[1] Archana Tapuria.

Thus, there was a need for a system to be developed to aid the clinical and administrative processes of assessing, diagnosing, managing, prescribing and treating older adults with mental health problems and adults with cognitive disorders. The system was also to record consent for patients and their carers to participate in research to facilitate recruitment of patients in clinical trials. Restricted 'researcher views' and generation of data in fully anonymised form is beyond the scope of the initial stages of the system. This memory clinic system was named 'Greymatters'.

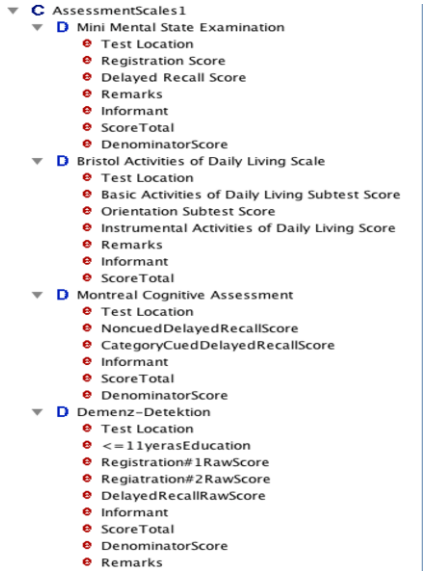
1. Methods

The main steps in the process were documenting formal set of requirements, clinical modelling using archetypes, knowledge driven application, iterative design, deployment and end user satisfaction testing.

Requirements were gathered from clinicians, pharmacists, and administrative staff from Berkshire Healthcare Foundation Trust (BHFT). A team of two clinicians, and three technicians from CHIME worked closely with the clinician who represented BHFT as the client. Technical support was provided by the Information Department of BHFT in relation to testing and deployment. They were handled with the help of a Wiki shared between CHIME and BHFT. Each issue was recorded and discussed on the Wiki and the solutions were posted there.

The software requirements specifications followed the IEEE Standard [4], and an electronic health record standard EN 13606 [5][6] was used. Clinical modelling was done through archetypes [7][8] and the project complied with data protection and privacy legislation.

The main areas covered were: Demographics; GP details; Alerts/allergies; Consent including research consent; Research orientated diagnosis and clinical registers; Cognitive symptoms; Assessment scales; Older Persons Mental Health Liaison Service Referral Data; Medical summary; Medication. An example screen is shown below.



2. Results

An evaluation was undertaken to assess user satisfaction and system usability of GreyMatters in 2013. The ASQ & CSUQ [9] were chosen as they have good internal consistency and allow assessment at overall system level as well as for individual system functions. The CSUQ provides 3 factors of analysis (System Usefulness, Information Quality, and Interface Quality) and an overall score. The ASQ asks for any given task 3 questions relating to satisfaction of: ease of use; time to complete task; and support information. Both the CSUQ and ASQ use a 7 point scale to record responses ranging from strongly agree (1) to strongly disagree (7) with positively expressed questions and a score of 4 representing the mid or neutral view.

A list of 16 past and present users of the system were emailed a copy of the CSUQ as well as a list of 7 scenarios that reflected real world use of the system. These ranged from searching for and registering a patient to entering clinic or research. They were asked to choose a minimum of 3 scenarios that reflected their normal use of the system and asked to complete the ASQ for each of the relevant scenarios.

There were a total of 10 responders (5 administrative staff, 3 clinicians and 2 research staff) who completed the CSUQ and a total of 29 ASQs covering 6 scenario areas. Results for the CSUQ and ASQ are presented in tables 1 and 2 respectively.

Averaged responses on the CSUQ (see table 1) for all user types show consistency across the 3 factors with overall score of 3.35. Breakdown of the staff groups suggest greater satisfaction from clinicians (overall score 2.32) than administrative staff (3.75). Analysis of individual user scores suggest polarised views in the clinician and administrative staff groups with responses ranging from 1-7 in both groups. Quality of supporting information was rated worst by the administrative group (4.06).

Responses on the ASQ (see table 2) show variation according to the task performed. Greater satisfaction was expressed for recording assessment scale data (2.25), recording a medication plan (2.60), recording research consent (2.79) and registering a patient (2.94). Dissatisfaction was expressed with recording a new drug (5.5) and entering liaison referral data (7.0). Clinicians and research staff were generally more satisfied than administrators. Analysis of individual responses again shows considerable polarity with responses ranging from 1-7.

Overall responses to the CSUQ and ASQ demonstrate mild to moderate satisfaction with the overall system and with individual tasks. Most notably recording of new drug and recording of liaison referral data were considered unsatisfactory although the low number of responders on these tasks (2 and 1 respectively) may reduce the validity of these results. It is apparent that certain individuals across the staff groups are strongly satisfied and others strongly dissatisfied with the same tasks and with the system overall.

It is possible that satisfaction scores are overall lower due to the extra complication of using this system in addition to the Trust's main electronic health record and also the need to maintain at least 3 other spread sheets to capture and manipulate required data. Further, limited resources have meant that written supporting information is scant and as yet updates to address known issues have not been possible. The results however support that the first version of the system is an acceptable tool for clinical, administrative, business and research use and forms a useful part of the wider information architecture.

Table 1: CSUQ results

	All	Admin	Clinical	Research
OVERALL (1-19)	3.35	3.75	2.32	3.34
SYSUSE (1-8)	3.35	3.74	2.25	3.42
INFOQUAL (9-15)	3.37	4.06	2.14	2.98
INTERQUAL (16-18)	3.33	3.23	3.00	3.78

Table 2: ASQ Results

All users n=10 Ave (range)	Over-all ASQ	Admin users n=5 Ave (range)	Ad-min ASQ	Research users n=2 Ave (range)	Rese-arch ASQ	Clinician users n=3 Ave (range)	Clini-cian ASQ	
	2.94		3.17		2.50			register a patient (n=5)
3 (1-6)		3.25 (1-6)		2.5 (2-3)				overall satisfied
2.67 (1-5)		2.75 (1-5)		2.5 (2-3)				satisfied with time
3.17 (1-7)		3.5 (1-7)		2.5 (2-3)				satisfied with support info
	2.79		3.78		1.83		2.44	record research consent (n=8)
2.63 (1-5)		3.33 (2-5)		2 (2-2)		2.33 (1-5)		overall satisfied
2.38 (1-4)		3.33 (3-4)		1.5 (1-2)		2 (1-3)		satisfied with time
3.38 (1-7)		4.67 (3-7)		2 (2-2)		3 (1-6)		satisfied with support info
	2.25		3.33		1.33		1.00	record assessment scale data (n=8)
2.25 (1-7)		3.25 (1-7)		1.5 (1-2)		1 (1-1)		overall satisfied
2.25 (1-7)		3.5 (1-7)		1 (1-1)		1 (1-1)		satisfied with time
2.25 (1-7)		3.25 (1-7)		1.5 (1-2)		1 (1-1)		satisfied with support info
	5.50		4.67				6.33	record new drug (n=2)
5 (4-6)		4 (4-4)				6 (6-6)		overall satisfied
5.5 (4-7)		4 (4-4)				7 (7-7)		satisfied with time
6 (6-6)		6 (6-6)				6 (6-6)		satisfied with support info
								record diagnosis (n=0)
-	-	-	-	-	-	-	-	-
	7.00		7.00					complete liaison referral (n=1)
7 (7-7)		7 (7-7)						overall satisfied
7 (7-7)		7 (7-7)						satisfied with time
7 (7-7)		7 (7-7)						satisfied with support info
	2.60		2.50				2.67	record medication plan (n=5)
2.6 (1-6)		2.5 (1-4)				2.67 (1-6)		overall satisfied
2.6 (1-6)		2.5 (1-4)				2.67 (1-6)		satisfied with time
2.6 (1-6)		2.5 (1-4)				2.67 (1-6)		satisfied with support info

3. Discussion

A challenge in modern healthcare is the constantly shifting requirements for information recording to meet stakeholder needs. GreyMatters has found a niche within the ecosystem of IT systems in the Trust. Its strength is that it provides flexibility to record clinical information that the other Trust systems can't. It can therefore be considered a supplementary or complementary health record that sits alongside the main Trust system. The use of multiple systems is not always ideal and presents a real challenge to time pressured staff. This and the lack of documentation and on screen help are reflected in the variability of user scores in the evaluation. Overall the assessment of the system in an early stage, suggests it is an acceptable solution.

The benefits of the system have been further enhanced by developing data flows between the different systems. For instance, new patient registrations within the main Trust system are automatically imported into GreyMatters. Data from GreyMatters and the other Trust systems are combined to produce textual and graphical reports which are delivered to individual users on a nightly basis. Data is automatically imported into the spreadsheets used by clinics to manage clinic workflow. A browser based data mining tool has been developed to enable proposed research feasibility testing as well as a recruitment tool for identification of research participants.

4. Conclusion

The well established standards on which the GreyMatters architecture is based provide the Trust with confidence that the system can meet the medico legal challenges of an electronic health record. The system has been deemed acceptable by most users although there is dissatisfaction with some aspects by some users and needs further work. Additional value has been added by listening carefully to how clinical, administrative and research staff work and by pushing data and reports to them automatically in a format they want.

References

[1] Improving services and support for people with dementia. Report by the Comptroller and Auditor General. HC 604 Session 2006-2007, 4 July 2007; National Audit Office.
[2] Memory Services National Accreditation Programme, Standards for Memory Services, Third Edition June 2012, Pub. No. CCQI131Royal College of Psychiatrists.
[3] http://dementiachallenge.dh.gov.uk/2013/12/12/g8-dementia-summit-agreements.
[4] IEEE Standards. 830-1998 - IEEE Recommended Practice for Software Requirements Specifications.
[5] Kalra D. Requirements for an Electronic Health Record Architecture. ISO18308:2010.
[6] Kalra D, Lloyd D. EN 13606 Electronic Health Record Communication Part 1: Reference Model. CEN TC/251, Brussels. February 2007.
[7] Ingram D, Beale T, Heard S, Kalra D. The openEHR Foundation. Accessed Jan 2012. Available at: http://www.openehr.org.
[8] Tapuria A, Kalra D, Kobayashi S. Contribution of Clinical Archetypes, and the Challenges, towards Achieving Semantic Interoperability for EHRs. *Healthc Inform Res* 2013; 19(4), 286 - 292.
[9] IBM Computer Usability Satisfaction Questionnaires: Psychometric Evaluation and Instructions for Use. Lewis JR. *International Journal of Human-Computer Interaction* 1995; v.7 n.1 p.57-78 2007.

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Adverse Drug Event Notification on a Semantic Interoperability Framework

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Abstract. Adverse drug events (ADEs) are common, costly and one of the most important issues in contemporary pharmacotherapy. Current drug safety surveillance methods are largely based on spontaneous reports. However, this is known to be rather ineffective. There is a lack of automated systems checking potential ADEs on routine data captured in electronic health records (EHRs); present systems are usually built directly on top of specific clinical information systems through proprietary interfaces. In the context of the European project "SALUS", we aim to provide an infrastructure as well as a tool-set for accessing and analyzing clinical patient data of heterogeneous clinical information systems utilizing standard methods. This paper focuses on two components of the SALUS architecture: The "Semantic Interoperability Layer" (SIL) enables an access to disparate EHR sources in order to provide the patient data in a common data model for ADE detection within the "ADE Detection and Notification Tool" (ANT). The SIL in combination with the ANT can be used in different clinical environments to increase ADE detection and reporting rates. Thus, our approach promises a profound impact in the domain of pharmacovigilance.

Keywords. Semantic interoperability, adverse drug event (ADE), pharmacovigilance, electronic health record (EHR)

Introduction

Adverse drug events (ADEs) are responsible for significant morbidity and mortality of patients. Current post-market drug safety surveillance activities are largely based on reports of suspected ADEs sent to the regulatory bodies by medical professionals. This process is historically referred to as "spontaneous reporting" as it relies on the active efforts by the reporter rather than systematic screening of a predefined cohort [1].

The major problem of the current drug surveillance system is underreporting. It has been estimated that only around 5% of all ADEs are reported through spontaneous reporting [2]. This is partially due to the fact that overwhelmed medical personnel does not always see reporting as a priority. Another issue is that detecting ADEs may not always be straightforward, hence can be overlooked. Identification of ADEs on a routine basis has been rather ineffective. In inpatients, manual chart review is used for

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ADE detection, but it is too time-consuming and costly to be routinely practical. To overcome this problem and utilize the increasing amount of digitally recorded clinical patient data, several studies have been carried out to monitor electronic health records (EHRs) for the detection of possible ADEs [3]. However, these efforts usually try to build ADE detection monitors directly on top of proprietary clinical information systems (CIS). Hence, each integration is a project in itself, and it is not possible to run different data analysis tools on top of already existing CIS in an ad-hoc manner.

In this paper, we will introduce the European project SALUS („Scalable, Standard based Interoperability Framework for Sustainable Proactive Post Market Safety Studies"), which aims to provide the necessary infrastructure and tool-set for accessing and analyzing the patients' EHR data to be collected from heterogeneous CIS [4]. The focus is on the SALUS "Semantic Interoperability Layer" (SIL) that enables a semantically standardized clinical data access, used by the "ADE Detection and Notification Tool" (ANT) in order to detect and notify suspicious cases of potential ADEs to the treating physician (see chapter 1). The implementations of the SALUS architecture and tools demonstrate the feasibility of our framework and are described as initial results in chapter 2, followed by a brief discussion in chapter 3.

1. Methods

Existing ADE detection approaches indicate that computer-based ADE detection is more effective than spontaneous reporting systems [3]. However, the systems developed so far are very specific. In contrast, we have designed comprehensive generic interoperability mechanisms in the context of the SALUS project.

Figure 1 gives an overview of the SALUS software architecture. At the bottom, the Interoperability Framework is depicted. This framework acts as a means for semantic mediation, utilizing several medical content/terminology standards and communication profiles. Using a single mediation framework enables the creation of n-to-n mappings between CIS and analysis tools to be run on top of these systems. The upper part of the figure depicts the internal mechanics of the ANT, and its integration with the SIL.

In this chapter, first, the semantic interoperability approach is further described in section 1.1, followed by a presentation of ANT in section 1.2.

1.1. SALUS Semantic Interoperability Layer (SIL)

The SALUS SIL enables access to disparate EHRs sources to retrieve structured patient medical summaries to be used for ADE detection. Medical summaries are made available in a common semantic model, the SALUS "Common Information Model" (CIM), on this layer.

SALUS CIM is a harmonized data model represented in an ontological format that covers the data requirements of the SALUS project. It acts as a common denominator for the existing standards used in the clinical care and clinical research domains. While building this model, several standard content models such as HL7/ASTM "Continuity of Care Document" (CCD), IHE "Patient Care Coordination" (PCC) templates, ISO/CEN "EN 13606 archetypes", and "Observational Medical Outcomes Partnership" (OMOP) were examined, and data elements were identified considering the SALUS data requirements. To avoid creating entities from scratch, already existing vocabularies were used as much as possible [5].

Two different methods are being used to retrieve medical summaries from the underlying CIS. For semantically enabled EHRs systems, we use an interface to query the CIS through the native "SPARQL Protocol And RDF Query Language" (SPARQL) endpoint they expose. In such systems the medical summary is retrieved in a local "Resource Description Framework" (RDF) model of the underlying EHR database. As an alternative option, we implement IHE based standards to query and subscribe to the CIS to collect medical summaries; namely IHE "Query for Existing Data" (QED) and "Care Management" (CM) have been implemented. In this way we communicate with the CIS through standard interfaces and are able to collect medical summaries in a format conforming to IHE PCC "Clinical Document Architecture" (CDA) based templates. The IHE PCC templates used in the SALUS project are introduced in [6]. In both cases, the CIM-Converter component executes transformation rules using the EYE reasoned engine [7] to represent the EHR response with SALUS CIM data elements.

SALUS SIL supports both query and subscription to patient medical summaries. The query feature enables the retrieval of clinical summaries for certain patients when a query is issued to SIL. The subscription feature allows a client application to receive notifications whenever the clinical summary of a patient is updated in the CIS.

Another important part of SALUS SIL is the terminology server. Since CIS and analysis applications use different code systems to represent clinical entities, the terminology server provides mappings between different code systems utilized in the SALUS project.

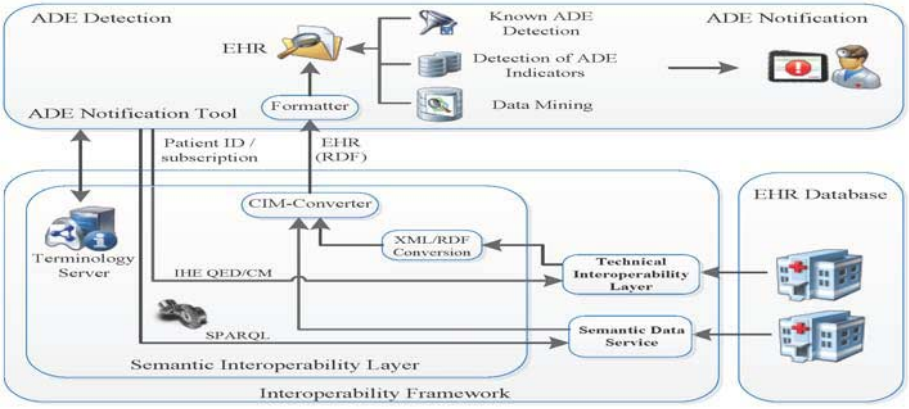


Figure 1. SALUS system overview.

1.2. Adverse Drug Event Detection and Notification Tool (ANT)

The SALUS ANT enables a semi-automatic ADE detection and notification of suspicious cases of potential ADEs to the treating physician. ANT can be divided into two major processes, the ADE detection process to reveal suspicious cases of ADEs in the patient data, and the notification process in order to present the detection results to the treating physician in an appropriate manner.

The primary objective of the overall ADE detection process is to detect currently unknown ADEs which are of interest to the regulatory bodies. Starting with a patient's EHR as input obtained by the SIL, the ADE detection process consists of a procedure involving three analysis steps. First, the current knowledge on known ADEs is

considered to filter out the already known ADEs. Therefore, a database containing known ADEs was created. Second, several detection rules are executed on the EHR in order to find ADE indicators. These rules are based on ADE detection approaches published in the literature, such as monitoring laboratory values, antidote prescriptions, ADE related diagnoses, reported but unconfirmed ADEs, and drug interactions. Third, a data mining algorithm is executed that analyses all EHRs of the clinical information system stored in a pre-processed EHR database according to the OMOP data model [8].

When an indicator or suspicious event is found during the ADE detection process, the notification process gets triggered. The objective is to facilitate a comfortable decision making process for the physician, whether or not a suspicious event really describes a present ADE. Consequently, the information presented to the doctor represents a compromise between the complete patient's EHR data and the relevant data for the decision. The physician needs to see the patient's course of treatment to understand the context. Thus, as a part of the ADE notification, we implemented a timeline visualization enabling an intuitive overview of the clinical data (see Figure 2). Additionally, the doctor can "zoom" into the timeline to see exact times of medications and diagnoses, or add further information like laboratory results or procedures.

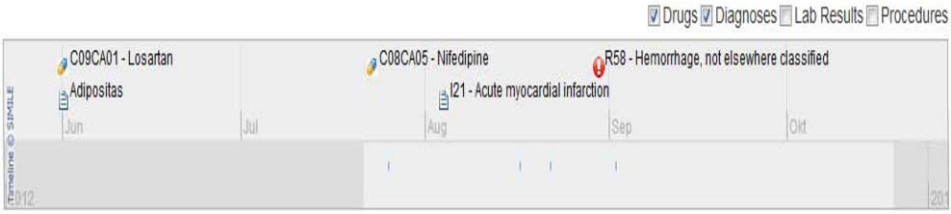


Figure 2. Timeline indicating the patient's course of treatment.

Finally, if the physician confirms a notification being a present, unknown ADE, the ADE reporting system of the SALUS project gets triggered [9] where the report is pre-populated using the patient data available from the EHR.

2. Results

Two CIS are available at the SALUS pilot sites: (1) a regional clinical Data Warehouse maintained in the Lombardy region in Italy, which collects data necessary for administrative and statistical purposes from almost all the public healthcare providers; (2) the AGFA ORBIS installation used as the CIS at the university clinic Dresden (UKD) covering 21 clinics in Saxony, Germany.

The first prototypes of the SALUS components have been deployed and tested in both pilot sites. The retrieval methods of SIL are utilized in these deployment sites and a unified interface is provided to ANT while consuming SIL. Considering these different pilot sites, the ADE detection rules of the ANT have been specifically designed by local experts according to their medical domain, but there are also general rules implemented that are used in both settings. In the current phase of the study, artificial patient data for testing purposes is generated in the CIS' own data formats and ADEs were detected for those test cases using the whole integrated SALUS system. Furthermore, initial tests with real patient data of the Italian clinical Data Warehouse were conducted successfully.

3. Discussion

Different rule-based data analysis algorithms can be used to detect ADE incidents and report them to the medical practitioners in order to increase ADE reporting rates. In the past, such algorithms were usually implemented in a proprietary way that is specific to the CIS on whose database the algorithm would be run. By introducing the standard based Interoperability Framework of SALUS, we enabled data screening in a machine processable manner, feeding these data to the analysis algorithms, and sending the analysis results back to the medical practitioners within an EHR session seamlessly.

In the next months, the SALUS prototypes will be evaluated with real EHRs at the university hospital Dresden, the largest hospital structure of Saxony, Germany, and in the Lombardy region in Italy, covering a population of 9.9 million citizens with about 215 million yearly records.

To conclude, one significant limitation of the SALUS approach is that data analysis is still limited to the data of individual CIS and thus individual health providers. Of course it would be very useful to perform such analyses on the complete clinical history of the patient, taking into account EHRs at hospitals as well as at ambulatory care providers, such as family doctors. Furthermore, it is well known that "over the counter" (OTC) medication may also play an important role in causing ADEs, and such information can only be tracked if a complete medication record of the patient, including OTC medication sold in pharmacies and drug stores could be taken into account. Nevertheless, we believe that the potential that even today's fragmented EHR landscape offers for improving our knowledge about health and care is far from being fully utilized, and SALUS is certainly one step in the right direction.

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References

[1] Arora D. Pharmacovigilance Methods. In: Pharmacovigilance – An Industry Perspective. Sonepat: Pharma Publisher; 2012. p. 25-40.
[2] Carleton BC, Smith MA. Drug safety: Side effects and mistakes or adverse reactions and deadly errors? BCMJ. 2006 Sep; 48(7): 329-33.
[3] Classen D, Pestotnik S, Evans R, Burke J, Battles J. Computerized surveillance of adverse drug events in hospital patients. Qual Saf Health Care. 2005 Jun; 14(3): 221-6.
[4] Software Research, Development and Consultancy Ltd. (SRDC) [Internet]. SALUS – Scalable, Standard based Interoperability Framework for Sustainable Proactive Post Market Safety Studies; 2012. Available from: http://www.salusproject.eu
[5] SALUS Consortium [Internet]. D4.1.2 SALUS Content models for the Functional Interoperability Profiles for Post Market Safety Studies – R2; 2014. Available from: http://www.srdc.com.tr/projects/salus/docs/D4.1.2.pdf
[6] SALUS Consortium [Internet]. D5.2.2 Query Based Interoperability Profiles and Open Source Toolsets – R2; 2014. Available from: http://www.srdc.com.tr/projects/salus/docs/D5.2.2.pdf
[7] De Roo J [Internet]. Euler Yet another proof Engine (EYE); 2014. Available from: http://eulersharp.sourceforge.net
[8] [8] Observational Medical Outcomes Partnership (OMOP) [Online]; 2013. Available from: http://omop.org
[9] [9] Parès Y, Declerck G, Hussain S, Ng R, Jaulent MC. Building a Time-Saving and Adaptable Tool to Report Adverse Drug Events. 14th World Congr. on Medical and Health Informatics; 2013 Aug 20-23; Copenhagen: Denmark.

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Ci4SeR - Curation Interface for Semantic Resources - Evaluation with Adverse Drug Reactions

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Abstract. Evaluation and validation have become a crucial problem for the development of semantic resources. We developed Ci4SeR, a Graphical User Interface to optimize the curation work (not taking into account structural aspects), suitable for any type of resource with lightweight description logic. We tested it on OntoADR, an ontology of adverse drug reactions. A single curator has reviewed 326 terms (1020 axioms) in an estimated time of 120 hours (2.71 concepts and 8.5 axioms reviewed per hour) and added 1874 new axioms (15.6 axioms per hour). Compared with previous manual endeavours, the interface allows increasing the speed-rate of reviewed concepts by 68% and axiom addition by 486%. A wider use of Ci4SeR would help semantic resources curation and improve completeness of knowledge modelling.

Keywords. Interface, curation, validation, evaluation, GUI, ontology, ADR

Introduction

Evaluation and validation have become a crucial problem for the development of reliable semantic resources. Content-validation methodologies have grown with the need of knowledge modelling and its reuse. Dedicated tools for semantic curation are required to alleviate the curation task, especially in the medical field. Available software for ontology edition is generally consultation-oriented [1][2][3]. For example, Rubin [4] has studied the use of Protégé for development and maintenance of RadLex, a terminology for radiology applications. According to his experience "some users may not find Protégé intuitive to use, or they may experience a learning curve". We also observed such limitation in the maintenance of OntoADR [5], an OWL file describing adverse drug reactions (ADRs) based on the MedDRA [6] terminology.

In OntoADR [5], each MedDRA term is defined by a set of axioms corresponding to a decomposition of its medical meaning. All formal definitions were generated through automated methods and thus require an expert validation. The curation task by a pharmacovigilance expert ("curator") consisted in manually reviewing the semantic

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definitions of MedDRA terms. Several limits in formal definitions of ADRs were observed, especially partial definitions, fluctuating granularity or even wrong axioms. This first review performed in an Excel spreadsheet proved to be very time-consuming.

Our contention is that a dedicated Graphical User Interface (GUI) would allow optimizing the curation workflow (not taking into account ontological structural aspects). The objective was then to build such a GUI and evaluate saving of time and completeness of formal definitions compared to previous manual approach. This interface has not been designed only for OntoADR but is suitable for any type of semantic resource, especially using lightweight description logic (i.e. such as EL++ [7]). This paper describes the Ci4SeR interface, its development and first results to quantify the performances that can be achieved with it.

1. Material and Methods

MedDRA [6]: The Medical Dictionary for Drug Regulatory Activities is a controlled terminology used to record and report ADRs. MedDRA has a 5-layers hierarchical structure. Preferred Terms (PT) are the main descriptors of ADRs. MedDRA version 16.0 (March 2013) was used in the presented work.

SNOMED-CT [8]: The Systematized Nomenclature of Medicine – Clinical Terms is a terminology providing a broad coverage of clinical terms, including "body structure", "findings", "disorders", "substances" and "procedures". SNOMED-CT uses a subset of the EL++ description logic formalism. The version of SNOMED-CT used is the January 2013 release that comprises 397,787 concepts.

UMLS [9]: The Unified Medical Language System (UMLS) is a multi-terminology knowledge source system. Its metathesaurus integrates many biomedical vocabularies, including SNOMED-CT and MedDRA. A major asset of the metathesaurus is that synonymous terms from the various vocabularies are mapped into one single concept. The version of UMLS used is the 2013AA release.

OntoADR [5]: Formal definitions of ADR terms were achieved using mappings between MedDRA and SNOMED-CT from the UMLS Metathesaurus or were designed semi-automatically or manually by medical experts and knowledge engineers [10]. OntoADR uses 26 relations inspired from SNOMED-CT, among others: HASFINDINGSITE, to specify the body site affected by a condition; HASASSOCIATEDMORPHOLOGY, to describe the morphologic changes that are characteristic features of a disease; or HASDEFINITIONALMANIFESTATION, to refer to manifestations (observations) that define diseases. OntoADR includes 34,994 concepts using a total of 157,572 definitional axioms; 20,856 concepts come from MedDRA, the others from SNOMED-CT.

Safety Topics: First efforts were focused on a ranked list of 23 medical conditions judged as important in pharmacovigilance developed by Trifirò & al. [11]. The present study shows the results of the curation applied to 6 safety topics (Bullous eruptions, acute renal failure, anaphylactic shock, rhabdomyolysis, aplastic anemia / pancytopenia and cardiac valve fibrosis).

Formal definitions of MedDRA terms: for each safety topic, groupings of MedDRA PTs have been realized in a semi-automatic way on the basis of the formal information contained in OntoADR [10]. A definition consists in a list of axioms; an axiom is generally described with one semantic property and one SNOMED-CT concept (e.g., HAS-ASSOCIATED-MORPHOLOGY SOME 'HEMORRHAGE'). A

pharmacovigilance expert proposed manual definitions when no definition was available a given term. This work gave us baseline data on the amount of work as well as time needed to define MedDRA terms.

Software specifications: two types of users are targeted: domain experts for the curation part and any user for the consultation part. Software requirements are intended to fit how an end-user usually performs such task: (1) Search for a given term using id or string match; (2) Display of a list of concepts to define with optional user-defined list; (3) Display of a given term definition (list of axioms); (4) Validation/Invalidation of an axiom and/or insertion of a new axiom, by selecting a property and a concept.

Other (simplified) requirements are:

- User identification: the system allows adding a user and his associated role;
- Collaborative system: multiple users can work together;
- Consultation mode for non-expert users (ease of use);
- Curation mode for domain-expert users;
- Logging history of any axiom changes and potential comments;
- Display of automatic propositions for axioms.

2. Results

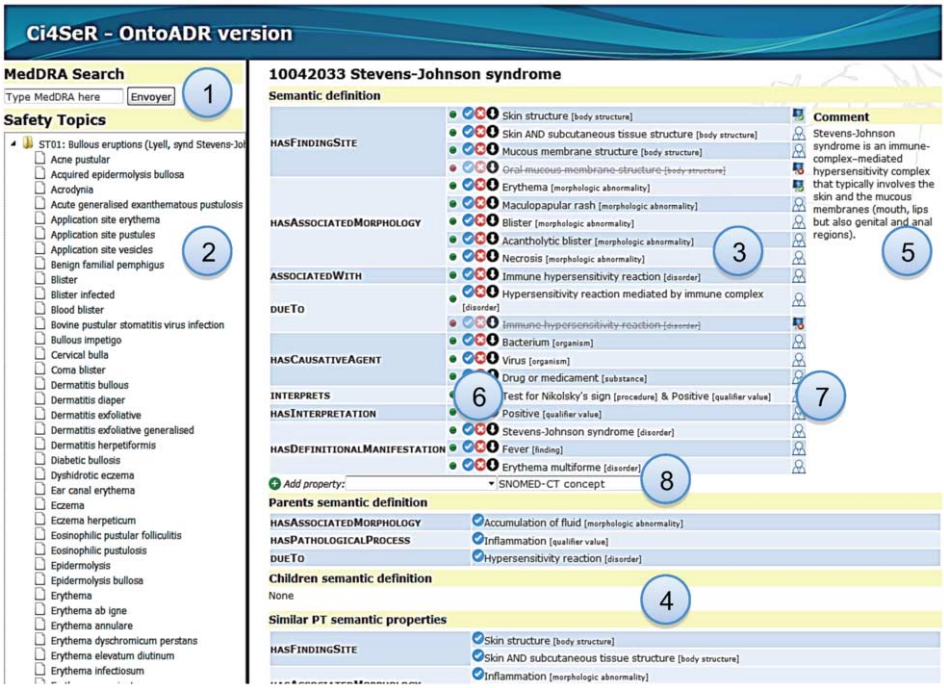


Figure 1. Screenshot of the current interface (see below for description of the various parts).

Multiple users are allowed to edit the resource simultaneously. This implies a centralized server and a web interface; we used an AMP-server (Apache+MySQL+PHP). The MySQL database stores all axioms and keeps tracks of the changes. The GUI is shown in Figure 1. The search function (1) (by keyword or id)

and the safety topic's list of terms (2) are displayed on the left part of the screen. The semantic definition with its axioms (3) is in the center, with automatic propositions below (4). User's comments are on the right side (5).

A set of three icons (6) allows validation, suppression or improvement of an axiom. The color of the dot before an axiom indicates its review state, green for validated, red for invalidated and yellow for pending validation. A "doctor" icon on a row (7) indicates an axiom added manually by the curator using the dedicated field (8).

If they exist, definitions of MedDRA parents and children terms are displayed (4). Automatic propositions (4) are generated using a merge of already existing definitions of all siblings' concepts. Axioms found several times are included in propositions. The software learns automatically as other terms are defined.

Using the Ci4SeR interface for an estimated time of 120 hours, a single curator has reviewed 326 MedDRA terms (2.71 concepts per hour), validated 702 (70 %) axioms, invalidated 318 (30 %) axioms (average of 8.5 axioms reviewed per hour) and added 1874 new axioms (average of 15.6 axioms added per hour).

3. Discussion

Comparison with other works: Henegar [12] defined 530 MedDRA terms in 300 hours (1.7 concepts per hour) with a custom list of properties and no assisting tool. The work proved tedious and time consuming, supporting the need of a better method.

In 2011, a single expert has manually defined 158 MedDRA terms using SNOMED-CT concepts in an Excel spreadsheet. In an estimated time of 100 hours, the expert work (which did not include any validation task) generated 324 definitional axioms (2.05 axioms per definition in average, 1.6 concepts per hour, and 3.2 axioms per hour). This previous expert and the curator using Ci4SeR in this study have a similar background: they are both junior pharmacists with no experience in knowledge engineering and SNOMED-CT, and similar experience with the MedDRA terminology.

In average, Ci4SeR allows to increase the speed-rate of reviewed concepts (number of concepts defined per hour) from 1.6 to 2.7 (+68%) and the speed-rate of reviewed axioms (number of axioms created per hour) from 3.2 to 15.6 (+486%). A double control of the curation work by another expert is expected to assert both results' quality and time saving. According to our estimates, using the GUI and based on an average of 3.0 terms defined per hour, one full-time expert in approximately 3 years would curate the remaining 20,000 MedDRA PTs.

Alternative methods: We did not retrieve in the literature, any software that meets the software specifications described in the Methods section. A collaborative version of the *Protégé* ontology editor [1] adding annotation and versioning was judged not suitable for uninitiated users and partially obsolete, as it was not maintained since 2009 and is thus not compatible with *Protégé* v4. *BoWiki* [2] and *MoKi* [3] tools for ontology curation and management were judged too annotation-oriented.

Evolution of the work and software improvement: the work, which was originally intended to be mainly a validation task, has become a curation work and development of axioms. Each MedDRA term had approximately 3.1 axioms on average before curation, and 8.4 relations per term after the curator's work using Ci4SeR. The interface has therefore been adapted to accelerate the process of adding axioms. The software program has also evolved according to user's requests. Most improvements have been made from the standpoint of ergonomics: ease and speed of use (automatic

refresh, scrolling, reducing the number of clicks, etc.). The comment field has been improved to justify changes.

Reuse of the interface: the software is directly compatible with any terminology using SNOMED-CT as concepts. It can be adapted to any other resource using the same description logic: EL++, or even any lightweight description logic with independent axioms. A wider use of Ci4SeR would help semantic resources curation and improve knowledge modelling.

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References

[1] Tania Tudorache, Jennifer Vendetti, Natalya F. Noy. Web-Protégé: A Lightweight OWL Ontology Editor for the Web. Stanford Center for Biomedical Informatics Research, Stanford University, CA, US. http://protegewiki.stanford.edu/wiki/Collaborative_Protege, consulted on 27/01/2014.

[2] Backhaus, M., Kelso, J., Bacher, J., Herre, H., Hoehndorf, R., Loebe, F., & Visagie, J. (2007, May). BOWiki-a Collaborative Annotation and Ontology Curation Framework. 16th International World Wide Web Conference, Banff, Alberta, Canada (2007).

[3] Dragoni, M., Ghidini, C., & Bosca, A. (2013). Multilingual MoKi: How to Manage Multilingual Ontologies in a Wiki. In *The Semantic Web: ESWC 2013 Satellite Events* (pp. 162-166). Springer Berlin Heidelberg..

[4] Rubin DL. Creating and curating a terminology for radiology: ontology modeling and analysis. J Digit Imaging 2008;21(4):355-62.

[5] Declerck G., Bousquet C., Sadou E., Souvignet J., Jaulent M.-C. (2012). OntoADR: an OWL-DL representation of MedDRA for semantic grouping of Adverse Drug Reaction terms. 24th Conference for Patient Classification Systems International (PCSI 2012), 17-19 octobre, Avignon (France).

[6] Brown, E. G., Wood, L., & Wood, S. (1999). The medical dictionary for regulatory activities (MedDRA). Drug Saf, 20(2), 109-117.

[7] EL – OWL, http://www.w3.org/2007/OWL/wiki/EL, consulted on 27/01/2014.

[8] SNOMED-CT, http://www.ihtsdo.org/snomed-ct/, consulted on 27/01/2014.

[9] Lindberg, D. A., Humphreys, B. L., & McCray, A. T. (1993). The Unified Medical Language System. Methods Inf Med, 32(4), 281-291.

[10] Declerck G, Bousquet C, Jaulent MC. Automatic generation of MedDRA terms groupings using an ontology. Stud Health Technol Inform. 2012;180:73-7.

[11] Trifirò G, Pariente A, Coloma PM, et al. EU-ADR group. Data mining on electronic health record databases for signal detection in pharmacovigilance: which events to monitor? Pharmacoepidemiol Drug Saf. 2009;18(12):1176-84.

[12] Henegar C, Bousquet C, Lillo-Le Louët A, Degoulet P, Jaulent MC. Building an ontology of adverse drug reactions for automated signal generation in pharmacovigilance. Comput Biol Med. 2006;36(7-8):748-67.

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EPR-based, quality-related process parameters: a nationwide assessment

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Abstract. The aim of the study was to determine whether or not primary care EPR-based data can be used to measure specific process parameters that can then, in turn, be used to assess the quality of care provided to chronic patients. We analysed data from a large research network that collects data from all Belgian GP practices through both manual and automatic extraction procedures. We built a number of quality-related process parameters and observed the concordance of our results with two external databases: a nationwide reimbursement database and a regional EPR-based network. We found that only the automatic data extraction method was suitable for building process parameters. The current research network may lead to an underestimation of the quality of care processes. We suggested ways to improve this network.

Keywords: computerised patient record, primary healthcare, data collection, quality indicators.

Introduction

In many countries, higher life expectancy is associated with increased prevalence of chronic diseases. Coping with this requires the provision of more integrated, evidence-based, multidisciplinary, patient-centred care, for instance using Wagner's chronic care model (CCM)[1]. The ultimate goal for this reengineering of the care process is improved care. Monitoring the quality of care is therefore of the utmost importance.

In 2009, the National Institute for Health and Disability Insurance (NIHDI) in Belgium launched the ambulatory care trajectories. These were the first nationwide implementation of the CCM for (subgroups of) patients suffering from Type 2 diabetes mellitus (DM-2) and chronic renal failure (CRF). By early 2013, over 50,000 patients had already been enrolled in the programme. The NIHDI also funded the ACHIL project (Ambulatory Care Health Information Laboratory), whose goal was to assess the effectiveness of the programme at improving quality of care, in terms of processes and outcomes. ACHIL uses data from general practitioners' Electronic Patient Records.

The use of routinely collected general practice data to assess quality of care remains challenging [2, 3]. In Belgium, more than 17 different software systems are currently used by nearly 10,000 practicing General Practitioners (GPs), and these are connected to different health data communication networks, such as regional networks, shared EPRs (Electronic Patient Records), and EPR-based research networks [4].

Process parameters are often used to assess quality of care [5-7]. In this paper, we investigate whether a large-scale research network that collects EPR-based data from GPs is suitable for measuring specific quality-related process parameters.

1. Methods

For this study, we used the limited mandatory ACHIL data that GPs must send for all their Care Trajectory (CT) patients. For DM-2 CT patients, the data parameters include age, gender, weight, height, systolic and diastolic blood pressure, LDL-cholesterol, and HbA1c. For CRF CT patients, the data parameters include age, gender, eGFR, systolic and diastolic blood pressure, PTH (parathormone), Hb (hemoglobin), and Creat (creatinin). Data was sent to the research centre in 2012.

To build the quality-related process parameters, we counted the number of measurements for each data parameter made between January 2010 and December 2011, for every patient that began a CT prior to 1 January 2011. For each parameter, we identified quality-related targets and computed the percentage of patients achieving these targets. For example, we computed the percentage of DM-2 CT patients with three or more HbA1c measurements/year during the period studied.

To identify the targets, we primarily used the follow-up plans for CT patients endorsed by the NIHDI and developed by the Belgian National Council for Quality Promotion. We also used national and international guidelines, reports, scientific papers, and advice from experts. Some intermediate (less constraining) targets were also analysed. Targets were defined according to the eligible patient populations described by the NIHDI. For DM-2 CT, this mainly included patients receiving 1 or 2 insulin injections or patients for whom starting insulin treatment was being considered. For CRF CT, it included mainly patients with eGFRs lower than 45 ml/min./1.73m² (see www.trajetdesoins.be).

When GPs were sending data to the research centre in 2012, they could choose either to manually enter one or more data measurements into a specific, secured ACHIL web application (the "manual method") or to perform an automatic data extraction from their EPR (the "upload method") [8]. We had to tackle various key issues: privacy protection and secondary IDs management, quality control procedures, standardized data format, defining validity dates and default values of the data, providing efficient support (documentation, help desk) to all the software producers and GPs, meeting technical and political constraints related to a nationwide application.

In this study, we compared the quality-related process parameter values calculated using the manual data collection method with those calculated using the automatic data extraction method (number of measurements/ number of years in the observed period). We then used triangulation [9] to observe the concordance of our results with two available external databases: the IMA and Intego databases.

The IMA database is a national reimbursement database that includes all reimbursed medical and paramedical interventions for all Belgian citizens with health insurance. Usable data for this study relates to the year 2010 and to all the patients starting a CT before 1 January 2010.

Intego is a regional EPR-based network of selected GPs. It has been operating since 1997 and currently consists of 97 GPs representing over 248,000 patients. Usable data for this study relates to the year 2011 and to CT patients registered in Intego and starting their CT before 31 December 2011.

2. Results

In the ACHIL database, we found 9792 patients who started a DM-2 CT before 1 January 2011. The manual method yielded 74,971 data measurements for 9000 patients for the period studied [2010-2011]. For 12 patients, no data was received for this period. The upload method yielded 28,981 data measurements for 792 patients.

We also found 7887 patients who started a CRF CT before 1 January 2011. The manual method yielded 56,301 data measurements for 7331 patients for the period studied [2010-2011]. For 6 patients, no data was received for this period. The upload method yielded 28,343 data measurements for 556 patients.

Table 1 shows the percentages of CT patients achieving several targets for both methods. The target "at least 1" measurement during the 2-year period identifies the percentage of patients with missing parameters. The target "≥ 1/year" shows the ability of each method to collect several measurements for a parameter (at least 2 measurements during the 2-year period). For each parameter, the most constraining targets are the quality-related targets.

Table 1. Percentage of CT patients achieving targets, by parameter and data collection method

DM-2 Care trajectory	Targets (2-year period)	Data collection		CRF Care trajectory	Targets (2-year period)	Data collection	
		Manual N= 9000	Upload N= 792			Manual N= 7331	Upload N= 556
HbA1C	at least 1	99,0%	83,5%	**eGFR (measured)**	at least 1	93,5%	56,8%
	≥ 1/year	20,8%	70,8%		≥ 1/year	16,3%	48,0%
	≥ 3/year	1,6%	36,1%		≥ 3/year	1,2%	30,2%
Syst BP	at least 1	99,2%	90,0%	**Creat**	at least 1	94,1%	82,0%
	≥ 1/year	21,6%	75,3%		≥ 1/year	16,8%	70,3%
	≥ 3/year	1,9%	47,2%		≥ 3/year	1,4%	40,8%
Diast BP	at least 1	99,2%	90,0%	**Syst BP**	at least 1	99,1%	86,2%
	≥ 1/year	21,6%	75,3%		≥ 1/year	18,3%	70,1%
	≥ 3/year	1,9%	47,0%		≥ 3/year	1,6%	45,5%
Weight	at least 1	96,1%	80,2%	**Diast BP**	at least 1	99,0%	86,2%
	≥ 1/year	19,5%	57,3%		≥ 1/year	18,3%	70,0%
	≥ 3/year	1,2%	27,0%		≥ 3/year	1,6%	45,5%
LDL cholest	at least 1	94,7%	71,1%	**PTH**	at least 1	64,3%	44,2%
	≥ 1/year	17,2%	49,0%		≥ 1/year	7,3%	25,2%
BMI (calculated)	at least 1	88,2%	67,8%	**Hb**	at least 1	90,9%	85,1%
	≥ 1/year	18,2%	49,6%		≥ 1/year	16,2%	75,4%
	≥ 3/year	1,2%	23,7%				

N: number of patients; Targets = number of measurements during a 2-year period

Table 2 shows the percentages of patients achieving some of the targets within the ACHIL databases (upload method) and within the two external databases. For the IMA database we used available data for the year 2010, for 3886 patients who started their CT before 1 January 2010. For the Intego database, we used available data for the year 2011, for 271 patients who started their CT before 31 December 2011. Only parameters that were available in one of the two external databases were considered.

Table 2. Percentage of CT patients achieving targets, by parameter and data source

Care Trajectory	Parameter	Target (number of measurements)	ACHIL (upload) [2010-2011] (792 patients)	Intego 2011 (271 patients)	IMA 2010 (3886 patients)
DM-2	HbA1C	≥ 1/year	70,8%	96,0%	97,0%
		≥ 3/year	36,1%	71,0%	67,0%
	Syst BP	≥ 1/year	75,3%	85,0%	n.a.
		≥ 3/year	47,2%	62,0%	n.a.
	Weight	≥ 1/year	57,3%	66,0%	n.a.
		≥ 3/year	27,0%	30,0%	n.a.
	LDL cholest	≥ 1/year	49,0%	91,0%	92,0%
			(556 patients)	(225 patients)	(5510 patients)
CRF	Creat	≥ 1/year	70,3%	96,0%	94,0%
		≥ 3/year	40,8%	65,0%	79,0%
	Syst BP	≥ 1/year	70,1%	82,0%	n.a.
		≥ 3/year	45,5%	63,0%	n.a.
	PTH	≥ 1/year	25,2%	n.a.	78,0%
	Hb	≥ 1/year	75,4%	94,0%	97,0%

3. Discussion

For the manual data collection method, we found a low level of missing data, i.e. low numbers of patients with no measurements for a given parameter (see Table 1), with the exception of BMI, Hb, and PTH, which showed 12%, 9 %, and 36% missing values, respectively. However, for each parameter, fewer than 22% of the patients had more than one value. A longitudinal process analysis would require several manual data collections, according to the targets (e.g. three times a year) or would require GPs to register several values during each data collection. For several parameters, this seems hardly acceptable for stakeholders. Manual data collection does not, therefore, seem suitable for building retrospective time series.

For all parameters (see Table 1), we observed more missing values for the upload procedure (up to 56% missing values for PTH). This could partly be explained by the low quality of the various EPR extraction modules developed by the software producers. There is no strong centralised quality control procedure for these modules. Another possible explanation is the non-communication of some results. For example, the results of a PTH analysis ordered by a specialist could be communicated to the specialist but not to the GP. We should also consider electronic data sent to the GP but not automatically recorded in the EPR and data not manually recorded by the GP. Data is not always adequately recorded in the EPR [2, 5].

The upload procedure allows retrospective time series to be built to support process analysis (see Table 1). However, this could lead to an underestimation of the number of patients achieving the targets of care processes (see Table 2). The high numbers of missing values may partly explain this underestimation. The Intego (EPR-based) network, which is based on selected GPs all using the same software system, highlights potential improvements in the national ACHIL (EPR-based) network.

Triangulation may increase confidence in research data and provide a clearer understanding of a problem and an effective way of developing timely

recommendations [9]. However, it is important that we bear in mind the limitations of this approach in the context of our study. The external databases used relate to different groups of GPs and CT patients and to different time periods. As a network, Intego is not representative of all GPs, while IMA is restricted to reimbursed interventions.

This paper deals with assessing the effectiveness of care processes, which is on the agenda in many countries [5-7]. However, other aspects of care quality should also be considered, such as the effectiveness of health outcomes, efficiency, satisfaction of patients, and satisfaction of health professionals [10].

4. Conclusions

Our study showed that, in Belgium, a large, nationwide, primary care, EPR-based research network can be used to measure process parameters that could, in turn, be used to assess some aspects of care quality. This network should be based on automatic extraction from EPRs.

We highlighted the need to improve the current research network and suggested the reinforcement of quality control procedures for data extraction modules, as well as improvements to data communication and registration within the EPR. Careful monitoring of these changes to the research network will be necessary in the future, in order to be able to differentiate between improvements in care quality that are due to care process reengineering and improvements in the information system itself.

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References

[1] Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. Milbank Q. 1996; 74(4):511-44.
[2] de Lusignan S, Van Weel C. The use of routinely collected computer data for research in primary care: Opportunities and challenges. Fam Pract. 2006; 23:253–63.
[3] Chan KS, Fowles JB, Weiner JP. Electronic Health Records and the Reliability and Validity of Quality Measures: A Review of the Literature. Med Care Res Rev. 2010; 67(5):503-27.
[4] De Clercq E, Van Casteren V, Jonckheer P, Burggraeve P. Primary Healthcare Research Network: The Belgian ResoPrim Recommendations. Stud Health Technol Inform. 2009; 150: 38-42.
[5] Barkhuysen P, de Grauw W, Akkermans R, Donkers J, Schers H, Biermans M. Is the quality of data in an electronic medical record sufficient for assessing the quality of primary care? JAMIA. 2013 Oct 21. doi: 10.1136/amiajnl-2012-001479.
[6] Peytremann-Bridevaux I, Bordet J, Burnand B. Diabetes care in Switzerland: good, but perfectible: a population-based cross-sectional survey. BMC Health Serv Res. 2013 Jun 25; 13:232.
[7] Visca M, Donatini A, Gini R, Federico B, Damiani G, Francesconi P, et al. Group versus single handed primary care: a performance evaluation of the care delivered to chronic patients by Italian GPs. Health Policy. 2013 Nov; 113(1-2):188-98.
[8] De Clercq E, Van Casteren V, Bossuyt N, Moreels S, Goderis G, Bartholomeeusen S, et al. Nation-Wide Primary Healthcare Research Network: a Privacy Protection Assessment. Stud Health Technol Inform. 2012; 174:23-8.
[9] Rutherford G, McFarland W, Spindler H, White K, Patel S, Aberle-Grasse J, et al. Public health triangulation: approach and application to synthesizing data to understand national and local HIV epidemics. BMC Public Health. 2010; 10(447). Doi: 10.1186/1471-2458-10-447.
[10] Reeves C, Bednad D. Defining Quality: Alternatives and implications. Acad Manage Rev. 1994; 19(3):419-45.

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Cross Hospital Bed Management System

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Abstract. The lack of adequate numbers of hospital beds to accommodate the injured is a main problem in public hospitals. For control of occupancy of bed, we design a dynamic system that announces status of bed when it change with admission or discharge of a patient. This system provide a wide network in country for bed management, especially for ICU and CCU beds that help us to distribute injured patient in the hospitals.

Keywords. Systems Integration, Beds/supply and distribution, Software Design, Database Management Systems, Hospital Information Systems

Introduction

The mortality in the groups of patients who were admitted to the CCU with delay was significantly higher overall in the groups of patients who were either not admitted or whose admission was delayed [1].

Lack of beds led to premature discharge in hospital. Premature discharges have a significant impact on mortality [2].

Each hour of waiting was independently associated with a 1.5% increased risk of ICU death. There is a significant association between time to admission and survival rates. Early admission to the ICU is more likely to produce positive outcomes [3].

A problem that has been encountered during mass-casualty incidents is the lack of adequate numbers of hospital beds to accommodate the injured. One solution for the lack of beds is the creation of baseline data systems. For example SAGEC 67, a free-access, information database concerning the availability of beds should help the participating countries, initially France, Germany, and Switzerland[4]. SAGEC 67 is a website, which helps the physician in case of mass casualty disaster to face the lack of beds in Europe[5].

We design and implement a national-wide bed management system for management cross hospital referral patient in crowded hospital that hasn't enough bed for admission patient. Also this system use for accommodate victims in mass-casualty incidents.

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1. Methods

We design a model for transferring bed status in hospitals. Model represent as WSDL[6] standard which can be interface for data collection from Hospital information System. Bed data of hospitals can transfer by SOAP[7] protocol. The data warehouse stores all bed status logs from hospitals. And design a web application for analysis bed status log and report beds available in hospitals.

These data include information on the geographical location of the hospitals, hospital wards and types of bed available in every ward, and in the end status of each bed, whether a bed is occupied or empty. The main point of this system is Direct Sending from the HIS to SEPAS without user intervention. Due to the seriousness of accidents patients, many hospital staff are reluctant to accept patient with acute conditions and require specific bed [ICU and CCU]. The online system by changing the status of bed to announce the new status to health care executives is very valuable.

2. Results

2.1. Design Data Model

Hospital bed is the principal axis of our data model design. Bed centric approach primary benefit is that hospital can be sending only one bed data in one SOAP transaction thus the occupied bandwidth is less and the processing time of SOAP Message will be less Although Hospitals can send more bed data in SOAP Message.

The bed status property of the beds data is a key property in data model of bed. This property indicates whether the bed is empty or not? The possible values for bed status property are shown in Table 1.

For best results in integrated report we used concept of DV_CODED_TEXT from OpenEHR[8] Data type [Shown in Figure 1].

The UML diagram of data model is shown in Figure 2.

Table 1. Values of bed status property

Code	Status	Description
1	Occupied	Bed is Not empty
2	Ready to accept patient	Bed is empty and ready for accept patient
3	Out of Service	Bed is off for some reason like corrupted
4	Reserved	Bed is reserved for a patient.
5	Patient in transition	The patient was transferred to another ward, but has not yet announced its acceptance by the destination. Bed will be released soon.
6	Patient in discharge	A patient discharge order issued by the doctor and the patient is being discharged affair. Bed will be released soon.

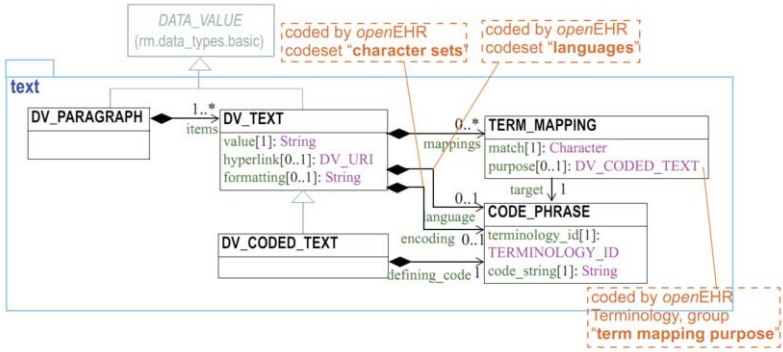


Figure 1. UML Diagram of DV_CODED_TEXT

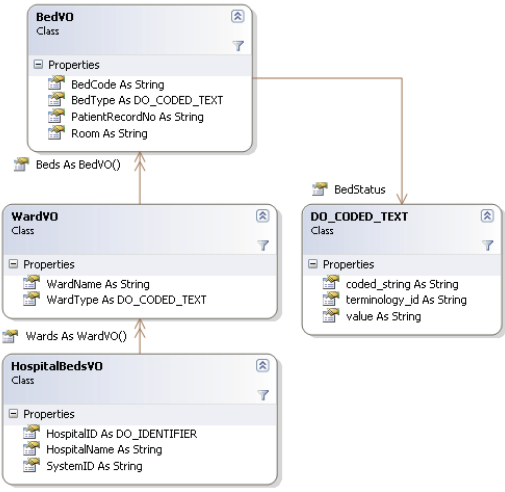


Figure 2. Class Diagram of Bed Data Model

2.2. Create web service

The data model was designed as a web service using .Net Framework technology. Web service launched by SEPAS Infrastructure. SEPAS Infrastructure is national infrastructure for Integrated Care Electronic Health Record. SEPAS Contains of ESB and essential component of SOA Architecture.

2.3. Bed Management Dashboard Development

We design database for store bed data which transfer from hospitals. And develop web site for analysis bed data and determined which bed in hospital is available.

"Guidance staff" is responsible for transfer patient between hospitals in public sector. We create user account for Employee of "Guidance staff" to have online access to bed data. Members of site can use the dashboard to find empty beds in hospitals at any time. ICU and CCU bed is important bed type for Employee of "Guidance staff". List of ICU and CCU empty beds grouped by hospitals Available in dashboard as shown in Figure.3 and Figure.4.

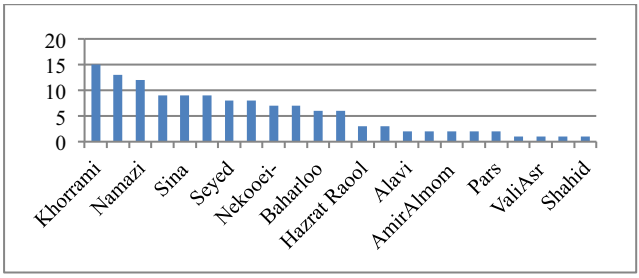


Figure 3. Count of ICU empty bed

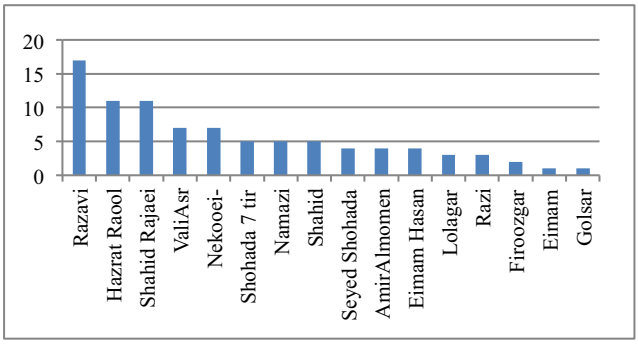


Figure 4. Count of CCU empty bed

2.4. Updating Hospital Information System

Bed Web service Tutorial Standard Document was written and we send the document for private company that develop Hospital Information System (HIS). The HIS must call bed web service and transfer bed data from HIS to bed management dashboard. Developer of HIS Updates software so that any change in Status of beds in HIS will lead to call Bed web service.

HIS companies that updated software for compatible by Bed management service were RahavardRayane ,Tirajeh, Rayavaran, TarasheHoushmand. 86 hospitals can connect to system via HIS.

3. Discussion

We design and implement cross-enterprise bed management system for overcrowded hospitals. The first purpose of our work is facilitating decision making in management of referral patients who need admission in hospitals, In particular need CCU and ICU admission. The incidence of bed and ward admission and the average length of stay can be used in calculating bed need[9]. ICU-services take about 15-20% of the hospital budgets[10]. Decision of number of ICU bed is critical decision for hospitals and government. One of the critical determinant of the work undertaken by public hospitals is the bed occupancy rates[11].

Average bed occupancy level has been the primary measure that has guided hospital bed capacity decisions at both policy and managerial levels[12]. Expand Capacity Hospitals' capacity can be expanded by adding new beds to meet incremental patient demand. Each additional hospital bed requires approximately $1 million in capital costs and more than $250,000 per bed annually for operating costs[13]. The information stored in this system can be used to calculate bed occupancy. In summary, the benefit of this system is conceivable as follows:

a. Developing a decision making system for management of referral patients who need admission in hospitals.
b. Calculating ratio of bed occupancy for each hospital.
c. Developing a decision making system for adding new beds to meet incremental patient demand as requirement especially for ICU and CCU bed.
d. Direct Sending status of bed from the HIS to SEPAS without user intervention.
e. This system has a potential benefit for the development of decision support systems and data mining in order to assist future planning.

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References

[1] Walker DM, Wicks M, Hubbard WN, Thomas RD. Increased mortality from inadequate provision of coronary care unit facilities. J R Soc Med. 1994 Apr;87[4]:211-2.
[2] Rodriguez-Carvajal M, Mora D, Doblas A, Garcia M, Dominguez P, Tristancho A, et al. [Impact of the premature discharge on hospital mortality after a stay in an intensive care unit]. Med Intensiva. 2011 Apr;35[3]:143-9.
[3] Cardoso LT, Grion CM, Matsuo T, Anami EH, Kauss IA, Seko L, et al. Impact of delayed admission to intensive care units on mortality of critically ill patients: a cohort study. Crit Care. 2011;15[1]:R28.
[4] Hadef H, Bartier JC, Delplancq H, Dupeyron JP. Using baseline data to address the lack of hospital beds during mass-casualty incidents. Prehosp Disaster Med. 2008 Jul-Aug;23[4]:377-9.
[5] Hadef H, Bartier JC, Pelaccia T. SAGEC 67, a free-access database linking at least three countries, for finding spare beds in the event of a mass casualty incident. Eur J Emerg Med. 2009 Aug;16[4]:183-7.
[6] Web Services Description Language [WSDL] W3C; 2001 [cited 2012]; Available from: http://www.w3.org/TR/wsdl.
[7] Simple Object Access Protocol [SOAP] 1.1. W3C; 2000 [cited 2010 2012/04/19]; Available from: http://www.w3.org/TR/2000/NOTE-SOAP-20000508/.
[8] openEHRArchitecture.[cited2012];Availablefrom:http://www.openehr.org/releases/1.0.2/architecture/overview.pdf.
[9] Pearson GA, Reynolds F, Stickley J. Calculating the need for intensive care beds. Arch Dis Child. 2012 Nov;97[11]:943-6.
[10] Wild C, Narath M. Evaluating and planning ICUs: methods and approaches to differentiate between need and demand. Health Policy. 2005 Mar;71[3]:289-301.
[11] Phillips A, Smallwood L. Hospital beds and the quality of a national health system. Aust J Rural Health. 2010 Jun;18[3]:93-5.
[12] Green LV. How many hospital beds? Inquiry. 2002 Winter;39[4]:400-12.
[13] Litvak E, Bisognano M. More patients, less payment: increasing hospital efficiency in the aftermath of health reform. Health Aff [Millwood]. 2011 Jan;30[1]:76-80.

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Interpretable Associations over DataCubes: Application to Hospital Managerial Decision Making

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Abstract. The world concern about the costs of the health care systems has raised the importance of counting on precise and interpretable tools, that help the health care institution's managers to make decisions to optimize the use of health resources. In this paper we propose a new Classification based on Association Rules (CAR) algorithm that improves the interpretability of the results, making it specially useful for decision making. Changing the usual way to obtain the rules we follow four goals: first to improve the interpretability of the result by obtaining rules meaningful and interpretable by themselves, secondly to reduce the complexity of the result obtaining a lower number of rules; thirdly, to obtain simpler rules, with less size in number of antecedents; and finally to avoid the usual over-fitting problem of the classification methods by obtaining a generic final result set, where specific rules for specific cases are avoided unless they are necessary. To prove the utility of our proposal we have used it in an example of decision support regarding the planning of the surgery rooms.

Keywords. CAR, Complexity Reduction, Classification, DataCube, Multidimensional Model, Interpretability Improvement.

Introduction

Today it is undeniable the world concern about the costs of the health industry [1] and the need to count on appropriate mechanisms to plan, invest and control properly the avail-able funding. However, the huge amounts of data produced in this sector makes difficult to process and understand the information. This is where data mining methods play a big role, as support in the decision making [2, 3, 4].

There is a wide variety of data mining methods. As Yoo et al. states in [5], they can be divided into three categories. Firstly there are classification methods where a set of at-tributes must be previously selected to perform the classification according to them. This is the case of the methods based on neural networks, support vector machine, bayesian algorithms and decision trees, among others. In the second place can be found algorithms for clustering, used mainly when there is no previous information

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about the objects to be classified. In this category there are basic, hierarchical and partition based clustering techniques. Finally can be found techniques that, in addition to classify, are useful to discover relations between data items, like the classification based on association rules (CAR) proposals.

In the last few years important advances have been performed (e.g. [6]) in the application of data mining methods over health care information with research purposes or to support medical diagnosis (e.g. [7]). Nevertheless as Jensen et al. indicate in [8], this is still an under-used source of information, mainly due to the nature of the medical data itself, as well as to the difficulties for the user to understand results of the data mining techniques, and therefore make the most of them.

This fact is even worse when we focus on health care management decision support where, to our best knowledge, there are quite few academic proposals [9,10], but they are more related to the business process [9] and its framework [10] than to the decision making support. Most of the hospital information systems, in the best of the cases, use commercial software packages. However, the information available about them is the one in their web sites, usually related to their advantages and successes, and in most of the cases there is no mention about the algorithms used. Nevertheless it is well known [5] that amongst all the data mining techniques the most comprehensible are those based on trees [11], for the structure of the results; while the most precise ones are the CAR methods, since they are exhaustive and explore all the possibilities in the classification and prediction processes. It makes them the most appropriated to take advantage of all the potential that the health information provides.

The main inconvenience of these methods is, as pointed above, that their results are difficult to understand. This is due to the rule set obtained with CAR proposals, that is used as an ordered list of rules. This set is checked in order, discarding the rules unsatisfied and stopping the process at the first one satisfied. In real systems the antecedents of these rules are usually complex and not directly meaningful, so the user must take into account the previously discarded rules to understand the full meaning of the classification performed. Another problem that classification methods (not only CAR based) must face is the over-fitting of the data.

Here we propose and exemplify a technique to solve theses problems and achieve the four goals mentioned above, based on three key points: the exploitation of the hierarchies defined over the dimensions of the data cubes, the change in the way the association rules are obtained, and also a change in the evaluation of the rules at the classification process.

In section 1, we show the adaptation of a previous algorithm to reduce the complexity of the resultant set of rules. An example about the performance of our proposal are presented in section 2, and finally we indicate our conclusions and final remarks in section 3.

1. Algorithm

Our proposal is based on an improvement of the Complexity Guided Association Rules Extraction method (COGARE) presented in [12]. Due to space limitation, in this section we just indicate the modifications required to extract association rules adapted for classification

Itemset generation. When generating the frequent itemsets we only change the candidates: the method only considers as candidates the itemsets containing an item of

the class variable. If the itemset is not frequent the method applies the generalization process but not on the class item (the granularity of this variable does not change in any moment).

Rule generation. At the rule generation stage, the method only takes into account the association rules of the form A → C, where C only has one item that belongs to the class variable. So for each frequent itemset found, the method only generates one rule.

Rule generalization. In the rule generalization phase the scheme is similar to the one used in the itemset generation, because the method tries to generalize the rule set considering all the variables but the class.

Iterative approach. One of the main changes of the algorithm is the use of an iterative approach. Most of the proposals first generate all the association rules and later select the classification rules from this set. In our approach we use the following iterative approach:

- First the method generates frequent itemsets of size 2 (one item from the class variable and another one from other variable).
- Then it generates the association rules of size two, pruning those with a certainty factor (CF) under the threshold given as parameter, and selects the rules from this set. Hence the method generates a classification model using simple rules (one antecedent and the class).
- Next the method calculates the frequent itemsets of size 3 using frequent itemsets of size 2. In this stage the method tries to reduce the number of rules deleting unnecessary frequent itemsets, as explained in the next subsection.
- After it the method generates the rules for the frequent itemsets of size 3, and selects the rules to classify.
- The method stops if the result is not better than using rules of size 2. If we obtain a better classification then we continue the process with itemsets of size 4, and so on.

Space reduction. The aim of this process is to reduce the candidate frequent itemsets to be generated. The main idea is to avoid building more specific rules/bigger itemsets in areas of the search space where the classification was made correctly with simpler rules.

The method takes the current classification rule set, and looks for areas correctly classified with the current rule set. Those areas are delimited by the rules with CF equal to 1 (all the elements which satisfy the antecedent of the rule have the same class). Next the process keeps out from the frequent itemsets those including the antecedent of any of these rules, and in the next iteration no itemset in those areas will be considered.

Avoiding the generation of larger and more complex rules in these areas, the use of unnecessary inserted items in the antecedent of the rules is also avoided, and hence the over-fitting they could introduce.

Rules selection. On each iteration the algorithm selects a set of rules to build the classifier. First the method sorts the rules according to the quality of each one in decreasing order (better rules first). Then it uses the first rule as initial classifier a computes its quality. The rest of the process checks iteratively whether the next rule improves the quality or not. If there is an improvement the technique selects the rule and proceeds to the next iteration. Otherwise, the rule is dismissed.

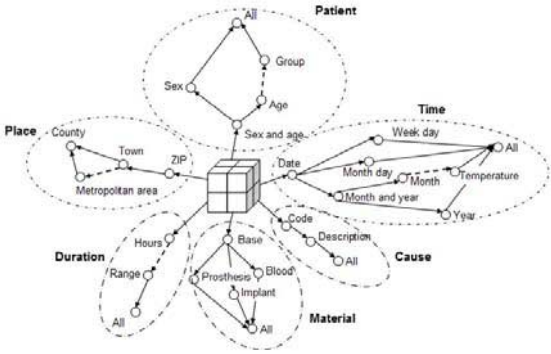


Figure 1. CMedical structure

```
1: N = Number of variables
2: FI2 = Generate frequent item sets of size 2
3: R2 = Generate rules from FI2
4: R1= Sort R2 according to rules quality (CF) descending
5: Ra = Selected rules from R1
6: FI2 = reduceSpace(FI2,Ra)
7: for i = 3 to N do
8:  FIi = Generate frequent item sets of size i from FIi-1
9:    Ri = Generate rules from FIi
10:      R = U'j=2 Ri
11:        R' = Sort R according to rules quality descending
12:        Rc = Selected rule from R'
13:        if Quality(Rc) > Quality(Ra) then
14:            Ra = Rc
15:            FIi =reduceSpace(FIi,Ra)
16:        else
17:            Finish and return Ra
18:        end if
19: end for
20: return Ra
```

Figure 2. Iterative process for rule generation

Rule evaluation. As mentioned above in most of the CAR proposals the rule set obtained is used as an ordered list of rules. In our proposal, we do not establish an order between rules since we use a classic inference schema, considering that a rule is satisfied with a degree $\oplus$ ($\mu(A_1)$,… $\mu(A_n)$), where A_is are the items in the antecedent and $\mu(A_i)$ the degree at which the record satisfies the item. As t-norm we use the minimum. We combine the result of each fired rule with the same consequent (class) with a t-conorm to obtain one unique value for each class (we use the *maximum*). The class with higher degree is the one selected to classify the new record.

2. Examples

Due to the lack of proposals designed to work over datacubes with which to perform a comparison, we test the validity of the proposed method in the the well known Wisconsin Diagnostic Breast Cancer (WDBC) at UCI

Features are computed from a digitized image of a fine needle aspirate (FNA) of a breast mass. They describe characteristics of the cell nuclei present in the image.

This schema is defined over data collected for non-postponed operations which were carried out in hospitals in Granada between 2002 and 2004. For the facts, we only consider the data when the patients are from Granada. There are 50,185 facts with one variable (*amount*) and 6 dimensions (Figure 1).

Classification With this DataCube we want to know the estimated duration of operations to be able to shuffle the surgery room in an efficient manner. So, we need to get the value for level *range* in dimension *Duration* considering the time in four classes: 0-1 *hours*, 2-4 *hours*, 5-10 and 10 *or more hours*. The main parameters for the process are the following:

- Support: 0.005
- CF: 0.1

To test the quality of the method we apply 10-fold cross-validation getting and average correct classification the 95.129%. As can be seen, the method gets a high accuracy

3. Conclusions

In this paper we have presented a modification of the COGARE algorithm for the ex-traction of interpretable association rules. With it four goals are achieved: having simpler rules, getting a lower number of them, improve the interpretability and comprehension of the system, and increase the the quality of the classifier avoiding the data over-fitting.

Finally we have shown that it is possible to use this approach for decision support, since each rule is a result per se that can be interpreted independently. It means that each rule helps to understand not only the criteria under which the classification is being performed, but also the characteristics that determine each class. As an example we have tested ir on a surgery planning scenario.

This research is still in progress and the algorithm is being tested under more data sets to be able to quantify the improvements in the above mentioned goals.

References

[1] Chia-ping Shen, Chinburen Jigjidsuren, Sarangerel Dorjgochoo, Chi-huang Chen, Wei-hsin Chen, Chih-kuo Hsu, Jin-ming Wu, Chih-wen Hsueh, Mei-shu Lai, Ching-ting Tan, Erdenebaatar Altangerel, and Feipei Lai. A data-mining framework for transnational healthcare system. *Journal of Medical Systems*, 36(4):2565–75, August 2012.

[2] O.T. Ali, A.B. Nassif, and L.F. Capretz. Business intelligence solutions in healthcare a case study: Transforming oltp system to bi solution. In *Communications and Information Technology (ICCIT), 2013 Third International Conference on*, pages 209–214, 2013.

[3] Wilfred Bonney. Applicability of business intelligence in electronic health record. *Procedia - Social and Behavioral Sciences*, 73(0):257 – 262, 2013. <ce:title>Proceedings of the 2nd International Conference on Integrated Information (IC-ININFO 2012),Budapest, Hungary,August 30 âA¸S September 3, 2012</ce:title>.

[4] Chai Zhengmeng and Jiang Haoxiang. A brief review on decision support systems and it's applications. In *IT in Medicine and Education (ITME), 2011 International Symposium on*, volume 2, pages 401–405, 2011.

[5] Illhoi Yoo, Patricia Alafaireet, Miroslav Marinov, Keila Pena-hernandez, Rajitha Gopidi, Jia-fu Chang, and Lei Hua. Data mining in healthcare and biomedicine: A survey of the literature. *Journal of Medical Systems*, 36(4):2431–48, August 2012.

[6] Peng Gao, Xin Zhou, Zhen-ning Wang, Yong-xi Song, Lin-lin Tong, Ying-ying Xu, Zhen-yu Yue, and Hui-mian Xu. Which is a more accurate predictor in colorectal survival analysis? nine data mining algorithms vs. the tnm staging system. *PLoS One*, 7(7):–, July 2012.

[7] S. Ruping, A. Anguita, A. Bucur, T.C. Cirstea, B. Jacobs, and A. Torge. Improving the implementation of clinical decision support systems. In *Engineering in Medicine and Biology Society (EMBC), 2013 35th Annual International Conference of the IEEE*, pages 3214–3217, 2013.

[8] Peter B Jensen, Lars J Jensen, and SÃ¿ren Brunak. Mining electronic health records: towards better research applications and clinical care. *Nature Reviews. Genetics*, 13(6):395–405, June 2012.

[9] Matthew L. Nelson and Ravi Sen. Business rules management in healthcare: A lifecycle approach. *Decision Support Systems* 2012.

[10] Neil Foshay and Craig Kuziemsky. Towards an implementation framework for business intelligence in healthcare. *International Journal of Information Management*, (0):–, 2013.

[11] Gregor Stiglic, Simon Kocbek, Igor Pernek, and Peter Kokol. Comprehensive decision tree models in bioinformatics. *PLoS One*, 7(3):–, March 2012.

[12] Nicolás Marín, C. Molina, José María Serrano, and A. Vila. A complexity guided algorithm for association rule extraction on fuzzy datacubes. *IEEE TRANSACTIONS ON FUZZY SYSTEMS*, 16:693–714, 2008.

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Trust-based information system architecture for personal wellness

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Abstract. Modern eHealth, ubiquitous health and personal wellness systems take place in an unsecure and ubiquitous information space where no predefined trust occurs. This paper presents novel information model and an architecture for trust based privacy management of personal health and wellness information in ubiquitous environment. The architecture enables a person to calculate a dynamic and context-aware trust value for each service provider, and using it to design personal privacy policies for trustworthy use of health and wellness services. For trust calculation a novel set of measurable context-aware and health information-sensitive attributes is developed. The architecture enables a person to manage his or her privacy in ubiquitous environment by formulating context-aware and service provider specific policies. Focus groups and information modelling was used for developing a wellness information model. System analysis method based on sequential steps that enable to combine results of analysis of privacy and trust concerns and the selection of trust and privacy services was used for development of the information system architecture. Its services (e.g. trust calculation, decision support, policy management and policy binding services) and developed attributes enable a person to define situation-aware policies that regulate the way his or her wellness and health information is processed.

Keywords. Wellness information, modelling, trust, privacy, information system architecture

Introduction

Healthcare systems currently perform a paradigmatic change where the focus is patient's holistic health and wellness management. The new paradigm is focused on preventive care, proactive services, and early detection of diseases, health promotion and maintenance, but it also supports healthy lifestyles [1-5]. The ubiquitous computing technology and the latest developments of the Internet have not only strong impacts to the ways healthcare services are offered but they have also enabled the rise of a new concept, ubiquitous health, that takes place in ubiquitous environment and therefore creates trust and privacy challenges that do not exist in the current regulated healthcare environment [5-7]. Therefore, a novel privacy management solution that takes into account features of ubiquitous environment, rich health information collected and used and the lack of predefined trust is needed.

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This paper studies ubiquitous health and personal wellness as meta-systems and ties together the results of our research on personal wellness information modelling and on trust-based information system architecture carried out during 2009-2012 [5, 8-14].

1. Methods

A holistic system theoretical approach was used to understand ubiquitous health as a concept, its features and trust and privacy concerns. First, an analysis of previous research concerning ubiquitous environment and systems was done. Thereafter, stepwise analysis and system-theoretical framework modelling were used to recognise the stakeholders, viewpoints and interconnections existing in the ubiquitous health and to develop novel privacy principles for it [5].

In personal wellness information modelling, literature analysis, context analysis and focus group methods were used. With literature analysis, we analysed the conceptualisations of personal wellness and personalised healthcare. We searched the following databases: ACM, ESBCOhost Academic Search Premier, IEEE, PubMed, ScienceDirect, SpringerLink and Google Scholar. For the final analysis 100 scientific articles were included. Context analysis with requirements elicitation techniques was applied to identify internal and external contexts for personal health. Regarding focus groups, four groups with six meetings and up to 10 participants, were used to understand how citizens understand the concept personal wellness, how they conceptualise it, and which factors are considered important for personal wellness [9].

The information architecture was developed by combining systems theory, systems engineering, requirements analysis and systems design. First, trust and privacy models was selected and principles developed in such a way they were in line with the general privacy principles and legislation, but at the same time took into account the identified features of the ubiquitous environment. Next, functional requirements and services were developed on the basis of earlier research analysis. Based on the selected principles, models and identified functional requirements the architectural services and their interconnections were developed using systems analysis methods [12-13]. Finally we carried out a feasibility study with a personal health case to assess whether the defined trust and privacy models apply. We used as a method a user-scenario with a detailed walk-through to assess whether the privacy models give a person means to control the access and disclose of his/her personal health information (PHI). We also defined relevant privacy attributes for the components based on literature analyses and empirical research [14].

2. Results

In this research, pervasive health is understood as a meta-system, and it is defined to be a network of systems offering health and wellness services for the person (the Data Subject) in unsecure information space. The novel privacy principles developed give the DS right to verify dynamically the trustworthiness of the service provider and the right to use personal polices to manage the way health and wellness information is processed. Furthermore, service providers have the responsibility to support the transparency and openness and therefore publish domain specific information required for trust calculation.

The developed personal wellness model consists of five internal components and the two external components social networks and environment. All these components are linked together, which reflects the complete and holistic nature of personal wellness [8-9]. The lifestyle component includes concepts concerning activities, behaviours, choices and risk factors related to the person's lifestyle. Emotional and mental wellness focuses on individual identity, psychological concepts, intellectual wellness, emotions, feelings, person's views and values. Occupational wellness concerns person's well-being at work, in studies, in unemployment or in retirement. Physiological wellness is about health and wellness, i.e. health status and conditions, diseases, disabilities, functioning, genetics, personal observations, monitoring and measuring of health data. The healthcare component presents the healthcare system, its services and systems, their accessibility, service providers and medical documentation. These five internal components are surrounded and affected by external components social networks and environment. Social networks include all social relations that affect a person, including digital social media connections and activities. Environment presents the digital and the physical environment related to a person, i.e. living environment, service environment, society, cultural environment and society regulations and norms. The environment is very flexible and dynamic and it may change over time [8-9].

The analysis of the features and privacy concerns showed that the widely used predefined and static regulatory privacy model of healthcare is insufficient. Instead, a model where privacy is a personal property should be used. This finding is in line with the developed privacy principles [12-13]. We found that in ubiquitous health a person needs rich service provider-specific trust information to make privacy decisions.

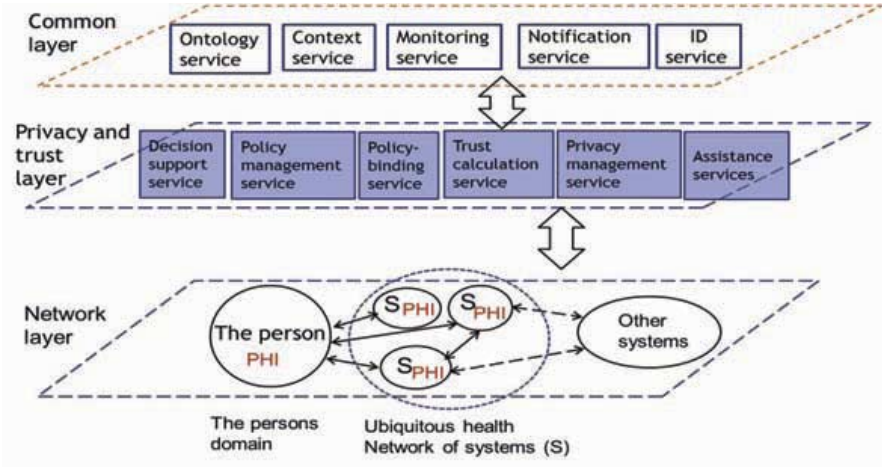


Figure 1: The framework model for the trust-based architecture [13]

The developed 3-layer model for privacy architecture is shown in Figure 1. The top layer consists of common services, and the middle layer includes privacy and trust services. The stakeholders, other users (e.g. secondary users) and personal health information are located at the lowest layer [13]. The trust calculation service offers for the DS rich context-aware trust information in the form of a calculated trust value and trust attributes. Trust attributes describe the level systems support awareness and transparency and how they follow privacy regulations and laws (e.g. EU-privacy relations and national data protection acts). The architecture mimics the way humans

use trust and therefore final trust decision is made by the DS. The role of the policy binding service is to help the DS to formulate computer understandable privacy and security policies. The notification service sends those policies to service providers.

In the feasibility study, we walked through the selected four wellness information model components, and in the scenario we used the person's privacy attributes defined for each component based on literature study and empirical research [5,12-14]. The walk-through showed that when information is transferred from a regulated system to a non-regulated system in pervasive environment, information is considered to be reliable when the person trusts that the sufficient procedures, safeguards and standards have been implemented in the regulated system. After the data is transferred, however, the original data security and privacy policies and values of privacy attributes are no more valid. In a pervasive environment it is difficult for a person to know exactly the actual privacy status of the service or the service provider. This is especially the case when a service provider is a non-regulated one such as in the lifestyle component, or with social networks or with non-certified Internet service providers.

3. Discussion

The developed principles, the personal wellness information model, and the privacy management architecture together offer a novel solution for a person to create trust, to select eHealth and eWellness services, and to manage personal privacy in a ubiquitous environment. The information model presents detailed citizen-based information and it addresses the wellness domain from an information systems science perspective and thus presents a starting point to develop personal wellness ontology. Wellness information and trust attributes are used by architecture's trust and privacy services for creating of computer understandable privacy polies. The privacy architecture gives to the DS tools and means to choose personal context-aware privacy policies for each system it is interacting with the help of computational trust information that covers a trust value and system-specific trust attributes. Selected trust attributes inform the DS how health service providers follow privacy regulations and laws regulating the DS's environment (e.g. which laws and how the service provider has implemented, and does it enable external verification of the implementation). A real benefit is that the architecture offers protection for the DS against many of privacy threats caused by the use of ubiquitous computing and unsecure environments.

The feasibility assessment showed that it is necessary that the DS is always informed of the privacy status of the services he/she is using and the DS can control the way data is processed. For example, specific privacy rules and services are needed for non-regulated environments if they are integrated or communicate with regulated health care services. We applied the self-regulating policies by defining the privacy attributes for each concept in the personal wellness information model. A rich set of context-aware privacy and trust services are offered the DS for trust building and privacy policy creation.

This research has resulted in models and methods for a person to be aware of and to manage the privacy of his/her personal health and wellness information. The results are still to be implemented and make them available and accessible for citizens. Implementation is important as many studies [15-17] indicate that privacy is a top reason for citizens' reluctance to adopt personal health systems.

The next step in our research is to develop a matrix that links trust attributes and privacy policies together. Policies should be easy to understand (i.e. an ontology is needed) and use in real life, and they should offer practical protection against privacy concerns existing in ubiquitous health and wellness [18].

References

[1] Codagnone C, Reconstructing the Whole: Present and Future of Personal Health Systems, PHS2020, European Commission, 2009, http://ec.europa.eu/information_society/activities/health/docs/projects/phs2020/phs2020-book-rev16082009.pdf.

[2] Teperi J, Porter ME, Vuorenkoski L, Baron J, The Finnish Health Care System: A Value-Based Perspective. Sitra Reports 82, 2009; http://www.sitra.fi/julkaisut/raportti82.pdf?download=Lataa+pdf.

[3] Varshney U, Pervasive Healthcare and Wireless Health Monitoring. Mobile Netw Appl 2009; 12:113-127.

[4] Hill JW, Powell P, The national healthcare crisis: Is eHealth a key solution? Business Horizons 52, 2009 265—277.

[5] Ruotsalainen P, Blobel B, Seppälä A, Sorvari H, Nykänen P, A Conceptual Framework and Principles for Trusted Pervasive Health. J Med Internet Res 2012; 14[2]:e52.

[6] Ohashi M, Hori M, Suzuki S, Citizen-centric e-healthcare management based on pervasive authentication - New ICT roadmap to active ageing. 4th International Conference on Pervasive Computing Technologies for Healthcare, Munich, March 2010, 1-8, doi: 10.4108/ICST. PERVASIVE HEALTH 2010.8910.

[7] Berry LL, Mirabito AM, Innovative healthcare delivery. Business Horizons 53, 2010; 157—169.

[8] Seppälä A, Nykänen P. Contextual analysis and modeling of personal wellness. In: Joaquim Filipe and Jan L. G. Dietz [Eds.] KEOD 2011, Proceedings of the International Conference Knowledge Engineering and Ontology Development - Paris, France, 26-29 October 2011: SciTePress - Science and Technology Publications, 202-207.

[9] Seppälä A, Nykänen P, Ruotsalainen P, Development of personal wellness information model for pervasive healthcare. Journal of Computer Networks and Communication, vol. 2012, article 596749, 10 pages.

[10] Nykänen P, Requirements for user-friendly personal eHealth information systems. International Council for Medical and Care Compunetics Conference. In: L Bos, B Blobel, A Marsh and D Carroll [eds.], Medical Care and Compunetics 5, Studies in Technology and Informatics 137, IOS Press, 2008, 367-372.

[11] Nykänen P, Ruotsalainen P, Blobel B and Seppälä A, Research on trusted personal health and wellness information in ubiquitous health information space. In: O. Dössel and WC Schlegel [Eds.]: WC 2009, IFMBE Proceedings 25/XII, 432–435, 2009.

[12] Ruotsalainen P, Blobel B, Nykänen P, Seppälä A, Sorvari H, Framework model and principles for trusted information sharing in pervasive health. In: A Moen, SK Andersen, J Aarts and P Hurlen [eds.], User Centred Networked Health Care. Proceedings of MIE2011, Oslo. IOS Press, Amsterdam, 2011, 497-501.

[13] Ruotsalainen P, Blobel B, Seppälä A, Nykänen P, Trust Enabled Privacy Management Architecture for Pervasive Health. Journal of Medical Internet Research, 2013, 1[2], e23.

[14] Nykänen P, Seppälä A, Ruotsalainen P, Blobel B, Feasibility analysis of the privacy attributes of the personal wellness information model. In: Lehmann CU, Ammenwerth E, Nøhr C [eds.], MEDINFO2013. Studies in Health Technology and Informatics 192. IOS Press, Amsterdam, 2013, [ISBN 978-1-61499-288-2 [print] | 978-1-61499-289-9 [online] Open Access], 219-223.

[15] Pavlou PA. State of the information privacy literature: where are we now and where should we go? MIS Quarterly. 2011; 35[4]:977–88.

[16] Belanger F, Crossler RE, Privacy in the digital age: a review of information privacy research in information systems. MIS Quarterly 2011:35[4]:1017–1041.

[17] Smith JH, Dinev T and Xu H, Information privacy research: an interdisciplinary review. MIS Quarterly 2011:35[4]: 989-1015.

[18] Seppälä A, Context-aware and Trust-based Personal Wellness Information Framework for Pervasive Health. Doctoral Dissertation. Acta Universitatis Tamperensis, 1924 Tampere University Press, 2014. ISSN 1455-616.

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Analysis of Central Enterprise Architecture Elements in Models of Six eHealth Projects

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Abstract. Large-scale initiatives for eHealth services have been established in many countries on regional or national level. The use of Enterprise Architecture has been suggested as a methodology to govern and support the initiation, specification and implementation of large-scale initiatives including the governance of business changes as well as information technology. This study reports an analysis of six health IT projects in relation to Enterprise Architecture elements, focusing on central EA elements and viewpoints in different projects.

Keywords. eHealth governance, health information systems, enterprise architecture, modelling

Introduction

Governments and service providers have initiated large-scale efforts to migrate towards network-centric operations in several application areas, including healthcare. This involves sharing information between organizations, personnel, clients and systems with networked software applications as a central enabling mechanism. National and regional initiatives have been established to support these goals [1]. In this context, EA (Enterprise Architecture) has been proposed as an essential mechanism to support holistic planning and alignment of business and IT in organizations and networks [2]. Successful large-scale eHealth initiatives require methods and conventions to support governance, analysis and design of solutions and support for traceability between healthcare needs and IT solutions [3]. EA frameworks provide tools such as taxonomies of models (artifacts) and elements (concepts) contained in the models, which form basis for analysis of both business and IT aspects.

This study was part of the SOLEA project[2] which was a multi-disciplinary project concentrating on service-oriented enterprise architecture in 2008-2011. One of the primary research questions was related to the representation of different elements of EA. The study was designed to examine different models and their representation types in several case projects. Discovery and analysis of common representation types and their mapping to central viewpoints was performed as part of the study. The results aim to highlight most commonly used representation types for different EA viewpoints and elements, and form basis for good modelling practices for different types of projects.

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1. Materials and Methods

The central concepts of the study are presented in Figure 1. The *target of the model* is a real-world phenomenon of interest for the modeller. Typically, there are several targets of models in a delimited *focus area* of the project. *Model* is a representation of this real work phenomenon. It corresponds to "artifact" in EA frameworks such as TOGAF [4]. Each model typically contains various *elements* representing real work items in the focus area of the modelling effort. Each model has a r*epresentation type* such as a structured or notation-driven presentation. Representation types are often derivatives of *basic representation types* such as lists, diagrams, matrices or narrative texts. Representation types can be reusable (such as UML diagram types) or ad hoc (such as free-format conceptual diagrams). *Elements* in models represent elements in real world. In this study, we have selected only the most important (primary) elements of each model, CAEs (central architecture elements). The elements are mapped to 17 *element types* found in widely used EA notation ArchiMate [5]. An element type has one *primary EA viewpoint* in EA viewpoint classification – in this study we have used *business*, *information*, *application* and *technology* viewpoints as defined in [4,6,7,8]. This allows us to calculate and observe the most important element types and primary EA viewpoints in models of different projects. In addition, some elements affect several viewpoints or are not specific to any one viewpoint, these were classified as *miscellaneous*. Summary of instantiations in a given project indicates how different element types and EA viewpoints have been emphasized in the project deliverables. To illustrate the instantiation of central concepts (Figure 1) used in analysis, the concepts are marked in italic in the following example. Organization X is a typical organization utilizing information systems to enable its business activities. The environment is documented in an "Architecture *Documentation* of Organization X". The documentation contains a *Model*: "Information Systems of Organization X", where "Systems Diagram" is the *Representation type* and the *"*Diagram*"* is the *Basic representation type*. The model has many different *elements*, each of which has an *element type.* In this diagram, elements describing information systems are especially important. The element type of these elements is "application". These application elements are *Central architecture elements* (*CAEs)* in the model. Their *primary EA viewpoint* is application architecture.

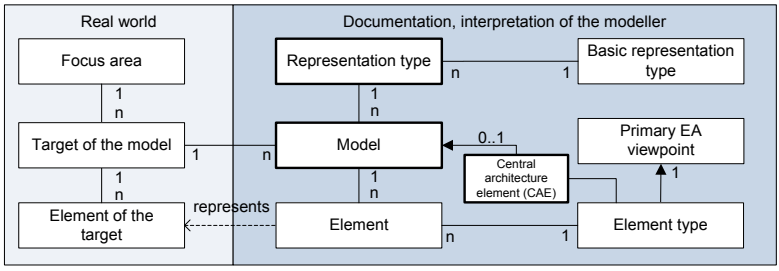


Figure 1. Basic concepts of the study.

We used the following research process in the study:

1. Selection of Enterprise Architecture models/frameworks to be utilized as well as drafting and selecting concepts used for classifying the collected data.
2. Construction of four structured information collection forms: a) general information of the project and its focus area, b) model catalog listing all models in

the documentation and other attributes of the models such as representation type, instance count of models etc., c) identification of primary elements and element types in each model, d) support forms for the research: list of ArchiMate elements, contents of the TOGAF Content Metamodel and additional form to analyze the model to support the recognition of models and representation types

3. Selection of case projects for the information collection (see below)
4. Material collection and classification for each case project, including a) study of deliverables and documentation, b) documentation of focus area and basic information, c) identification, naming and classification of all targets of models, d) identification and naming of representation types and subtypes from all models, e) calculation and classification of models, f) identification and calculation of central architecture elements (CAEs) in the deliverables, g) summary and assessment of architectural governance level and further development ideas (not discussed here)
5. Case-specific summary and analysis: a) Implementation of analysis model tooling, including production and verification of calculation formulas, b) Case-specific classification of models, production of summaries and result diagrams, case-specific discussion and analysis in relation to results
6. Summative analysis of the data collected from the documentation of all projects: a) (re)grouping of the models, b) comparison between case datasets, c) production of comparison tables and diagrams, d) comparison and analysis of the cases
7. Conclusions and reporting, resulting in a 117-page report in Finnish [9].

Our case material was extracted from architecture deliverables of six projects. All projects focused on specification for several different eHealth solutions or systems and were related to national or multi-organizational eHealth programmes or projects:

1. TAPAS: regional and local reference architecture for health information systems by the Finnish Association of Local and Regional Authorities
2. MyWellbeing: a sub-project related to reference architecture for citizen-centric health and wellbeing tool (Coper), an R&D effort funded by Finnish Funding Agency for Technology and Innovation TEKES and carried out by number of universities, companies and service providers [10]
3. TJSERT: Certification requirements for systems and organizations to support national ePrescription, by the National Institute of Health and Welfare in Finland
4. eKat: national architectural guidelines for eBooking of health services by the Ministry of Social Affairs and Health, coordinated by City of Oulu [11]
5. SOLEA SE: subproject of SOLEA related to the architecture for service events to support patient documentation in relation to the national EPR [12]
6. OpenCDA: HL7 CDA implementation guide project for ePrescription by HL7 Finland Association and the National Insurance Institute Kela [13].

2. Results

The documentation of selected six eHealth projects consisted of 218 different targets of the modeling. There were 803 identified models of 135 different representation types in total. Figure 2 summarizes the number of models, number of targets of the models, and identified representation types from each project. Figure 3 summarizes EA viewpoints of CAEs in models in each case project. Table 1 summarizes most common representation types found in all case projects.

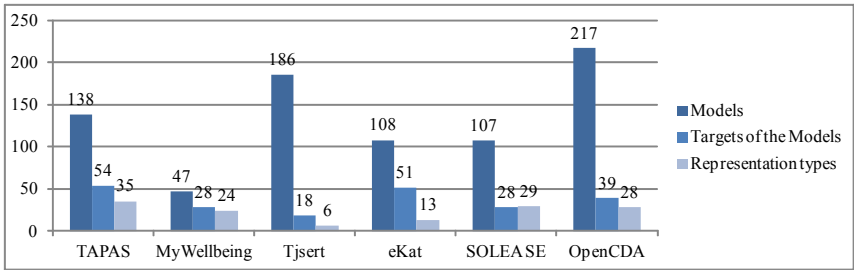


Figure 2. Number of models, targets and model representation types in case projects.

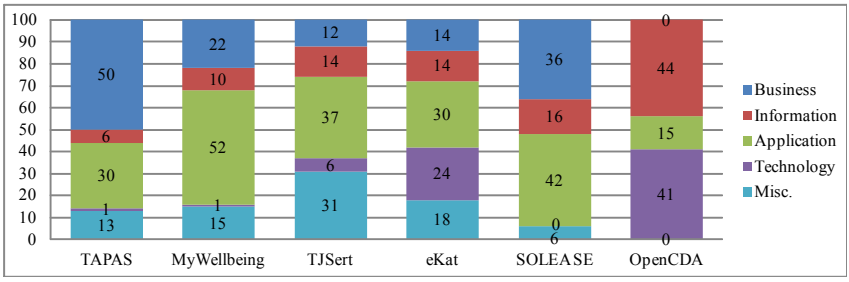


Figure 3. EA viewpoints of Central Architecture Elements (CAEs) in case projects.

Table 1. Most common representation types in all case projects.

Representation type/basic type	Number of targets	Number of instances	Number of cases	Misc.	Business	Application	Information	Technology
narrative text	70	137	6	20	26	31	31	8
list or catalogue	41	58	4	11	16	12	12	5
architecture diagram	19	36	6	1	14	31	5	3
data directory or information list	18	24	4	0	1	0	16	12
requirements catalogue	16	183	3	19	11	26	8	3
generic structured table	14	33	3	5	6	3	5	3
XML extract	14	67	1	0	0	0	0	14
hierarchical catalogue or list	9	9	2	5	3	1	1	2
list of design decisions / principles	6	15	2	3	4	9	3	0
catalogue of IT / application services	6	14	3	1	2	11	1	0
code fragment	5	19	2	0	0	0	4	5
list of concepts	4	4	4	0	1	0	3	0
process diagram	4	9	2	0	5	1	2	0
concept diagram	3	7	2	0	1	0	3	0
scenario description	2	4	2	0	4	1	0	0

3. Discussion and conclusions

The quantitative analysis of models required combines interpretation by the researchers in the selection of CAEs and naming of representation types, for example, and the usefulness of models is not qualitatively evaluated as such (although such evaluation was performed in some case projects). Thus, the resulting numbers cannot be treated as absolute. Despite this, the results provide some interesting insight into the modeling conventions of eHealth projects. Differences between analyzed projects are evident based on the results. Projects focusing on healthcare-specific reference architectures for further implementation in several care organizations have many elements in business

viewpoint, regardless of the scope of the project (e.g. regional guideline, specific horizontal reference architecture on national level). As depicted in Figure 2, some projects had many models in which only few representation types were used. Other projects such as MyWellbeing covered a majority of needs using somewhat few models. In some projects such as SOLEA SE, central targets were represented using several different representation types to provide a holistic view through different kinds of models. TJSert is an example of a project for specific clinical and administrative process in which a large number of models were specified using uniformed requirements structure (resulting in few representation types in comparison to the number of models). The OpenCDA is an example of an eHealth interoperability project which relies on external documentation for business aspects such as use cases.

As depicted in Table 1, Generic representation types were most frequently used. Technology-oriented projects used more formal representations. Some representation types are clearly most specific for a given EA viewpoint such as XML extracts or code fragments in technology-oriented targets, or architecture diagrams in application or business viewpoints. The selection of useful representation types for different types of healthcare needs in models also requires qualitative assessment and selection of formalism level which must be based on the intended audience of models.

Acknowledgements

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References

[1] Suna T. Finnish National Archive of Health Information (KanTa): General Concepts and Information Model, *Fujitsu Sci Tech J* 47(1) (2011), 49-57.
[2] Winter R., Fischer R. Essential Layers, Artifacts, and Dependencies of Enterprise Architecture, *EDOCW'06* (2006), 30.
[3] Whitehouse D, George C, Duquenoy P. eHealth: legal, ethical and governance challenges: an overview, *Proc. Med-e-Tel 2011* (2011), 353-358.
[4] Open Group, Open Group Standard, TOGAF Version 9.0, 2011.
[5] Open Group, ArchiMate® 2.1 Specification, 2013.
[6] Schekkerman J. *How to Survive in the Jungle of Enterprise Architecture*, 2nd edition, Trafford Publishing, Victoria, British Columbia, 2004.
[7] Pereira CM, Sousa P. Enterprise architecture: business and IT alignment*, Proceedings of the 2005 ACM symposium on Applied computing* (2005), 1344-1345.
[8] Pulkkinen M, Hirvonen A. EA Planning, Development and Management Process for Agile Enterprise Development, *Proc. HICSS-38* (2005), 223c.
[9] Virkanen H, Järvinen J, Mykkänen J, Sammelvuo I. *Arkkitehtuurikuvausten kohteet ja kuvaustavat - kooste case-tutkimuksen tuloksista* (in Finnish), University of Eastern Finland, Aalto University, 2012.
[10] Tuomainen M, Mykkänen J. Reference Architecture of Application Services for Personal Wellbeing Information Management, *Stud Health Technol Inform* **169** (2011), 98-102.
[11] Mykkänen J, Tuomainen M, Kortekangas P, Niska A, Task analysis and application services for cross-organizational scheduling and citizen eBooking, *Stud Health Technol Inform* **150** (2009), 332-336.
[12] Mykkänen J, Virkanen H, Kortekangas P, Savolainen S, Itälä T. Task Analysis and Interoperable Application Services for Service Event Management, *Stud Health Technol Inform* **169** (2011), 295-299.
[13] Porrasmaa J, Mykkänen J, Tarhonen T, Jalonen M, Kemppainen P, Ensio A, Pakarinen V. Application of HL7 CDA R2 and V3 messaging for national ePrescription in Finland, *9th International HL7 Interoperability Conference 2008, IHIC 2008* (2008), 193-194.

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Multi-provider Architecture for Cloud Outsourcing of Medical Imaging Repositories

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Abstract. Over the last few years, the extended usage of medical imaging procedures has raised the medical community attention towards the optimization of their workflows. More recently, the federation of multiple institutions into a seamless distribution network has brought hope of increased quality healthcare services along with more efficient resource management. As a result, medical institutions are constantly looking for the best infrastructure to deploy their imaging archives. In this scenario, public cloud infrastructures arise as major candidates, as they offer elastic storage space, optimal data availability without great requirements of maintenance costs or IT personnel, in a pay-as-you-go model. However, standard methodologies still do not take full advantage of outsourced archives, namely because their integration with other in-house solutions is troublesome. This document proposes a multi-provider architecture for integration of outsourced archives with in-house PACS resources, taking advantage of foreign providers to store medical imaging studies, without disregarding security. It enables the retrieval of images from multiple archives simultaneously, improving performance, data availability and avoiding the vendor-locking problem. Moreover it enables load balancing and cache techniques.

Keywords. Medical Imaging, Cloud, PACS, DICOM

Introduction

Medical imaging procedures have been so widely used, that even small healthcare institutions can produce a significant number of examinations [1]. PACS (Picture Archive and Communications System) is the common designation for information systems that manage the storage and distribution of medical image studies [2]. They present clear advantages, when compared to their analogic contenders [3].The DICOM standard [4] figures as a crucial part of any PACS, interconnecting archives, acquisition devices and visualization workstations [2, 5]. Since DICOM is vendor neutral and generally supported by every acquisition device, it is the most important standard in the medical image distribution field.

The integration of multi-domain medical imaging repositories has recently suffered major incentives through the XDS-I (Cross-Enterprise Document Sharing for images) and the IHE initiative [6]. They aim at the interoperation of multiple institutions on a broader level, by sharing performed studies, patient records or medical infrastructures. The DICOM standard is integrated in these initiatives as a lower level protocol for

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communications and data definition. However, this proposal targets the outsourcing of intra-institutional PACS archives to the Cloud. We consider intra-institutional processes all the transactions between different sites that have the same governance.

In this scenario, medical institutions face the difficult task of selecting on which Cloud infrastructures to deploy their PACS resources, namely their repositories. Traditionally, medical institutions deployed their archives in in-house solutions [7], because it reduces latencies in study storage and retrieval, and promotes security as sensitive data is stored inside the institution. On the downside, there are great financial costs associated with the maintenance of an in-house datacenter, demanding significant IT expertise and dedicated facilities. Therefore, outsourcing storage of medical imaging studies to foreign providers seems a more valid option to small-medium institutions.

Nowadays, Cloud providers are natural solutions because they offer elastic storage and optimal data availability, even disaster recovery facilities. Moreover, neither IT expertise, nor adequate facilities are required [7]. However, regardless of these benefits, medical institutions are still reluctant in outsourcing their archives, namely because these entities gained fame of exploring clients data and usage profiles to their benefit. Furthermore, current solutions fail to integrate in-house with outsourced solutions, as absent in the standard.

In this document, we present a multi-provider architecture that makes the use storage services from distinct Cloud providers possible, providing a service abstraction layer and ensuring DICOM interoperability. For instance, it is possible to use multiple archives simultaneously to store and retrieve the same study or image. The solution involves the splitting of medical images into segments. Our DICOM Router Platform is able to recombine the image fragments and present them seamlessly to the users through a native DICOM interface. As a result, it allows the improvement of study transference performance and enables load balancing techniques for PACS archives.

1. Background

DICOM is an application layer protocol which uses the TCP/IP for transport. DICOM applications are addressed by AETitle (Application Entity Title), messages exchanged by applications are called DIMSE (DICOM Message Service Elements) [5]. The Standard follows a client/server architecture. It uses the concept of services, in which a SCP (Service Class Provider) application provides a predefined functionality to others, the SCU (Service Class User). The standard provides a set of services that support the general usage of an institutional PACS, such as, Query/Retrieve, Storage and Printing.

Query/Retrieve and Storage are the most common services associated with image transference. The Storage service is used to upload images to a repository, for instance, by acquisition devices. In the Storage Service, the SCU sends to the SCP a C-Store-Rq (Request) containing the DICOM objects, usually an image, to be stored. The SCP acknowledges the reception of the objects by replying with a C-Store-Rsp (Response).

On the other hand, the Query/Retrieve is used to search and download images from a repository, for instance, when a physician reviews a study. It involves two commands, C-Find and C-Move. The C-Find request allows the SCU to query about the existence of objects, by meta-data fields, such as patient name or modality. In the Retrieve service, firstly, the SCP sends a C-Move request, selecting which objects to move. When the SCP receives a C-Move request, it sequentially starts a Storage session for

each image, as previously described. The C-Move session terminates when every image is transferred to the SCU.

However, the DICOM standard has demonstrated some performance inefficiency when ported to Internet environments [8-10]. In public environments, such as Internet, the traffic might be disallowed and connectivity difficult to achieve without expertize or permissions [11]. As such, the Standard also defines a set of web services called WADO (Web-Access to DICOM Objects). However, it supports more rendering functionality, instead of the full Query-Retrieve, which makes it unpractical to be used standalone by physicians. Nevertheless, in 2011, new REST web services were introduced, namely the STOW-RS [12] and the QIDO-RS [13]. These services have turned the protocol more compliant with the IHE initiative, although their compatibility with acquisition equipment is still reduced. As such, storage directly on foreign providers may be troublesome.

Recently, there has been a considerable effort in applying the Cloud computing paradigm to PACS storage. Cloud computing facilities, such as storage space, may be used as a highly reliable commodity [1, 7, 11]. Nevertheless, none of them takes advantage of multiple storage providers to excel medical image transference in terms of performance, reliability and scalability. Moreover, in security terms, proposed solution gives additional thrust to healthcare professionals, as they may limit the ability of external providers to assemble the image files by not outsourcing part of the image.

2. Proposal

2.1. DICOM Router Platform

In the past few years we have developed a distributed PACS architecture that supports geo-distributed institutions interconnected by common Internet connections [1, 11]. Our goal is to share the same PACS between multiple institutions, promoting tele-radiology by easing access to PACS archives from outside institutional boundaries without requiring extensive IT knowledge from the medical personnel. Moreover, it provides anytime-anywhere access to the PACS, and solves the no direct connectivity issue when the applications are behind restrictive network configurations (see Figure 1).

Our architecture is based on two main software components, the DICOM Router (a) and the DICOM Bridge Router (b). It enables remote calls to standard DICOM Query/Retrieve and Storage services by offering a proxy, which implements an

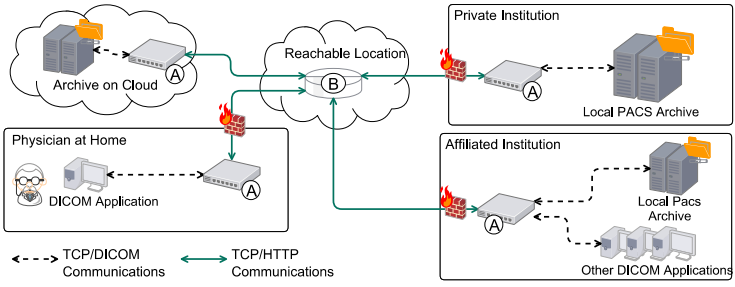


Figure 1. DICOM Router Platform sample deployment scenario.

optimized transference algorithm [8], to the remote application. DICOM Routers communicate via the well-known HTTP/SSL Protocol its broad usage has conducted

network security managers to allow this traffic to cross firewalls. The DICOM Bridge Router relays communications between routers and provides security functionalities to the PACS, namely router authentication and application advertisement. Absent the Bridge Router, peer-to-peer communications would be hard to achieve, as the HTTP is inherently client-server oriented and the majority of institutions connected to Internet often use NAT (network address translation).
Foreign Applications services are discovered by advertising the AETitle of appended applications to every router. Therefore each router creates a routing table matching AETitles to routers. As a result, when a router receives a request, it looks up in its routing table for the SCP AETitle presented in the request.

2.2. Integration of multiple repositories

In order to take full advantage of multiple repositories, we used a file splitting technique. This method divides DICOM images in portions called chunks, enabling more flexibility when dealing with image data. For instance, it is possible to divide images into two distinct repositories. Moreover, it is possible to outsource only a portion of the image to an untrustworthy provider. This is very helpful when handling large images, such as CT. Nevertheless it supports every modality. As conventional archives do not support incomplete images, the DICOM Router implements an innovator cache mechanism. It indexes the DICOM meta-data before splitting the image file and discarding the undesirable parts. Along with file splitting, it also uses compression to optimize both storage space and the transference performance.

Figure 2 describes the proposed method for integrating multiple repositories in the DICOM Retrieve Service. The process is initiated by an institutional client application which sends a C-Move RQ to the Intranet Router that immediately forwards the request to the Bridge. The DICOM Bridge Router broadcasts the request to every DICOM Router advertising the requests' SCP AETitle. This procedure initiates a small C-Move session, which orchestrates the transference, namely, it defines which chunks each archive has to upload. This is performed in parallel, as such: the overhead introduced by the increasing number of archives is minimized. See stage 1.

When a SCP Router receives a request, it queries its archive about the images contained in the desired study. The archive responds with a list of images, which actually need to be transferred to the SCU Application. If the archive does not have an entire image, the router only sends information of the available chunks. This list is sent back to the Bridge. This procedure is executed simultaneous in every router. See box A.

After receiving all Routers' responses, the Bridge has all the necessary information to schedule the transference, i.e. to assign which router will upload which chunk. The scheduling algorithm is implemented in an external plugin. By doing so, we virtually support every scheduling behavior possible. This is very important, as different institutions have different intentions towards the Platform. Upon finishing the scheduling, a message is sent to every router with a list of images or chunks that the router needs to upload. In parallel, the Bridge also sends an informative message to the SCU Router with information about the images that will be transferred. See stage 2.

When each SCP Router receives the upload list, it immediately starts uploading the images to the SCU Router. If the Router has all the requested chunks cached, it avoids requesting the image from the Archive, compressing and splitting its data. Once again, this procedure is parallel to every router (see block B). While receiving the image data, the SCU Router immediately assembles the completed images and sends them to the

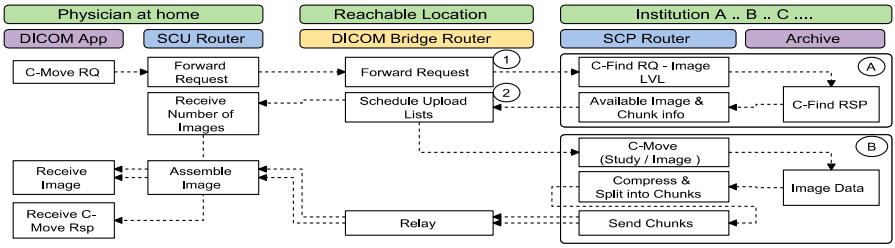


Figure 2. Image retrieval workflow on multiple repositories.

SCU application. When every image is moved, the router finally closes the association sending the C-Move RSP message.

3. Conclusions

This document proposes a multi-provider architecture for Cloud outsourcing of medical imaging repositories. The solution provides an abstraction layer for DICOM Storage and Query/Retrieve services. Moreover, it also enhances the performance in image retrieval and enables load-balancing techniques. By offering a native DICOM interface, it assures the full compliance with other vendor neutral solutions. The institutions are enabled to deploy in-house archives and outsourced solutions seamlessly. For instance, our affiliated institutions are using this solution to support services in two distinct locations. There is an in-house archive in each institution along with a central repository deployed in a private cloud provider. Physicians can review studies in external locations, retrieving data from multiple repositories in simultaneous.

References

[1] Silva LB, Costa C, Oliveira J. A PACS archive architecture supported on cloud services. Int J CARS. 2012;7(3):349-58.
[2] Huang HK. PACS and Imaging Informatics: Basic Principles and Applications: Wiley; 2010.
[3] Srinivasan M. Saving time, improving satisfaction: the impact of a digital radiology system on physician workflow and system efficiency. Digital Medicine. 2012;1(1).
[4] ACR-NEMA. Digital Imaging and Communications in Medicine (DICOM). Rosslyn, VA: National Electrical Manufacturers Association; 1993.
[5] Pianykh OS. Digital Imaging and Communications in Medicine (DICOM): A Practical Introduction and Survival Guide: Springer; 2008.
[6] Gibaud B. The quest for standards in medical imaging. European journal of radiolgy. 2011;78(2):190-8.
[7] Ukis V, Tirunellai Rajamani S, Balachandran B, Friese T, editors. Architecture of Cloud-Based Advanced Medical Image Visualization Solution. Cloud Computing in Emerging Markets (CCEM), 2013 IEEE International Conference on; 2013 16-18 Oct. 2013.
[8] Godinho TM, Silva LAB, Viana-Ferreira C, Costa C, Oliveira JL, editors. Enhanced regional network for medical imaging repositories. 8th Iberian Conference on Information Systems and Technologies (CISTI 2013), Lisboa, Portugal; 2013.
[9] Maani R, Camorlinga S, Arnason N, Eskicioglu R, editors. A practical fast method for medical imaging transmission based on the DICOM protocol2010.
[10] Maani R, Camorlinga S, Arnason N. A Parallel Method to Improve Medical Image Transmission. Journal of Digital Imaging. 2012;25(1):101-9.
[11] Silva LB, Costa C, Oliveira J. DICOM relay over the cloud. Int J CARS. 2012:1-11.
[12] Nema ACR. DICOM Supplement 163: STore Over the Web by REpresentations State Transfer (REST) Services (STOW-RS). 2011.
[13] Nema ACR. DICOM Supplement 166: Query based on ID for DICOM Objects by Representational State Transfer (REST) Services (QIDO-RS). 2011.

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Semantic Krippendorff's α for measuring inter-rater agreement in SNOMED CT coding studies

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Abstract. Semantic interoperability requires consistency in use of terminologies such as SNOMED CT. Inter-rater agreement measurement can be used to quantify this consistency among terminology users. Increasingly, studies of SNOMED CT include inter-rater agreement measures. However, published studies do not consider distance between concepts when calculating the inter-rater agreement measures. In this paper we propose a semantic inter-rater agreement measure for use with SNOMED CT encoded data. A semantic Krippendorff's α measure is implemented using a path-length based difference function. The measure is tested using three different datasets. Results show that the proposed semantic measure is sensitive to seriousness of coding differences whereas a nominal measure is not. The proposed measure reflects the intuition that distance matters when comparing uses of SNOMED CT.

Keywords. SNOMED CT, Inter-rater agreement, Coding studies

Introduction

Semantic interoperability in health care requires utilization of controlled clinical terminologies [1]. However, the understanding of terms of a terminology may differ posing a challenge to both developers and users of terminologies. When using terminologies to code clinical information, different codes are sometimes selected to represent the same idea. This variance in coding can be quantified by inter-rater agreement measurement. This is now an established area for example described by Gwet [2].

Currently, the implementation of SNOMED Clinical Terms (SNOMED CT) in clinical information systems is growing [3]. Through various studies SNOMED CT has proven to meet clinical documentation needs with respect to content coverage [4-6]. However, coding disagreement when using SNOMED CT leads to limited applicability, because retrieval, aggregation and comparison of clinical data across systems cannot be done in an accurate and trustworthy manner. Consequently, studies of SNOMED CT use have suggested how to improve coding consistency [7, 8].

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Increasingly, studies of SNOMED CT include inter-rater agreement measures. Fung et al. and Vikström et al. have used Cohen's (unweighted) Kappa [9, 10], Hwang et al. and Chiang et al. have used percentage agreement [11, 12] and Andrews et al. have used Krippendorff's α [13]. Common to these reported assessments of inter-rater agreement is that calculations are done without considerations of the relationships between the concepts of SNOMED CT, i.e. calculations are done assuming that SNOMED CT concepts are on a nominal scale.

Using a different scale is the point of departure of our study because it could possibly take into account the seriousness of coding variations. For example, in a local EHR implementation the term "Blood pressure" may denote a field where systolic and diastolic blood pressure can be entered. Using SNOMED CT, two coders A and B could possibly suggest *75367002|blood pressure (observable entity)|* and *251076008|non-invasive arterial pressure (observable entity)|* respectively, whereas another coder C might suggest *46973005|blood pressure taking (procedure)|*. Coders A and B choose concepts in an ancestor-descendant relationship with different granularity, whereas coder C choose a concept from a different (arguably the wrong) hierarchy.

Coding with different granularity is a much less serious problem when querying or aggregating than choosing different hierarchies. When querying for content using SNOMED CT, granularity differences are easily managed by including descendants in the query. Choosing a difference function that reflects this type of semantic differences could possibly extend the meaning of inter-rater agreement measures to not only include the number of matches between coders but also the seriousness of non-matches.

The aim of this study is to introduce semantic weighting in inter-rater agreement measurement and to implement and test such a measure. The aim is also to discuss properties of this measure and the added value of a semantic agreement measure to inter-rater agreement studies.

1. Methods

1.1. A semantic difference function and Krippendorff's α

We selected to base our semantic inter-rater agreement measure on s Krippendorff's α [14]. Krippendorff's α requires a difference function to express the seriousness of coding errors. For the purpose of this study, a simple path length based the difference function was selected. The difference function represented the disposition to find both concepts when performing retrieval at various levels of generalization according to the SNOMED CT hierarchy, which is a commonly proposed SNOMED CT use case [15]. We define the difference function *lcsPath* as the largest distance (dist), counted as Is-A relationships, between either of the concepts and the least common subsumer (LCS). If more than one path exists from a concept to the LCS, the shortest path is used. The distance is squared to give preference to shorter distances.

$$lcsPath_{ck} \stackrel{\text{def}}{=} (\max(\min(\,\text{dist}(c, \text{LCS}(c,k))), \min(\,\text{dist}(k, \text{LCS}(c,k)))))^2$$

To be accepted as a Krippendorff's α difference function, *lscPath* obeys the following properties: $\delta_{ck} \geq 0$ for all c, k. $\delta_{ck}=0$ for all c=k, and $\delta_{ck}=\delta_{kc}$ for all c, k.

For example, *lcsPath* between *75367002|blood pressure (observable entity)|* and *251076008|non-invasive arterial pressure (observable entity)|* is 2^2=4 whereas the distance *lcsPath* between *75367002|blood pressure (observable entity)|* and *46973005|blood pressure taking (procedure)|* is 5^2=25.

The Krippendorff's α calculations were done in R 3.0.1 by modifying the "irr" package [16] and bootstrapping calculations were done by modifying Mike Gruszczynski's bootstrapping function [17]. Calculations were repeated in Matlab® R2013b by modifying Jana Eggink's α function [18]. Distance matrices corresponding to the difference function applied to coding data was created using a Java program. Software is available with open-source licenses on GitHub[2].

The international release of SNOMED CT from July 2013 was used in these tests.

1.2. Evaluation of semantic Krippendorff's α

In order to evaluate the semantic inter-rater agreement measure we created three datasets with different properties. All sets included a constant number of exact matches.

For the dataset AB we used an extract from a Swedish national cross-mapping project. The dataset contained 490 procedure codes cross-mapped to SNOMED CT by two human coders: A and B. The two human coders did agree on one single SNOMED CT concept in 354 (72 %) of the 490 cases. All SNOMED CT concepts used by the two human coders were from the Procedure hierarchy.

We then constructed a coder C by injecting SNOMED CT codes into coder B replicating errors a novice coder might make. For the non-matching pairs (where A and B did not agree) we manually replaced 20 (4 % of 490) concepts from coder B with concepts with similar descriptions but from a different hierarchy (6 Clinical finding, 4 Substance and 9 Observable entity and 1 Specimen). Using coder C and A, we constructed the dataset AC.

We then constructed a coder D by injecting random concepts from the international release of SNOMED CT into coder B for all non-matching pairs. Using coder D and A, we constructed the dataset AD

For all datasets we calculated nominal and semantic Krippendorff's α as well as confidence intervals using the bootstrap approach with 10,000 iterations as suggested by Hayes and Krippendorff [19].

2. Results

Characteristics of the datasets and results are shown in Table 1. The value of nominal α is almost constant while the semantic α is decreased when anomalies are introduced. For nominal α, there are small differences hidden when rounding results to two significant digits due to different number of unique codes between datasets. Only a few SNOMED CT concepts were used more than once in any of the datasets.

[2] https://github.com/LiU-IMT/semantic_kripp_alpha

Table 1. Number of unique concepts used and results for nominal and semantic Krippendorff's α

	Dataset AB (A:human-B:human)	Dataset AC (A:human- C:novice)	Dataset AD (A:human-C:random)
Unique S. CT concepts	613	614	619
Concepts used ≥ once	9 (1.5 %)	9 (1.5 %)	6 (1.0 %)
Nominal α (95 % CI)	0.72 (0.68-0.76)	0.72 (0.68-0.76)	0.72 (0.68-0.76)
Semantic α (95 % CI)	0.89 (0.86-0.92)	0.84 (0.80-0.88)	0.47 (0.41-0.53)

3. Discussion

We have proposed, implemented and evaluated a semantic inter-rater agreement measure for use with SNOMED CT encoded data. We chose to use Krippendorff's α for evaluation but other inter-rater agreement measures could have been used, for example weighted Cohen's Kappa or derivatives thereof. Our results show that the proposed semantic measure is sensitive to seriousness of coding differences whereas a nominal measure is not.

Inter-rater agreement measures may be sensitive to prevalence in data leading to paradoxes in measure results [2]. In our datasets duplicate codes accounts for less than 1.5 % of all codes used and, thus, the prevalence of any specific concept being selected by a coder is low. Although the proposed measure may be sensitive to prevalence, for heterogeneous datasets as ours this is not an issue.

For any situation with less than perfect agreement, the added value of a semantic inter-rater agreement measure lies in any numerical difference from its nominal counterpart. The magnitude of this difference depends on the nature and degree of the disagreement. In this study we constructed two coders C and D to have a clear semantic distinction between datasets AB, AC and AD. Even though the two latter datasets were not real they suited the need to demonstrate certain properties of semantic Krippendorff's α. Future studies will show how semantic inter-rater agreement measures perform on real datasets in relation to nominal ones.

The difference function, *lcsPath*, was based on a simple path-based similarity estimate. However, simple path-based estimates have been criticized for ignoring taxonomical depth and being incongruent with human perception of similarity [20]. One example is that when using our function the distance between the clinically unrelated entities *250411006|bone marrow finding (finding)|* and *106048009|respiratory finding (finding)|* is 1 because the concepts have the common parent *118234003|finding by site (finding)|*. Moreover, the distance between *58840004|decreased breath sounds (finding)|* and *65503000|absent breath sounds (finding)|* is also 1 because they have the common parent *128254003|respiratory auscultation finding (finding)|*. Using a more sophisticated similarity measure based on information content like intrinsic Lin [20, 21] give similarities of 0.32 (respiration – bone marrow case) and 0.89 (breath sounds case). This example clearly illustrates that human understanding of similarity is better supported with more sophisticated similarity measures. On the other hand, the difference function should be concurrent with the terminological query and aggregation properties of the clinical information systems in which the coded information is used. This could be a problem for sophisticated similarity estimates. Consequently, choosing *lcsPath* is concurrent with the before mentioned retrieval use case proposed by IHTSDO [15]. However, for other use cases another difference function may be needed.

In conclusion, when comparing uses of SNOMED CT the intuition is that the distance between concepts matters. As shown here, the proposed semantic agreement measure reflects this intuition whereas commonly used measures do not.

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References

[1] European Commission. *Semantic Interoperability for Better Health and Safer Healthcare*, 2009.
[2] K. L. Gwet, *Handbook of inter-rater reliability: the definitive guide to measuring the extent of agreement among raters*. Gaithersburg, MD: Advanced Analytics, LLC, 2012.
[3] D. Lee, N. de Keizer, F. Lau, and R. Cornet, "Literature review of SNOMED CT use," *J Am Med Inform Assoc*, vol. 21, no. e1, pp. e11–19, Feb. 2014.
[4] H. A. Park, C. Lundberg, A. Coenen, and D. Konicek, "Evaluation of the content coverage of SNOMED CT representing ICNP seven-axis version 1 concepts," *Methods Inf Med*, vol. 50, no. 5, pp. 472–478, 2011.
[5] S. T. Rosenbloom, S. H. Brown, D. Froehling, B. A. Bauer, D. L. Wahner-Roedler, W. M. Gregg, and P. L. Elkin, "Using SNOMED CT to represent two interface terminologies," *J Am Med Inform Assoc*, vol. 16, no. 1, pp. 81–88, Feb. 2009.
[6] H. Wasserman and J. Wang, "An applied evaluation of SNOMED CT as a clinical vocabulary for the computerized diagnosis and problem list," *AMIA Annu Symp Proc*, pp. 699–703, 2003.
[7] A. Randorff Højen and K. Rosenbeck Gøeg, "Snomed CT implementation. Mapping guidelines facilitating reuse of data," *Methods Inf Med*, vol. 51, no. 6, pp. 529–538, Dec. 2012.
[8] D. H. Lee, F. Y. Lau, and H. Quan, "A method for encoding clinical datasets with SNOMED CT," *BMC Med Inform Decis Mak*, vol. 10, p. 53, 2010.
[9] K. W. Fung, W. T. Hole, S. J. Nelson, S. Srinivasan, T. Powell, and L. Roth, "Integrating SNOMED CT into the UMLS: an exploration of different views of synonymy and quality of editing," *J Am Med Inform Assoc*, vol. 12, no. 4, pp. 486–494, Aug. 2005.
[10] A. Vikström, Y. Skånér, L.-E. Strender, and G. H. Nilsson, "Mapping the categories of the Swedish primary health care version of ICD-10 to SNOMED CT concepts: rule development and intercoder reliability in a mapping trial," *BMC Med Inform Decis Mak*, vol. 7, p. 9, 2007.
[11] J. C. Hwang, A. C. Yu, D. S. Casper, J. Starren, J. J. Cimino, and M. F. Chiang, "Representation of ophthalmology concepts by electronic systems: intercoder agreement among physicians using controlled terminologies," *Ophthalmology*, vol. 113, no. 4, pp. 511–9, Apr. 2006.
[12] M. F. Chiang, J. C. Hwang, A. C. Yu, D. S. Casper, J. J. Cimino, and J. B. Starren, "Reliability of SNOMED-CT coding by three physicians using two terminology browsers," *AMIA Annu Symp Proc*, pp. 131–135, 2006.
[13] J. E. Andrews, R. L. Richesson, and J. Krischer, "Variation of SNOMED CT coding of clinical research concepts among coding experts," *J Am Med Inform Assoc*, vol. 14, no. 4, pp. 497–506, Aug. 2007.
[14] K. Krippendorff, *Content analysis: an introduction to its methodology*. Thousand Oaks, Calif.: Sage, 2004.
[15] IHTSDO, "SNOMED CT Starter Guide," chapter 3, 2014. [Online]. Available: http://snomed.org/starterguide.pdf
[16] M. Gamer, J. Lemon, I. Fellows, and P. Singh, "irr: Various Coefficients of Interrater Reliability and Agreement," 2012. [Online]. Available: http://CRAN.R-project.org/package=irr.
[17] M. Gruszczynski, "kripp.boot." [Online]. Available: https://github.com/MikeGruz/kripp.boot.
[18] J. Eggink, "Krippendorff's Alpha." [Online]. Available: http://www.mathworks.com/matlabcentral/fileexchange/36016-krippendorffs-alpha.
[19] A. F. Hayes and K. Krippendorff, "Answering the Call for a Standard Reliability Measure for Coding Data," *Communication Methods and Measures*, vol. 1, no. 1, pp. 77–89, 2007.
[20] D. Sánchez and M. Batet, "Semantic similarity estimation in the biomedical domain: an ontology-based information-theoretic perspective," *J Biomed Inform*, vol. 44, no. 5, pp. 749–759, Oct. 2011.
[21] D. Lin, "An information-theoretic definition of similarity," in *ICML*, 1998, vol. 98, pp. 296–304.

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Preservation of Information in Terminology Transcoding

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Abstract. Linking interface terminologies (IT) to reference terminologies (RT) in flow of terminologies may allow health information system to be both usable and interoperable. Two French university hospitals worked independently on such a flow from the prescription of lab-test to the display of the corresponding results. The aim of this study was to evaluate the transmission of information in these two hospitals communication. An expert, supported by natural language processing tool, created the gold standard link between the 2 prescription ITs i.e. the terms that share the same meaning. A semantic pathway was defined to allow the mapping of one prescription IT to the other, through LOINC® and SNOMED®, the RT chosen by each hospital, respectively. The capacity of the semantic pathway to identify the correct links was computed. The expert found 218 links between the 2 prescription ITs (containing 580 and 374 terms that are linked to RT). The semantic pathway correctly identifies 96 of these links (44.0% [37.4-50.6]). The recall was not as good as expected, even though the semantic pathway was created in order to maximize it. Using different RT in different hospitals is not an efficient solution. The use of LOINC® seems to be preferable as a RT for prescription.

Keywords. Terminology as topic; CPOE; SNOMED; LOINC

Introduction

The enhancement of health quality promised by e-health (from electronic health record to e-prescribing and clinical decision support system) [1] requires all the information system involved to be interoperable, i.e. information in one system are correctly interpreted in others, without any information loss. HL7, one of the most used standards in medicine, suggests the use of reference terminologies (RT) to achieve this interoperability [2]. These terminologies are "designed to provide exact and complete representations of a given domain's knowledge, including its entities and ideas, and their interrelationship" [3]. This completeness is the strength but also the weakness of RT: they are difficult to use for health professional and may not be as complete as desired by users [4].

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Many authors [5, 6] showed that the terminology itself has a great impact on the usability and the quality of the data. In order to avoid errors in structuring information and time loss due to cumbersome RT, it has been suggested to employ interface terminologies (IT), dedicated to one use and one kind of user. Such terminology should help "clinicians' entry of patient-related information into computer programs" [4]. Theoretically, IT should not be well-structured terminology. Instead, they should be mapped to RT which provide them the structure they lack [4, 7] and may allow interoperability between different ITs.

Computerized Physician Order Entry (CPOE) is one particular use case of IT: orderable laboratory tests, drugs and procedures are legion and terms designing them in classically used terminology may be non-intuitive for users [6], problems that an IT may resolve. Some work has already been done for drugs with RxTerm [8], an IT for RxNorm, and for medical imaging with RadLex Playbook [9], an IT for RadLex.

Theoretically, two concepts, from two terminologies, mapped with an exact-match relation should have the same meaning. Nevertheless, it has been shown that even if these links maybe useful, they are not perfect [10]. In flow of terminologies, this is of utmost importance because there are numerous transcodings between terminologies. It is then necessary to evaluate the correctness of the information at different point in the flow. We can't find any evaluation of interoperability using the above-mentionned IT/RT.

The main objective of this study was to explore information preservation between two different ITs, which are both linked to a different RT.

1. Methods

The prescription is currently computerized both at some wards of Assistance Publique-Hôpitaux de Paris (APHP) and Rouen University Hospital (RUH). All the prescriptions are computerized but this paper focus on lab-tests. In these two university hospitals, the computerization leads to set up two flows of terminologies from the ordering of a laboratory test to the display of the corresponding results. Three main ITs were identified: one IT for prescription included in CPOE, one IT for execution, which is part of the Laboratory Information System (LIS), and one IT for results display.

Some RT were introduced in the flows to allow interoperability (see figure 1). APHP and RUH use the same model but not the same terminologies: i) Execution terminologies, which can barely be considered as ITs, are integrated in the Laboratory Information Systems (LIS). They gather all the lab-tests that are performed in each hospital, ii) ITs (both prescription and result) have been created specifically for each hospital, iii) RT between execution and results was LOINC® for both APHP and RUH, those links were all created manually by biologist experts, and, iv) RT between prescription and execution was LOINC for RUH and SNOMED International® for APHP. At APHP, the prescription IT to SNOMED Int. link was performed manually. At RUH, the prescription IT was linked to the execution terminology. The link between execution terminology and LOINC was then "pushed" to prescription IT by transitivity, allowing the full flow to be instantiated.

The work is still in progress and all the terminologies and mapping are not fully available yet. This study will focus on prescription ITs and their link to RT. APHP prescription IT contains 1 854 terms. Microbiology terms (n=433) were excluded from

this study because RUH prescription IT does not cover this domain. RUH prescription IT contains 677 terms, which were all included in this study.

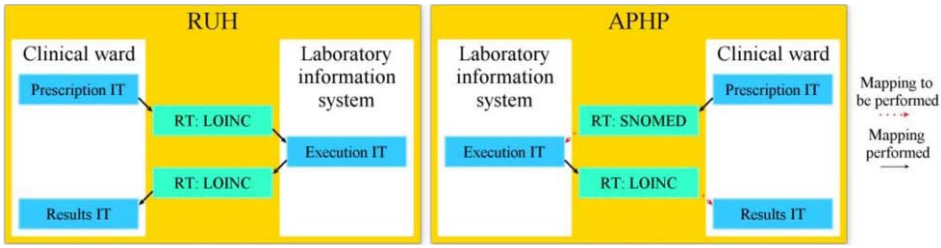


Figure 1. Instanciation of the IT/RT modelization for RUH and APHP

For an APHP system to understand a RUH prescription (or inversely), the RUH prescription IT term has to be mapped in APHP prescription IT term. Such mapping may be obtain using Unified Medical Language System® (UMLS®), adapting Bodenreider methods [11]. Briefly, it consists in using terms parts to link SNOMED and LOINC. Bodenreider shows that using the six parts of LOINC terms lead to a near zero recall. Actually, the only part that leads to an interesting recall is the analyte part (i.e. the thing that is measured or analyzed) [11]. There is a link between a SNOMED term and a LOINC term if their analyte parts share the same Concept Unique Identifier in UMLS. SNOMED CT® provides better results than SNOMED Int., therefore the first was used, using links provided by IHTSDO®, the international organization who support the SNOMED terminologies (http://www.ihtsdo.org/). The full semantic pathway between the prescription ITs is presented on figure 2.

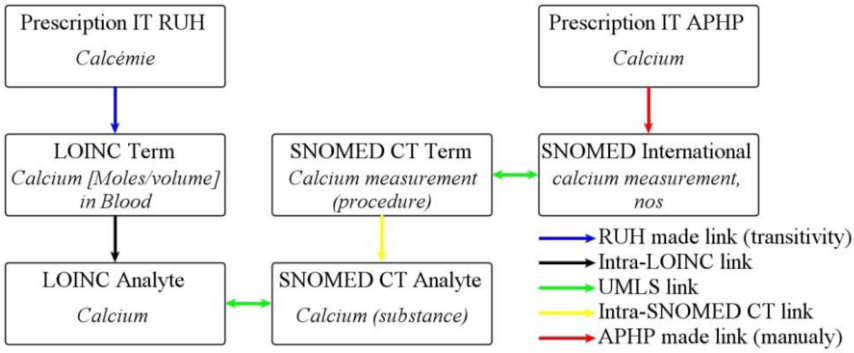


Figure 2. Semantic pathway between RUH and APHP prescription (in italic the calcemia example)

A lexical method using Natural Language Processing (NLP) tool [12] was used to propose some candidate synonymy between the two prescription IT. To enhance NLP tools performance, naming convention at APHP and RUH were studied and systematic differences were accounted for. A biologist (STL) validated both lexical and semantic automatic mapping and search the whole prescription ITs to find all the other correct links between RUH and APHP prescription ITs.

Relevance of semantic links was assessed using recall. It is defined as the ratio between the number of correct links found by semantic pathway and the number of correct links found by the expert. The precision was of low interest because the link between LOINC and SNOMED was performed to maximize recall and therefore introduce a lot of noise. The recall was computed using only correct links where both RUH and APHP prescription ITs terms are linked to the RT.

2. Results

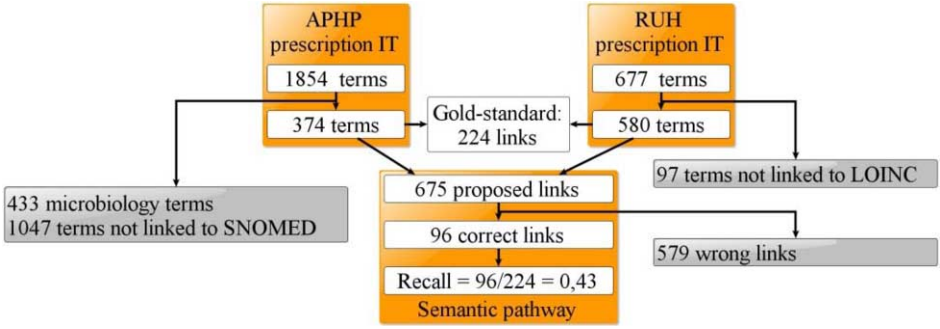


Figure 3. Flow chart

The NLP tool provides 404 links between RUH and APHP prescription ITs, 131 of them are correct. The manual review of the whole terminologies provides 144 more correct links, leading to 275 correct links between RUH and APHP prescription ITs. Only 580 out of 677 (=85.7%) RUH prescription IT terms and 374 out of 1421 (=26.3%) APHP prescription IT terms are linked to the RT. This lead to the exclusion of 51 correct links for recall computation: one (or both) prescription IT terms are not linked to the RT.

The semantic pathway proposed 675 potential links. Only 96 of them were correct, leading to a recall of 42.9% $[36.4\text{-}49.3]_{CI95\%}$ (see figure 3).

3. Discussion

The semantic pathway between the two prescription ITs only allows the recall of 42.9% of the prescription. The meaning of the 56 other percent is lost during transcoding.

No similar study was found during the literature review. Fung & Bodenreider [13] used UMLS to find links between SNOMED CT and ICD-9 and compared it to the IHTSDO gold-standard. They found a poor recall and a quite good precision. These results are not comparable to those presented in this study, but there is no need of comparison to conclude to the poor effectiveness of the semantic pathway in this study.

The main limit of this study is obvious when looking at the figure 2: the semantic pathway is far too complex to avoid losing information. The links between LOINC-analyte and SNOMED CT-analyte and between SNOMED CT-term and SNOMED CT-analyte are the two links responsible for most of information loss. Nevertheless, as stated by Bodenreider [11], these two links are the only available to set a link between LOINC and SNOMED. LOINC is frequently reported as a terminology to structure the analyses that were performed, also APHP thought to use SNOMED for prescription. However, the provision, by Regenstrief, of "LOINC top 300 order" [14], the existence of a metadata "Order vs. Observation" available for lots of LOINC terms and the existence of panels (a LOINC term that gathered multiple other LOINC term, allowing the prescription of multiple lab-tests with one term) reveal that LOINC is also usable as a prescription terminology. APHP has decided to change its RT from SNOMED to LOINC. This will make the semantic pathway far easier: from APHP prescription IT to LOINC to RUH prescription IT, and probably decrease the loss of information between

the two hospitals. This work already provides APHP a cross-mapping table between its prescription IT and LOINC.

The poor coverage of RT is the result of: i) an unfinished work, all the possible links have not been created at the time of this study, and, ii) coverage issues in the RT, as already highlighted [3, 15, 16]. The relative easiness of adding terms in LOINC, compared to SNOMED [15], pleads, again, for the use of LOINC at prescription level.

The intersection between the 2 prescription ITs is low: only 275 prescription terms have been identified as equivalent between RUH and APHP. It results from the method used to build the gold-standard: the expert should create highly probable link only. This set of prescription may constitute the basis of a shared prescription IT in the 2 university hospitals and further.

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References

[1] Committee on Quality of Health Care in America, Institute of Medicine: Crossing the Quality Chasm: *a New Health System for the 21st Century*. Washington, D.C.: National Academy Press, 2001.
[2] HL7: Observation Reporting. In HL7 Messag Stand version 251. Ann Arbor, 2007.
[3] Rosenbloom ST, Brown SH, Froehling D, Bauer BA, Wahner-Roedler DL, Gregg WM, Elkin PL: Using SNOMED CT to represent two interface terminologies. *J Am Med Informatics Assoc* **16** (2009), 81–8.
[4] Rosenbloom ST, Miller RA, Johnson KB, Elkin PL, Brown SH: Interface terminologies: facilitating direct entry of clinical data into electronic health record systems. *J Am Med Informatics Assoc* **13** (2006), 277–88.
[5] Cimino JJ, Patel VL, Kushniruk AW: Studying the human-computer-terminology interface. *J Am Med Informatics Assoc* **8** (2001), 163–73.
[6] Passiment E, Meisel JL, Fontanesi J, Fritsma G, Aleryani S, Marques M: Decoding laboratory test names: a major challenge to appropriate patient care. *J Gen Intern Med* **28** (2013), 453–8.
[7] Kanter AS, Wang AY, Masarie FE, Naeymi-Rad F, Safran C: Interface terminologies: bridging the gap between theory and reality for Africa. *Stud Health Technol Inform* **136** (2008), 27–32.
[8] Fung KW, McDonald C, Bray BE: RxTerms – a drug interface terminology derived from RxNorm. In *AMIA Annu Symp Proc* (2008), 227–31.
[9] RadLex Playbook [http://rsna.org/RadLex_Playbook.aspx]
[10] Zhang S, Bodenreider O: Experience in Aligning Anatomical Ontologies. *Int J Semant Web Inf Syst* **3** (2007), 1–26.
[11] Bodenreider O: Issues in mapping LOINC laboratory tests to SNOMED CT. In AMIA Annu Symp Proc (2008), 51–5.
[12] Merabti T, Soualmia LF, Grosjean J, Joubert M, Darmoni SJ: Aligning Biomedical Terminologies in French: Towards Semantic Interoperability in Medical Applications. In *Med Informatics*. Edited by Mordechai S, Sahu R. InTech (2012), 41–68.
[13] Fung KW, Bodenreider O: Utilizing the UMLS for semantic mapping between terminologies. In *AMIA Annu Symp Proc* (2005), 266–70.
[14] LOINC: Common Lab Orders Value Set, 2011.
[15] Vreeman DJ, Stark M, Tomashefski GL, Phillips DR, Dexter PR: Embracing change in a health information exchange. *AMIA Annu Symp Proc* (2008), 768–72.
[16] Mantena S, Schadow G: Evaluation of the VA/KP problem list subset of SNOMED as a clinical terminology for electronic prescription clinical decision support. *AMIA Annu Symp Proc* (2007), 498–502.

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CIPROS - A checklist with items for a patient registry software system

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Abstract. Patient registries are an important instrument in medical research. Their implementation uses complex software systems to meet the wide spectrum of challenges. There is a wide range of systems available and a critical appraisal of their architecture is needed. Therefore, we developed, based on a systematic review of the literature, a checklist for patient registry software systems (CIPROS) which is organised in 67 items and 10 sections. CIPROS supports developers to assess requirements of an existing system. It also supports the reporting of patient registry software system descriptions in papers and it can be a first step to create standards for patient registry software systems.

Keywords. Checklist, patient registry software system, technical requirements

Introduction

Patient Registries are essential for medical research, clinical epidemiology, and quality management. The successful implementation and use of a registry depends on a thoroughly and accurate planning and construction of a suitable IT infrastructure. A definition of the registry is needed as well as descriptions how to plan and run the registry. Focus should also be the legal and ethical aspects as well as the strategies of patient recruitment [1]. Müller et al. [2] summarized these points in a checklist for Registries for Health Services Research.

In spite the availability of commercial and open-source software systems, many institutions develop own solutions which fit their needs and they are flexible to address changing requirements. Therefore, guidance is needed to support assessment and selection of an existing, or to plan the development of a new registry software system.

To this end, we developed CIPROS (a **c**hecklist with **i**tems for a **p**atient **r**egistry s**o**ftware **s**ystem) and present it in the style of an explanation and elaboration paper which is inspired by [3]. The checklist is derived from a systematic review of the literature and own experiences in this field [4].

Especially three initiatives with the aim to support clinical research and interoperability in providing adequate software systems and semantic infrastructure

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inspired our work: (1) The caBIG® program from the National Cancer Institute [5] certified existing software systems, according special criteria with bronze, silver, and gold; (2) The recent National Cancer Informatics Program [6] aims to support interoperability in Medical Research in providing open-source code for biomedical informatics software applications and in providing semantic infrastructures; (3) A National Metadata Repository for Clinical Studies and Registries is provided by TMF e.V. [7]. There is also an ongoing project at [7] which defines common requirements for cohorts and registry-IT.

1. Methods

Our Systematic Review identified papers with patient registry software system descriptions. In order to get exhaustive results on papers containing patient registry software system descriptions the following search in Pubmed was applied: *"(registry or registries) AND (eCRF or EDC or CDMS or CTMS or web) AND (software or open-source or open source or Java)"*. This search resulted in 132 findings when performed at 17th of January 2014.

We classified the 132 papers according to their content by reading title and the abstract. A total of 42 (32%) provided a system description or at least a short system description. A total of 23 (17%) were about biological information systems, 23 (17%) were about infrastructures for clinical or other medical systems, 30 (22%) deal with other aspects and had no system description. Eleven papers (9%) were only published as abstract; three papers (3%) were written in languages other than English or German.

A qualitative analysis was performed on the 42 papers containing a system description by searching them for relevant software specific features. We tried to classify the identified software specific features in system components, functional aspects, or design steps. The features come mainly from the more actual papers (published after 2005). Older papers (published before 2005) with system descriptions did not provide essential aspects used for the item creation process.

2. Results

The qualitative analysis elicited 67 different items which are involved in describing registry software systems. Inspired by the caBIG® [5] criteria we created a checklist organized in ten logical system components, functional aspects or design steps which is presented in subsection 2.1.

2.1. Checklist of Items - without Description

1. *Architecture*: System architecture, Platform independence
2. *Development and Training*: Design model, Framework-based design, Questionnaire builder, Usability testing, Performance testing, User manual, User training, User feedback
3. *Interfaces*: *End-user Interfaces*: Web-Interface, Compatibility, Email-alerts, Messaging interface, Online discussion forum, Mobile interface, Patient interface; *Programming interface*: Third-party access, API for inserting data,

API for retrieving data, Data update mechanism; *Interfaces to other systems*: Interface to CIS, Integration of biological data, Extensibility is possible

4. *Interoperability*: Open Source; *Semantics and Standardization*: CRFs, Metadata, Vocabularies, XML Schema
5. *Internationality*: Multilingualism
6. *Data management and data quality*: Pseudonymous patient identifier, CRF is divided in parts, Customizable CRF parts, Minimal and extended dataset, All data types are supported, Special data types are possible, Multiple choice is used, No predefined selection, Data validation components, Data query tool, Interface for manual data check, Manual data queries, Data query flags, Plausibility flags, Insertion of unplanned visits.
7. *Data Analysis*: Query builder for researches, Report generation, Download of datasets, Graphical presentation of results, Risk analysis
8. *Security aspects*: Authorized users, Role-based access, Encrypted data transfer, Encrypted data storage, Audit trail, Master-slave replication, Backup-management, Firewall, Server room.
9. *General Features*: Costs are an argument, several projects simultaneously, Update mechanism, Source documentation in pdf.
10. *Organizational*: Compliance with regulations, Informed Consent, Rights on the data, data protection guidelines.

The following subsection 2.2 represents for the items 4.2 - 4.5 a short Description and the relevant references.

2.2. A Part of the Checklist of Items - with Description

Table 1. A Part of the Checklist of Items to consider when choosing or developing a software system for patient registries.

Aspect / Topic	Item No.	Description	Relevant References
Interoperability	**4**		
…			
Semantics & Standardization			
CRFs	4.2	Standardized CRFs are used whenever possible.	[9], [10]
Metadata	4.3	Ontology-based, standardized metadata are used.	[8], [9]
Vocabularies	4.4	Ontology-based, standardized vocabularies are used.	[8], [9]
XML Schema	4.5	An XML schema definition (XSD) is available for structured data exchange.	[11], [12], [13]

The list of the 42 reference papers used to build the list and the Complete Table with Checklist Items and Description are available from the corresponding author.

For the items 4.2 - 4.5 in Table 1, we describe in the following subsection the item creation process.

2.3. Item Creation Process of some Items

The literature sees standardization as an essential aspect of a registry and points to different aspects of standardization which are summarized in items 4.2 to 4.5 The

seriation of the four items is open to discussion. We chose the proposed order following a time-perspective of data capture, data storage, and exchange of data.
One Requirement of the caBIG® [5] criteria is the use of standardized vocabularies / terminologies and ontologies (as a prerequisite to facilitate cooperation by better data transfer within different registries). Natter et al. [8] describe a shared ontology service in their project which enables communication between different components. In [9] and [10] Sherman et al. describe the use of controlled terminologies and metadata in their registry projects to get the caBIG® Bronze certification. Therefore, we created Items 4.3 and 4.4 for standardized vocabularies and metadata. The standardization of questionnaires is also described and proposed in [9] and [10] we created Item 4.2 for this issue.

Xie et al. describes in [11] the data integration from different previous registries in their new registry using structured data exchange with XML. Messiaen et al. describe in [12] structured data exchange between different Registries with XML. Plotnicki et al. describe this feature also in [13] to allow the data transfer within different organizations and to avoid repeated data entry. We created Item 4.5 to support this important feature.

In the following subsection we present one Item out of the full Example and the Explanation selection.

2.4. Example and Explanation of Item 3.1

Item 3.1 The patient registry software system has a web-interface.
Example:

The CERTAIN web application … supports therefore not only the data entry, presentation, visualization, and export, but also the automatic and manual data validation. These functionalities are active at any time and location, requiring only a common web browser and internet access. [13]
Explanation:

The literature identifies a web-interface for patient registry software systems as the proper way to communicate with distributed users. Web-based data entry is a comfortable and a state of the art way to collect patient data for multi-center registries. All data are immediately available in the database. First quality checks can automatically be performed. The data from all centers are collected in the same way, no specific data-integration with the data from different centers is necessary. No additional software must be installed at the client side. When a software update is necessary, it must only be installed at the server, the clients get a new version when they log in next time.

3. Discussion

The aim of the CIPROS checklist is to provide study coordinators, developers and decision makers with an instrument to evaluate existing systems while checking it by the proposed items. All presented features should be checked for relevance when embarking in the development of a registry project. They also are valuable in choosing an existing system or in developing an own solution. Another aim of our checklist is to provide persons reporting about patient registry software systems an instrument to check and present the features of their system. Like the CONSORT Statement [3],

which improved the reporting of clinical trials by focusing on its relevant aspects, our checklist can help, making the description of a patient registry software system description more transparent. The CIPROS checklist can help to create standards in reporting registry-based medical research, for which is also a need.

Since compared to the literature on clinical studies the literature on registry software systems is not well structured, it may be the case that our systematic review missed some relevant work. However, the list proposed is seen as a starting point to discuss the relevant features of such systems and to develop a more structured presentation of software systems for patient registries.

This checklist is a proposal which considers the actual situation. Maybe in the future other techniques become popular which recommend an update of this checklist.

References

[1] Gliklich RE, Dreyer NA, eds. *Registries for Evaluating Patient Outcomes: A User's Guide, Second Edition.* Rockville, AHRQ Publication No. 10-EHC049, 2010.

[2] Müller D, Augustin M, Banik N, Baumann W, Bestehorn K, Kieschke J, Lefering R, Maier B, Mathis S, Rustenbach SJ, Sauerland S, Semler SC, Stausberg J, Sturm H, Unger C, Neugebauer EAM. Memorandum Register für die Versorgungsforschung. *Das Gesundheitswesen* **72** (2010), 824-839.

[3] Altman DG, Schulz KF, Moher D, Egger M, Davidoff F, Elbourne D, Gøtzsche PC, Lang T; CONSORT GROUP (Consolidated Standards of Reporting Trials). The revised CONSORT statement for reporting randomized trials: explanation and elaboration. *Ann Intern Med.* **134** (2001), 663-694.

[4] Lindörfer D, Müller TH, Integration und Analyse von Patienten mit Chronischer Myeloischer Leukämie (CML) in 25 Europäischen Ländern mit webbasierter elektronischer Datenerfassung. In: Schmücker P, Elsässer K-H, Hayna S (Hrsg.): *Tagungsband der 55. GMDS Jahrestagung 2010,* Mannheim, 2010.

[5] National Cancer Institute. The caBIG program has been retired. Available: https://cabig.nci.nih.gov/. (Accessed, January 13, 2014).

[6] National Cancer Institute. National Cancer Informatics Program. Available: http://cbiit.nci.nih.gov/ncip. (Accessed January 13, 2014).

[7] TMF e.V. Available: http://www.tmf-ev.de/ (Accessed Jan, 23 2014).

[8] Natter MD, Quan J, Ortiz DM, Bousvaros A, Ilowite NT, Inman CJ, Marsolo K, McMurry AJ, Sandborg CI, Schanberg LE, Wallace CA, Warren RW, Weber GM, Mandl KD. An i2b2-based, generalizable, open source, self-scaling chronic disease registry. *J Am Med Inform Assoc.* **20(1)** (2013) 172-179.

[9] Sherman S, Shats O, Fleissner E, Bascom G, Yiee K, Copur M, Crow K, Rooney J, Mateen Z, Ketcham MA, Feng J, Sherman A, Gleason M, Kinarsky L, Silva-Lopez E, Edney J, Reed E, Berger A, Cowan K. Multicenter breast cancer collaborative registry. *Cancer Inform.* **10** (2011), 217-226.

[10] Sherman S, Shats O, Ketcham MA, Anderson MA, Whitcomb DC, Lynch HT, Ghiorzo P, Rubinstein WS, Sasson AR, Grizzle WE, Haynatzki G, Feng J, Sherman A, Kinarsky L, Brand RE. PCCR: Pancreatic Cancer Collaborative Registry. *Cancer Inform.* **10** (2011) 83-91.

[11] Xie F, Zhang D, Wu J, Zhang Y, Yang Q, Sun X, Cheng J, Chen X. Design and implementation of the first nationwide, web-based Chinese Renal Data System (CNRDS). *BMC Med Inform Decis Mak.* 2012, **12**:11.

[12] Messiaen C, Le Mignot L, Rath A, Richard JB, Dufour E, Ben Said M, Jais JP, Verloes A, Le Merrer M, Bodemer C, Baujat G, Gerard-Blanluet M, Bourdon-Lanoy E, Salomon R, Ayme S, Landais P. CEMARA: a Web dynamic application within a N-tier architecture for rare diseases. *Stud Health Technol Inform.* **136 (**2008) 51-56.

[13] Plotnicki L, Kohl CD, Höcker B, Krupka K, Rahmel A, Pape L, Hoyer P, Marks SD, Webb NJ, Söylemezoglu O, Topaloglu R, Szabo AJ, Seeman T, Marlies Cornelissen EA, Knops N, Grenda R, Tönshoff B. The CERTAIN Registry: a novel, web-based registry and research platform for pediatric renal transplantation in Europe. *Transplant Proc.* **45** (2013), 1414-1417.

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Towards a semantic PACS: Using Semantic Web technology to represent imaging data

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Abstract. The DICOM standard is ubiquitous within medicine. However, improved DICOM semantics would significantly enhance search operations. Furthermore, databases of current PACS systems are not flexible enough for the demands within image analysis research. In this paper, we investigated if we can use Semantic Web technology, to store and represent metadata of DICOM image files, as well as linking additional computational results to image metadata. Therefore, we developed a proof of concept containing two applications: one to store commonly used DICOM metadata in an RDF repository, and one to calculate imaging biomarkers based on DICOM images, and store the biomarker values in an RDF repository. This enabled us to search for all patients with a gross tumor volume calculated to be larger than 50 cc. We have shown that we can successfully store the DICOM metadata in an RDF repository and are refining our proof of concept with regards to volume naming, value representation, and the applications themselves.

Keywords. DICOM, Semantic Web, knowledge representation, semantic interoperability, SPARQL, Imaging

Introduction

The DICOM standard [1] is ubiquitous within medicine, especially in diagnostic-related departments (e.g. radiology, radiation therapy or nuclear medicine). The standard fulfils a twofold function, describing the image (meta)data using a key-value pair system (often called DICOM *tags*), and also as a communication protocol for transmitting this kind of data.

Over the years, the DICOM standard has added support for imaging modalities and steadily more metadata. One of these metadata features is the referencing structure based on unique identifiers (UIDs) to indicate relations between modalities, for instance, to state that a PET-CT image contains two separate image series that were scanned at the same time. Within radiotherapy, the DICOM standard is extended to record the tumor delineations of a physician (an RTSTRUCT), or to define the actual radiation treatment plan (RTPLAN) including dosimetry information (RTDOSE).

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The relationships between RTSTRUCT, RTDOSE, and RTPLAN are unidirectional: RTSTRUCT refers to CT/PET/MRI, RTPLAN refers to RTSTRUCT, and RTDOSE refers to RTPLAN. This directionality leads to difficulties when traversing the DICOM modalities, especially in the opposite direction. For example, if a user has a CT scan, and wants to retrieve the radiation treatment plan (RTPLAN), he has to search for the RTSTRUCT object based on the specific CT scan, and from there search for the RTPLAN object based on the RTSTRUCT object. This is an inefficient operation because all RTSTRUCT files, and all RTPLAN files for the patient need to be processed to find the correct treatment plan.

Another issue is related to imaging biomarkers. Imaging biomarkers are essential to developing prognostic and predictive models for radiotherapy [2,3]. As this field is evolving rapidly, we need a flexible solution that can be easily extended with new features in order to store biomarkers. We need to store imaging biomarkers while maintaining a link between the biomarker and the images/modalities from which the biomarker was calculated [4]. A direct link between image and biomarker can be established based on the UID of the DICOM file(s). However, additional metadata of the image should then be processed before storage, which is not common practice in a picture archiving and communication system (PACS).

To address the issues described above, we need a flexible storage solution for (additional) metadata, while still being able to define a formal structure to represent data already available in the DICOM standard. One of these flexible storage solutions, different from traditional databases is based on the Semantic Web technology [5]. Our definition of the Semantic Web is that it uses linked data and standardized terminologies (ontologies), therefore making it possible for everyone to contribute to a web of knowledge [6]. This linked data can be stored in a Resource Description Framework (RDF) repository, which can be viewed as a single table with three columns (subject, predicate and object) and where every row is called a triple. When we unify the object of a triple with its equal in another triple's subject, we build a graph of the data. This RDF repository can be queried using a specific query language: SPARQL (SPARQL Protocol and RDF Query Language), which performs pattern matching on the available graph of data [7].

In this study, we hypothesize that we can use Semantic Web technology to store and represent metadata of DICOM image files and additional computational results linked to the image metadata.

1. Methods

To test our hypothesis, we separated the actions into three different tasks. The first task addressed the storage and representation of DICOM metadata in an RDF repository. The second task targeted the storage of additional computational results, related to the images. The third task was to implement a proof of concept.

1.1. Storage and representation of DICOM metadata

To store the data in an RDF repository (and make it accessible via a SPARQL endpoint), we first developed an ontology representing the most common DICOM metadata elements. This ontology serves as a definition of our data domain, and as a contract regarding the structure and data elements if anyone wants to contribute or

query our data [8]. Our ontology can be found at the NCBO Bioportal [9] ontology browser as "Semantic DICOM Ontology" [10]. Although the ontology is still under development, the basic concepts/structure is stable, as it is based on the DICOM standard itself.

This ontology is used by our Semantic DICOM (SeDI) conversion service. This service is written in Java, using the dcm4che library [11]. For every DICOM file, the application will check whether specific tags defined in the ontology are present in the DICOM file, and creates RDF triples based on the rules defined in the ontology. As our conversion service keeps the basic ontological rules (e.g. regarding domain and range) in mind, the data representation will follow our ontological structure. After creating RDF triples, the triples are exposed via a SPARQL endpoint.

1.2. Storage of additional computation results

To calculate additional imaging biomarkers, we developed a pipeline application, which also accepts data using the DICOM communication protocol and uses a plug-in architecture for different computational modules. This pipeline application is developed in Java using the dcm4che [11] and Spring Dependency Injection [12] libraries.

Computational modules can be developed outside the direct scope of our pipeline application as with an API for calculation modules, every type of calculation can be plugged into the pipeline (when wrapped with Java code). This enhances the flexibility to add computations when needed.

Afterwards the results can be exported to different types of storage, including an RDF repository. When using the RDF export module (which triggers a SPARQL update/insert query) the application tries to execute a pre-defined query (containing placeholders for calculated values) on a given RDF repository, and can insert/update triples. Users can create their own insert/update query and are not bound to a specific ontology, which leaves room for end-users to commit the results to the ontology of their choice.

1.3. Proof of concept: query patients and their tumor volume

To test our hypothesis, we implemented a proof of concept setup (Figure 1) where the results of two systems were stored in separate RDF repositories (Figure 1). We used 10 randomly selected patients form our PACS (with different tumor locations) which were sent to both the SeDI conversion service, and the computation pipeline. Both of the applications and triple stores resided on computers in different countries.

To structure the output of our computational pipeline, we used the Radiation Oncology Ontology (under development), which is able to extend the Semantic DICOM ontology for the radiotherapy domain. For our hypothesis test, we linked our calculation output to the identification of the delineated volume of interest (representing the gross tumor volume), stored in the RDF repository of the SeDI conversion service.

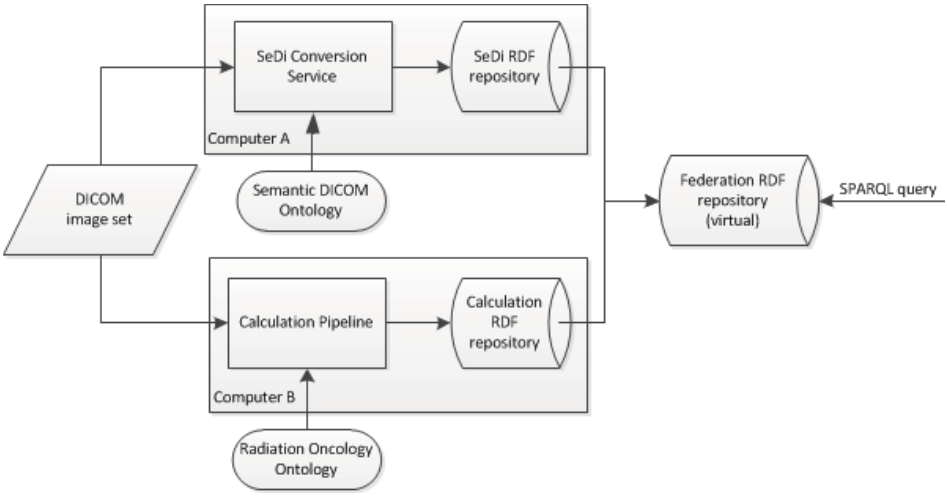


Figure 1. Setup proof of concept

2. Results

We successfully parsed the DICOM tags specified in the ontology and stored the resulting triples in our RDF repository. The created concepts were structured according to the DICOM hierarchy of patients, studies, series and images, as specified in the SeDI ontology.

For 6 out of 10 patients, our computation pipeline could calculate the gross tumor volume. 4 out of 10 patients resulted in no calculation result, because the gross tumor volume was not named correctly using our local clinical standard for volume descriptions.

When performing a query on the federated endpoint for patients with a tumor volume larger than 50 cc, 5 patients were returned. When querying for all patients and tumor volumes, the query resulted in all 6 patients, where one patient had a volume of 2 cc, and was therefore not returned in our primary query results.

3. Discussion

We successfully implemented a proof of concept to store the semantics of imaging data important to biomarker research, and were able to use it to retrieve data which was more extensive and enriched in comparison to information available in a PACS database. Therefore, our results confirmed our hypothesis.

The storage of DICOM information in an RDF repository has an advantage over generic solutions where PACS databases store the entire (or very small parts of the) header. Such PACS relational databases are less flexible in changing data structures (and data), where the Semantic Web technology is more flexible in nature. For instance, within an RDF repository, adding extra information at a later point in time does not alter or change the existing data. Furthermore, it creates the possibility for everyone to link their own additional findings to the already available datasets. Therefore, we

expect that the Semantic Web technology will provide a more suitable framework for research purposes, where questions regarding data (and/or calculated features) are still changing. Such a framework can increase the possibilities for data mining, especially when resources are linked to eCRF or EHR data stored in other RDF repositories which are accessible as linked data and through SPARQL endpoints.

We still plan to address several issues. At first, 4 out of 10 patients did not have a proper name describing the gross tumor volume (within the DICOM metadata). This description is a free-text field in many delineation applications; therefore we cannot expect that delineation descriptions are always correct. We need a proper (ontological) mapping to determine relevant delineation descriptions. The RTOG made a first attempt to standardize delineation naming [13], however it would take several years to reach compliance to this standard. Second, we have created two different applications, which operate without coordination. In future work, we plan to implement a messaging system where the SeDI conversion service will notify the computation pipeline that the DICOM metadata has been stored in a RDF repository, and that computation on this image set can start. Third, although we are able to store the data in an RDF repository, we have not made use of the Value Representation (VR) types available in the DICOM metadata. Currently, all values are stored as text, instead of using the Value Representation (VR) type. This will be solved in our ontology, and incorporated into our SeDI conversion service.

We have shown that a semantic representation of DICOM related information enables us to query for image features that are important to biomarkers in radiotherapy. Our work towards a semantic PACS for radiotherapy can eventually be generalized to store and retrieve images using the semantics of other domains.

References

[1] The National Electrical Manufacturers Association, Digital Imaging and Communications in Medicine (DICOM), NEMA Publications, PS3.1-PS3.12, 2011.
[2] A.P. Abernethy, L.M. Etheredge, P.A. Ganz, P. Wallace, R.R. German, C. Neti, et al., Rapid-learning system for cancer care, J. Clin. Oncol. Off. J. Am. Soc. Clin. Oncol. 28 (2010) 4268–4274.
[3] P. Lambin, E. Roelofs, B. Reymen, E.R. Velazquez, J. Buijsen, C.M.L. Zegers, et al., Rapid Learning health care in oncology – An approach towards decision support systems enabling customised radiotherapy, Radiother. Oncol. (2013).
[4] M.A. Levy, J.B. Freymann, J.S. Kirby, A. Fedorov, F.M. Fennessy, S.A. Eschrich, et al., Informatics methods to enable sharing of quantitative imaging research data, Magn. Reson. Imaging. 30 (2012) 1249–1256.
[5] T. Berners-Lee, J. Hendler, O. Lassila, The semantic web, Sci. Am. 284 (2001) 28–37.
[6] T. Berners-Lee, Linked data-the story so far, Int. J. Semantic Web Inf. Syst. 5 (2009) 1–22.
[7] D. Allemang, Semantic Web for the working ontologist effective modeling in RDFS and OWL, Morgan Kaufmann/Elsevier, Waltham, MA, 2011.
[8] N.F. de Keizer, A. Abu-Hanna, J.H. Zwetsloot-Schonk, Understanding terminological systems. I: Terminology and typology, Methods Inf. Med. 39 (2000) 16–21.
[9] D.L. Rubin, D.A. Moreira, P. Kanjamala, M.A. Musen, BioPortal: A Web Portal to Biomedical Ontologies., in: AAAI Spring Symp. Symbiotic Relatsh. Semantic Web Knowl. Eng., 2008: pp. 74–77.
[10] D. Grittner, J. van Soest, T. Lustberg, M.S. Marshall, P. Feltens, A. Dekker, Semantic DICOM Ontology, http://bioportal.bioontology.org/ontologies/SEDI. (2014).
[11] dcm4che, http://www.dcm4che.org/. (2014).
[12] Spring Framework, Http://spring.io/. (2014).
[13] L. Santanam, C. Hurkmans, S. Mutic, C. van Vliet-Vroegindeweij, S. Brame, W. Straube, et al., Standardizing Naming Conventions in Radiation Oncology, Int. J. Radiat. Oncol. 83 (2012) 1344–1349.

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EHR-based disease registries to support integrated care in a health neighbourhood: an ontology-based methodology

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Abstract. Disease registries derived from Electronic Health Records (EHRs) are widely used for chronic disease management. We approached registries from the perspective of integrated care in a health neighbourhood, considering data quality issues such as semantic interoperability (consistency), accuracy, completeness and duplication. Our proposition is that a realist ontological approach is required to accurately identify patients in an EHR or data repository, assess data quality and fitness for use by the multidisciplinary integrated care team. We report on this approach with routinely collected data in a practice based research network in Australia.

Keywords. EHR, patient registries, data quality, routinely collected data, data repository, health neighbourhood, integrated care

Introduction

Disease registries derived from Electronic Health Records (EHR) are widely used for chronic disease management (CDM). However, not enough is known about the quality of EHR-based registers in the UK [1] and Australia [2]; even less is known about whether they improved CDM, patient safety or quality outcomes. Usually created through "blackbox" extraction tools, increasing use of registries for clinical care can increase the likelihood and scope of data errors and adverse events [2]. The design and development of EHR-based disease registries is not transparent [3] and aspects of their quality have been examined in the UK [4] and Australia [5]. Our proposition [6] is that a realist [7] and ontological [8] approach is required to systematically and accurately identify patients in an EHR or data repository [9], and assess/manage data quality and fitness for use by the multidisciplinary care or research team [5].

The realist approach to this evolving yet complex domain includes: **1. Context (**i.e. CDM, integrated care, evidence based practice); **2. Mechanisms** (i.e. methods to assess/manage data quality (DQ) and support data, knowledge, clinical and interdisciplinary integration); and **3. Impacts/outcomes** (i.e. DQ and fitness for use of disease registries, and, over the long term, safety and quality of integrated care).

The ontological approach includes the collection of formal, machine-processable and human-interpretable representations of the entities and their relations within a defined domain [10]. A formal ontological model of the domain data and metadata can specify a unified context, enabling intelligent software agents to act in spite of

differences in concepts and terminology from different EHRs. By incorporating defined rules, ontologies can generate logical inferences and control the inclusion/exclusion of relevant objects, such as the patient with a diagnosis of diabetes mellitus (DM) Reason For Visit (RFV), pathology (Path) tests, medication (Rx), or cycle of care service payments [10]. We have summarized this realist ontological approach to automated assessment/management of the quality of routinely collected data, relevant concepts and their relationships in integrated care [11].

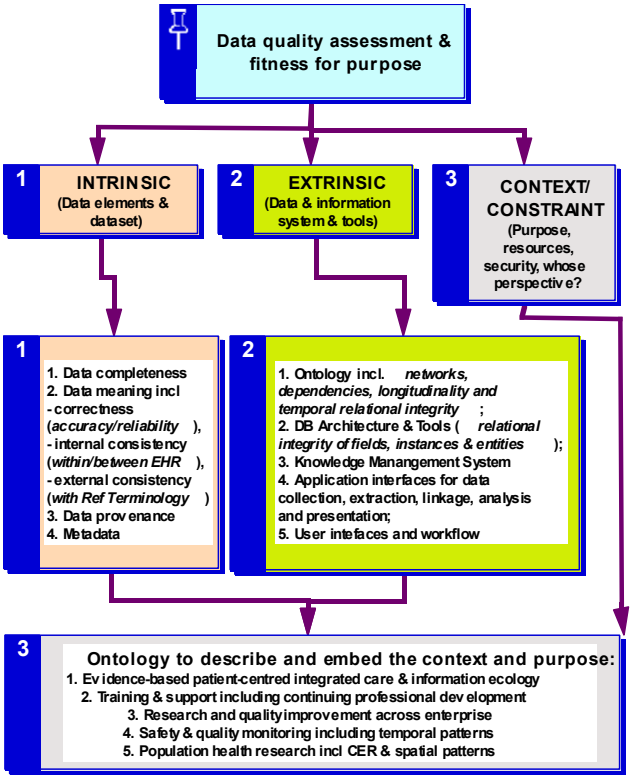


Figure 1. Data quality & fitness for purpose framework.

The International Standards Organisation (ISO) defined data quality (DQ) as: "*the totality of features & characteristics of an entity that bears on its ability to satisfy stated and implied needs*" (ISO 8402-1986, Quality Vocabulary). Fitness for purpose (FFP) is a multidimensional concept with intrinsic components and extrinsic associations to meet benchmark [12]. The literature [11], guided the development of a conceptual framework for DQ and FFP (Figure 1), with intrinsic, extrinsic and contextual dimensions. Intrinsic concepts cover the data elements and dataset, including the metadata, semantics (data meaning), provenance (who authored, where, when?) and constraints to the data meanings. Extrinsic concepts cover the information system, including concept representation, ontology, temporal relationships system architecture and user interface. Contextual determinants include the objectives of stakeholders such as the integrated care practitioner/team, resource constraints, security requirements and legislation.

Data elements are assessed intrinsically in terms of consistency, correctness; data sets in terms of completeness and duplicate records [6]. We are developing ontology-based tools to assess the information required to support integrated care in terms of relational, historical and temporal integrity between concepts. Contextual determinants constrain and guide clinical and organizational strategies to improve DQ as well as unify different concepts and terminology from different EHRs. The formal process of ontology development includes knowledge acquisition, conceptualisation, semantic modelling, knowledge representation and validation [13]. A layered approach [14] is used to incorporate clinical guidelines and rule-based modules. This paper discusses

the realist ontological approach to developing automated, valid and reliable methods to define *T2DM cases*, manage DQ and determine fitness for purpose.

1. Methods

Setting: The UNSW electronic Practice Based Research Network (ePBRN) pilot group of 4 general practices (N=64,770 patients) has validated tools, data, and management and governance protocols. Internal validation included regular data and metadata checks, including probabilistic matching to assess the extent of duplicate patients and patients shared within the local health neighbourhood of hospital, community health, general practice and other primary care services. External validation involved comparisons with other tools [4]. The overall aim is to transition from traditional SQL and schematic relational database management of "big data" to use of ontologies and semantic tools with minimally-relational databases using.

DM ontology for case-finding: Defined rules were used to generate logical inferences and control the inclusion/exclusion of patients with a DM RFV; DM Pathology (Path) such as HbA1C, glucose tolerance test; DM medication (Rx) or glucose testing scripts, or a DM cycle of care item in the Medicare Benefit Schedule (MBS). Duplicate records/patients within and across EHRs were excluded.

DQ ontology: The conceptualization and specification of the DQ ontology (Figure 1) included core dimensions such as accuracy, completeness, correctness, consistency and timeliness [6], duplicate records (to account for aggregating multiple EHRs), temporal pattern (to account for the constantly changing clinical "big data") and timeliness which is important in integrated care. Validation of the conceptualization included discussions with practitioners and consumers of health care.

Formalisation: Tools used included a popular open source ontology editor and knowledgebase framework (Protégé, http://protege.stanford.edu/); reference terminology (SNOMED-CT-Au); representation languages (Web Ontology Language (OWL) http://www.w3.org/TR/owl-features/), XML and RDF (Resource Description Framework)); query languages (SPARQL Protocol and RDF Query Language); rules languages (Semantic Web Rule Language (SWRL)); logic ontology reasoners to provide automated support for reasoning tasks in ontology and instance checking through -ontopPro- (http://ontop.inf.unibz.it/), an ontology based data access (OBDA) application [15]. Patient data, associated with instances of ontology classes or properties, were populated through -ontopPro-. The knowledge component of the infrastructure, relating to defined conceptual terminologies, was built using SNOMED CT-AU and OWL. The RDF schema is mapped to logics to support formal semantics and reasoning [16], which describes precisely the meaning of specific knowledge to minimise subjective intuitions and different interpretations by different actors or machines [14].

Implementation used Microsoft SQL Server and Transact-SQL™ to link server objects with heterogeneous datasets from multiple EHRs [16]. A manual validation of the results of the SQL queries was conducted with the smallest participating ePBRN practice (Practice 1).

2. Results

Ontological approach to find cases for a diabetes registry: A lower than expected T2DM prevalence rate of 2.8% was found. Table 1 shows the effect of data completeness of relevant indicators (RFV, Rx, Path) on the accuracy of identification. The ontological (1.1-5.7% across practices) was more sensitive than the single factor (0.2-4.8%) approach, compensating for individual data incompleteness and inconsistency. Data quality is therefore a significant factor. The denominator was also important as patients may not be accurately flagged as active and inactive in the EHRs.

Table 1. T2DM cases by Reason for Visit (RFV), Medication (Rx), Pathology (Path) and ontology approach

Attributes studied	**Practice1 (N=3 863)**	**Practice2 (N=7 028)**	**Practice3 (N=2 3,162)**	**Practice4 (N=3 0,717)**	**All practices (N=6 4,770)**
Data Completeness of :	**All (DM only)**	**All (DM only)**	**All (DM only)**	**All (DM only)**	**All (DM only)**
All RFV (All DM RFV)	95% (4.3%)	87% (5.7%)	92% (4.9%)	99% (6.5%)	95% (5.8%)
All Rx (All DM Rx)	80% (2.4%)	94% (8.4%)	96% (5.4%)	96% (6.6%)	95% (6.4%)
All Path (All DM Path)	16% (0.8%)	61% (8.0%)	63% (1.3%)	66% (1.5%)	62% 2.4%)
All 3 (RFV+Rx+Path)	82%	90%	90%	92%	90%
T2DM identified by:	**N (%)**	**N (%)**	**N (%)**	**N (%)**	**N (%)**
T2DM RFV	37 (0.9)	231 (3.3)	387 (1.4)	787 (2.6)	1,442 (2.2)
T2DM Rx	19 (0.5)	332 (4.7)	446 (1.9)	803 (2.6)	1,600 (2.5)
T2DM Path	8 (0.2)	334 (4.8)	468 (2.0)	809 (2.6)	1,619 (2.5)
T2DM ontology	43 (1.1)	403 (5.7)	602 (2.5)	1,042 (3.4)	2,090 (3.2)

Duplication and other dimensions of data quality: Up to 13% patient records matched across the participating EHRs, suggesting that DQ assessment should include the extent of duplication of data across the health neighbourhood and within practices, where there can be up to 3% duplication. This has implications for clinical use of EHR data in integrated and shared care as well as secondary uses for research, population health and policy guidance.

Specifying and formalising the ontological approach: The formal specification of the ontologies developed is available as Protégé files. The ontology was validated in Practice 1, using –ontopPro- to map to the relational database and implement the built-in reasoners. This technical aspect is the subject of another paper, which will also compare the utility and validity of SQL-based schematic and inductive versus ontology-based semantic approaches and tools.

3. Discussion

Ontologies deal with reality (*being*) and the transformation (*becoming*) of concepts as they interact with one another over time. The ePBRN research confirmed the need for a realist and ontological approach to the quality of routinely collected data in EHRs and EHR-based disease registries - to understand what is being done in what context and with what impact. This is important, given that the processes and knowledge base are continually evolving and require ongoing monitoring, evaluation and reflection. The research and development must be grounded in the real world of health practice, where data is noisy and continually changing and the DQ is variable. DQ management of

information from multiple EHRs to support integrated care and population health must exclude duplicated records.

An ontological approach to the creation of patient registries from EHRs is essential to optimise accuracy (10). The quality of the disease registry is only as good as the EHR from which it is created. Improved DQ require integrated and ecological approaches to the governance and provenance of DQ across the data cycle from collection to management to display and secondary use in other applications such as electronic decision support [17]. The quality of electronic data collected as part of routine clinical practice is determined by more than just the GIGO – garbage in garbage out - principle. Data models are influenced by the database management system, security and access management software, processes for data collection and management, and the people who enter and use data [4].

The validated ontologies and software tools will support automated methods to extract, link and manage data as well as assess/manage the data quality and semantic interoperability challenges in various semantic contexts in collaborative "big clinical data" environments. The challenges are surmountable and strategies sustainable.

References

[1] de Lusignan S, Sadek N, Mulnier H, Tahir A, Russell-Jones D, Khunti K. Miscoding, misclassification and misdiagnosis of diabetes in primary care. Diabet Med. 2012 Feb; 29(2): 181-9.

[2] Liaw S, Taggart J, Yu H, de Lusignan S. Data extraction from electronic health records – existing tools may be unreliable and potentially unsafe. Aust Fam Physician. 2013; 42(11): 820-3.

[3] Mehta A. The how (and why) of disease registers. Early Human Development. 2010;86(11):723-8.

[4] Martin D, Wright J. Disease prevalence in the English population: a comparison of primary care registers and prevalence models. Soc Sci & Med 2009; 68(2): 266-74.

[5] Liaw S, Taggart J, Dennis S, Yeo A. Data quality and fitness for purpose of routinely collected data – a case study from an ePBRN. AMIA Annual Symposium 2011; Washington DC: Springer Verlag; 2011.

[6] Liyanage H, Liaw S, Kuziemsky C, de Lusignan S. Ontologies to improve chronic disease management research and quality improvement studies – a conceptual framework. In: Aronsky D, Leong S, editors. Medinfo 2013; Copenhagen: Elsevier Press; 2013.

[7] Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review - a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy. 2005;10(Suppl 1):21-34.

[8] Gruber TR. Toward principles for the design of ontologies used for knowledge sharing. Int J Human-Comput Stud. 1995;43(5-6).

[9] de Lusignan S, Liaw S, Michalakidis G, Jones S. Defining data sets and creating data dictionaries for quality improvement and research in chronic disease using routinely collected data: an ontology driven approach BCS Informatics in Primary Care. 2011;19(3):127-34(8).

[10] Rubin D, Lewis S, Mungall C, et al. National Center for Biomedical Ontology: advancing biomedicine through structured organization of scientific knowledge. OMICS (Summer). 2006; 10(2): 185-98.

[11] Liaw S, Rahimi A, Ray P, et al. Towards an ontology for data quality in integrated chronic disease: a realist review of the literature. Int J Med Inform 2013; 82(1): 10–24.

[12] Wang RY. A product perspective on total data quality management. Communications of the ACM. 1998; 41(2):58-65.

[13] Kuziemsky C, Lau F. A four stage approach for ontology-based health information system design. Artificial Intelligence in Medicine 2010; 50: 18.

[14] Chalortham N, Buranarach M, Supnithi T. Ontology Development for T2DM Clinical Support System 2009 3 March 2011. URL: http://text.hlt.nectec.or.th/ontology/sites/default/files/CRdm2css_0.pdf.

[15] Rodríguez-Muro M, Calvanese D. Quest, a System for Ontology Based Data Access. KRDB Research Centre for Knowledge and Data, Free University of Bozen-Bolzano, 2012.

[16] Yu H, Liaw S, Taggart J, Rahimi A. Using Ontologies to Identify Patients with Diabetes in EHRs. Int Semantic Web Conference 2013; Sydney Australia: Springer-Verlag Berlin Heidelberg.

[17] de Lusignan S, Liaw S, Krause P, et al. Key concepts to assess the readiness of data for International research: Data quality, lineage and provenance, extraction and processing errors, traceability, and curation. IMIA Yearbook of Medical Informatics. 2011: 112-21

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Web-Based Training: Readiness and Perceptions of Nurses

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Abstract: This study was conducted as a descriptive study in order to determine the views of nurses working a university hospital on web-based training. Population consisted of all the nurses working in the hospital. It was found out that nurses use computer at the moderate level (46.5 %), they benefit from Internet at a good level (46.5 %), almost all of them use Internet to make searches about professional issues (94.6%), they want to update their professional knowledge (90.1%) and they find it difficult to reach information on such grounds as time constraint (81.1 %) and lack of appropriate environment (62.1 %) and they want to receive a web-based training (87.1 %). It is important that web-based training programmes be generalised in the field of nursing where there exists a time problem, studies as regards to how to integrate these programmes into continuing education be increased and their results be reflected on the practices.

Keywords: web based training, distance education, nurse

Introduction

Web-based training (WBT) programmes which have become widespread in the health care education have greatly contributed to the professional development of nurses who constitute an integral part of the healthcare system [1,2]. The relevant literature [3,4,5] puts forward that WBT is an interactive training model which does not have time and space constraints, can be customised, provides reliable information and contributes to the development of clinical knowledge and skills of nurses. It is important that WBT programmes forming a part of distance education be developed to create high quality learning environments for the nursing students, graduates and professionals [5,6]. In this respect, the aim of the present study is to determine the background knowledge and views of the nurses working in the University Hospital as regards to the WBT.

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1. Methods

Data used in the research consisted of the data obtained at the first phase of the master's thesis. It was a descriptive research where the population consisted of the nurses (N=250) working in a university hospital. A total of 202 nurses participated in the research. Ethical approval was received from the ethics board of the university while the essential legal permission was received from the university hospital. SPSS-11 (Statistical Package for the Social Sciences) statistical package program was used in the assessment of the data.

2. Results

2.1. Characteristics of Nurses in relation to the Use of Computer and Internet

When the characteristics of nurses in relation to the use of computer and internet are examined, it is seen that more than half of the nurses (68.3 %) received training on the use of computer. When the nurses were asked to classify their levels of using computer, 46.5 % of them classified their levels as "moderate" while 46.5 % of them identified their levels as "good" when they were asked to identify their levels of benefiting from the internet. Almost all of the nurses (94.6 %) expressed that they use internet for making searches about professional matters.

2.2. Views as regards to Updating the Professional Knowledge

Almost nurses (90.1 %) expressed that they want to update their professional knowledge and need updating their professional knowledge mostly in the field of diseases-medical diagnoses (39.2 %). Nurses' have difficulty in access to information and (46.5 %) this difficulty mostly results from time constraints (81.1 %) and lack of appropriate environment (62.1 %). However, 98 % of the nurses reach the information they need through internet (Table 1).

Table 1: Characteristics of Nurses in relation to Access to Professional Information

CHARACTERISTICS	n	%
Those having difficulty in access to information*	**94**	**46.5**
Time constraint	77	81.1
Lack of appropriate environment	59	62.1
Lack of source book	36	37.9
Economic obstacles	20	21.1
Those not having difficulty in access to information	**108**	**53.3**
Methods of access to information *		
Searching through the internet	198	98
Asking the colleague	132	65.3
Consulting a physician	118	58.4
Reading the relevant literature	109	54

* As more than one answer were given to this question, the value of "n" rose.

2.3. Views concerning the WBT

The majority of the nurses (87.1 %) were found to be eager to receive WBT. On the other hand, 26.9 % of the nurses found it unnecessary to receive WBT.

Table 2: Views of the Nurses in relation to WBT

VIEWS	n	%
Those who want to receive WBT*	**176**	**87.1**
It ensures easy and fast access to professional information wherever you want.	53	41.7
It helps repeating and renewing the information as well as personal development.	52	40.9
Nurses are in need of WBT	15	11.8
It contributes nursing.	15	11.8
No answer.	75	37.1
Those who do not want to receive WBT*	**26**	**12.9**
Finding it unnecessary	7	26.9
Time constraint	6	23.1
Preferring face-to-face communication	4	15.4
Believing to have the necessary knowledge	2	7.7
No answer.	7	29.9

* As more than one answer were given to this question, the value of "n" rose.

3. Discussion

3.1. Characteristics of the Nurses in relation to the Use of Computer and Internet

Rapid developments in the field of knowledge and information have also affected health care systems and this has necessitated the health care professionals to be able to reach the reliable information in a fast manner [7]. In turn, the use of computer and internet has become an inevitable requirement to meet this need [4,5,6]. Thus, the nurses' statuses of using computer and internet were assessed in this study.

According to the literature, computer skills of nurses and their experiences in the use of computer affect their attitudes towards the use of computer in a positive manner [9,10]. The fact that the nurses participating in our research have a sound background in terms of the use of computer may ensure that they display a positive attitude towards the relevant trainings. Besides, the fact that nurses use internet mostly to acquire professional knowledge is a positive result for the WBT system as it increases the rate of using internet among nurses.

3.2.Views as regards to Updating the Professional Knowledge

Nurses should constantly improve and update their knowledge and skills to achieve the desired clinical competence level [11]. Nurses participating in this research expressed as well that they need to renew their professional knowledge. They stated that they need to renew their knowledge mainly in the field of diseases-medical diagnoses. In this respect, WBT technologies are assessed as an opportunity.

It is emphasized that nurses should renew their knowledge by using the clinical guidelines in order to be able to fulfil their responsibilities in the clinic and they need to use internet so as to be able to follow these guidelines. As ineffective use of resources in access to information will lead to false retrieval, effective use of internet is supported. In a relevant study, it was reported that the difficulties experienced by the nurses in access to information resulted from the inadequacy in reviewing the literature [12]. As to the present study, almost half of the nurses expressed that they have difficulty on such grounds as time constraint and lack of appropriate environment. These results imply that the use of WBT programs within the scope of the continuing education in nursing where time- and space-related problems are experienced may be effective in solving the problems reported by the nurses participating in this research.

3.3. Views concerning WBT

As the continuing education gains more importance increasingly throughout the world, more flexible education opportunities have been needed. This necessity has been accompanied by political and technological developments as well [13]. Thus, the use of information technologies and online learning environments in the nursing education has become a new trend and gained popularity [14,15].

The participants of our study expressed that they would prefer WBT model Similar results had been obtained in the previous studies where the views of the nurses who had received WBT about this training model were examined. For instance, the study conducted by Liang and Wu [14] reported that nurses had positive attitudes towards this training model. In the study carried out by Haggstrom et al. [16], nurses were reported to find the web-based course highly useful and fruitful in terms of their theoretical and professional developments. Nurses also expressed that their analytical skills improved. Yamagishi et al. [17] detected that the WBT that the nurses were provided with made a significant increase in their levels of knowledge and assertiveness. Korhonen and Lammintakanen [18] reported in their studies that WBT program improved health care skills. In the research conducted by Schmitt et al. [19], nurses who were provided with a WBT expressed that WBT system was easier than the conventional education system although the course lasted for a long time and they had difficulty in reaching some information at home.

As a consequence, we can say that nurses are ready for this training model considering their skills in relation to the use of computer and internet, willingness to update their knowledge and moderate attitudes towards WBT. It can be recommended for the field of nursing where the time-related problems are intensely experienced that WBT programs are extended, the studies as regards to how to integrate this training model into the continuing education are increased and their results are reflected on the practices.

References

[1] Atack L, Becoming a web-based learner; registered nurses' experiences. *Journal of Advanced Nursing*, 44(3) (2003), 289-297.

[2] Atack L, Rankin J, A descriptive study of registered nurses_ experiences with web-based learning. *Journal of Advanced Nursing* 40 (2002), 457–465.

[3] Abbey B, *Instructional and Cognitive Impacts of Web Based Education*. Idea Group Publishing, USA, 2000.

[4] Montgomery KS, Fitzpatrick JJ, *Essentials of Internet Use in Nursing*, Springer Publishing Company, New York, 2002.
[5] O'Neil CA, Fisher CA, Newbold SK, *Devoloping Online Learning Environments in Nursing Education*, Springer Publishing Company, New York, 2009.
[6] Hedger A, Legal and ethical issues and trends web-based education in graduate nursing programs. *Clinical Scholars* 1(2) (2008), 121-124.
[7] Cobb S.C, Comparison of oncology nurse and physician use of the internet for continuing education. *The Journal of Continuing Education in Nursing*, 34(4) (2003), 184-188.
[8] Manjon BF, Perez JMS, Pulido JAG, Rodriguez MAV, Rodriguez JB, *Computers and Education*, Springer Publishing Company, New York, 2007.
[9] Koivunen M, Va¨lima¨ ki M, Koskinen A, Staggers N, Katajisto J, The impact of individual factors on healthcare staff"s computer use in psychiatric hospitals. *Journal of Clinical Nursing*, 18 (2008), 1141–1150
[10] Alquraini H, Alhashem AM, Shah MA, Chowdhury RI, Factors influencing nurses' attitudes towards the use of computerized health information systems in Kuwaiti hospitals. *Journal of Advanced Nursing* 57(4) (2007), 375–381.
[11] Munro K.M, Continuing professional development and the charity paradigm: Interrelated individual, collective and organizational issues about continuing Professional development. *Nurse Education Today*, 28(2008), 953–961.
[12] Verhoeven F, Steehouder MF, Hendrix RMG, Van Gemert-Pijnen JEWC, How nurses seek and evaluate clinical guidelines on the Internet. *Journal of Advanced Nursing*, 66(1) (2010), 114–127.
[13] Kenny A, Online learning: enhancing nurse education?. *Journal of Advanced Nursing*, 33(2) (2002), 127–135
[14] Liang JY, Wu SK, Nurses' motivations for Web-based learning and the role of Internet self-efficacy. *Innovations in Education and Teaching International* 47(1) (2010), 25–37.
[15] Wilkinson A, Forbes A, Bloomfield J, Gee CF, An exploration of four web based open and flexible learning modules in post-registration nurse education. *International. Journal of Nursing Studies*, 41(2004), 411–424.
[16] Hasggstrom E, Hofsen A, Wadensten B, Nurses' opinions about a web-based distance course in a specialist education programme for the care of older people: a questionnaire study. *International Journal of Older People Nursing* 4 (2009), 177–184.
[17] Yamagishi M, Kobayashı T, Kobayashı T, Nagami M, Shimazu A, Kageyama T, Effect of web-based assertion training for stress management of Japanese nurses. *Journal of Nursing Management*, 15(2007), 603–607
[18] Korhonen T, Lammintakanen J, Web-based learning in professional development: experiences of Finnish nurse managers. *Journal of Nursing Management*,13 (2005), 500–507.
[19] Schmitt BM, Titler MG, Herr KA, Ardery G, Challenges of web-based education in educating nurses about evidence-based acute pain management practices for older adults. *The Journal of Continuing Education in Nursing,* 35(3) (2004), 121-127 .

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Information Model for Learning Nursing Terminology

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Abstract. Standardized terminologies are introduced in healthcare with the intention of improving information quality, which is important for enhancing the quality of healthcare itself. The International Classification for Nursing Practice (ICNP®) is a unified language system that presents an ontology for nursing terminology; it is meant for documentation of nursing diagnoses, nursing interventions and patient outcomes. This paper presents an information model and an application for teaching nursing students how to use ICNP to assist in the planning of nursing care. The model is an integration of ICNP and our catalog ontology, patient journal ontology, and ontology defining task sets. The application for learning nursing terminology offers descriptions of patient situations and then prompts the student to supply nursing statements for diagnoses, goals and interventions. The nursing statements may be selected from catalogues containing premade solutions based on ICNP, or they may be constructed directly by selecting terms from ICNP.

Keywords. Healthcare terminology, International Classification of Nursing Practice ®, Nursing Education, OWL, UML.

1. Introduction

Correct and professional use of nursing terminology in nursing documentation is critical for nurses to communicate their impact on patient care. The nursing terminology used in this project is described in The International Classification for Nursing Practice (ICNP®), which is expressed in the Web Ontology Language (OWL) [1]. ICNP is meant to improve communication among nurses and between nurses and other health care professionals; enable comparison of nursing data across clinical populations, healthcare settings, geographic areas and time; and stimulate nursing research through links to data available in health information systems [2]. ICNP consists of more than 3000 terminology terms. Some are specific nursing terms, and others are more general terms meant for composing nursing statements. A nursing statement may be composed in advance, i.e., a pre-coordinated statement, or it may be composed on the fly at the edge of care, i.e., a post-coordinated statement. The 2013 version of ICNP contains 783 pre-coordinated diagnosis and outcome statements and 809 pre-coordinated intervention statements [3].

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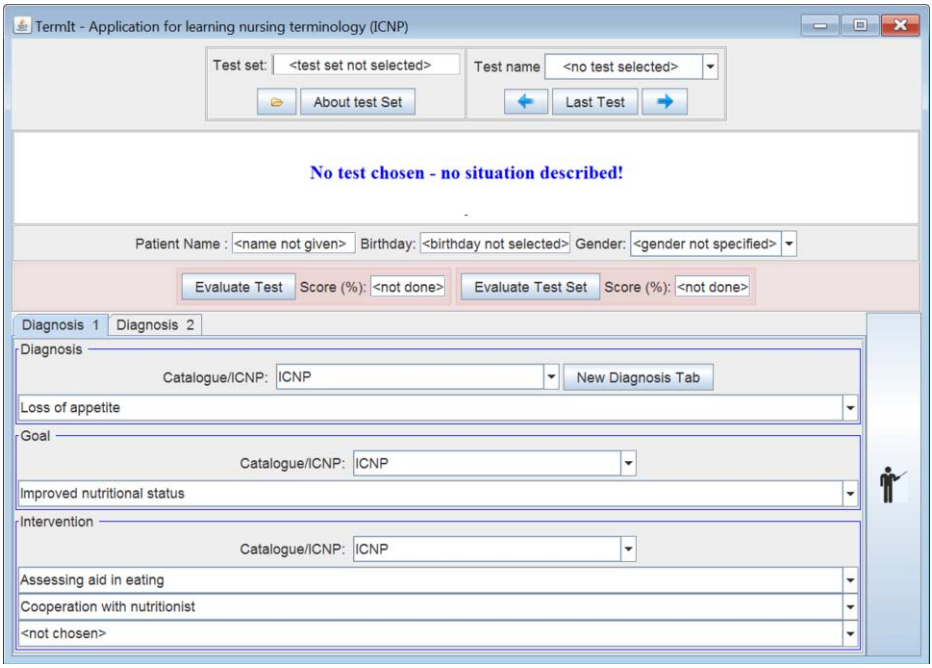


Figure 1. Screenshot of TermIt, an application for learning nursing terminology.

The main purpose of the project is to develop an application for teaching nursing students how to use ICNP to assist in the planning of nursing care. Conceptually, the application is a nursing care planning system tailored as a pedagogical tool for teaching the terminology. In other words, based on the description of a patient situation, the student is to propose diagnosis, goal and intervention statements. The proposed statements will then be evaluated in comparison to teacher-provided statements.

The use of care plans is based on the use of the nursing process [4]. The process model chosen for the application contains three steps: Diagnosis, goal and intervention. ICNP has been used with the following steps: Diagnosis, intervention and outcome. Viewing goal statements as equivalent to outcome statements allows our chosen process model to integrate well with ICNP.

Research and development projects involving ICNP have worldwide participation but are focused mainly on practice settings [3]. There is limited evidence regarding the effectiveness of teaching strategy on nursing care planning, and the absence of quality nursing documentation is an on-going problem [5]. To our knowledge, no application for teaching ICNP to nursing students has been developed. Studies have shown that in addition to providing a framework for navigation, the 7-axis model has been used successfully by applications to guide data entry and support data analysis. However, the trend has been toward the use of pre-coordinated concepts [3]. Subsets of pre-coordinated concepts, perhaps as found in ICNP catalogues, may be used to support data entry and analysis within specific contexts. Note that ICNP catalogues do not equate to ICNP subsets, as they may contain additional information such as organizing categories and even concepts drawn from other terminologies [3]. Our application will allow students to select terms and statements directly from ICNP or

from catalogues with premade statements. Our information model is presented in the following figures. Figure 2(a) gives an overview of the involved ontologies.

2. Methods

OWL is an ontology language with formally defined meaning [1] based on Description Logic [6]. Choosing OWL as our representational language allows us to integrate easily with ICNP and other OWL ontologies. The strong inference support available will allow us to analyze relationships between diagnosis, treatment and outcome by examining patient journals. In regard to the learning application, inference may be used to find which tests are difficult, etc.

The application is being implemented in Java. The programming interface to the ontology is Apache Jena™. The Jena framework is meant for building Semantic Web [7] applications and it offers a collection of tools and Java libraries [8]. Jena also supports SPARQL Protocol and RDF Query Language (SPARQL) [9], which may be used to insert, change and query data. UML was used for defining the application as well as presenting the models. We chose to present the models in UML instead of a visual language meant to express OWL because we are accustomed to the concrete syntax of UML and also because it provides a relatively compact presentation.

3. Results and Discussion

In our approach, a nursing care plan may have several time ordered cycles, which again are composed of cyclic steps. The cyclic steps can be of type Diagnosis, etc. A portion of this is shown in Figure 2(b). The type of test we support is closely tied to our nursing process model. A test contains a description of a situation in the form of either text or HTML (not shown in figure 2(b)); the task of the student is then to specify a diagnosis, goal, and intervention by writing or selecting from either ICNP or catalogues. Possible solutions and their associated scores (e.g., 100% correct) are defined by a teacher, and these are used to grade student-proposed statements. A nursing statement is seen as a phrase that may be composed of text or sub-phrases (see Figure 2(c)); a phrase may be found in ICNP, and that phrase may then reference the corresponding concept in ICNP as well (Phenomenon is superclass to all classes in ICNP). Some text may not be found in ICNP and consequently have no reference to ICNP; in the future, other

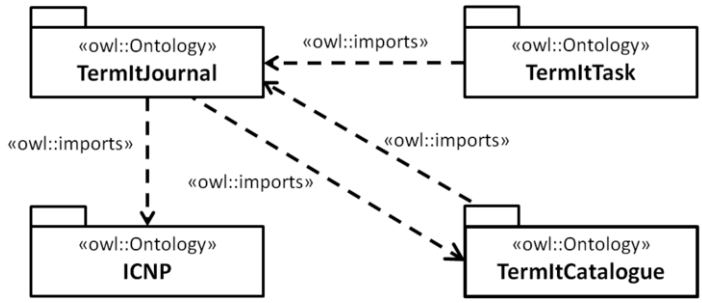


Figure 2. a)

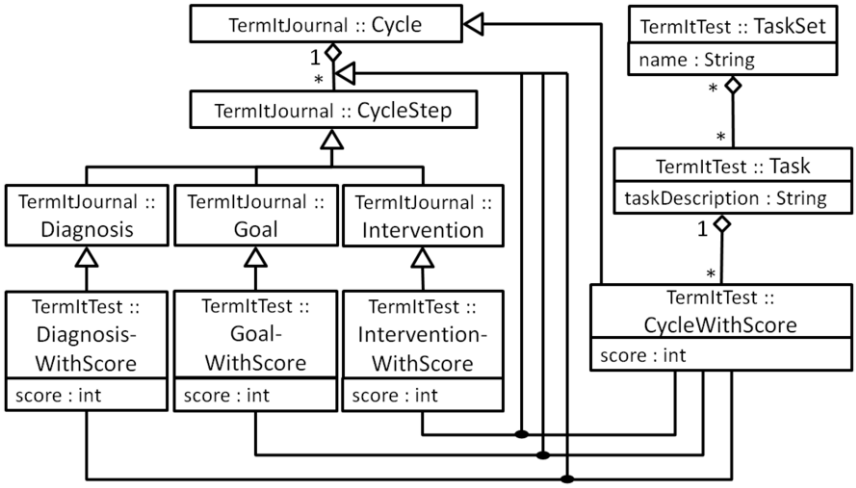


Figure 2. b)

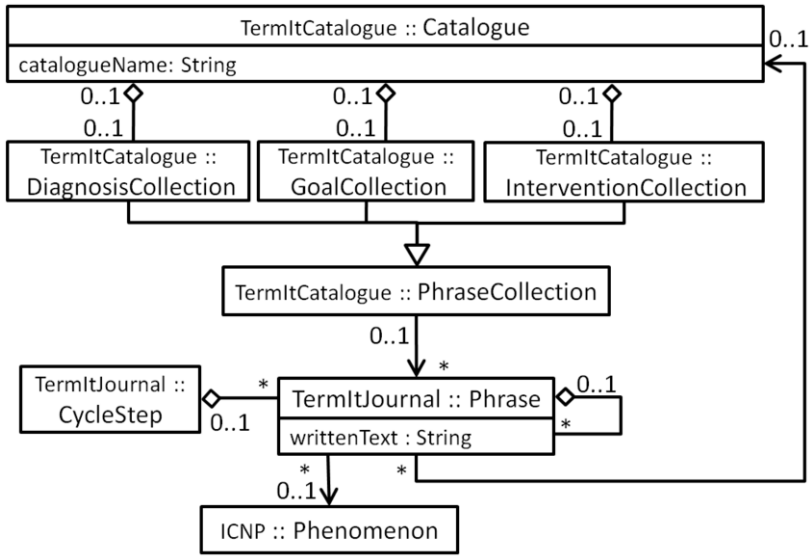


Figure 2. (c)

Figure 2. (a, b, c) Integrating the ontologies (simplified).

terminologies (ontologies) may also be referenced. A catalogue contains pre-coordinated diagnosis statements [10, 11], etc. The terms of such a statement may be found in ICNP and referenced (see Figure 2(c)).

A pedagogical application with ICNP integration may ensure that nursing students learn to observe in a more analytical way and better document those observations. The model presented enables nursing students to use the elements in the nursing process as a structure for nursing documentation. Further research should focus on developing

evidence-based ICNP terminology subsets for nursing education, development and testing applications; however, it is also important to explore the nursing record quality and how it may have been affected by introducing standardized terminology.

References

[1] W3C, *OWL 2 Web Ontology Language*, (2012). Available: http://www.w3.org/TR/2012/REC-owl2-primer-20121211/. [Accessed June 2013].

[2] International Council of Nurses (ICN), *International Classificatiom for Nursing Practice (ICNP®) Information Sheet*, Available: http://www.icn.ch/images/stories/documents/pillars/Practice/icnp/ICNP_FAQs.pdf. [Accessed June 2013].

[3] International Council of Nurses (ICN), *International Classification for Nursing Practice-Technical implementation guide*, 2013. Available: http://www.icn.ch/images/stories/documents/publications/free_publications/ICNP_Technical_Implementation_Guide.pdf

[4] L. J. Carpenito-Moyet , *Understanding the nursing process: concept mapping and care planning for students*, Philadelphia: Lippincott Williams & Wilkins, 2007.

[5] K. Häyrinen, J. Lammintakanenn og K. Saranto, Evaluation of electronic nursing documentation--nursing process model and standardized terminologies as keys to visible and transparent nursing, *International Journal of Medical Informatics,* **8** (2010), p. 554-64.

[6] F. Baader, D. Calvanese, D. L. McGuinness og F. van Harmelen, *The Description Logic Handbook: Theory, Implementation and Applications*, New York, NY, USA: Cambridge University Press, 2003.

[7] W3C, *Semantic Web*, Available: http://www.w3.org/standards/semanticweb/. [Accessed June 2013].

[8] Apache Jena project, *Apache Jena*, Available: http://jena.apache.org/. [Accessed July 2013].

[9] W3C, *SPARQL Query Language for RDF*, 2008.

[10] International Council of Nurses (ICN), *Guidelines for ICNP catalogue Development,* Geneva Switzerland, 2008.

[11] A. Coenen, T. Y. Kim, C. C. Bartz, K. Jansen and N. Hardiker, ICNP Catalogues for supporting nursing content in electronic health records, *Stud Health Technol Inform,* **180**, (2012), p. 1075-8.

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Identifying gaps between current and expected ICT competencies of nurses in Serbia

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Abstract. Introducing of ICT in the health care system in Serbia started 19 years ago and systematic training of nurses and technicians has not been realized yet. The primary objective of this paper is to determine the gap between the sets of ICT competencies of nurses and technicians acquiring education and experience and the necessary skill set required for their daily work. The qualitative research included questioning of the focus group of experts and 400 nurses and technicians employed in secondary and tertiary health institutions in Serbia. Based on the analysis of existing literature we choose the Informatics competencies for nurses at four levels of practice (Staggers, Gassert, Curran, 2001), and for the purposes of this study, we used a list of competencies of the first, and partially of the second and third level**.** At the start, the group of 12experts had the task to eliminate some of listed competencies to express the subjective expectations of the ICT competencies of nurses. After that nurses and medical technicians were expected to grade, by Likert scale, their level of knowledge and skills for each of the 39 competencies, respectively. The answers were analyzed using measure of central tendency and distribution of results was done by median. Comparison of perceived competence of the nurses and the desired/expected level by managers shows that there is difference in 25 of the 39 offered statements. Managers expect that nurses are great users of administrative applications for staff scheduling and for maintaining employee records, while nurses declared that these programs they use relatively poorly or not at all. The larger gap is also observed when it comes to computer skill for documenting patient care - experts expect that nurses do it well, and nurses, again, estimate that their documentation skills are relatively poor. The same situation is with use of ICT for patient education. It can be concluded that further training is required in the field of ICT, either through additional training in the workplace, either through formal education. Due to the fact that ICT competencies are becoming part of the basic, functional sets, it should be considered the correction of curricula of secondary schools for nurses.

Keywords. ICT Competencies, Nurses, Education

Introduction

Ongoing development and implementation of ICT in the health care system of Republic of Serbia, implies new competencies of nurses and technicians who are 35.2% of total staff (125.000). Informatization of our health care system started 19 years ago. The first strategic document about this issue predicted introduction of the HIS in the period 1997-2002 [1]. Centralized HIS, even today, has not been implemented in practice. The systematic training has not been done yet, despite the fact

that the deadline for determination of ICT standard knowledge and skills for civil servants was 2010 [2]. Because of the lack of qualified non-medical personnel who would provide technical assistance, it is expected from nurses and technicians, except obligatory use of computer, to have knowledge and skills to perform complex tasks like maintenance systems, monitoring and improvement of software solutions, electronic billing services, etc. At secondary nursing school in Serbia, ICT is studying for one year. The curriculum was revised in 2003/2004 and is identical for all secondary schools (not only medical). At the public nursing colleges in the country, nurses learn about ICT on the classes of the Computer Science or Healthcare Statistics and Informatics. The primary objective of this paper is to determine the gap between the sets of ICT competencies of nurses and technicians acquiring by education and experience and the necessary set of competencies that are required from them in their daily work. Starting point is the assumption that the current system of formal nursing education does not provide ICT knowledge and skills needed to perform their current duties in this field.

1. Methods

The study was conducted in the period 09.09.2012 - 01.04. 2013. and included questioning of two groups: the focus group of experts, and nurses and technicians. Based on the analysis of existing literature, we choose Informatics competencies for nurses at four levels of practice [3]. For the purposes of this study we used a list of competencies of the first, and partially second and third level. In the group of experts were 12 medical specialists, direct superiors of nurses, who are employed in institutions of secondary and tertiary level in Serbia at various management levels. Testing of experts was conducted by Delphi method, sending the questionnaire by e-mail, and after the 2nd round, a consensus was reached. The questionnaire contained a list of competencies and experts were asked to comment on each one using the Likert scale having in mind the wide context - the current situation in the national health care system, the objective circumstances in institutions where they are employed as well as their subjective expectations of their team nurses.

Based on the results of this survey, the questionnaire (a list of 39 informatics competencies) for nurses and medical technicians was designed. By Likert scale, respondents were asked to grade their level of knowledge and skills for each one, so that 1 was for "not at all", 2-"relatively poor", 3- "neither true nor false", 4-"right, very good" and 5 was for "right, excellent". This survey included 400 nurses and medical technicians - employed in secondary and tertiary institutions in Serbia. As a valid were considered only properly completed ones (375). The both group of answers were analyzed using measure of central tendency, and distribution of results was done by median. For dispersion forecasts around the mean, as a measure of dispersion, quartiles were used. Statistical analysis was done by SPSS 10.0.

2. Results

Results of the analysis of questionnaires for nurses suggest that when it comes to system computer skills, the average answer was that they very well know how to use

operating systems, existing external peripheral devices and have basic computer-technology skills. In the category of administration, the highest average level of knowledge - very good (4), respondents indicate when it comes to the use of applications for practice management. The respondents have stated that, averagely, they use relatively poorly (2) the applications for staff scheduling and not at all (1) - administrative programs to track employees. Statements in the field of communications are mostly very good (4) qualified. There are 30.4% of those who don't use (1) e-mail. Statements in the area of data access are generally rated as "either true or false" (3). If we look at the percentage, most of the respondents do not use at all (1) sources of data that relate to practice and care, data used locally for patient care or on-line literature searches.

Having in mind that just a few HISs in our country are with integrated nursing care applications, it is not surprising answer that respondents use them relatively poorly (2). Even 45.1% said they do not use them at all (1). In the category of education the best average rating - 4 was for the competency "Uses of ICT for personal education." Nurses relatively poorly (2) use information management technologies for patient education. The same situation is with use of computer applications for statistical analysis and nursing research. In the field of monitoring, high average rating - 4 for use of computerized systems for patient monitoring was expected. However, it is not insignificant percentage of 28.9 of those who do not know how to use them at all! Every third nurse said that they do not use complex, computerized, medical devices for the diagnosis or patient treatment. Regarding the privacy and security informatics skills, respondents, on average, are undecided (3). However, one in three does not discuss the principles of data integrity, professional ethics and legal requirements, and 38.4% do not describe ways to protect data. The level of knowledge and skills of nurses and technicians match the expectations of the focus group at 33.9%. In fact, when comparing the responses of the expert group and their expectations for the ICT competence of nurses, with the attitudes of the sampled population, there is a difference in 25 of the 39 offered statements.

3. Discussion

3.1. Comparison of perceived competence and the expected level of ICT competencies

Comparison of perceived competence in the examined group and the desired/expected level by managers shows that there is a discrepancy in two-thirds of statements (Table 1). Competencies in table are grouped based on the gap width between expected and self-reported competency levels.

Table 1. Observed gap with the responses of the expert group (E) and nurses and technicians (NT)

Competencies	E	NT
Uses operating systems (e.g., copy, delete, change directories)	5	4
Uses existing external peripheral devices (e.g., CD-ROMs, zip drives)	5	4
Demonstrates basic technology skills (e.g., turn computer off & on, print documents)	5	4
Uses administrative applications for practice management (e.g., searches for patient, retrieves demographics, billing data)	5	4
Use e-mail (e.g., create, send, respond, use attachments)	5	4
Uses computerized patient monitoring systems	5	4
Uses word processing	5	4
Demonstrates keyboarding (typing) skills	5	4

Uses telecommunication devices (e.g., modems or other devices) to communicate with other systems (e.g., access data, upload, download)	4	3
Conducts on-line literature searches	4	3
Discusses the principles of data integrity, professional ethics and legal requirements	4	3
Uses computer applications for statistical analysis and nursing research	3	2
Describes ways to protect data	3	2
Uses applications for structured data entry (e.g., patient acuity or classification applications)	5	3
Uses the Internet to locate, download items of interest (e.g., patient, nursing resources)	5	3
Accesses, enters, and retrieves data used locally for patient care (e.g., uses HIS, CIS for plans of care, assessments, interventions, notes, discharge planning)	5	3
Uses an application to document patient care	4	2
Uses information management technologies for patient education	4	2
Uses administrative applications for staff scheduling	5	2
Teaches users/clients about effective and ethical uses of applications and systems Plans and develops application/system training programs for users, clients	4	1
Uses administrative applications for maintaining employee records	5	1

3.2. Literature analysis

Reviewing publications we found that most of the studies in this field relate to the nurses in the U.S. [4, 5, 6, 7, 8, 9], a few to European nurses [10, 11, 12], while there are no studies on this topic in this specific region. The subject of studies mostly were nursing students [13, 14] or their educators [15, 16, 17] while the lowest number of publications relates to working nurses [18]. Searching the publications in this field, we have not found articles in which there is comparison of the required and existing ICT competencies.

In the literature, majority of the discussions deal with privacy and confidentiality issues, and the authors agree that nurses must possess competences in this field.

3.3. Conclusions and recommendations

Observed gap in the daily work implies inefficiency, delays, frustration and conflict, which consequently affect on the quality of provided care. We recommend significant changes in the organizational culture of Serbian hospitals where nursing training costs must be seen as an investment, not as a luxury. There must be a feedback from employers in the health care system directed toward the education system. We should avoid formal, factual and superficial training, it is necessary to insist on understanding and putting technology in the context of everyday activities.

It can be concluded that further training is required in the field of ICT, either through an additional training in the workplace, nor through formal education. Due to the fact that ICT competencies are becoming part of the basic, functional sets, it should be considered the correction of curricula of secondary schools for nurses.

References

[1] The Regulation of the unique health information system program development. Official Gazette of RS No 12/95. (1995).

[2] The Regulation on the program, development and organisation of the integrated health informatic system E-Health.Official Gazette of RS No 55/2009. (2009).

[3] Project delivery of improved local services [Internet]. Bulletin of the Ministry of Health and the World bank 5. Belgrade: Ministry of health and Project delivery of improved local services (DILS) March

2012); [updated: March, 2012; cited: 05.27.2013.] Available at: http://www.dils.gov.rs/documents/files/bilteni/Peti%20broj%20biltena%20projekata%20DILS&RZS-DF.pdf.
[4] Staggers N, Gassert CA, Curran C. Informatics competencies for nurses at four levels of practice. J Nurs Educ. 2001 Oct; 40 (7): 303-16.
[5] Ball M, Douglas J. Integrating nursing and informatics. In: Ball, Marion J. et al, editors. Nursing informatics: where caring and technology meet. New York: Springer-Verlag; 1988, p. 11-17.
[6] Grobe S. Computers' use for professional practice: what do nurses need to know. In: Wainwright P, editor. Nursing informatics. Edinburgh: Churchill Livingsone; 1994, p. 129-138.
[7] McGowan, JJ.Commentary: Information technologies and the transformation of nursing education.Nurs Outlook. 2008 sep/oct; 56: p.231
[8] Staggers N, Gassert CA. Health Professional's Views of Informatics Education: Findings from the AMIA 1999 spring Conference. J Am Med Inform Assoc. 2000 December; 7(6)
[9] Hebert M. A national education strategy to develop nursing informatics competencies. Nurs Leadersh (Tor Ont). 2000 may-jun;13(2):11-4.
[10] McNeil BJ, Elfrink V, Beyea SC, Pierce ST, Bickford CJ. Computer Literacy Study:Report Of Qualitative Findings. J Prof Nurs. 2006 January–February;22: p.52-59.
[11] Hasman A, Sosa M. Education and training of health informatics in Europe. IOS Press; 1995
[12] Procter PM. Nurses, computers and information technology.London: Chapman & Hall; 1992.
[13] Gassert C.A.,McDowell D.Evaluating graduate and undergraduate nursing students' computer skills to determine the need to continue teaching computer literacy. 8th Medinfo 95: medical informatics towards the 21st century:from theory to practice. 1995; São Paulo:Brazil
[14] Austin SI.Baccalaureate nursing faculty performance of nursing computer literacy skills and curriculum integration of these skills through teaching practice. J Nurs Educ. 1999; 38: p.261-266.
[15] Saranto K, Tallberg M.Nursing informatics in nursing education: a challenge to nurse teachers. Nurse Educ Today. 1998; 18.
[16] Armstrong ML.Computer competence for nurse educators. Image. 1986; 18.
[17] Bryson DM.The computer-literate nurse. Comput Nurs. 1991; 9: p.100-107.
[18] Carter BE, Axford RL.Assessment of computer learning needs and priorities of registered nurses practicing in hospitals. Comput Nurs. 1993;11: p.122-126.

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The expectations of nurses about the implementation of a barcoded medication administration system: a qualitative study

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Abstract: The implementation of a health system like the Barcode Administration System (BCMA) often disrupts the workflow of nursing staff. Taking into account that system acceptance by nurses is one of the most important factors for successful implementation, this paper describes nurses' expectations regarding the introduction of BCMA. For this purpose, interviews were conducted with 18 nurses in different units of an academic medical center in Argentina. Analysis of the interviews produced six main themes. Among these themes two factors were identified as determinants for system acceptance: ease of use perceptions and usefulness.

Keywords: Barcode Medication Administration (BCMA), patient safety, implementation strategies, qualitative studies

Introduction

Literature reviews show that more than a million injuries and between 44,000 and 98,000 deaths per year are attributable to medical errors in the United States. [1] Preventable adverse events occurred most often during ordering (56%) and administering (24%) medication [2]. In a recent study of the Analysis of Event Reports, it was found that 43.4% of errors related to medication occurred during the administration stage [3]. Studies have demonstrated a reduction of 54% to 86% in error rates of drug administration with the introduction of the Barcode Medication Administration (BCMA). BCMA is also important for improving both the accuracy in the administration of medication and the quality and completeness of medication records [4,5].

BCMA requires the introduction of new technology into the daily work of nurses. The introduction of such an innovation has the potential to disrupt work routines [6].

In order to fit the innovation to the work environment, a thorough and comprehensive analysis is required of the norms, standards and work culture involved. Workflow must also be redesigned or the implementation could fail. Lack of system acceptance by users has been described as one of the major barriers to BCMA implementation [7].

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The aim of this study was to understand nurses' expectation about BCMA and through this understanding provide adequate future implementation of local processes and user preferences, with the objective of improving the acceptance of new technology.

1. Methods

We performed a qualitative study to explore nurses' perceptions of a future BCMA implementation. Data was obtained via individual, face-to-face, semi-structured interviews with nurses from seven wards of Hospital Italiano de Buenos Aires (HIBA) between March 2011 and October 2012

HIBA is a non-profit academic medical center. It has two hospitals and 24 outpatient clinics. HIBA's Health Information System (HIS) includes a problem-oriented patient-centered electronic medical record (home-grown system) that is used by all nurses.

We began the study with nurses from two units where BCMA implementation was going to occur in the study's first phase and continued interviewing nurses from other units during the second phase of the study.

Data was collected over a period of four weeks in the first phase and a period of six weeks for the second phase. Interviews usually lasted between 20 and 30 minutes and all of them were recorded

A purpose sample was performed. A nurse informatics specialist assisted in identifying key informant nurses. For a broad spectrum of responses, different profiles were interviewed in terms of gender, age, role and work shift.

A literature review of different papers about BCMA implementation was completed and then the primary investigator defined a set of criteria defining possible themes for developing the interview guide. Changes in the workflow, possible benefits and possible problems and issues in the ongoing implementation process became the focus for questions.

Two of the investigators (VT and DB) transcribed the interviews. The words of those interviewed were utilized to create a first list of codes. Then, the two investigators independently reviewed the field notes and organized themes using spreadsheet software (Microsoft Excel, Redmond, WA). As a result, a coding tree was built around the key themes. Within these themes, different levels of codes were constructed. Following on, the two investigators performed a second round of reviewing transcripts using final categorization and discussed the concluding results. We also performed member checking, reviewing our results with a subset of our subjects to ensure we had accurately captured meaning.

Categories, themes, codes and quotes were used together to guide the summary and interpretation of the results. Quotes are expressed in English but were translated from Spanish.

2. Results

18 Nurses were interviewed, five from the ICU and the rest from general wards. The average age was 34. Three nurses worked on weekends during two morning shifts and

three afternoon shifts, and the rest worked during weekdays After analysis, six themes were developed; they are stated below:

Medication administration process theme: When nurses were asked about changes that they thought would appear while administering medication, several subthemes emerged. These subthemes were included in subsequent interviews for a deeper understanding.

One of the mains advantages that nurses visualized was an improvement in patient identification. “We will know that we're facing the correct patient”. With the development of this system, patients will use a wristband containing patient identification information. Nurses thought that this could be a positive change, that is, “the benefits of knowing who we are assisting”. However, it was also mentioned that too many of the wristbands will need to be changed because they become blurred or stained and the patient may have to wait hours or days to receive a new one.

Another subtheme that emerged was related to the identification of medication. “We have a certain amount of medications that have many similarities and although they are different drugs they are visually identical”. With BCMA, nurses expected improvements in the identification of medications.

Nurses expect this system to improve patient safety by decreasing medication errors. To verify the correct administration of the medication to the patient, nurses have to check the five 'corrects' or five 'rights': right patient, right drug, right dose, right route and right administration time. BCMA facilitates this process and nurses were aware of this: “We use the verification of the five Rights to administer medication to the patient, the right patient, the right dose, etc. ... but that is a process that we do mentally, so sometimes we forget something… This system will help us to verify the five rights and decrease errors".

Another process that will change is the recording of the drugs that are administered. Nurses perceive it as a good change that could improve record completeness and quality. “Everything is recorded and there won't be errors”

Trust /Distrust: It was noted in interviews that the new system could give nurses peace of mind and security. “ The system gives us a sense of security and safety ... for the patient and for us, too …we will have the peace of mind that what we're administering is what really needs to be given to that patient”. One of the concerns mentioned in one interview concerned security in the medication preparation process: “How sure can I be that the syringes will contain the correct medication and have been correctly prepared?”

Professional development: Some nurses associated the new technology with professional advancement through statements like “decreasing the possibility for error,” and “we will become more skilled”.

Nurse-patient relationship: Some nurses were fearful about BCMA interfering in relationships with their patients and as a result creating discomfort for patients and/or nurses. They asked themselves what the patient's reaction would be upon seeing nurses scanning the medication before its administration. “I think the patient might feel uncomfortable if we check the medication in front of them”. One nurse mentioned that patients might be suspicious of the use of new technologies if they do not understand or have not had previous experience of

said technology. Another nurse stated that the new interventions could generate distrust among patients, which could lead to them feeling uncomfortable.

Technical issues: In the interviews, nurses were concerned about a number of different technical problems, such as the use of wired devices. They mentioned that this could make it problematic to work within patients' rooms. "I don't know if the cable will be long enough … if we are going to be at the bedside with a device that is not wireless we are going to have problems with cable lengths".

Nurses were worried about their training needs and stated several times, "I don't know how the system will work, it is difficult to imagine". Furthermore, they also verbalized the necessity for someone that knew how to use the system to accompany them during the first months of its implementation. "When the implementation starts, I would like to have some nurses trained in using the new system during every shift to help us with the system use".

Implementation process: One theme that emerged during the interviews was the nurses' need for being involved during the implementation process. "Communication and frequent meetings … it is important that we have meetings when we start working with this new technology to be aware of new problems that may arise". Effective and efficient communication between those involved will make it possible to analyze the implementation's weaknesses and problems, and also to find solutions to them.

Offering support is a good way of making the user feel comfortable during implementation. This need was explicitly stated in some interviews, for example, "When the implementation starts I would like to have super-user nurses on every shift to help us with the system".

3. Discussion

It is important to consider, as described by the Technology Acceptance Model [8], that a prerequisite for the adoption of technology is given by the attitude displayed towards it. This factor is based on two aspects: ease of use and usefulness. By linking nurse interviews with these two determinants, we noted that the nurses associated this introduction of technology with important factors such as effectiveness, increased productivity, having more complete patient records, higher care quality, as well as a decrease of errors as factors associated with usefulness. Nurses also mentioned that the introduction of this technology can be related to personal growth, hospital growth and better patient care. Nurses also mentioned reservations regarding the introduction of new technology, such as a lack of knowledge about using the system and the need of training, which will be crucial to the process of adopting BCMA.

The expressed need for communication and support has been described as an important step for effecting changes in management [9]. Also described by Novack et al. institutionally supported clinicians who facilitate adoption and use of health IT systems can improve the safety and effectiveness of implementation through the management of unintended consequences [10].

This paper has some limitations, as we only assessed one institution, an academic medical center; thus, we might be able to find different opinions if we replicate the study in other healthcare institutions. As a qualitative study, there were some limitations implicit in the methodology; we tried to diminish these by using different

strategies to rigorously enhance trustworthiness, such as reflexivity, triangulation and member checking.

This study has given us a better understanding of the preferences, concerns and expectations of nurses regarding the introduction of a new technology. As a future work, we expect to be performing new qualitative findings in a bid to understand nurses' preferences at the point where the technology will be available in Hospital Italiano de Buenos Aires.

References

[1] Kohn LT, Corrigan J, Donaldson MS. To err is human building a safer health system. Washington, D.C.: National Academy Press; 2000

[2] Weingart SN, Wilson RM, Gibberd RW, Harrison B. Epidemiology of medical error. BMJ. **7237** (2000), 774-7.

[3] Yang, A, Grissinger, M. *Wrong-patient medication errors: an analysis of event reports in Pennsylvania and strategies for prevention*. Pennsylvania Patient Safety Authority; ECRI; Institute for Safe Medication Practices, 2013.

[4] Paoletti RD, Suess TM, Lesko MG, Feroli AA, Kennel JA, Mahler JM, et al. Using bar-code technology and medication observation methodology for safer medication administration. *Am. J. Health Syst. Pharm.* **5** (2007) 536-543.

[5] Poon EG, Keohane CA, Yoon CS, Ditmore M, Bane A, Levtzion-Korach O, et al. Effect of bar-code technology on the safety of medication administration. *N. Engl. J. Med*. **18** (2010) 1698-1707.

[6] McDonald CJ. Computerization Can Create Safety Hazards: A Bar-Coding Near Miss. *Annals of Internal Medicine* **7** (2006), 510-516.

[7] Nanji KC, Cina J, Patel N, Churchill W, Gandhi TK, Poon EG. Overcoming barriers to the implementation of a pharmacy bar code scanning system for medication dispensing: a case study. *J. Am. Med. Inform. Assoc*. **5** (2009), 645-650.

[8] Davis, FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Quarterly*, **3** (1989) 319-340.

[9] Ash JS, Stavri PZ, Dykstra R, Fournier L. Implementing computerized physician order entry: the importance of special people. *Int. J. Med. Inform*. **69** (2003), 235-50.

[10] Novak LL, Anders S, Gadd CS, Lorenzi NM. Mediation of adoption and use: a key strategy for mitigating unintended consequences of health IT implementation. *J. Am. Med. Inform. Assoc*. **6** (2012), 1043-9.

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How are Electronic Medical Records Used by Nurse Practitioners?

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Abstract. In this paper we describe how nurse practitioners (NPs) use electronic medical records (EMR) features and functions at: (1) an individual and (2) a clinic level to support patient wellness and chronic disease management activities. Fifteen NPs from British Columbia (BC), Canada participated in a qualitative, semi-structured interview study. NPs used EMRs with individual patients and at a clinic level to support wellness and chronic disease management activities. NP's used clinic notes, reminders, tasks and careplans to support wellness and disease management activities in individual patients while reports were used to manage patients at a clinic level.

Keywords. nurse practitioners, electronic medical records, adoption, nursing informatics

Introduction

Nurse practitioners (NPs) represent a growing group of healthcare providers in North America. NPs care for and support well individuals and those with chronic and complex medical conditions. Yet, as a group they represent one of the least studied health professionals in terms of their use of EMRs. To date, most studies involving EMRs have focused on physician and nurse adoption and use of the technology. Fewer researchers have attempted to understand NPs adoption and use of EMRs [1]. In this paper we describe how NPs have employed EMR features and functions at: (1) an individual and (2) a clinic level to support patient wellness and chronic disease management activities.

1. Review of the Literature

1.1. What is a Nurse Practitioner?

NPs are Masters or Doctorally prepared advanced practice nurses that can "diagnose and treat diseases and health conditions, educate and support patients who have health issues that range from simple to complex, and acute to chronic" [2]. NP's were

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introduced to BC by the Ministry of Health to improve patient access to primary healthcare. In 2005 legislation was proclaimed formalizing the role in the BC healthcare system [3]. Today, there are 574 NPs who are registered in BC (i.e. currently practicing and provisional) [2]. They work in regional health authorities across the province in acute, long-term, and primary healthcare practice settings. Across Canada there are 2800 NPs who are providing healthcare [4].

1.2. The Electronic Medical Record Use and Nurse Practitioners

NPs have become key stakeholders and users of EMRs. Federal, provincial, state and territorial governments in North America have identified that NPs need aid and support in using EMRs. To date federal government funding in North America has focused upon physician adoption of EMRs [1]. Little research has been published about NPs' use of EMRs at a country level. Researchers in BC, Canada have begun to study NPs' use of EMRs [see 1]. In Canada there has emerged an interest in understanding how EMRs can be customized and implemented to support NP's. Canada Health Infoway is investing $380 million to help physicians and NPs implement EMRs [6]. In BC the Physician Information Technology Office has begun to determine best practices around EMR data management and storage in NP-physician practices [7].

2. Methods

2.1. Participants and Recruitment

NPs who were practicing in the province of BC, and who used an EMR in their practice, were invited to participate in this study. Email invitations were sent to those NPs who had participated in a provincial Nurse Practitioner Practice Pattern survey [8] and had consented to be contacted to participate in further research about NPs.

2.2. Nurse Practitioner Practice Settings

The study took place in the province of BC which is the third largest province in Canada (larger than the countries of France, Germany and the Netherlands combined). Healthcare delivery in BC occurs across urban, rural and remote settings. Most NP's are employees and work in clinics as part of healthcare teams (i.e., with physicians, social workers, therapists and medical office assistants).

2.3. Procedure

NP's who were using EMRs in their practice were emailed and asked to participate in the semi-structured interview study. Those NPs who expressed an interest in participating in the study emailed a member of the research team who then sent a consent form, and set up dates and times to conduct the interview by telephone. During the telephone interview, the researcher first obtained the NP's verbal consent to participate in the study. Following this, NP participants were asked a series of demographic and interview questions. Interviews took 30 to 45 minutes to complete and were audio recorded. Many of the questions focused on how NPs use EMRs in

their practice. A subset of questions were aimed at learning more about how NPs used EMRs with individual patients and at a clinic level to support wellness and chronic disease management activities across patient groups. The study received ethical approval from the University of Victoria Human Research Ethics Board.

2.4. Analysis

Descriptive statistics were used to learn about the demographic characteristics of the study participants. Qualitative semi-structured interviews were transcribed and imported into NVivo9®. A coding scheme was developed by two health informatics researchers using constant comparison. Initially, the researchers coded three interview transcripts separately and then reviewed the developed coding schemes together. The coding schemes were reviewed and all discrepancies in coding were resolved through discussion between the two researchers. Once the inductively derived coding scheme was agreed upon by the researchers, a researcher coded the remaining transcripts.

3. Results

In this section of this paper we present data on the demographic characteristics of our study participants and the results of our analyses of the telephone interview data.

3.1. Participant Demographic Characteristics

Fifteen NPs who were practicing in a primary care setting participated in the study and saturation was reached in the data [9]. Participants were either using a paperless EMR system (8/15; 53%) or an electronic-paper hybrid system (7/15; 46%). The majority of participants worked with at least one physician (14/15; 93%), RN (9/15; 60%) and NP (8/15; 53%). The mean time NPs spent on a computer for work purposes was between 23 to 25 hours per week, of which a mean of 16 to 18 hours were spent on their EMR. These participants also completed in the Nurse Practitioner Practice Patterns survey, where the majority of the people that took part were female (29/34; 85%) with an average age of 46 years. Participants were educated at the Masters level in Nursing. On average, participants had 19 years of nursing experience prior to becoming an NP with a mean length of time practicing as an NP of about three years [1].

3.2. Semi-structured Interview Data

Two themes emerged during the analysis of the data. NPs used the EMR for: (1) individual patient management, and (2) clinic patient population management. Clinical notes, reminders, tasks and careplans were used to promote individual patient wellness activities and manage patient chronic illnesses. EMR search, list generation and report functions were used to manage the clinic's patient population (see Table 1).

Table 1. NP Use of EMR Features and Functions

Individual Patient Management	Clinic Patient Population Management
Clinical Notes	Reports (also referred to as Searches and Lists)
Reminders	• Example: Type of medications
Tasks	• Example: Laboratory test results
Careplans	

NP participants used EMRs for individual patient management and described using clinical notes and reminder functions embedded in the EMR to care for and support individual patient needs (see left side of Table 1). Here, NPs noted patient wellness and chronic illness management issues that required NP follow-up in individual patient records. NPs used clinic notes for follow-up on patient wellness and chronic disease management issues. Here, some NPs made clinical notes in the EMR about specific health issues that required further patient follow-up, for example:

"I would just make a note…you're over 50 so you need to come for a physical, you need blood work … and different things depending on if they're male or female." (NP)

Reminders were used by NPs to ensure physical exams (e.g. Papanicolaou test - Pap tests, prostate exams), laboratory tests (e.g., bloodwork) and diagnostic tests (e.g., mammograms) were undertaken and followed up on as described by one NP below:

"We enter all of their results in there and we use it to create reminders. So then when they're due for their Pap for example, every time their chart is open the reminder pops up saying "patient overdue for Pap test" (NP)

Alternatively, NPs used tasks and careplans to initiate chronic disease or wellness interventions as illustrated by the following statement:

"You might send a task to yourself or you might generate a careplan in order to be able to have the record flag you (to discuss health concerns) when the person comes in the next time" (NP)

NPs used other EMR functions to manage patients with similar health issues in the clinic (see right hand column of Table 1 – Clinic Patient Population Management). Sometimes this work would be done by the NP and in other cases the healthcare team did this (i.e. the NP was part of the healthcare team). Individually, NPs used EMR searches (sometimes referred to as list generation or report functions) to manage clinic patients. EMR searches/lists/reports involved querying the systems databases using specific information requests to identify patients who might require specific types of interventions or follow-up [5]. For example, the NP or the healthcare team might be interested in obtaining a list of patients who are taking a particular medication, have a specific physiologic problem (e.g., hypertension) or a laboratory result that was outside of a normal range. For example, some participants indicated:

"You could search that…extrapolate from that, that those people on Warfarin may need, ….annual or regular blood work to monitor their Warfarin levels" (NP)

Others identified:

"I want a list of all my patients who have a blood pressure over 150 and then if I get that list and it would be based on their last office visit. I get that list and I could choose to call those people in because that's outside of the target and have a follow-up visit with them" (NP)

Clinic teams (including the NP) would use reports to identify vulnerable or at risk patients. The following interview excerpt illustrates this:

"At the practice (or clinic) level with the other people on the team, you might identify specific groups of patients, that have issues and you might look at what's actually been

done with them, and use that information to follow-up on things that have been missed, like hemoglobin A1C (glycated hemoglobin)". (NP)

NPs not only used the EMR to track an individual patient's actual or potential health issues, they also used the EMR to identify patients that visited the clinic that would benefit from a wellness or a chronic disease management intervention or one that was missed. In some cases these reports helped NPs deliver programs that would improve patient health at a clinic population level. Overall, EMR functions were used by NPs to support their own practice as well as the collective work undertaken by the healthcare team. NPs used differing EMR features and functions when managing individual patients versus managing patients that received services at the clinic.

4. Discussion

NPs are important members of the healthcare team as they represent a growing and significant group of providers that are responsible for supporting and managing patients in primary care settings. Even as national governments are promoting physician adoption of EMRs in primary care practice settings throughout North America, there is little known about how NPs adopt and use this technology in their practice. Research emerging from Canada has shown that NPs are adopting EMRs at a rapid rate, yet a significant group of these NPs believe the technology does not adequately support their practice [1]. In this qualitative study we begin to develop an understanding of how NPs use EMRs to support patient wellness and clinic population management. Specifically, NPs are using clinical notes, reminders, tasks and careplans to support/manage individual patient health needs, while EMR reports are being used to identify vulnerable or at risk patients who are visiting the clinic. A limitation of this study is its generalizability: there were only 15 participants, it occurred in only one province in Canada and participants self-selected for participation in the study [9]. Future research will need to examine the challenges and issues that NPs encounter when adopting the technology, including developing a better understanding about NP user EMR interface, usability, workflow and interoperability needs with several vendor and open source EMRs. Additional research may involve comparing and contrasting physician versus NP EMR user needs. Such research is needed to design, develop and implement EMRs that can effectively support other health professionals.

References

[1] E. B. Borycki et al., Electronic record adoption and usage among NPs in BC, CJNR (in press)
[2] BCNPA. NPs provide accessible, efficient and effective healthcare that meets the highest standards of practice. http://bcnpa.org/
[3] BCNPA (2012). Position statement: Nurse practitioners in primary care. Vancouver: BCNPA.
[4] Canadian Institute of Health Information (2009). Regulated nurses: Canadian trends 2005-2009. CIHI.
[5] Henry J. Kaiser Family Foundation. http://kff.org/other/state-indicator/total -nurse practitioner/
[6] Canada Health Infoway. Infoway invests $380 million to help physicians and nurse practitioners implement electronic medical record (EMR) systems. https:www.infoway-inforoute.ca.
[7] Physician Information Technology Office. Data sharing between a shared care nurse practitioner and family physician. http://www.pito.bc.ca/support/communities-of-practice/idp/data-sharing-langley/
[8] E. Sangster-Gormely et. al. A survey of Nurse Practitioner Practice Patterns in BC. University of Victoria, Victoria, British Columbia, 2012.
[9] Jackson, W. and N. Verberg. Methods: Doing Social Research. Toronto, Ontario, 2007.

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General vs Health Specialized Search Engine: a Blind Comparative Evaluation of Top Search Results

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Abstract. This paper presents the results of a blind comparison of top ten search results retrieved by Google.ch (French) and Khresmoi for everyone, a health specialized search engine. Participants – students of the Faculty of Medicine of the University of Geneva had to complete three tasks and select their preferred results. The majority of the participants have largely preferred Google results while Khresmoi results showed potential to compete in specific topics. The coverage of the results seems to be one of the reasons. The second being that participants do not know how to select quality and transparent health web pages. More awareness, tools and education about the matter is required for the students of Medicine to be able to efficiently distinguish trustworthy online health information.

Keywords. Internet, search engine, user evaluation, quality

Introduction

The Internet is being increasingly used across the world, such as for health-related matters: looking for disease and treatment, information, diet and sport regimes, vaccinations for exotic destinations etc. A survey has confirmed that "eight in ten online health enquiries start at a search engine" [1]. However, quality of online health information is an issue. The main characteristic of online health information is its heterogeneity and variability from shark cartilage for cancer to evidence-based peer-reviewed articles. Due to heterogeneity of users and their general and health literacy, they can be misled and ultimately take health-related decisions based on inaccurate information. Google being the most popular gate to access online health content does not differentiate and quality may be compromised for coverage.

The EU project Khresmoi (2010-2014, project No. 257528), which attempts to develop trustworthy online search engines targeting the general public, physicians and radiologists prioritizes quality over quantity. Khresmoi for everyone (hereinafter K4E accessible at: http://everyone.khresmoi.eu/) is one of the results of this project. On the first stages of the project, a large-scale survey was designed and conducted to determine users needs towards future search engines [2]. Upon identifying the

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requirements, a first prototype was developed which required evaluation of users. Two types of user evaluations have been conducted to ascertain K4E usability and acceptance by the end-users: an evaluation focussed on blind comparison of top search results from Google and K4E (detailed in this article) and another one studying how users interact with a prototype and its functionalities.

At the stage of conducting the evaluation, K4E index largely contained 8.300 HONcode certified sites [3]. Specifically, the evaluation test described here aims at answering the following research questions:

- Are users satisfied with K4E results compared with general search engine results (in terms of more relevant search results and more comprehensible results)?
- What are their criteria for quality and relevance of health search results?

This paper presents a slice of findings described in a full report [4].

1. Methods

The blind comparison method has been chosen to assess the perception of the search results avoiding the "branding" bias.

We used health topics identified by Pew Research Center's Internet & American Life Project [5] to define real-life representative scenarios. Eight topics were retained: we have excluded "health insurance" and "how to reduce your healthcare costs" as these specifically address the US context and rather focus on healthcare system, as well as "any other health issue" due to its vagueness. Additionally, two topics "drug safety and recalls" and "a drug you saw advertised" were merged to define a single scenario.

To define a specific scenario within each topic we have consulted health forums, news and other types of information on the Internet (Tab.1). The queries that we proposed for each scenario were short and concise (terms only, see Tab.1), trying to imitate the most common end-user search behaviour.

The evaluation took place for a few days during two weeks in February 2013 in the Faculty of Medicine's library of the University of Geneva. Twenty-nine participants were recruited via a newsletter emailed by the library, flyers and posters distributed in the premises, all of them were students. Students were chosen largely due to the ease to enrol them in our study. Refreshments were provided as compensation.

The evaluations sessions lasting for on average 40 minutes were conducted in French only. Introduction was followed by signing a consent forms, then each participant was requested to make a test via a specifically developed online platform allowing blind comparison[2]. The first step was to fill in demographic and Internet usage questionnaires. The second was to complete a randomly assigned task which included reading a health scenario, examining two anonymized lists of top ten search results returned by K4E and Google.ch (in French) presented in a-Google like format and answering a questionnaire regarding which list and specific results users preferred (preferences 1, 2 and 3 out of both lists of results). Upon completing the first task, participants were asked to complete two other randomly assigned tasks.

[2] Platform can be accessed at http://cmulinux4.unige.ch/kgc_hybrid/home.php?mode=blind

2. Results

Out of 29 recruited students three were excluded as they did not meet the inclusion criteria, hence overall the responses of 26 students of the Faculty of Medicine were analysed. Out of them, 18 were males and 8 were females with an average age of 21±2 (mean±sd) years old mostly in their first three years of study, all French-speakers.

All the students confirmed a daily use of the Internet and 25 out of 26 (96%) agreed to be well or very well experienced in information search on the Internet. For online health searches, 14 out of 26 (54%) of the students seemed to be only occasional online health information seekers (we asked about the frequency of such searches for personal, not study-related purposes). All the students except one (25 out of 26 = 96%) reported searching online health information concerning at least one of the eight suggested health topics while 20 of them searched in more than one health topic (3±2). "Specific disease or medical problem" and "Certain medical treatments or procedures" were the most sought health topics with 23 and 18 cases respectively.

In general, when asked about their trust with regards to online health information, 21 out of 26 students (81%) named different factors but agreed that quality could be improved. The most common criteria to trust online health information was the presence of references (14 out of 26=54%). Other important aspects were language/vocabulary, presentation and structure of the information and author information (8 out of 26=31%). One participant mentioned HONcode seal, although we explicitly avoided mentioning it during the presentation of the study.

About three quarters of participants preferred results from Google. However, the magnitude of the differences in the preferences between search engines varied between scenarios (Tab.1). Concerning specifically the first chosen results, the differences between the proportion of participants who preferred Google and those who preferred K4E was the lowest for scenario 1 and 2, 14% and 23% respectively. K4E results were particularly preferred for scenario 6, which was about pregnancy and more precisely about taking a decision regarding amniocentesis. The scenarios where Google was strongly preferred by the participants were scenarios 4, 5 and 8 (food safety, drug safety and taking care of elderly persons respectively) with differences in the proportions being over 80%. Specifically, 90% and 100% of the participants respectively for scenario 4 and 8 selected their first chosen results from Google. In between (from 33% to 44% of preference towards Google comparing with K4E) there were scenarios 1, 2, 3 and 7.

Table 1. Health topics and corresponding queries.

Scenario	Selected health topics based on [4]	Health query (original in French and translated into English)	Percentage of participants whose preference 1, 2 or 3 was from	
			K4E	Google
1	Specific disease or medical problem	Goutte régime (gout diet)	29	71
2	Certain medical treatment or procedure	TDAH médicament stimulants effects (ADHD stimulant drug effects)	31	69
3	How to loose weight or how to control your weight	Perdre poids rapidement (lose weight fast)	33	67
4	Food safety or recalls	Lait cru risques (raw milk risks)	10	90

5	Drug safety or recalls / a drug you saw advertised	Risques trop antidoulers (too many painkillers risks)	14	86
6	Pregnancy and childbirth	Amniocentèse risques (amniocentesis risks)	43	57
7	Medical test results	Sida aide Genève (AIDS help Geneva)	28	72
8	Caring for an aging relative or friends	Aide personne-agée maison (at home elderly care)	13	87

3. Discussion

As mentioned above the most popular answer regarding how participants judge quality of the health information on the Internet was presence of references, few participants also specified that they check for possible bias or compare with previous knowledge. On the other hand, once end users access a website, quality concerns disappear despite the online navigation skills of the end user [6], which seems to be the case for medical students in our study. In general, it seems that the skills to critically evaluate the online health information need to be further developed in this participant sample. The important steps are to, first of all, raise awareness, secondly, educate and train the users, and finally propose adequate tools [7]. We suppose that by providing the end users with K4E and branding it as a search engine with trustworthy content, a safe environment will be created and end users will be more protected from the possible harms fraudulent online health information can bring.

One of the possible reasons to explain the difference between scenarios where Google was largely preferred is coverage of certain topics in the database of HONcode certified websites. Only 1 out 23 URLs and 5 out of 21 domains of the most selected Google results existed in Khresmoi index. Amongst the 70% of the URL selected by the participants in Google but not present in K4E, only one URL was from a governmental website and two others could be potentially HONcode compliant. The other results could not be certified by HON as none of them respected a set of ethical criteria defined by the HONcode, hence we cannot consider them trustworthy.

The Khresmoi prototype index at that stage of its development largely contained HONcode-certified websites. About 8,300 websites comprising the HONcode-certified database have all undergone a rigorous certification process to ensure the website's transparency and a certain ethical commitment of website editors and content providers. However, as applying for the certification is a voluntary process, the database contains various kinds of websites related to human health, but does not explicitly cover all health-related topics. Additionally, the HONcode certification process itself eliminates certain types of websites such as sites making various claims without proper evidence backing (various fat loss sites, miracle pain relief sites, one cure from all diseases etc.). There is no classification of the websites in the database by health topic similar to the one defined by [1], nevertheless certifiers have noticed that the websites corresponding to the scenarios where Google strongly overtook K4E (4, 5, 8) are presented in minor quantities. From other hand, for the ones where K4E was chosen in more cases (especially pregnancy), there are more websites in the database. Additionally, compared to the other scenarios, scenario 6 was most likely to be the most contradictory in terms of online information existing on the web regarding this topic. The fact that the participants preferred Google less significantly than in other cases

shows that K4E has a potential to be eventually preferred by the end-users when they research health topics for which many contradicting opinions exist on web.

To make it possible for K4E to be more preferred by end users, more resources of a high quality were consequently indexed in K4E. These selected websites were not certified by HON, as it is a volunteer process initiated by a website but they largely met quality and transparency criteria defined by HONcode and contained information about health topics underrepresented in a corpus of HONcode certified web sites.

We have also seen that few participants selected the same results for the same scenarios, though there were some results, which were commonly chosen by the participants. It seems that the concept of relevancy is highly subjective and differs from one user to another. Possible relationships with previous health knowledge of end users should be investigated.

The study has numerous limitations related to sample, methods and set up. First of all, a convenience sample chosen does not represent the general population. Follow-up evaluations are being conducted in 2014 to eliminate this bias with a larger sample size. The tasks proposed were mostly exploratory (both learning and investigating), while end-users often simply look up different definitions. We used keywords queries, which are more common, but excluded the possibility of natural language queries, users could indeed choose to type a different query in a usual settings.

In general, we can conclude that the search results provided by Google have been preferred due to wider coverage of resources and lack of verification by the participants with regard to the trustworthiness of the web pages. Results obtained in the current study demonstrated that awareness and skills amongst the medical students still need to be improved. The general public would likely have lower general and health literacy than a cohort of medical students, so it is possible that results obtained using a more heterogeneous and representative cohort would demonstrate an even lower prioritization of quality than was demonstrated in [8].

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References

[1] Fox S, Duggan M. Health Online 2013. Washington, D.C. : Pew Research Center's Internet & American Life Project, 2013.

[2] Pletneva N, Vargas A, Boyer C. D8.1.1. Requirements for the general public health search. 2011.

[3] Boyer C, Baujard V, Geissbuhler A. (2011). Evolution of health web certification through the HONcode experience. Stud Health Technol Inform. , 169:53-7.

[4] Baroz F., Boyer C., Gschwandtner M., Goeriot L., Hajic J., Hanbury A., Kritz M., Leixa J, Palotti J., Pletneva N., Ruiz de Catañeda R., Sachs A., Samwald M., Schneller P., Stefanov V., Uresova Z. D10.1 Report in user tests with initial search system. 2013.

[5] Fox S. (2011). Health Topics. Washington, D.C.: Pew Research Center's Internet & American Life Project.

[6] Feufel MA, Stahl SF. (2012). What do Web-Use Skill Differences Imply for Online Health Information Searches? J Med Internet Res , 14(3):e87.

[7] Christmann S. EuroHealthNet. (2005). Health Literacy and Internet. Recommendations to promote Health Literacy by the means of the Internet.

[8] Birru MS, Monaco VM, Charles L, Drew H, Njie V, Bierria T, Detlefsen E, Steinman RA (2004). Internet Usage by Low-Literacy Adults Seeking Health Information: An Observational Analysis. J Med Internet Res , 6(3):e25.

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A perspective of adaptation in healthcare

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Abstract. Emerging new technologies in healthcare has proven great promises for managing patient care. In recent years, the evolution of Information and Communication Technologies pushes many research studies to think about treatment plan adaptation in this area. The main goal is to accelerate the decision making by dynamically generating new treatment due to unexpected situations. This paper portrays the treatment adaptation from a new perspective inspired from the human nervous system named autonomic computing. Thus, the selected potential studies are classified according to the maturity levels of this paradigm. To guarantee optimal and accurate treatment adaptation, challenges related to medical knowledge and data are identified and future directions to be explored in healthcare systems are discussed.

Keywords. Treatment adaptation, personalized decision, autonomic computing, challenges

Introduction

Clinical Decision Support Systems (CDSS) [1] have shown great efficiency in managing patients' health and providing personalized treatment based on Information and Communication Technologies (ICT). The main goal of CDSS is to assess clinical staff to take the right decision by providing relevant information about patients and clinical knowledge to enhance patient care. The development of CDSS [2] may focus on monitoring (provide what is true about a patient including the treatment history and patient profile), diagnosing patient health (decide which disease the patient has), and generating clinical recommendations (define the appropriate treatment based on patient profile). However, generating personalized treatment requires taking into consideration both patient conditions and environment factors that influence response to therapy. To provide the appropriate treatment plan and to avoid health complications, new mechanisms that dynamically monitor, detect unexpected situations and adapt the current treatment are required.

In this paper, we analyse the different approaches dealing with treatment adaptation and personalization in medicine. We classify existing approaches relative to the autonomic computing maturity levels [3,4]. The autonomic computing (AC) is a paradigm introduced by IBM in 2001. Inspired by the human nervous system, an autonomic system is able to continuously monitor and control the managed elements in order to handle events that may be analysed as requirements for adaptation. Thus, by

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mapping this definition in the healthcare domain, the patient treatment adaptation refers to the ability to dynamically predict and/or detect unexpected situations (e.g. treatment execution failure, environment changes, etc.) and to adjust or modify the current personalized treatment plan (managed element) according to the patient profile.

Following that, we detail the classification based on the autonomic computing. Then, we outline the trends and challenges of patient treatment adaptation. Finally, we discuss how our research directions can cope with some of these challenges.

1. Methods

We reviewed studies published between 2005 and 2013 by addressing the fields of treatment adaptation and clinical decision support. We searched scientific publications in *Pubmed*, *IEEE*, *ACM*, *ScienceDirect* and *Springer* libraries using different combinations of the following keywords: *"context aware, treatment personalization/adaptation, clinical pathway, decision making, automated recommendations, knowledge-based clinical decision support system, and challenges in CDSS"*. We selected publications from a restricted number of journals from the biomedical domain such as *Journal of Biomedical Informatics*, *IEEE Transactions on Information Technology in Biomedicine*, *Artificial Intelligence in Medicine, British Medical Journal, Journal of Medical Systems,* and *Decision Support Systems*.Moreover, we systematically analysed the reference list of the selected publications in order to identify relevant references. We made a first investigation to compile a first list of the pre-selected papers searching for those dealing with "*automating*", "*adaptation*" or "*personalization*" of treatment plan in order to improve the patient care. We excluded studies focusing on diagnostic and those that were too generic or lacking the description of decision support content and adaptation. Finally, the selected papers were classified according to the autonomic computing maturity levels and components.

2. Results

We found that the automation of the personalized treatment is evolving towards the implementation of adaptive treatment plan. Figure 1 portrays the classification of the selected papers based on the autonomic computing maturity levels, the autonomic manager components and the managed elements. From our vision, the managed elements can be either the patient treatment or the healthcare resources and business process. Thus, the adaptation of patient-specific treatment refers to changing their life style [8] and advises about patient behaviour [7] or/and adjusting the pharmacological plan as presented in [5, 6, 8, 9, 10, 11, 13, 14]. The approaches presented in [5, 10, 12] are interested in the adaptation of the healthcare business process which mainly concerns the definition of tasks to be executed in the patient treatment workflow such as laboratory tests, ECG test, etc. The autonomic computing includes the autonomic manager involving four components: *Monitoring*, *Analysis*, *Planning* and *Execution*. These components have access to a common knowledge which contains medical policies and rules, symptoms, treatments etc.

The *Monitoring* captures the data about the managed elements and stores it in the knowledge. We noted that in healthcare, the *Monitoring* can be achieved manually via physicians or automatically through medical sensors. The *Analysis*, which refers to

diagnostic in medicine, detects or predicts possible unexpected situations and identifies the cause based on symptoms. If detected, it sends alarms to the *Planning* which implements methods for selecting the personalized treatment according to the defined policies. Finally, the *Execution* performs the new treatment plan and stores the enactment of the treatment in the knowledge. Also, the *Execution* can either be automatically done or needs the physician's approval for enacting the treatment.

Automating these functions might demonstrate five maturity levels- *basic*, *managed*, *predictive*, *adaptive* and *autonomic* - depending on the business requirements [3]. The *basic* level refers to manually managing the patient treatment. Collecting patient data, analyzing and taking decisions about the treatment plan are done by the physicians. On the *managed* level, new technologies such as sensors are introduced to collect disparate data, but it is the role of the physicians to diagnose and foresee any new treatment for the patient. On the *predictive* level, the system can automatically analyze the data and provide general recommendations about the patient treatment. In this case, the physician's approval is required. On the *adaptive* level, the system is not limited to generating general recommendations but it also provides specific to-do actions. If the treatment is patient-specific, the physician approval is crucial for an automatic execution. And finally, the highest maturity level is the *autonomic*. Based on medical goals and requirements, the system is able to take the right decision and learn to create new policies to adapt the treatment plan.

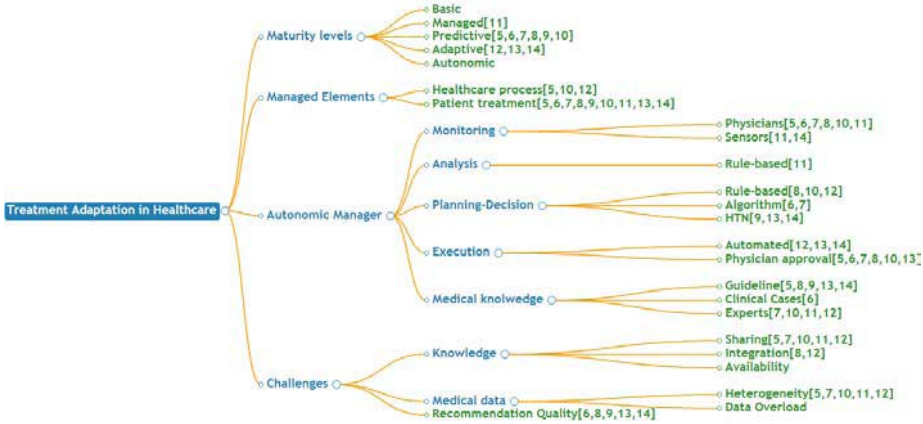


Figure 1.A classification of treatment plan adaptation according to autonomic computing

As presented in Figure 1, automating the AC functions in healthcare can reach the managed level [11], predictive level [5, 6, 7, 8, 9, 10] or adaptive level [12, 13, 14]. Lasierra et al. [11] adopted the medical sensors to remotely monitor patients, detect unexpected situations and alert physicians in order to establish the personalized treatment. In the context of K4CARE project, a Case Profile Ontology (CPO) [5] is provided and used to personalize chronic disease. However, the integration of the generated interventions is manually achieved by physicians. Yao and Kumar [10] proposed a CDSS that automatically generates the recommendation concerning the patient treatment plan based on SWRL-rules. Ontology is used to acquire the patient and resources context. González-Ferrer et al. [9] developed a system based on a planning technique named Hierarchical Task Network (HTN) to automatically generate the best treatment plan. Huang et al. [6] proposed a recommendation service that matches patient status with medical interventions based on mathematical model. Grando et al. [8] proposed a state-based goal framework associated to an aggregation

function based on the argument-weight. These proposed solutions mainly differ in the Planning-Decision approach. Both Huang et al. [6] and Emerencia et al. [7] provided sophisticated algorithms to calculate the best recommendation, whereas Grando et al. [8] and Yao and Kumar [10] conceived a rule-based approach to generate recommendations. From our vision, based on the autonomic computing, these systems have reached the predictive maturity level since they are able to generate recommendations. The physician approval is still required.

Fewer works were presented on the adaptation level. Alexandrou et al. [12] proposed an ontology based solution able to automatically observe the execution of each task specific to a patient treatment workflow process and to dynamically adapt the treatment schema concerning the healthcare business process. In contrast to [12], Milla-Millán et al. [13] complemented the approach proposed in [9] and generated the patient-specific treatment plan. They contributed by providing an approach based on PELEA architecture in order to enable the continuous planning and monitoring of the patient state during the treatment enactment. The system provides specific actions related to the patient treatment to be taken. After physician approval, the new treatment is automatically incorporated in the system and the monitoring of the new treatment starts again. The work of Sánchez-Garzón et al. [14] represents a continuity of this work by integrating the monitoring of patients' daily activities in an ambient environment. Based on the Clinical Practise Guidelines, the system is able to repair the current plan and to automatically update the medical record.

To conclude, the highest maturity level reached in these works is the adaptive level. The main goal of the adaptive level is to facilitate and accelerate the decision making process in order to guarantee an optimal patient care by automatically detecting deviations and repairing the treatment plan. The physician approval remains necessary for the treatment enactment.

3. Discussion

Behind managing and adapting the patient treatment plan, a set of challenges need to be considered for improving the efficiency of CDSS. For instance, the work presented in [6, 8, 9, 13, 14] mainly focused on the recommendation quality based on advanced methods such HTN or the mathematical model when generating recommendations. The works presented in [5, 7, 10, 11, 12] pointed out the importance of considering the semantic heterogeneity by providing a common model based on Semantic Web Technology and ontologies when acquiring the information about resources, patient and/or medical knowledge including medical problems. Obviously, Semantic Web is not limited to solve the heterogeneity challenge but also opens the door to share the medical knowledge, which represents one of the main challenges in healthcare. Certainly in such systems, it is not enough to guarantee only the sharing. The knowledge availability, which is not considered in these works, remains a requirement [15] in healthcare knowledge management. Another challenge that has already been mentioned in [16] is knowledge integration and update. This challenge was partially covered in [8, 12], where it was described how experts can add new rules from a user-friendly interface. Moreover, the presented works seldom emphasize the challenges owing to the ICT evolution that may impact the treatment plan accuracy. With the connected medical devices and sensors, the amount of generated data will keep increasing. By 2020, the number of medical mobile connected devices is expected to

increase by 100% to nearly 12 billion [17]. Big data remains a challenge to be considered in future works.

To address these challenges, we aim at providing a multi-layer management architecture dealing with medical data, knowledge and services with different maturity levels based on the autonomic computing paradigm. Our first challenge will focus on providing a big data solution that deals with medical data velocity and variety which systematically impact the medical decision, and on implementing mechanisms that identify high quality of data and extract useful knowledge from the generated data. Since knowledge is the main basis for adaptation and decision making, our second challenge will mainly concentrate on providing knowledge that is shareable, and that also is accessible anytime by participants from anywhere who are involved in patient care. Thus, the Knowledge as a Service (KaaS) approach coupled with the semantic web is envisaged in our work to take the advantages of availability, accessibility and sharing the medical knowledge.

References

[1] Kawamoto K, Houlihan CA, Balas EA, Lobach DF. Improving clinical practice using clinical decision support systems: a systematic review of trials to identify features critical to success. British Medical Journal. 2005;330(7494):765.
[2] Wright A, Sittig DF. A four-phase model of the evolution of clinical decision support architectures. International Journal of Medical Informatics. 2008, 77(10):641-9.
[3] Jacob B., Lanyon-Hogg R, Nadgir DK, and Yassin AF. A Practical Guide to the IBM Autonomic Computing Toolkit. IBM Redbooks ;2004.
[4] KephartJO. and ChessDM. The vision of autonomic computing, *Computer (*2003*)*, 41-50.
[5] Riaño D, Real F, López-Vallverdú J A, Campana F, Ercolani S, Mecocci P, Annicchiarico R, Caltagirone C, An ontology-based personalization of health-care knowledge to support clinical decisions for chronically ill patients, Journal of Biomedical Informatics, 2012; 45(3):429-46.
[6] Huang Z, Lu X, Duan H. Using Recommendation to Support Adaptive Clinical Pathways. Journal of Medical Systems. 2012; 36(3):1849-60.
[7] Emerencia A, van der Krieke L, Sytema S, Petkov N, Aiello M. Generating personalized advice for schizophrenia patients, Artificial Intelligence in Medicine.2013; 58(1):23-36.
[8] Grando MA, Glasspool D, Boxwala A. A. Argumentation logic for the flexible enactment of goal-based medical guidelines, Journal of Biomedical Informatics. 2012; 45(5):938-49.
[9] González-Ferrer A, ten Teije A, Fernández-Olivares J, Milian K. Automated generation of patient-tailored electronic care pathways by translating computer-interpretable guidelines into hierarchical task networks, Artificial Intelligence in Medicine. 2013; 57(2):91-109.
[10] Yao W, Kumar A, CONFlexFlow: Integrating Flexible clinical pathways into clinical decision support systems using context and rules, Decision Support Systems. 2013; 55(2):499-515.
[11] Lasierra N., Alesanco A., Guillén S., García J. A three stage ontology-driven solution to provide personalized care to chronic patients at home, Journal of Biomedical Informatics.2013; 46(3):516-29.
[12] Alexandrou, DA.,Skitsas, IE.,Mentzas, G.N., A Holistic Environment for the Design and Execution of Self-Adaptive Clinical Pathways, Information Technology in Biomedicine, IEEE Transactions on. 2011;15(1):108-18.
[13] Milla-Millán G, Fernández-Olivares J, Sánchez-Garzón I, Prior D, Castillo L. Knowledge-Driven Adaptive Execution of Care Pathways Based on Continuous Planning Techniques, Process Support and Knowledge Representation in Health Care, Springerlink. 2012; 42-55.
[14] Sánchez-Garzón I, Milla-Millán G, Fernández-Olivares J, Context-Aware Generation and Adaptive Execution of Daily Living Care Pathways. Ambient Assisted Living and Home Care. 2012; 362-370.
[15] Revere D, Turner AM, Madhavan A, Rambo N, Bugni PF, Kimball A, Fuller SS., Understanding the information needs of public health practitioners: a literature review to inform design of an interactive digital knowledge management system, Journal of Biomedical Informatics. 2007;40(4):410-21.
[16] Sittig DF, Wright A, Osheroff JA, Middleton B, Teich JM, Ash JS, Campbell E, Bates DW. Grand challenges in clinical decision support. Journal of Biomedical Informatics. 2008; 41(2):387-92.
[17] https://blogs.oracle.com/java/entry/mhealth_powered_by_java1, last visit January17, 2014.

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Telepulmonology and telespirometry

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Abstract. Taking and interpreting spirometry tests has proven difficult in primary care practice. This may lead to mis- or underdiagnosis of pulmonary diseases, among others chronic obstructive pulmonary disease.. Telespirometry and telepulmonology consultation (TPC) may play a role in monitoring and improving the quality of the spirometry tests, supporting GPs in interpreting spirometry test results and reducing the number of physical referrals to the pulmonologist. In telespirometry up to 10% of spirometry results uploaded by GPs were randomly sent to a pulmonologist. Both the GP or practice nurse and the pulmonologist interpreted the spirometry results and gave their diagnostic findings. Additionally the pulmonologist assessed the quality of the test. In TPC a GP could digitally consult a pulmonologist for advice or referral of patients. On sending and closing the TPC consult the GP was presented a number of questions. Based on these questions the percentage of prevented physical referrals and the educational effect experienced by the GPs were determined. Almost a third of the 227 telespirometry tests was of *Moderate* or *Bad* quality. The Kappa of the interobserver agreement on diagnostic findings between GP and pulmonologist was 0.38. Between April 2009 and January 2014, GPS sent 4.488 TPCs to pulmonologists. Sixty-nine percent of the TPCs were sent to gain advice, the others were sent in order to prevent a physical referral. Overall telepulmonology reduced the number of physical referrals by 22%. In 90% of the TPCs the GPs indicated they had learned from the consult.

Keywords. telepulmonology, telespirometry, quality, efficiency

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a chronic lung disorder that currently constitutes the fourth leading cause of death worldwide and is thought to be the third leading cause of death by 2030 [1]. Spirometry is required to diagnose COPD. It is a lung function test that is commonly conducted in general practice to diagnose and monitor patients with respiratory diseases.

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COPD is often mis- or undiagnosed, partly due to the fact that taking spirometry tests of sufficient quality and correctly interpreting them has proven difficult in primary care practice [2-5].

In a study of White et al. clinically significant disagreements in the interpretation of spirometry test results between general practitioners (GPs) and pulmonologists were found in 49 out of 168 tests (Kappa = 0.39) [6]. In another study, in 20% of the 1.044 patients diagnosed with COPD in primary care practice the spirometry test results did not indicate COPD [5].

Telespirometry is a telemedicine application aimed to support in monitoring, and eventually improving, the quality of the spirometry tests taken in primary care practice. In telespirometry up to 10% of the spirometry tests are randomly send to a pulmonologist who then comments on the quality of the spirometry tests. Complementary to this telepulmonology is a telemedicine application in which the GP is supported by a pulmonologist in interpreting spirometry tests. Telepulmonology may also play a role in decreasing the number of physical referrals of patients to the pulmonologist.

The Italian Alliance study assessed the feasibility of store-and-forward telepulmonology and found it to be well accepted and easily performed by a large number of GPs [7]. Two other studies concluded that the web-based remote support of pulmonologists improved the quality of spirometry tests taken in primary care practice [8-9].

As described, the goal of telespirometry is to monitor and eventually improve the quality of the spirometry tests taken in primary practice. This study only assessed the quality of the spirometry tests according to the pulmonologist and compared the diagnostic findings of the GP or practice nurse with the diagnostic findings of the pulmonologist. The effect of telespirometry on quality improvement of the spirometry tests taken by GPs was outside the scope of this study.

Telepulmonology aims to support GPs in diagnosing patients and setting treatment plans, with or without the intention to prevent a physical referral of a patient to the pulmonologist. We therefore assessed whether the use of telepulmonology in daily primary care practice helped the GP in his decision making on diagnoses and treatment plans, whether the GP learned from the telepulmonology consult and whether physical referrals of the patient were prevented.

1. Methods

1.1. Inclusion

All GPs in the Netherlands, in possession of a spirometer that could be linked to a computer, could start using telepulmonology. The GPs themselves decided for which patients they found telepulmonology suitable. All data were collected from routine clinical practice. Eligible patients gave oral informed consent for the telepulmonology consultation.

1.2. Telespirometry

Spirometry tests were taken by a grader (GP or practice nurse) and subsequently uploaded as PDFs to a secured web-based teleconsultation system (KSYOS

TeleMedical Centre, Amstelveen, The Netherlands). The grader then interpreted the test results and added the diagnostic findings and some other patient data. At random up to 10% of these spirometry tests were sent to one out of 8 pulmonologists. The pulmonologist assessed the quality of the spirometry test and provided a diagnosis based on the spirometry test results. Additionally the pulmonologist could add comments or provide tips to GPs on how to improve the quality of the test. The telespirometry test could be converted into a telepulmonology consult (TPC) if the GP had a specific question to the pulmonologist.

In interpreting the spirometry results, both the grader and the pulmonologist could choose from 9 common diagnostic categories of pulmonary diseases. Kappa was calculated to assess the interobserver agreement on diagnostic findings between the grader of the spirometry test and the pulmonologist.

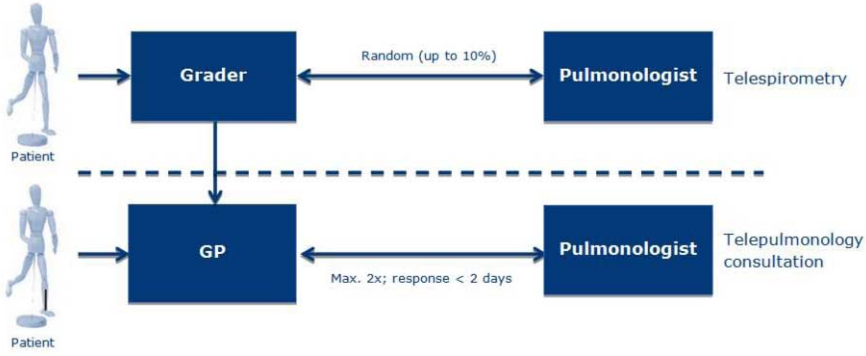


Figure 1. Overview of telespirometry and telepulmonology

1.3. Telepulmonology consultation

If a GP had a specific question a TPC could be sent to the pulmonologist. This could be done for two reasons: to ask for advice on a patient's diagnosis or treatment or to prevent a physical referral to the pulmonologist. A TPC consisted of a maximum of four PDFs of a patient's spirometry test results, medical history, relevant medication and the question of the GP to the pulmonologist. On sending (Q1) and closing (Q2,Q3,Q4) the TPC the GP received the following questions:

- Q1: Without telepulmonology, would you have physically referred this patient to the pulmonologist?
- Q2: Do you now refer this patient physically to the pulmonologist?
- Q3: Did you learn from the pulmonologist's response?
- Q4: Are you and your patient helped with the pulmonologist's response?

Based on Q1 and Q2 the percentage of prevented physical referrals could be calculated. A physical referral was prevented if a GP answered Q1 with *Yes* and Q2 with *No*. Q3 and Q4 could be answered with *Yes, No* or *Slightly*. Q3 informed us on the educational effect that was experienced by the GP's when using telepulmonology.

The pulmonologist received an e-mail notification as soon as a new TPC had arrived. The pulmonologist had to response within two working days. After receiving

the pulmonologist's answer, the GP could start one more round of communication with the pulmonologist.

2. Results

2.1. Telespirometry

Between December 2011 and January 2014, 227 telespirometry tests were presented to 8 pulmonologists. The quality of the spirometry test was classified as *Good* in 69% of the tests, *Moderate* in 23% of the tests and *Bad* in 8% of the tests. The Kappa for the interobserver agreement on patients' diagnostic findings was 0.38.

2.2. Telepulmonology consultation

Between April 2009 and January 2014, 4.488 telepulmonology consultations (TPCs) were sent by 342 GPs to 43 pulmonologists. The answers of the GPs on questions posed were available for 3.126 TPCs. For thirty-one percent (*n*=955) of these TPCs GPs indicated that these TPCs were sent to prevent a physical referral to the pulmonologist. Fifty-nine percent (*n*=565) of these 955 TPCs indeed prevented a physical referral of the patient to the pulmonologist. For 69% (*n*=2171) of the TPCs, GPs indicated that these results were sent to obtain the advice of a pulmonologist, not to prevent a physical referral. These patients would thus not have been physically referred without telepulmonology. However, as a consequence of using telepulmonology, sixteen percent of these 2171 patients was physically referred to the pulmonologist (*n*=354). When taking these extra physical referrals into account the use of telepulmonology lead to an overall decrease of physical referrals of 22%.

In 72% (*n*=2241) of the TPCs the GP indicated that (s)he and the patient were helped with the pulmonologist's response, in 24% (*n*=746) of the TPCs, they felt slightly helped and in 4% (*n*=139) of the TCPs, the pulmonologist's response did not help them. In 90% (*n*=2807) of the TPCs the GP indicated (s)he had (slightly) learned from the answer of the pulmonologist. In sixty-eight percent (*n*=2120) of the TPCs, the GP answered Q3 with *Yes*, in 22% (*n*=687) with *Slightly* and in 10% (*n*=319) with *No*.

3. Discussion

Approximately two thirds of the spirometry tests were classified as *Good* by the pulmonologist, meaning the quality of a third of the spirometry tests was *Moderate* or *Bad.* Additionally, the interobserver agreement between graders and pulmonologists on patients' diagnostic findings was only moderate. These results are consistent with the results of two other studies, illustrating an ongoing need for support among primary care workers in interpreting spirometry tests [6, 10].

The high percentage of TPCs sent by GPs for gaining advice from a pulmonologist likewise confirms a continuous need of support among GPs in interpreting spirometry results. In 90% of the TPCs the GP indicated (s)he had learned something from the TPC and in over 95% of the TPCs the GP indicated (s)he and the patient were helped with the response of the pulmonologist.

Telepulmonology thus seems an effective way to support GPs in interpreting spirometry results, making treatment decisions and diagnosing patients.

Additionally telepulmonology showed to decrease the number of physical referrals to the pulmonologist. Of the TPCs sent by GPs to pulmonologists to prevent a physical referral of patients, almost 60% indeed prevented a physical referral. The overall reduction in physical referrals was 22%, due to extra referrals in the group of TPCs sent by GPs with the primary aim to gain advice from the pulmonologist. On advice of the pulmonologist, these patients, who the GP would not have physically referred without telepulmonology, were physically referred to the pulmonologist. . Telepulmonology thus did not only reduce the number of unnecessary physical referrals, but also triaged the right patients to be physically referred to a pulmonologist.

Making the quality of the spirometry tests taken by GPs transparent can help in determining who of the GPs could benefit from additional training in taking spirometry tests of sufficient quality. Future research could study whether the combination of telespirometry and targeted additional trainings are effective in increasing the quality of the GPs spirometry tests. When these GPs would succeed in taking spirometry tests of satisfying quality, they may likewise be more successful in correctly interpreting the results and deciding on a patient's diagnosis and treatment. After targeted training of GPs performing less in taking spirometry tests, the impact of their learning on their ability to make wright decisions on patients' diagnosis and treatment could be studied.

When such learning effects among GPs could be achieved, the need for TPCs could diminish while the number of patients who would not be seen by a pulmonologist, but would nevertheless be diagnosed and treated adequately would increase.

References

[1] World Health Organization. http://www.who.int/mediacentre/factsheets/fs310/en/

[2] H. Sandelowsky, B. Stallberg, A. Nager and J. Hasselstrom, The prevalence of undiagnosed chronic obstructive pulmonary disease in a primary care population with respiratory tract infections – a case finding study, *BMC Fam Pract* **12** (2011):122.

[3] T. Takahashi, M. Ichinose, H. Inoue, K. Shirato, T. Hattori and T. Takishima, Underdiagnosis and undertreatment of COPD in primary care settings, *Respirology* **8** (2003):504-8.

[4] D. Bellamy and J. Smith, Role of primary care in early diagnosis and effective management of COPD, *Int J Clin Pract* **61** (2007):8,1380-9.

[5] M. Strong, A. Green, E. Goyder, G. Miles, A.C.K. Lee, G. Basran and J. Cooke, Accuracy of diagnosis and classification of COPD in primary and specialist nurse-led respiratory care in Rotherham, UK: a cross-sectional study, *Prim Care Respir J* **23 (**2014);x,x-x.

[6] P. White, W. Wong, T. Fleming and B. Gray, Primary care spirometry: test quality and the feasibility and usefulness of specialist reporting, *Br J Gen Pract* 2007,701-5.

[7] M. Bonavia, G. Averame, W. Canonica et al. Feasibility and validation of telespirometry in general practice: the Italian "Alliance" study. *Respir Med* **103** (2009),1732-7.

[8] F. Burgos, C. Disdier, E. Lopez de Santamaria et al. Telemedicine enhances quality of forces spirometry in primary care. *Eur Respir J* **39** (2012):6,1313-8.

[9] N.M. Malanda, E. Lopez de Santa Maria, A. Gutierrez, J.C. Bayon, L. Garcia and J.B. Galdiz, Brief communication Telemedicine spirometry training and quality assurance program in primary care centers of a public health system, *Telemedicine and eHealth* **20 (**2014**)**:4,1-5.

[10] P.J.P. Poels, T.R.J. Schermer, R.P. Akkermans et al. General practitioners' needs for ongoing support for the interpretation of spirometry tests. *Eur J Gen Pract* **13** (2007),16-9.

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A Computational Infrastructure for Evaluating Care-coordination and Telehealth Services in Europe

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Abstract. This paper presents the computational framework that is employed for the analysis of health related key drivers and indicators within ACT, a project aiming to improve the deployment of Care Coordination and Telehealth services/ programmes across Europe, through an iterative evidence collection-evaluation-refinement process. An open-source solution is proposed, combining a series of established software technologies. The paper focuses on technical aspects of the framework and presents a worked example of a usage scenario.

Keywords. Data collection, survey, evaluation, telehealth, care coordination

Introduction

Managing the disability, needs and expectations of patients with chronic diseases and their social and financial consequences is an important issue the European national health systems are facing. In Europe today, there are at least 10 million patients with heart failure [1,2], 20 million with COPD [3] and 60 million with diabetes [4]. The direct financial cost of managing these conditions is enormous (e.g. in EU the annual cost for diabetes is estimated at $100 billion [5]). Integrating clinical management with telehealth services could improve both the quality and the efficiency of care, leading to benefits for patients, health professionals and services while constraining costs.

Many studies have highlighted the value of Coordinated Care as well as Telehealth systems (CC&TH) on the aid of chronically ill patients [6]. However, existing CC&TH systems are limited to pilot or small range installations. In order to maximize the beneficial effects of CC&TH, structural and organizational reforms of the existing health care systems are required. The ACT programme (http://www.act-programme.eu) is the first EU-wide project to tackle such challenges, aiming to produce and distribute guidelines for successful exploitation of CC&TH over Europe. ACT focuses on chronic pathological conditions, such as heart failure, diabetes, chronic obstructive pulmonary disease, and comorbidities. The main objectives of ACT are: i) to understand the working mechanism of existing CC&TH services, by gathering data from 5 regions

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already deploy such services (Basque Country, Catalonia, Groningen, Lombardy and Scotland) and ii) to produce and share with European healthcare authorities a set of guidelines that facilitate the deployment of high-quality CC&TH services in EU.

A major requirement for this goal has been the organisation and harmonisation of health-related information. In this respect, gathered data are organized as *Key Drivers* (i.e. generic aspects of healthcare programmes determining their quality with respect to CC&TH) and *Key Indicators* (i.e., measurable healthcare outcomes used for assessing the drivers) [7]. In order to explore the relation between the key drivers and indicators, the programme has developed an analysis framework, called the *ACT Evaluation Engine*. Besides the analysis requirements, iteratively provided by the end-users, a basic pillar of the Evaluation Engine is the computational backbone that will allow centralised data collection, web-based analysis and visualisation in a secure, flexible and user-friendly manner. Web-based analytics constitute an active field of research and development in the ICT domain; however few applications have been deployed in the health information technology [8]. In this paper we present a prototype design and implementation of the Evaluation Engine's computational infrastructure that is based on open source technology, in order to support the required health information management and analysis under diverse criteria of regional distribution, health programmes, user needs and privileges, as well as indicators.

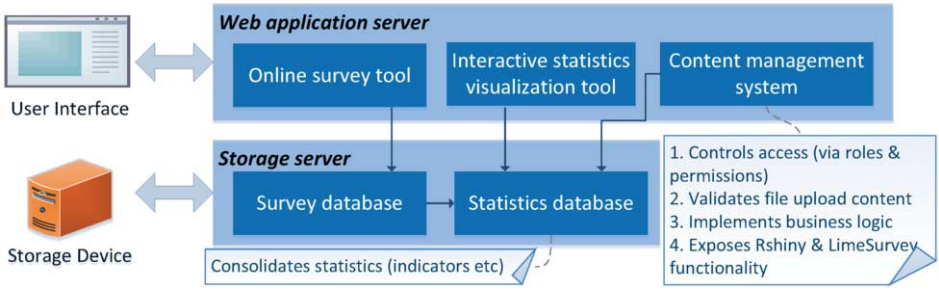


Figure 1. Overall system architecture

1. Methods

The main system functionality specifies that data are entered in the system using two distinct methods: *uploading structured excel files* and *filling out online surveys*. Both of these user interaction pathways are integrated in a unified web system, based on open source components. This system handles the data validation, consolidation, analysis and gives emphasis on visualising the results in an interactive fashion. Fig. 1 depicts the system architecture, identifying its basic modules, the *Storage server* and the *Web application server*, as well as their respective components. Since the Storage Server can be easily implemented by off-the-shelf data storage technologies, in this paper we focus on the components of the Web Application Server, which are of most interest.

1.1. Web Application Server Components

Content management system (CMS). CMSs are considered as one of the most popular tools to build a web application. Using a CMS, the main functionality is already built in

and needs only to be configured to the specific application's needs. Specifically, this built in functionality includes a) keeping the content of the web site updated, which can be accomplished by users, not needing extra development, and b) defining roles, privileges and permissions is integrated in the CMS's normal data model. Additionally, its modular architecture allows easy integration of new functionalities, often developed by the CMS's community.

CMS provides the single point of final user interaction with the system. According to her defined permissions, the user can upload regional data, fill out the online surveys, and access data analysis and visualizations, through **one single interaction point**, using **one account**, having a **unified transparent interaction experience**. To implement this module, we adopted a widely used open source content management system, Drupal. We chose Drupal because it has a mature yet broad spectrum of modules and supported functionality, and an active development community. Furthermore, its modular structure allows extending the already provided functionality and the integration with other informational systems.

Online survey tool. The online survey tool is used to enable online surveys' creation, design and management. While there are many web platforms providing such services, we chose LimeSurvey (http://www.limesurvey.org/en/) as our online survey tool. One of its important features is that it can be integrated with Drupal by using an already built module which has a wide user basis and therefore can be considered thoroughly tested. Therefore, the access to the survey is controlled through the central access mechanism incorporated in Drupal, using the same user credentials (username and password) with Drupal. The use of LimeSurvey during the online survey filling is totally transparent to the end user. Moreover, it is a free software tool, and thus it can be setup as a stand-alone server in our physical server, having the total process control.

Interactive statistics & visualization tool. Visualizing results in interactive fashion is one of ACT primary goals. The interactive visualization tool is implemented using R Studio-Shiny server [http://www.rstudio.com/shiny]. R-Shiny is an open source software package designed to integrate the power of statistical processing language of R with interactive web applications. Shiny allows simple HTML pages to interactively execute R scripts and takes advantage of R's visualizing capabilities, in order to graphically present the analysis results on the webpage. Shiny applications can be further extended by using JavaScript and jQuery. The R-script execution and the use of the analysis and visualization mechanisms inside HTML pages are controlled via the User Interface (UI) rendering engine of the R-Shiny web server.

The HTML pages produced by R-Shiny have been integrated with the basic CMS by a custom in-house Drupal module. Therefore, access to the data analysis functionality can be controlled via the CMS control access mechanism, and the use of Shiny during the interactive visualization of analysis results is transparent to the end user, who navigates through a single unified web application.

1.2. Evaluation Engine Workflow

The data workflow in our system is modeled using the successive steps of data entry, validation, storage, integration and interactive statistical analysis and visualization.

Data Entry and Validation. In the proposed platform, the data can be entered in the system via two endpoint procedures, the online survey and uploading files following predefined templates. Both services are accessible for the user using a single web

access point, the CMS web site. Data validation is very crucial in preventing errors, and thus is placed early in the data workflow. Validation pertains to both data entry points,. For the online surveys, javascript-based validation checks the format of each data field entry. For the file upload process, a special CMS module parses the file, as soon as it is uploaded, and applies a custom set of rules in order to validate the data contained, with respect to the template followed. In case of an error, the user is guided to immediately correct the error and reenter the correct data.

Storage and Data Integration. When the user fills an online survey, the data are saved in the survey database. As soon as the whole survey has been filled, the survey data are automatically transferred to the so called statistics database. When a user uploads regional data in a form of an excel file, data are validated and saved in the statistics database where they are consolidated with the survey data. The Data Integration step is triggered each time an online survey has been submitted. As a result, all useful data are consolidated in a unifying database, the Statistics database, further used as the single data source of statistical analysis and visualization process.

Statistical analysis and visualization. In this ending step, the statistical analysis is performed. The user, according to her access permissions, can select multiple variables from different regions, saved in the Statistics database, and process them in a custom way. R shiny interface enables interactive selection of data, application of analysis methods, and export of results.

2. Results

In order to evaluate the whole architecture we developed a prototype according to a scenario where a user fills the survey and access the interactive analysing results view.

Supposing a region representative logs into the system using her username and password, she will see the menu option to “Fill Survey”. Clicking on the specific option and following the specific instructions (selecting language etc.) she will be led to the survey filling form, shown in Fig. 2.a.

When the user completes the online survey, the data are stored in the *statistics database.* Then she could access the interactive results analysing page through the menu option “Data Analysis” (Fig. 2.b), according to the user’s permissions. The user could define the analysis indicators and the respective parameters to adjust the analysis procedure. The data that are available for the analysis depends on the permissions each user has on the ACT programme.

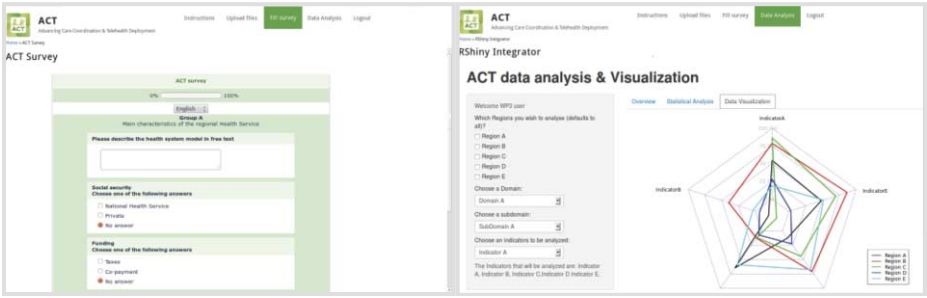


Figure 2. a) Executing an online survey, b) Interactive analyzing results page

3. Discussion

This paper presents the computational backbone of the ACT evaluation engine, supporting the data management and analysis methodology of ACT. Based on user input and requirements from different regions and domains, the functionality will be iteratively enriched, to support analysis at multiple dimensions.

Among the main functionalities to be included in the next period are the refinements of the data upload validation engine and the statistical processing of the consolidated data. These improvements will follow the data needs of the ACT project as they have not yet been finalized. Moreover, we plan to add many visualization capabilities focusing on user interaction. For example, we intend to add the capability of using predefined analysis scenarios and saving custom scenarios defined by user.

This computational infrastructure will be used and evaluated as part of the ACT's Evaluation Engine, and is expected to adequately serve as a tool for the generation of useful new knowledge on the organization of ehealth services. Furthermore, based on the generalization ability of the Evaluation Engine design methodology, the proposed infrastructure is planned to be extended and evaluated in other health-related domains, where web analytics are required, e.g. in the field of health technology assessment.

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References

[1] McMurray JJ, Adamopoulos S *et al.* ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012: The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2012 of the European Society of Cardiology. *Eur Heart J* 2012;33(14): 1787-1847.
[2] Braunschweig F, Cowie MR *et al.* What are the costs of heart failure? *Europace* 2011;13:ii13–ii17.
[3] Raherison C, Girodet PO. Epidemiology of COPD. *Eur Respir Rev* 2009;18(114): 213-221.
[4] Shaw JE, Sicree RA, Zimmet PZ. Global estimates of the prevelance of diabetes for 2010 and 2030. *Diabetes Res Clin Pr* 2010; 87: 4-14.
[5] Zhang P, Zhang X, *et al.* Global healthcare expenditure on diabetes for 2010 and 2030. *Diabetes Res Clin Pr* 2010: 87: 293-301.
[6] Inglis S, Clark R, *et al.* Structured telephone support or telemonitoring programs for patients with chronic heart failure. *Cochrane Database Syst Rev* 2010: 1-138.
[7] Schonenberg H, Pauws S, *et al.* Evaluation framework for care coordination & telehealth deployment. In *Healthinf2014*, Angers, France; 2014.
[8] Gotz D, Stavropoulos H, *et al.* ICDA: A Platform for Intelligent Care Delivery Analytics. In *AMIA Annu Symp Proc.* 2012, Chicago, USA: 264–273; 2012.

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Disturbing or Facilitating? – On the Usability of Swedish eHealth Systems 2013

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Abstract. As many evaluations show, healthcare organizations do not accomplish the intended effects of their eHealth systems due to inadequate usability. On behalf of the Swedish Ministry of Health and Social Affairs, the usability of current eHealth systems in Swedish healthcare have been analysed from the perspective of healthcare and social service professionals. The objective of the study was to report on current problems, potential solutions as well as to relate these to research in relevant areas. Using a participatory approach, seven workshops were held where researchers within health informatics collaborated with staff from different care providers, representatives of the national associations of health and social care professionals and the national eHealth system vendor organization. This paper presents a foundation for further development of eHealth systems, condensed into 10 issues that the Swedish health and social care professionals find imperative to improve. The study emphasizes that the development of eHealth systems is always a matter of organizational and process development and must be integrated into the care practice improvement process. Further, based on the findings, some identified challenges are discussed.

Keywords. eHealth systems, user participation, Participatory design, healthcare and welfare development, evaluation, validation, usability, patient-centricity.

Introduction

eHealth systems, i.e. information technology (IT) applied in the health and social care sector, has great potential to enhance efficiency, improve quality of life and strengthen innovativeness in health and social care. Extensive resources are currently being invested in eHealth development at local, regional and national levels of society. To achieve the maximum benefits from these investments, eHealth systems that really *support* health and social care professionals in their work, focusing on health as an effect of the care and treatment given, are required. However, technology is in health and social care often regarded as a barrier to providing good healthcare in an efficient way [1]. Specifically, insufficient usability of the systems is identified as a major obstacle [1,2,3]. Unfortunately, little effort is put into health information system

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development according to usability requirements and methodology, leading to bottlenecks in eHealth systems when implemented into daily practice [3,5].

1. Background

The Swedish National Strategy for eHealth in Health and Social Care [6] identifies useful and accessible information, as well as decision-making support for staff as important priority areas. In a review (RiR 2011:19), the Swedish National Audit Office concluded that the eHealth strategy has not been able to secure the benefits from the efforts made. Current IT-systems do still not give health and social care professionals access to "the right information at the right time" [7]. The Gartner report [2], commissioned by the Ministry of Health and Social Affairs, indicated that professionals primarily identified a need for improvement of the usability of eHealth systems to increase their utilization. Based on the mentioned evaluations, the Swedish Ministry of Health and Social Affairs acknowledged the need to address usability issues in eHealth from a national perspective [5], which was the starting point for the study presented in this paper; Usability of Swedish eHealth Systems 2013 (USeHS).

2. Method

The national associations of health and social care professionals carried out a joint initiative in the autumn of 2012 to create the project financed by the Ministry of Health and Social Affairs. The aim of the project was to collect and highlight lessons learned and examples of best practice as a basis for improved integration of health and social care providers and their IT support, as well as answering the following questions:

- Which problems do care professionals experience as users of eHealth systems?
- Which solutions do they regard as being most important?
- How do these findings relate to existing research regarding usability in eHealth?

The concept of usability, according to the international standard for usability 9241-11, focuses on a specific user in a specific context performing a specific task [4]. Therefore it is challenging to address usability issues on an overall national level with the aim to create national strategies. Therefore, such an initiative needs to be approached by a bottom-up approach and by involving the real end-users [8].

The research approach of this work is based on three principles; user-centered development, cross-organizational health and social care and real patient-centered processes [8]. Hence, a participatory approach was adopted, inspired by the 'Scandinavian tradition' emphasizing participation in design [9,10,11]. The major Swedish national associations of health and social care professionals were a driving force and members (actual end-users) from each organization were involved from the start of the study. In order to collect data, representatives of health and social care staff, researchers in the area of usability in health informatics, and representatives of suppliers of eHealth systems have participated in nine workshops [8]. In the first workshop researchers, representatives from care profession organizations and the ministry of health set the focus and aim for the following workshops. In workshops 2 and 3 end-users worked together with researchers to identify problems, and propose potential solutions and future work scenarios. The fourth workshop involved vendors,

while workshop 5-7 focused on discussing the results with other researchers and user representatives throughout Sweden. Finally, in workshop 8 the results were prioritized into an action list, and workshop 9 was an open workshop at a national eHealth conference where more feedback and comments were gathered.

3. Results

As a first step, current eHealth usability problems were identified based on users' experiences. After that, potential solutions to the problems were proposed and prioritized in the workshops as well as by representatives of eHealth systems vendors and other Swedish eHealth researchers [5]. In this paper, the focus is not on describing the problems but rather to emphasize what needs to be done in order to improve the situation. Important actions to perform locally, in each healthcare organization, were formulated, as well as suggestions for how to operationalize usability improvement work from a national perspective. Further, examples of eHealth systems and services with high usability for healthcare professionals were identified.

3.1. Ten priorities for improving usability

The development of eHealth systems is always a matter of organizational and process development and must be integrated into the care practice improvement process. To stress this, the USeHS study highlights the following ten priorities for improving usability. Addressing them is imperative in order to capitalize on the potential of eHealth systems.

1. eHealth systems must be managed, evaluated, supervised and continuously optimized in relation to the usability needs of the organization that it is intended to support. There is a need for more collaborative efforts to integrate work processes and eHealth systems into a coherent and meaningful whole.
2. Increased participation of usability experts, health informatics specialists and users is required in the development, implementation and evaluation of eHealth systems. Care professionals must be involved in managing each eHealth project.
3. All health and social care professionals must have a basic understanding of the opportunities offered by eHealth systems, as well as adequate knowledge of how the eHealth systems should be used and how work processes relate to eHealth systems. Training and enhancement of informatics skills must be prioritized in the education and then continue in employment. Education in health informatics must be substantially expanded and take into account sector-independent knowledge in the area of informatics as well.
4. The technical prerequisites to document and access information must be met at the point of care. The need is particularly great in the social care sector where access to technical support is low and mobile work is common.
5. The technical infrastructure must be sufficiently powerful and reliable enough for users to be able to rely on it. Security solutions must be implemented so that users can perform their work without unnecessary interruptions. The systems must be developed in order to ensure that response times are kept to a minimum. The IT environment is becoming increasingly complex, partly as a consequence of increasing requirements for exchange of information between health and social care providers. To manage this, care providers must coordinate their organizations for the operation and administration of eHealth systems more efficiently.

6. Health and social care staff must be able to move between different eHealth systems and still be able to find vital information quickly in time-critical situations. This requires the presentation of certain types of health and social care information to be structured and standardized graphically, while still supporting personalization, based on e.g. role, activity and situation.
7. Multiple recording of the same data must be eliminated. A set of information should be recorded only once and communicated automatically in its existing or aggregated form to other systems. The work on the National Interdisciplinary Terminology and the National Information Structure as well as the implementation of automated transfer of data must be accelerated.
8. Important information must follow the care recipient across health and social care provider boundaries to facilitate person-centered health and social care. Unnecessary legal obstacles must be eliminated. At the same time, eHealth systems must be developed to support the enforcement of legal and ethical requirements when data flows across health and social care provider boundaries.
9. Research on the usability of eHealth systems must be strengthened and the knowledge applied in practice. More usable systems lead to improved capture and recording of data, which in turn can provide improved feedback to the care staff and valid data for research.
10. eHealth skills are a strategic development resource that must be present at all levels of management in health and social care. Understanding of usability is the key to achieve benefits of eHealth systems, and essential for good and reliable health and social care.

4. Discussion and conclusion

Based on the findings, some of the challenges are discussed, both from the health and social care sectors' as well as the researchers' point of view.

The users stated that the eHealth systems of tomorrow must follow the work processes much better. The systems must provide overview, take little time to assimilate and navigate and give the user a sense of control. This is in blatant contrast to the present situation, where the users need to add manual check-points in and between systems, both in terms of information and documentation. The systems need to be adjusted to the particular task in question and the circumstances in which it is carried out. Multiple recording of the same information as well as constant log-ins and log-outs are issues that must be prioritized and dealt with immediately [5]. In the health and social care of municipalities, access to mobile and situation–based eHealth systems and tools must improve substantially [12].

Usability in current eHealth systems must be improved to guarantee patient safety and support a person-centered health and social care as well as optimal use of resources [13]. The users point out that there is a need for digital tools and systems where the information follows the care recipient across care provider boundaries and where the presentation of information is adapted to the users' professions, situations and previous choices or preferences. Certain types of health and social care information must be structured uniformly no matter which care provider is involved. E.g., standardized support for medication management is needed in order to reduce the risk of errors in the medication supply chain, and uniform access to vital information is necessary in order to guarantee safe and timely decision-making in time-critical situations [14].

Based on the results achieved in USeHS, it is clear that the research about what is required to improve the usability of eHealth systems needs to be increased in order to

support future successful development of eHealth systems. Furthermore, the results show that there seems to be a lack of knowledge in healthcare organizations concerning how usability work should be conducted.

The relationship between poor usability and stress factors does not seem to be well known in organizations, although healthcare professionals explicitly identify IT-related disturbances as a major health and safety problem. Furthermore, continuous monitoring of the usability of eHealth systems at the national level, which could serve as a basis for collaboration and supervision in developing and adopting eHealth systems, is currently missing. Specific evaluations have been made [1]. However, a long-term follow-up on how usability evolves over time is still missing. Finally, there is a need to deepen and disseminate the knowledge in the health and social care domains about eHealth in general and about the usability aspect of eHealth systems in particular.

References

[1] Users Award, *Vård IT-rapporten 2010 - en sammanfattning* och *Vård-IT-rapporten 2010* Enkätundersökningar, flödesstudier och uppföljning av Vård-IT-kartan 2004: ,in Swedish. Retrieved 5 Jan 2014. http://www.usersaward.com/

[2] Gartner, *eHälsa i Sverige – nuläge och framtida mål*: Rapport för Socialdepartementet 2012: 330006695

[3] Viitanen J, Hyppönen H, Lääveri T, Vänskä J, Reponen J, Winblad I, *National questionnaire study on clinical ICT systems proofs: Physicians suffer from poor usability*. Int J Med Inf, 80 (2011), 708-725

[4] International Organization for Standardization, *ISO 9241-11:1998, Part 11: Guidance on usability* http://www.iso.org/iso/home/store/catalogue_tc/catalogue_detail.htm?csnumber=16883

[5] Scandurra I, Störande eller stödjande? Om eHälsosystemens användbarhet 2013 Retrieved 5 Feb 2014 http://www.storandeellerstodjande.se

[6] Socialdepartementet, *Nationell eHälsa - strategin för tillgänglig och säker information inom vård och omsorg,* S2010.020 (2010). Retrieved 5 Feb 2014. http://www.regeringen.se/sb/d/108/a/148429

[7] Riksrevisionen, *.Rätt information vid rätt tillfälle inom vård och omsorg – samverkan utan verkan? RiR 2011:19.* Retrieved 2 feb 2014. http://www.riksrevisionen.se/sv/rapporter/Rapporter/EFF/2011/

[8] Scandurra I, Åhlfeldt R, Persson A, Hägglund M., *Building Usability into National eHealth Strategies, an Action Research Approach.* The 4th Infrastructure workshop on Infrastructures for Healthcare: Action Research, Interventions, and Participatory Design. Tromsö, Norway, June 2013

[9] Bødker S, Ehn P, Sjögren D & Sundblad Y., *Cooperative design perspectives on 20 years with "the Scandinavian IT Design Model".* Proceedings of the first Nordic conference on Human-computer interaction. Association for Computing Machinery, 2000.

[10] Stirna, J. Persson, A. Sandkuhl, K., *Participative enterprise modelling: experiences and recommendations,* in Krogstie, J. Opdahl, A.L. Sindre, G. (Eds.): 19th Int Conf on Advanced Information Systems Engineering (CAiSE 2007), LNCS 4495, 2007, Springer Verlag

[11] Scandurra I, Hägglund M, Koch S, From user needs to system specifications: multi-disciplinary thematic seminars as a collaborative design method for development of health information systems Journal of biomedical informatics 2008:41 (4): 557-569

[12] Rigby M, Hill P, Koch S, Keeling D. Social Care Informatics as an Essential Part of Holistic Health Care: A Call for Action. Int J Med Inform (2011) 80: 544-554

[13] Söderström, E., Åhlfeldt, R-M and Eriksson, N. , *Trusting digitized patient-related information: The need for a new approach,* In Furnell and Clarke (eds.), Proceedings of the 5th International Symposium on Human Aspects of Information Security and Assurance (2011), London, pp.119-129, ISBN: 978-1-84102-284-0

[14] Åhlfeldt, R., Persson, A., Krasniqi, H., and Wåhlander, K. *Supporting Active Patient and Healthcare Collaboration - A Prototype for Future Healthcare Information Systems*. In Sibte, Abidi and Bath (eds.), Proceedings of the 16th International Symposium on Health Information Management Research (ISHIMR 2013). Halifax, June 26-28 2013, pp 13-23, ISSN: 2048-4712

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SNOMED CT adoption in Denmark - why is it so hard?

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Abstract. What prevents the National Health Care Terminology based on SNOMED CT from being implemented in the EHR systems and ongoing EHR implementations in Denmark? SNOMED CT was translated into Danish language from 2006-2009 and by 2013 it is not yet implemented in a clinical information system. Fourteen key persons broadly representing all major stakeholders in the process of system configuration accepted an invitation to discuss questions about what kind of challenges they experience in handling terminology in clinical information systems today and what they expect from a future implementation of a SNOMED CT based national terminology. Three types of challenges of terminology implementations resulted from two parallel focus group interviews: 1. Methods to manage terminology-implementation like preventing inconsistency and redundant representations of identical information. 2. The existing terminology and classifications used are sufficient to accommodate the required governance and 3. SNOMED CT is expected to be immature for system-implementation. These results suggest further research in methods to facilitate implementation of a complex terminology and studies that evaluate SNOMED CT in clinical use; but the results also support national and regional decision makers regarding what kind of challenges they must manage.

Keywords. SNOMED CT, Terminology management, Implementation.

Introduction

Semantic Interoperability in the Context of e-Health requires consistent representation of clinical data [1, 2]. Consistency across systems, organisations and countries can be achieved through implementation of international standard terminologies as SNOMED CT. The Danish National Board of Health has chosen to adopt international standards and has translated SNOMED CT into Danish. SNOMED CT is developed to support effective communication and reuse of meaningful health information [3]. Despite national recommendations and a translated version of SNOMED CT, actual implementation and use is limited, if not non-existing.

In 1999, A. Rector argued for why clinical terminologies for software are hard to implement. He states that it is necessary to validate the potential and applicability of clinical terminologies through actual software implementations [4]. However, a recent literature review of SNOMED CT in use [4] show that the main research addresses theoretical and pre-development studies, and experiences from actual SNOMED CT implementations requires a look beyond the scientific literature. Further research explore SNOMED CT implementations through interviews with people who have

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experience with SNOMED CT implementation, either as development, pilot projects or production systems[5].

The objective of this study was to explore what challenges adoption of SNOMED CT face in a Danish perspective. A national Danish Health Terminology based on a translation of SNOMED CT was ready for use in 2009. All Danish regions have worked on implementation of configurable electronic health records in different versions since 2007, but the Danish Health Terminology is currently not in use and the question is why? This study was set up to explore what challenges health-it vendors, health information managers and national e-health authorities experience today and expect of a future adoption of a SNOMED CT based terminology.

1. Method

Answering the question demands for a broad national investigation and the question has a political dimension that requires a special set-up. These prerequisites demands for a method that motivates experts representing main stakeholders to share experiences and thoughts about the challenges they face when they implement terminology in clinical information systems. Representatives from three groups of stakeholders were invited for this study: medical terminology experts, regional information managers from all five regions in Denmark and content managers from five leading vendors of Electronic Health Record Systems. A total of 19 persons were invited to participate and 14 persons took part in the workshop representing: 4 terminology experts (two from the Danish SNOMED CT National Release Center (NRC) and two from a vendor of national terminology software), 5 Information Managers representing four of five Danish regions and 5 vendor representatives (system developers and health IT managers) from five companies.

The workshop was conducted in three steps:

First step: The experts individually answered four questions in writing about their prior understanding and experience working with clinical terminology at arrival at the workshop. The purpose of this questionnaire was two-fold: we wanted to remind the participants of the purpose of the workshop and to check that the groups of stakeholders were as homogeneous within the groups as expected.

Second step: The experts were divided into four groups each representing all stakeholders. The groups were given identical written assignments and a computer. The assignment focused on the process of selecting standardized concepts from SNOMED CT to represent an example of a Danish physical examination template using local terminology. The groups were equipped with The HealthTerm application [7] and a SNOMED CT visualization prototype SNOVIEW [8] along with a set of mapping guidelines to restrict the scope of the assignment. Throughout the session the authors observed the groups, their work and their discussions. The purpose of the mapping assignment was to provide a common framework for discussions in the pending interview.

Third step: The four groups were paired two and two for two separate one-hour group interviews. The observations were used to pair the groups in order to obtain two comparable groups. The two interview-groups were given identical questions where time was limited for each question. The questions are presented in Table **1.**

Table 1 Themes and questions for Focus Group Interview (translated from Danish)

Existing practice of terminology management	What considerations are made about future use of data in a configuration process?
	Where do you look-up concepts to be used in new templates for clinical data entry?
	What influence your selection of terms in a configuration process?
	How do you ensure consistency and prevent ambiguity in a configuration process?
Challenges	What challenges do you expect SNOMED CT adoption to bring?

Numerous approaches exist for analyzing the large amount of data generated by focus group interviews, and often a combination of approaches is applied [6, 7]. These approaches can be characterized as inductive approaches [8, 9]. The method applied in this study is inspired by the general inductive approach presented by [8]. The recordings from the two interviews were transcribed and the content of each interview was categorized and finally the categories were compared to assess similarities and further group the challenges identified.

2. Results

Three main themes grouping challenges to SNOMED CT adoption were derived from the two parallel focus group interviews. The two main themes were introduced in the interview guide, but a third theme appeared in both transcriptions: Regional terminology implementation is regulated by the well-established Danish health-information infrastructure and governance model. The challenges derived from the discussions within these three themes are summed up in Table 2 and further explained in the following sections.

Table 2 Challenges derived from the focus group interviews categorized in three themes.

Methods to implement and manage terminology	Implementation of terminology requires clinical as well as technical knowledge and experience
	Implementation of terminology requires tools to facilitate consistency in CIS across existing organizational boarders
	Implementation of terminology is labor intensive and time consuming
Danish health-information infrastructure and governance	The existing CIS are based on national classifications and are well-established in clinical practice
	The existing national governance structure is based on national classifications in terms of national statistics, epidemiologic research and financial re-imbursement
Expectations related to SNOMED CT as terminology	SNOMED CT's coverage of content is not complete. The standardized terms available at present are inadequate for clinical use
	Selecting appropriate concepts from SNOMED CT is labor intensive, time consuming and requires knowledge and experience
	The benefits of SNOMED CT are theoretically promising but lack of demonstrated utility of applying SNOMED CT decreases motivation for initiatives to use this new terminology

2.1. Challenges related to methods of terminology implementation and management

The group work as well as the interview session emphasized the importance of understanding the structure of SNOMED CT and its content is a very important aspect of initiating a SNOMED CT mapping process. The focus group discussion clarified that information management and maintenance is a heavy task, as it induces a risk for inconsistency and redundant representations of identical information. Terminology

management requires deep insight to the operating codes for example when creating clinical overviews containing information from different clinical templates. The participants described how software tools and spread sheets currently are used for managing and keeping an overview of the content within the systems. These tools are important, whether incorporated in the CIS or developed in-house. Further, it was explained that the main approach for searching specific interface terms is by lexical searches, meaning that it is necessary to know the exact terms used. There seemed to be consensus regarding the way to ensure consistency by strict management and discipline when implementing the interface terminology.

2.2. Challenges related to national health information infrastructure and governance

In both focus group discussions it became evident that the national infrastructure and governance has great impact on the course of directions on the regional strategy for use of terminology and influence the position and initiatives of the vendors.

The regional representatives described how most of the content within their system is developed locally in cooperation with clinicians and vendors, and state that the process of defining content and interface terms is a very extensive task demanding for overview and insight to both the technical framework and the clinical documentation practice. Generally, the CIS applied in Denmark today supports the use of ICD10, NCSP, ICF and other classification systems required for reporting. In addition, self-invented legacy codes are used to represent the information, which is not covered by the classifications or not required for reporting to national registers. One participant explained that the primary motivation for applying local terminology, compared to applying for example SNOMED CT, is that this approach quickly fulfills the basic and immediate documentation needs.

2.3. Expected challenges related to SNOMED CT as terminology

Despite different backgrounds and knowledge of SNOMED CT most participants joined the discussions on expectations to SNOMED CT adoption in Danish healthcare. The lack of SNOMED CT demonstrations and use cases made one of the interviewees question whether SNOMED CT would ever become operational in a Danish context.

Some participants expressed concerns about the utility of SNOMED CT due to the completeness of the terminology at present. It was argued that missing relationships in SNOMED CT and lacking content within specific sub-hierarchies was a barrier to SNOMED CT adoption in clinical practice. A framework for the terminology exists, but browsing the terminology often leads to fault findings which reduce the belief/trust in the terminology. Supporting this, an interviewee stated, that it is a major challenge that synonyms have not been developed for the Danish translation. This limited 'prove' of utility resulted in lack of motivation to implement SNOMED CT. SNOMED CT has not demonstrated yet that it can actually bring value for the end users in their daily practice, nor demonstrated the utility of SNOMED CT for secondary purposes.

3. Conclusion

The existing research on SNOMED CT adoption has mainly focused on theoretical foundation and terminological aspects of SNOMED CT [4]. The result of this study

emphasize three main types of challenges which must be overcome in order to initiate SNOMED CT adoption in Denmark with the objective to enhance use and re-use of clinical data for various purposes and stakeholders.

The setup for this study was carefully chosen to reflect the community of practice within the relatively small domain in Denmark, and important issues for the Danish authorities and the research community were identified.

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References

[1] V. N. Stroetmann, D. Kalra, P. Lewalle, A. L. Rector, J. M. Rodrigues, K. A. Stroetmann, G. Surjan, B. Ustun, M. Virtanen and P. E. Zanstra. Semantic Interoperability for Better Health and Safer Healthcare, 2009 ISSN 978-92-79-11139-6.

[2] D. M. Lopez and B. Blobel. A Development Framework for Semantically Interoperable Health Information Systems. *International Journal of Medical Informatics*, 2009, vol. 78, no. 2. pp. 83-103.

[3] IHTSDO. *International Health Terminology Standards Development Organisation.* ihtsdo. Available from:http://www.ihtsdo.org/.

[4] D. Lee, N. F. de Keizer, F. Lau and R. Cornet. Literature Review of SNOMED CT Use. *Journal of the American Medical Informatics Association*, 2013.

[5] D. Lee, R. Cornet, F. Lau and N. F. de Keizer. A Survey of SNOMED CT Implementations. *Journal of Biomedical Informatics*, 2012.

[6] R. Barbour, *Doing Focus Groups.* SAGE Publications Limited, 2008.

[7] Fatemeh Rabiee. Focus-Group Interview and Data Analysis. *Proceedings of the Nutrition Society*, 2004, vol. 63, no. 4. pp. 655.

[8] D. R. Thomas. A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*, 2006, vol. 27, no. 2. pp. 237-246.

[9] J. Sim. Collecting and Analysing Qualitative Data: Issues Raised by the Focus Group. *Journal of Advanced Nursing*, 1998, vol. 28, no. 2. pp. 345-352.

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Multinational surveys for monitoring eHealth policy implementations – usefulness and pitfalls

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Abstract. Development of multinational variables for monitoring eHealth policy implementations is a complex task and requires multidisciplinary, knowledge-based international collaboration. Experts in an interdisciplinary workshop identified useful data and pitfalls for comparative variable development. The results are presented and discussed in this paper.

Keywords. Evaluation, implementation, national monitoring, indicators, methodology, eHealth policies.

Introduction

Most Nordic countries have developed policies for eHealth, and conduct regular monitoring activities on eHealth in order to be informed about distribution and usage. However, although healthcare systems and demographics are similar, there is no harmonisation between policy development, monitoring activities, data collection or contents for Nordic benchmarking and learning.

The Nordic eHealth Research Network (NeRN) is aiming at identifying similarities and differences in the Nordic national eHealth policies and surveys. More precisely, the purpose is: "to develop, test and assess a common set of indicators for monitoring eHealth availability, use, and impacts in the Nordic countries and Greenland, Faroe and Åland Islands, for use by national and international policy makers and scientific communities to support development of Nordic welfare" [1]. The network is collaborating with the OECD eHealth indicator work [2].

A robust, transparent indicator methodology to guide the work was developed with inspiration from environmental sciences [3] combining top-down and bottom-up indicator development. The methodology has been described by Hyppönen et.al.[4], and emphasizes involvement of different stakeholders, who will be impacted by the technologies to be implemented. To involve them, several workshops have been arranged. An expert workshop "Towards an International Minimum Dataset for Monitoring National Health Information System Implementations" was organized at

MIE 2011, where different participants provided viewpoints on main categories of data required at different stages of implementation [5]. The results of the workshop were reported as a paper at MIE 2012 [6]. The results were used to generate a long list of indicators, which was completed with results of an analysis of eHealth policies as well as existing measures used in the Nordic countries. These results were again mediated to eHealth experts in a workshop "Aligning National eHealth policy goals with indicators of eHealth policy effects. Challenges and opportunities" that took place in the Medinfo 2013 conference in Copenhagen. The objective of the workshop was twofold: first to introduce the audience to methods for and results of assessing the content of eHealth policy documents and existing measures, and secondly to share experiences when trying to accomplish this in a Nordic context, where monitoring data has previously been collected in different countries mainly with nationally designed surveys targeted to health care professionals and/or CIO's of organizations.

Moreover, it was considered important to collect feedback and ideas from the audience.

1. Methods

The expert workshop at MedInfo 2013 was organized in three phases: first introductions to the topic and presentation of the experiences and results gained by NeRN, secondly a work group session and thirdly a presentation of the results from the discussions in the groups.

Phase 1, *introductions to the topic*, included a discussion of the current situation with monitoring in the Nordic countries. A faculty of Nordic eHealth researchers introduced the topics: Hannele Hyppönen from Finland presented methodology issues, Arild Faxvaag from Norway presented the eHealth policy analysis, Sabine Koch from Sweden discussed the development of a common set of indicators, Hannele Hyppönen talked about aligning data sets that already have been collected with the OECD model survey and Kristian Skauli from the Norwegian Ministry of Health discussed experiences with, and lessons learned from the interaction between researchers and policy makers in the domain of eHealth.

In phase 2, workshop participants were asked to form two groups, and were given the following questions to consider, first individually and then within the group:

- *What are the pitfalls when trying to develop a multinational survey for monitoring of policy implementations?*
- *How to ensure that the data is useful for policy makers?*

NeRN members moderated the discussions in the groups. The participants were asked to write keywords on post-it-notes. These were handed in to the moderator after the group work session. The duration of the group work was 20 minutes.

In phase 3, the moderators presented the results from the group discussions to all the participants of the workshop. Subsequently, the oral presentations and the post-it notes were transcribed and analyzed.

2. Results

17 international experts participated during the workshop, with an average of 8 in each group. The participants had different professional backgrounds (medicine, nursing, technology, social sciences). The group work produced 25 post-it notes with 63 statements of condensed comments to the two questions.

The following themes were identified as potential pitfalls when trying to develop a multinational survey for monitoring of policy implementations: 1) Stakeholders' interests, 2) Goals and foci over time, 3) Health culture, health system, health demography, and professional healthcare practices, 4) Professional qualifications, competences, and educational systems, 5) Data definition, data selection and data collection, and 6) Concepts, translations of concepts, cultural implications of concepts, wording, clarity and depth of questions, and joint terminology.

The following issues were regarded important to ensure that the data was useful to the policy makers: 1) Process transparency, 2) Research- and experience-based policy development, 3) Provision of data, 4) Collection of future needs of eHealth systems.

3. Discussion

3.1. Pitfalls

When dealing with the first question, the pitfalls when trying to develop a multinational survey for monitoring, the participants emphasized *differences* on various levels.

One of the pitfalls pointed out was that different stakeholders have different interests, which may also vary from country to country depending e.g on the maturity level of the eHealth systems and services. In general, the authorities have political, organizational and economic interests for implementing eHealth systems, healthcare professionals need systems that are usable in the everyday treatment of the patients. Furthermore, IT-developers are interested in the technological aspects of the systems whereas patients want their privacy to be maintained and to receive the best treatment. However, the needs and preferences of the stakeholders are not permanent. Goals and foci may change over time. The challenge for the policy makers is to find compromises between the diverging needs and preferences of the different stakeholders that are applicable over time. The challenge for survey developers is to define relevant indicators based on comprehensive data from all stakeholders.

Another identified pitfall in the development of multinational surveys was that socio-contextual aspects, such as health culture, health system, health demography and professional healthcare practices differ from nation to nation, and from region to region. Differences in the organization of the health provision and services, differences in the prevalence of diseases and differences in the conduct of healthcare (linked to for example availability of medical technology) are complex aspects to identify and compare. Monitoring activities must take into account the complexity embedded in these socio-contextual aspects.

The workshop participants also emphasized the fact that although healthcare professionals across nations may belong to the same professional affiliation does not mean they have corresponding qualifications. Professional competences and professional qualifications are not always equivalent across the nations. This depends on the requirements and the curricula of the educational systems, which, although loyal

to the international standards, may not deliver equivalent education. The respondents of surveys may thus not have the same understanding of the problems raised in the questions.

Additionally, linguistic and semantic issues, such as variations in the use of concepts, translations of concepts, cultural implications of concepts, wording, clarity and depth of questions and lack of joint terminology, was discussed by the informants as issues that complicate the development of unified multinational surveys. Clarity of semantics and coherence across the national surveys was considered crucial for obtaining comparable data.

In overcoming the challenges described above, close multinational cooperation and attention must be paid to designing the surveys. Data from the different countries must be coherent and comparable, and this requires that data definition, data selection and data collection is synchronized. Moreover, an identification of the relevant stakeholders, and inclusion of their representatives in the policy and survey development was considered important for the transparency of the process and for the relevance and quality of the monitoring.

3.2. Useful data

Data must be useful to the national as well as international policy makers. The participants in the workshop touched upon the following issues when discussing the second question, how to ensure that the monitoring results are useful: process transparency, research- and experience-based policy development, provision of data, and focus on improvement.

The informants emphasized the importance of transparency in the process around monitoring policy implementations, so that all parties are informed and invited to give input. It was considered important to give the opportunity for asking questions and implementing potential changes. Involvement of the potential users and stakeholders in participating countries was considered imperative in all phases of the multinational indicator definition process. The informants suggested involving policy makers in the data definition and the data collection process to ensure that the information derived was relevant. Moreover, they suggested that interdisciplinary teamwork should be facilitated for in the process. A strong focus should be on the patients. Transparency also calls for public sharing of the methodology and results for continuous commenting.

The informants discussed that a way of ensuring the usefulness of data is providing the data that the policy makers want. One way of ensuring this is to operationalize eHealth policy goals to measurable variables. Another way is to collect different stakeholders' views on best features and development needs. It was also emphasized as important that the researchers and survey makers were included in the policy making process, to ensure that policy development would be knowledge-based. Confronting barriers and benefits from previous eHealth experiences (research and implementations) would inform the monitoring activity, but also help saving time and resources.

The provision of good, relevant data was considered crucial for the usefulness of the monitoring activity. The informants emphasized that log data should be exploited in monitoring activities to a greater extent than it is today. A discussion was raised about the availability of log data in the different countries, an issue that is dependent on political decisions.

4. Conclusion

Stakeholder involvement is an important way to avoid the pitfall of varying interests as well as differences in the way health care is organized. In the National eHealth Strategy Toolkit [7] concerning monitoring and evaluation, WHO supports the significance of stakeholder involvement, and emphasizes the importance of reviewing and confirming outcomes and outputs focus areas with prioritized stakeholders. WHO suggests that this also provides an opportunity to build stakeholders support, gather stakeholders input on indicators that could be used and communicate the expected outcomes relevant to stakeholders. However, the critical point may occur when the stakeholder's interests are conflicting. Which interests will be prioritized and what is at stake for whom? Studies on aspects concerning power relations, roles and rhetoric may contribute to insights about these questions. *Socio-contextual aspects*, such as health culture, health system, health demography, healthcare practices and professional qualifications, must be taken into consideration when developing surveys, since the point of departure in one country may differ significantly from another. WHO [7] suggests defining baseline measures and timeframes in order to identify the developmental steps. The Nordic countries are comparable, but have different organization and frequency of the monitoring activities. Diverging timeframes in monitoring activities influences the comparability of survey data across the Nordic countries. Focus on data provision, exchange and use tasks as guided by the OECD [8] is a way to overcome organizational differences. The monitoring activities, including survey development, should lead to improvement of existing practices, and the policy makers should be given hope of improvements. One way of ensuring improvement is to ask questions so that they suggest improvements. Close attention must be put on linguistic and semantic issues in the surveys, in order for the wording, concepts, terminologies and nomenclature to be accurate and in depth. This requires multidisciplinary research-based knowledge with involvement from relevant stakeholders.

The results from this workshop provide important input about the needs for the Nordic cooperation on strategy development and indicators for monitoring. The results will also be used to inform the OECD eHealth indicator work.

References

[1] Hyppönen, Faxvaag, Gilstad, Hardardottir, Jerlvall, Kangas, Koch, Nøhr, Pehrrsson, Reponen, Walldius, Vimarlund. *Nordic eHelath Indicators. Organisation of research, first results and the plan for the furture*, Nordic Council of Ministers, 2013

[2] The OECD eHealth indicator work (http://www.oecd.org/health/ict)

[3] Reed MS, Fraser EDG, Dougill AJ. An adaptive learning process for developing and applying sustainability indicators with local communities. *Ecological Economics* 59 (2006) 406–418

[4] Hyppönen , Ammenwerth , de Keizer. Exploring a methodology for eHealth indicator development. *Stud Health Technol Inform* (2012);180:338-42.

[5] Hyppönen , Ammenwerth , Nohr , Faxvaag , Walldius. Towards an International Minimum Dataset for Monitoring National Health Information System Implementations, in Moen et al. (Eds.) *23rd International Conference of the European Federation for Medical Informatics,* MIE (2011)

[6] Hyppönen , Ammenwerth , Nohr , Faxvaag , Walldius. eHealth indicators: results of an expert workshop. *Stud Health Technol Inform.* (2012);180:328-32

[7])WHO National eHealth Strategy Toolkit, http://www.itu.int/pub/D-STR-E_HEALTH.(2012)

[8] DRAFT OECD guide to measuring ICTs in the health sector. Internal document for the OECD task forces, 20120452. (2013)

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Prospective Assessment of an innovative test for prostate cancer screening using the VITA process model framework

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Abstract. Healthcare innovations are crucial for enhancing patient treatment and a high-quality healthcare system. However, bringing new technologies, methods and procedures into the healthcare market is challenging. Enormous amounts of financial, personnel and organizational resources are required with no upfront certainty for the medical and economic benefit. A new and innovative approach uses interdisciplinary medical, technical and economic expertise to forecast effects of healthcare innovations already at the early research and concept phase of an idea and before major investments are made. A process model framework was developed to operationalize this structured assessment of healthcare innovations. The Visionary Iterative Tailored Approach (VITA) is based on conceptual modeling, simulation and health economics evaluation. Its application for the prospective assessment of an innovative prostate cancer screening is presented.

Keywords. Conceptual modeling, simulation, health economics evaluation, decision making, healthcare innovation, prostate cancer screening

Introduction

Prospective Health Technology Assessment (ProHTA) is a new approach of so-called technology forecasting using simulation and health economics evaluation to assess healthcare innovations [1]. In order to prevent misinvestments the resource intensive development of healthcare innovations is addressed at the early concept and research stage before major investments have been made. Assessing the innovations future impact on the healthcare system supports decision making for either optimizing or early aborting development processes.

This new and innovative approach involves data and information on prevention, treatment and care next to demographic and epidemiologic information as well as costs.

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Interdisciplinary stakeholders with medical, technical, economic and entrepreneurial knowledge and expertise work closely together. The challenge is to capture this broad and vast knowledge in order to prepare data and models for the simulation. A structured approach becomes fundamental to consolidate complex settings and interdisciplinary stakeholders with different knowledge and views as well as to support service delivery for healthcare decision making.

Therefore, we developed a structured framework for the prospective assessment of healthcare innovations called the Visionary Iterative Tailored Approach (VITA). Two case studies to assess healthcare innovations, one for acute ischemic stroke treatment and one for prostate cancer screening, were used to develop the VITA framework. In the following the VITA process model framework is presented together with an exemplary application for the prospective assessment of an innovative test for prostate cancer screening.

1. Methods

VITA is based on process models from software engineering combined with project management principles and adjusted to the healthcare simulation context. Based on conceptual modeling to bridge the real world with the simulation model world, medical knowledge and economic figures are transformed into executable simulation scenarios. The simulation results are analyzed by health economics evaluation in order to support decision making in healthcare. It was developed in the course of a prospective assessment of mobile stroke units for acute ischemic stroke treatment [2]. An analysis and process model benchmark helped to revise and to adjust the initial approach, leading to a comprehensive process model framework. An overview of the VITA

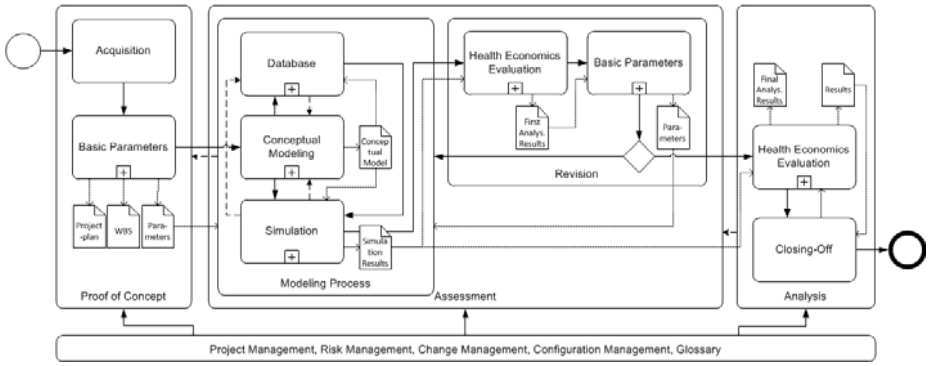


Figure 1: VITA process model framework

framework is given in Figure 1.

The *proof of concept phase* starts with the acquisition of an idea for a healthcare innovation, and first checks the feasibility of the assessment needs. A positive prospect triggers the *assessment phase* based on defined basic parameters such as objective, time, costs and participants. Subsequently a conceptual model is developed together with a knowledge database to prepare the simulation [3]. Based on the first simulation output a basic health economics evaluation is accomplished to check model and simulation. In case of adjustments to the basic parameters (especially input and output specifications) an iteration of the modeling process is initiated. Although more than one iteration is

possible it is not preferred due to economic reasons (time, costs and personnel). The final *analysis phase* can be accomplished, if no (further) revision is carried out. A thorough health economics evaluation of the latest simulation output is performed to achieve the assessments objective, respectively to answer the research question. The result of the analysis is thereby not a simple Yes or No in favor or against an innovation but rather a detailed evaluation and calculation of advantages, benefits and drawbacks within the healthcare context.

The whole process model framework as outlined in Figure 1 is described in narrative text with generic templates for project management (e.g. project plan, work breakdown structure), modeling (graphic notation, Word and Excel templates for data structuring) and simulation (computer code for e.g. demography) representing a comprehensive guideline. VITA supports a structured team process to ensure correctness, understandability, usefulness and applicability for all interdisciplinary stakeholders throughout the prospective assessment of a healthcare innovation.

2. Results

In the following, the application of VITA for the assessment of an innovative biomarker for prostate cancer (PCa) screening is described. PCa is the second most frequently diagnosed cancer in men worldwide [4]. The prognosis of the cancer, i.e. the patient's outcome, depends on the tumor stage at diagnosis. Thus, early detection is crucial for prostate cancer therapy. But PCa screening based on the prostate specific antigen (PSA) is a controversial issue [5]. Due to a high sensitivity but low specificity of the PSA test, prostate cancer screening became infamous for overdiagnosis and overtreatment next to increasing costs of care [6]. A PSA-complementary test with high specificity could help to increase screening benefits (early tumor detection) beyond harms (painful interventions and adverse effects).

The initial objective of our PCa case study was defined as: "What specificity is required of a PSA-complementary test in order to facilitate comprehensive and evidence-based statutory PCa screening in Germany?" The proof of concept phase revealed, that this initial question was too general. PCa treatment is complex and data and information on the various treatment options are insufficient or not available. Therefore, the objective was refined to differentiate between overdiagnosis and overtreatment, first of all concentrating on early PCa diagnosis to the point of prostate biopsy. The revised objective was defined as follows: "What are the cost savings that can be achieved by reducing the number of false positive biopsies in combination with avoided complications, depending on the variable specificity of an innovative PSA-complementary test when PSA $\geq$ 4 ng/ml?" In order to answer this question, a hypothetical prostate cancer screening workflow developed. It is based on prostate cancer prevention in Germany [7] and extended with an innovative PSA-complementary test.

Within the assessment phase, the conceptual model was derived from clinical guidelines and medical journals predominantly listed in PubMed. Scientific information and data for prostate cancer diagnosis as well as expert knowledge on patient behavior is supplemented by information on screening programs, statistical data and health related costs. Epidemiologic as well as demographic data on men aged between 45 and 80 years is received from the Federal Statistical Office in Germany [8]. Costs considering medical examinations and biopsy diagnosis are calculated referring

to the doctor's fee scale from the German National Association of Statutory Health Insurance Physicians [9]. Costs of follow-up treatment due to medical complications of biopsies were calculated considering literature from the review.

Sensitivity, specificity and costs of the innovative test are variable input parameters to the simulation scenarios. As output parameters we defined the number of prostate biopsies together with total costs for PCa screening including the innovative test. Thereby the number of biopsies are on the one hand calculated for solely PSA-based screening and on the other hand for the innovative screening supplemented with the PSA-complementary test. Regarding costs, savings due to avoided biopsies and biopsy complications are calculated together with additional costs for the innovative test.

The simulation is implemented as hybrid system-dynamic and discrete-event simulation. Executing the simulation with the innovative screening program for 10 years in Germany and studying three different specificities of the innovative test (70%, 80% and 90%) as well as three different costs (20€, 50€ and 100€) revealed cost neutrality of the innovative screening (compare Figure 2).

The analysis phase showed that the innovative prostate cancer screening is cost-effective at costs of 20 Euro and a specificity of at least 70% for the innovative test. For costs of 50 Euro a specificity of 80% is needed to be at least cost-neutral and with costs of 100 Euro the innovative screening would not be cost-effective even with a specificity of 90%. Higher specificity values are assumed to be not realistic. Further health economics evaluations can be calculated based on the simulation results.

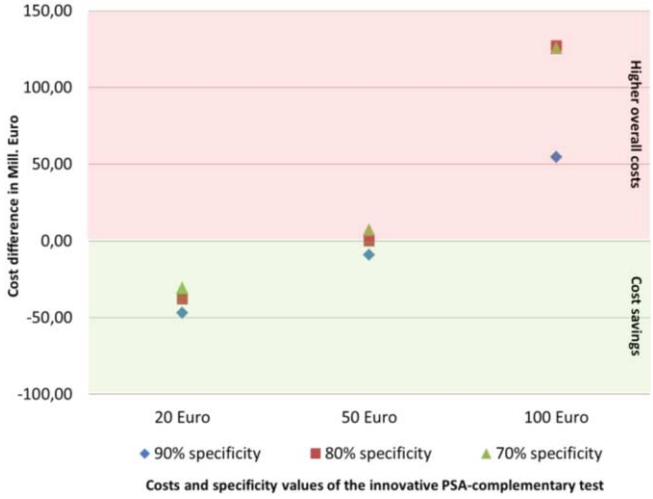


Figure 2: Results of the prostate cancer case study

3. Discussion

Our simulation showed that it is possible to improve screening results by complementing PSA-testing with an additional, innovative test. However, to support screening evidence, also the impact of an innovative PSA-complementary test on overtreatment needs to be assessed. Therefore an extension of the scenario towards staging and therapy is required. Nevertheless, a PSA-complementary test could help to

support evidence for prostate cancer screening by showing that unnecessary (false positive) biopsies can be reduced and thus costs can be saved.

Using the Visionary Iterative Tailored Approach enabled us to successfully consolidate an interdisciplinary team for the prospective assessment of a healthcare innovation. The VITA framework supported our close collaboration with different expertise and views on data, models, simulation and health economics evaluation throughout the process. Future research will now concentrate on assessing further case studies in cardiology and breast cancer treatment to use and improve the VITA process model framework. Furthermore, a thorough business plan for the prospective assessment of healthcare innovations is underway to optimize service delivery in healthcare decision making.

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References

[1] Gantner-Bär M, Djanatliev A, Prokosch HU, Sedlmayr M, Conceptual Modeling for Prospective Health Technology Assessment, *Studies in Health Technology and Informatics*, Vol. 180 (2012), 33-37

[2] Djanatliev A, Kolominsky-Rabas P, Hofmann BM, Aisenbrey A, German R, Hybrid simulation approach for prospective assessment of Mobile Stroke Units, *Proceedings of the 2nd Int. Conference on Simulation and Modeling Methodologies, Technologies and Applications*, 2012, 357-366

[3] Baumgärtel P, Lenz R, Towards data and data quality management for large scale healthcare simulations - Position Paper, *HEALTHINF 2012 - Proceedings of the International Conference on Health Informatics*, 2012, 275-280

[4] Ferlay J, Shinh R, Bray F, Forman D, Mathers C, Parkin DM, *GLOBOCAN 2008 v2.0: Cancer Incidence and Mortality Worldwide*, IARC CancerBase No. 10. Lyon, France, 2010.

[5] Moyer VA, Force USPST. Screening for prostate cancer: U.S. Preventive Services Task Force recommendation statement. *Annals of Internal Medicine*. 2012;157(2):120-34.

[6] Klotz L, Prostate cancer overdiagnosis and overtreatment, *Curr Opin Endocrinol Diabetes Obes* **20** (2013), 204–209

[7] Deutsche Gesellschaft für Urologie, Interdisziplinäre Leitlinie der Qualität S3 zur Früherkennung, Diagnose und Therapie der verschiedenen Stadien des Prostatakarzinoms, *http://www.dgu.de/fileadmin/MDB/PDF/S3_LL_PCa_-110331_Version1.03.pdf* [5. Feb. 2014], 2009

[8] Statistisches Bundesamt, *https://www.destatis.de/DE/Startseite.html* [5. Feb. 2014], 2013

[9] Kassenärztliche Bundesvereinigung, Einheitlicher Bewertungsmaßstab, *http://www.kbv.de/8156.html* [5. Feb. 2014], 2013

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Security challenges in integration of a PHR-S into a standards based national EHR

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Abstract. Health related data provided by patients themselves is expected to play a major role in future healthcare. Data from personal health devices, vaccination records, health diaries or observations of daily living, for instance, is stored in personal health records (PHR) which are maintained by personal health record systems (PHR-S). Combining this information with medical records provided by healthcare providers in electronic health records (EHR) is one of the next steps towards "personal care". Austria currently sets up a nationwide EHR system that incorporates all healthcare providers and is technically based on international standards (IHE, HL7, OASIS, …). Looking at the expected potential of merging PHR and EHR data it is worth to analyse integration approaches. Although knowing that an integration requires the coordination of processes, information models and technical architectures, this paper specifically focusses on security issues by evaluating general security requirements for a PHR-S (based on HL7 PHR-S FM), comparing them with the information security specifications for the Austrian's national EHR (based on ISO/IES 27000 series) and identifying the main challenges as well as possible approaches.

Keywords. Personal Health Record, EHR, Security, ISO 27000, HL7, IHE

Introduction

Health related data provided by patients themselves is expected to play a major role in future healthcare. Data from personal health devices, vaccination records, health diaries or observations of daily living, for instance, is stored in personal health records ("PHR", see [2] for definition) which are maintained by personal health record systems ("PHR-S", see [3] for definition). Combining this information with medical records provided by healthcare providers in electronic health records (EHR) is one of the next steps towards "personal care" [1].

The first definition for Austria's national electronic healthcare record called "ELGA" included a clause stating that ELGA will also hold data provided by the patient itself. Finally ELGA is implemented as a "real" EHR containing only health information provided by healthcare professionals. In fact by law a patient can control the access to his/her record, but he/she cannot provide additional data. During the next few years every healthcare provider (HCP) in Austria will be connected to the ELGA system which will be a closed domain reserved for HCP. In such a context a PHR can

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be usually accessed by a health professional over the internet (which is usually hardly realized), but not as integrated additional source of health information. Therefore integration of PHR data into the ELGA system would probable add value for patients and healthcare professionals. The general technical principals of such an integration of the PHR-S have been outlined in [4]. This paper focusses on security issues.

1. Methods

To find the key issues regarding security two different security frameworks were evaluated: the HL7 PHR-S Functional Model as general model for PHR-S and the ISO/IEC 27000 series as the base definition for the ELGA information security requirements. In a first step a mapping was done. In a second step the results were analysed in the context of the technical specifications of the used standards and frameworks (e.g. IHE, OASIS) to identify security issues in integration and to propose standard based approaches.

1.1. General security requirements for PHR-S

General security requirements for PHR-S can be taken from Health Level 7 (HL7) PHR working group's standardization work. They defined the PHR-S Functional Model [3] which is a standardized model of the functions that may be present in PHR Systems. The PHR-S FM contains three sections: Personal Health, Supportive, and Information Infrastructure. The Information Infrastructure part incorporates a set of security functions a personal health record system shall provide to enforce security and privacy (**Table 1** shows examples) as well as a list of conformance criteria.

Table 1: HL7 PHR-S FM - Security functions (excerpt, for details see [3, p.120ff])

#ID	Name	Short description	#crit.
IN.3.1	Entity Authentication	The PHR-S must provide mechanisms for users and applications to be authenticated.	7
IN 3.2	Entity Authorization	Manage the sets of access-control permissions granted to entities that use a PHR-S (PHR-S Users).	5
IN 3.3	Entity Access Control	Verify and enforce access control to all PHR-S components, PHR information and functions to prevent unauthorized	3
…			
IN 3.10	Secure Messaging	Enable secure electronic communication between PHR Account Holders and Health Care Providers.	2

1.2. Security Framework for Austria's national EHR

Security and privacy requirements for Austria's EHR are mainly based on two statutory provisions: the ELGA act [5], which is the regulatory basis for the national EHR and defines the requirements for electronic information exchange between healthcare provider as well as high level rules for health information storage and access to healthcare data, and the data privacy act regulating the handling of sensitive personal information.

Actually the regulatory is very high level and not comparable to detailed specifications such as from the US-HIPAA. Furthermore constantly changing security requirements and the permanent need for adapting security policies and continuously monitoring and assessment of the measures led to the decision for implementing of an

Information Security Management System (ISMS) based on the ISO/IEC 27000 standards series – namely 27001 (definition ISMS [6]), 27002 (Code of practice [7]) and 27799 (Information security management in health [8]). The ISO/IEC 27001 defines how to implement and run an ISMS based on a risk management approach in "Plan-Do-Check-Act" cycles for continuous improvement [6]. The standard defines 14 Objectives with 35 subcategories and 114 controls to reach the objectives. Even though the scope of an ISMS is usually defined only for one organization it has been shown that a cross organizational ISMS could be implemented and be used in the ELGA context [9].

1.3. ELGA Architecture, Standards and Frameworks

The architecture of the Austria EHR is based on the IHE infrastructure framework consisting of several communities connected by XCA and running an IHE XDS infrastructure for HL7 CDA document exchange (see [10] for details). A Master Patient Index (MPI), a Healthcare Provider Index (HCP-I) are provided as common central components as well as a Policy Administration Point (PAP) as part of a XACML infrastructure ([11], [12]) for enabling citizens maintaining their access policies. Multiple security token services (local, on community level and central) based on IHE XUA profile ensure authentication and authorization of users and organizations cross organizational and community borders. The whole infrastructure is run in a closed network reserved for ELGA participants, i.e. HCPs. The only gateway to public networks is a patient internet portal providing functionalities to access documents, see the access audit logs and maintain access policies.

2. Results

2.1. Relationship PHR-S functions - ISO 27001 objectives

HL7 PHR-S FM functions can be more or less seen as controls in the context of ISO 27001. **Table 2** shows the relationship between the functions and the ISO/IEC 27001 objectives. The last columns shows the issues to be handled and solved for the PHR-EHR integration.

Table 2: relationship between HL7 PHR-S FM and ISO 27001 objectives

HL7 function	**controls ISO 27001 objective**		**Integration Issue**
IN.3.1 Entity Authentication	A 9	Access Control (9.1, 9.4)	identity management
IN 3.2 Entity Authorization	A 9 A 12	Access Control (9.1, 9.4) Operations Security (12.4)	identity management / information classification / policy bridging
IN 3.3 Entity Access Control	A 9	Access Control (9.4)	information classification / policy bridging
IN 3.4 Non-Repudiation	-		Not yet defined for ELGA
IN 3.5 Secure Data Exchange	A 13 A 10	Communication Security Cryptography	Trust
IN 3.6 Secure Data Routing	A 13	Communication Security	None
IN 3.7 Information Attestation	-		Not defined for ELGA
IN 3.8 Patient Privacy and Confidentiality	A 18	Compliance	None
IN 3.9 Service Availability	A 12	Operations security	Trust / ISO 27001 integration
IN3.10 Secure Messaging	A 13	Comm. Security (13.2)	None

2.2. Main Integration issues

2.2.1. Identity management

Usually a PHR-S has its own user management, comprising patients and healthcare providers. Authentication and further access control is based on these identities. Therefore a federated identity management has to be established along with a reliable and user friendly identity mapping procedure provided by the PHR-S to map local users to the ELGA users. Possible solutions (e.g. using the Austrian citizen card) are discussed in [15].

2.2.2. Information classification and policy bridging

As the national EHR is a closed domain reserved for healthcare providers a PHR-S has to be in an own domain. The possible architectural integration of the PHR-S as an own IHE community has been shown in [4] and the technical implementation of XACML components (see 1.3) is not the big issue. The challenge is that both domains usually use different semantics and different granularities for categorizing healthcare information. Both can be handled either by using well know coding systems such as LOINC or Snomed CT or by explicitly security labelling information, e.g. with HL7 Healthcare Privacy and Security Classification System ("HCS" [16]). Also typically both domains use diverse information classifications and consequently diverse access policies. To overcome this problem the ISO 22600 [14] defines a negotiation process known as "policy bridging" to set up a common domain.

2.2.3. Trust

Trust has to be establish on three levels:

a) Technically trust is usually based on electronic X.509 certificates which have to be managed by a trustworthy Certification Authority (CA) providing a Public Key Infrastructure (PKI). When there is no central CA efforts for cross-certification can be enormous – a bridge CA can offer a solution ([17]).
b) Content from a PHR provided by the patient her-/himself is not as reliable as content provided by a healthcare provider. The ISO TR 14292 states "*.., the source of the data (personal or provider) should be clearly distinguishable."* [4, p.5]. Therefore data has to be specially marked or classified. This can be implemented using the HL7 HCS and the HL7 CDA Implementation Guide Data Segmentation for Privacy (DS4P) [16].
c) A PHR-S can only be trustworthy when the provider maintains a certain level of security to ensure Privacy. This means the provider has to be part of the ELGA ISMS and involved in the shared PDCA cycle shown in Fig. 1 between ELGA security forum and organisations running a community. At least specific security controls according to [6] have to be implemented and will be audited.

3. Discussion

Technical integration of PHR-S into a large, complex but standard based EHR infrastructure is manageable and realizable. The big challenges are the organizational

requirements that need negotiation between two domains and different semantics. Also ISO/IEC 27001 compliance is probably bound to big efforts for a PHR-S provider.

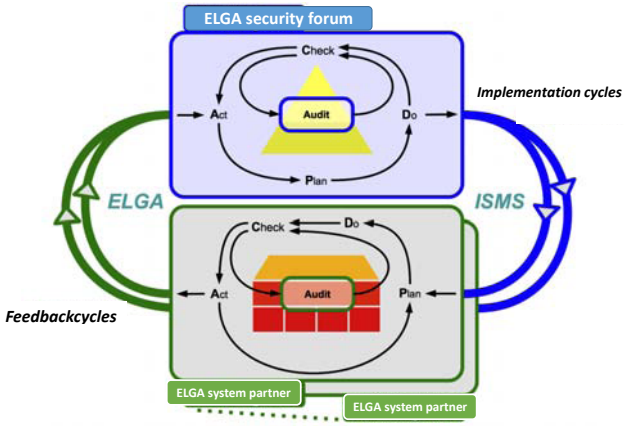


Figure 1: Shared PDCA Cycle

References

[1] Blobel B, Pharow P, Norgal T. How to Enhance Integrated Care towards the Personal Health Paradigm. In MEDINFO 2007: Proceedings of the 12th World Congress on Health, IOS Press, 2007, p.172-176
[2] ISO TR 14292:2012: Health informatics — Personal health records — Definition, scope and context. ISO copyright office, Switzerland, 2012
[3] Health Level Seven International, PHR-S FM Personal Health Record System Functional Model (PHR-S FM), 2013. http://www.hl7.org/implement/standards/product_brief.cfm?product_id=88. [24.01.2014].
[4] Mense A, Urbauer P, Frohner M, Sauermann S, Integration von Personal Health Records (PHR) in die österreichische elektronische Gesundheitsakte (ELGA), eHealth 2013, Vienna
[5] Elektronische Gesundheitsakte-Gesetz – ELGA-G, BGBl. I Nr. 111/2012, https://www.ris.bka.gv.at/Dokumente/BgblAuth/BGBLA_2012_I_111/BGBLA_2012_I_111.pdf
[6] ISO/IEC 27001:2013, Information security management systems - Requirements, ISO copyright office, Switzerland, 2013
[7] ISO/IEC 27002:2005, Code of practice for information security management, ISO copyright office, Switzerland, 2005
[8] ISO/IEC 27799:2008, Information security management in health using ISO/IEC 27002, ISO copyright office, Switzerland, 2008
[9] Mense A, et. al; Concepts for a standard based cross-organisational information security management system in the context of a nationwide EHR, Studies in Health Technology/Informatics, Vol.192, 2013
[10] IHE International, IHE IT Infrastructure (ITI) Technical Framework, Rev.10.0, IHE International, 2013
[11] Moses, T.: eXtensible Access Control Markup Language (XACML) Version 2. OASIS Standard, http://docs.oasis-open.org/xacml/2.0/access_control-xacml-2.0-core-spec-os.pdf, 2005
[12] Lockhart, H., Parducci, B.: Cross-Enterprise Security and Privacy Authorization (XSPA) Profile of XACML v2.0 for Healthcare, http://xml.coverpages.org/xspa-xacml-profile-CD01-29664.pdf, 2008
[13] Schator A, Rauchegger G. ELGA Architektur-Überblick. Präsentation eHealth2012, Wien, http://www.ehealth20xx.at/eHealth2012/downloads/presentations/ELGA/1_Schator.pdf, [30.01.2014]
[14] ISO TS 22600-2, C ISO/IEC 27002:2005, Code of practice for information security management, ISO copyright office, Switzerland, 2005
[15] Mense A, et al.: Federated Identity Management for management and integration of personal health data archives. In: Proceedings of the 10th ICICTH, July 2012, Greece
[16] HL7 International: HL7 Implementation Guide: Data Segmentation for Privacy (DS4P), Release 1; http://gforge.hl7.org/gf/project/security/frs/?action=FrsReleaseBrowse&frs_package_id=229
[17] Millán G L et al.: PKI-based trust management in inter-domain scenarios; Computers & Security, Vol. 29-2, p. 278-290, Elsevier, 2010

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Towards National eHealth Implementation - A Comparative Study on WHO/ITU National eHealth Strategy Toolkit In Iran

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Abstract. Experiences has shown that utilization of ICT in health sector requires national commitment and planned efforts to make the best use of existing capacity. Establishing the main directions as well as planning the detailed steps needed are key to achieving longer-term goals such as health sector efficiency, reform or more fundamental transformation. Collaboration between the health and ICT sectors, both public and private, is central to this effort. As the major United Nations agencies for health and telecommunications respectively, the World Health Organization (WHO) and the International Telecommunication Union (ITU) have recognized the importance of collaboration for eHealth in their global resolutions, which encourage countries to develop national eHealth strategies; the National eHealth Strategy Toolkit is the proof of these recommendations. In this study a mapping of eHealth components in WHO/ITU National eHealth Strategy Toolkit and our national eHealth vision is presented.

Keywords. eHealth, Strategy, eHealth Strategy, Planning Techniques, Electronic Health Record, Health Information Systems, Health Service

Introduction

The term eHealth only came into use in the year 2000, but has since become widely prevalent. The scope of the topic was not immediately discernable from that of the wider health informatics field, for which over 320000 publications are listed in Medline alone, and it is not explicitly represented within the existing Medical Subject Headings (MeSH)[1] taxonomy[2].

In 1980s and 1990s, some leading healthcare organizations began to demonstrate the quality and efficiency potential of electronic health records (EHRs)[3]. In the past three decades researches demonstrate that eHealth activities such as electronic patient records, electronic prescribing, and the National Electronic Library for Health, etc can improve quality and efficiency of health services and be cost effective[4-8]. Thus, many countries funded lots of money to gain benefits of eHealth [3, 9]. In literature review at some of the national initiatives to develop an information infrastructure for healthcare, some of the challenges were presented by these very different approaches around the world.[10]. The European Union Action Plan for eHealth was published in April 2004 and endorsed by the EU health ministers in June 2004 which means that, for the first time, Europe has a coherent agenda for eHealth implementation [11].

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The Fifty-eighth World Health Assembly in May 2005, adopted Resolution WHA58.28 establishing an eHealth strategy for WHO. The resolution urged Member States to plan for appropriate eHealth services in their countries[12]. Inappropriate eHealth strategy and plan definition is a barrier to effective investment, and successful implementation of eHealth solutions[13]. In a joint effort WHO and ITU have tried to solve the issue by development of the National eHealth Strategy Toolkit that introduces and reviews components and processes that must be considered in eHealth planning[14].

ITU is the leading United Nations agency for information and communication technologies. ITU's role in helping the world communicate, spans 3 core sectors: radiocommunication, standardization and development[15].

The National eHealth Strategy Toolkit is an expert guide that provides governments, their ministries and stakeholders a solid foundation to develop and implement a national eHealth vision, action plan and monitoring framework[16].

Along with International commitment on development of eHealth, national efforts in Iran had started, too. Preparation of National eHealth vision started in 2006. The purpose of this study is to map implemented and ongoing projects and activities of our national eHealth vision and presented eHealth components in WHO/ITU Toolkit.

1. Methods

1.1. Design

In order to evaluate our National eHealth, we adopted an exploratory, interview-based methodology. Approval for this research was obtained from the Ministry of Health and Medical Education (MOHME).

1.2. Sampling

the experts of eHealth were interviewed to collect data regarding technical, executive, and other aspects of eHealth development in Iran. These experts were selected from variety of stakeholders including professors at universities, Electronic Health Record development team, experts at research deputy of MOHME.

1.3. Data collection

These interviews took place in 2013 and several websites, documents and outputs of eHealth projects were studied as well.

1.4. Data analysis

All realized activities are sorted out and mapped with National Component map in WHO/ITU National eHealth Strategy Toolkit[16].

2. Results

2.1. eHealth Governance

In 2003, Iran approved and signed a 20-year vision that describes national development in several disciplines including healthcare. This vision is to be implemented in terms of four 5-year Country Programs (CP) started from 2005 and to be ended in 2025[17].

In 2004, the 4th CP was approved and launched according to which MOHME is responsible to design and deploy Integrated Health Information System to improve performance, provide high quality health services [18].

In 2005, a comparative study on eHealth all over the world was done determining Iran's place in eHealth area from several aspects[19].

In 2008, Iranian High Council of Health approved an Act requiring MOHME to prepare action plan to create and develop National Integrated Care Electronic Health Record (ICEHR); it was prepared jointly with Ministries of welfare, ICT, Iranian High Council of IT and Iranian Legal Medicine Organization [20].

The 5th CP was launched in 2011; According to Act 35, MOHME was required to deploy National ICEHR and Healthcare Facility Information Systems in coordination with Statistical Center of Iran (SCI), National Organization for Civil Registration (NOCR), maintaining confidentiality of data[21].

Thus, national commitment was formed to implement and deliver eHealth. As it is suggested in WHO/ITU National eHealth Strategy Toolkit, Minister of Health and Medical Education should take the leadership of eHealth development which is the same case for Iran.

2.2. eHealth Solutions

According to interviews and assessments regarding present state, implementation of the following activities was on the agenda; the implemented solutions are explained below according to WHO/ITU National eHealth Strategy Toolkit.

2.2.1. Individual Electronic Health Record

Iranian ICEHR (locally called SEPAS) was implemented in 2010. According to the interview with SEPAS development team, it has a distributed and service-oriented architecture based on ISO 13606 standard that creates and maintains ICEHR for each individual. Decentralization of SEPAS enables healthcare facilities to purchase Health Information Systems (HIS) independently.

2.2.2. Health Service Delivery

In order to ensure quality of electronic health service delivery in HIS products, they are evaluated every 2 years based on criteria declared by IT Office of MOHME[22]. All of the components mentioned in this part of WHO/ITU National eHealth Strategy Toolkit are present in the document of Functional Evaluation of HIS products[22].

2.2.3. Health Information

ICEHR is implemented for several purposes; Its primary purpose is to improve healthcare service delivery. The secondary purpose is to utilize the nationwide

integrated data for research, management reports, etc[23]. According to the interviews, management dashboards have been developed on integrated data and are available for relevant stakeholders complying privacy issues.

2.2.4. Health Care Management

An application of eHealth implementation is better management of epidemics. In June 2009 Influenza pandemic happened globally and spread to Iran as well. Since proper management of epidemics needs taking right actions in right place and right time, there was a need for data registry and integration through SEPAS in Iran. The management dashboard based on integrated data helps high officials of Communicable Disease Center at MOHME to monitor trend of epidemics and prepare necessary actions.

2.3. eHealth Infrastructure

In addition to software requirements, communication infrastructure, and hardware equipments must be provided to implement eHealth. In the interview with eHealth high officials in Iran, at the start of the process, a large proportion of healthcare facilities lacked computer systems and high bandwidth network(locally called SHAMS Network). MOHME jointly with Ministry of ICT mobilized healthcare facilities to computer systems and SHAMS. In order to register healthcare facilities capable of interoperating with SEPAS, an identification system is developed. This identifier is a mandatory reference of further communications.

2.4. eHealth Enablers

2.4.1. Privacy

Considering novelty of eHealth in Iran, executive regulations are not defined for privacy maintenance, yet. However, according to evaluation of HIS products, capability to store and maintain patient consents, and permissions related to surgeries and other interventions are considered as mandatory.

2.4.2. Standards

Since HIS products vary in functionality, they must be ranked amongst peer competitors. In this regard, a set of functionality criteria have been published, according to which are assessed and certified. Additionally, SEPAS is implemented according to ISO 13606 enabling several information systems interoperate with each other. In order to achieve semantic interoperability, a committee consisting of experts in health terminologies is formed called MAXA responsible to prepare and disseminate approved healthcare coding to be used in HIS.

2.4.3. Compliance

Functionality of HIS products are evaluated every 2 years and are certified property to their assessment score. In order to guarantee data interchange compliance, HIS vendors are required to get certification of interoperability with SEPAS complying ISO 13606. This certificate is considered in annual evaluation of hospitals, too.

3. Discussion

It has not been long that eHealth has been taken into consideration in Iran. Although lots of efforts have been done to implement eHealth in many aspects in healthcare domain, there is many to do in this regard. This study shows that the steps taken so far have been in line with WHO/ITU National eHealth Strategy Toolkit. Now the core eHealth team in Iran is restructuring after almost a 10-year process, reviewing its action plan and building up a dedicated committee to tackle with development issues and barriers in this regard.

References.

[1] Lipscomb CE. Medical Subject Headings (MeSH). Bull Med Libr Assoc. 2000 Jul;88(3):265-6.
[2] Pagliari C, Sloan D, Gregor P, Sullivan F, Detmer D, Kahan JP, et al. What is eHealth (4): a scoping exercise to map the field. J Med Internet Res. 2005;7(1):e9.
[3] Kuperman GJ. Health-information exchange: why are we doing it, and what are we doing? J Am Med Inform Assoc. 2011 Sep-Oct;18(5):678-82.
[4] Furukawa MF. Electronic medical records and efficiency and productivity during office visits. Am J Manag Care. 2011 Apr;17(4):296-303.
[5] Chaudhry B, Wang J, Wu S, Maglione M, Mojica W, Roth E, et al. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. Ann Intern Med. 2006 May 16;144(10):742-52.
[6] Bar-Dayan Y, Saed H, Boaz M, Misch Y, Shahar T, Husiascky I, et al. Using electronic health records to save money. J Am Med Inform Assoc. 2013 Jun;20(e1):e17-20.
[7] Eisenstein EL, Anstrom KJ, Macri JM, Crosslin DR, Johnson FS, Kawamoto K, et al. Assessing the potential economic value of health information technology interventions in a community-based health network. AMIA Annu Symp Proc. 2005:221-5.
[8] Detmer DE. Improving health and reducing costs through information technology. Acad Med. 1998 Mar;73(3):286-7.
[9] Webster PC. Centralized, nationwide electronic health records schemes under assault. CMAJ. 2011 Oct 18;183(15):E1105-6.
[10] McConnell H. International efforts in implementing national health information infrastructure and electronic health records. World Hosp Health Serv. 2004;40(1):33-7, 9-40, 50-2.
[11] Olsson S, Lymberis A, Whitehouse D. European Commission activities in eHealth. Int J Circumpolar Health. 2004 Dec;63(4):310-6.
[12] Adopted from who global observatory website: Global Observatory for eHealth. [cited 2014]; Available from: http://www.who.int/goe/en/.
[13] Scott RE, Mars M. Principles and framework for eHealth strategy development. J Med Internet Res. 2013;15(7):e155.
[14] Hamilton C. The WHO-ITU national eHealth strategy toolkit as an effective approach to national strategy development and implementation. Stud Health Technol Inform. 2013;192:913-6.
[15] International Telecommunication Union. [cited 2014]; Available from: http://www.itu.int/en/about/Pages/default.aspx.
[16] Organization WH. International Telecommunication Union. National eHealth strategy toolkit. 2012.
[17] 20-year vision of Islamic Republic of Iran. [cited 2014]; Available from: http://www.dolat.ir/PDF/20years.pdf.
[18] The 4th Country Development Programme of Islamic Republic of Iran. [cited 2014]; Available from: http://www.dmk.ir/Dorsapax/userfiles/file/02.pdf.
[19] Iranian Comprehensive Plan on Information Technology.
[20] Act of Iranian High Council of Health. [cited 2014]; Available from: http://siasat.behdasht.gov.ir/index.aspx?siteid=291&pageid=31599.
[21] The 5th Country Development Programme of Islamic Republic of Iran. [cited 2014]; Available from: www.dmk.ir/dorsapax/userfiles/file/5th.pdf.
[22] Functional Criteria of Hospital Information Systems. [cited 2014]; Available from: http://behdasht.gov.ir/uploads/101_1475_29_HIS_Criteria_v.4.3.docx.
[23] ISO. Electronic health record -- Definition, scope and context. 2005.

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Localizing the HL7 Personal Health Monitoring Record for Danish Telemedicine

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Abstract. Telemedicine holds a promise of lowering cost in health care and improving the life quality of chronic ill patients by allowing monitoring in the home. The *Personal Health Monitoring Record* (PHMR) is an international HL7 standard data format for encoding measurements made by devices in the home. However, the standard needs localization to national requirements in order to facilitate semantic interoperability between clinical systems. In this paper, we report experiences and decisions from the current effort to localize PHMR in Denmark, and highlight issues relevant for any adoption of the standard.

Introduction

Denmark, as many other countries, is facing a challenge in health care due to a population with longer expected lifetimes, increased frequency of chronic diseases, and a relative drop in the work-capable population. Telemedicine, here interpreted as remotely monitoring patients' vital signs in their homes, is seen as a path to lower costs and increased life quality. A typical scenario is a diabetes patient that several times as day measures her glucose level using a device in the home that transfers measured values to a regional hospital for review by clinicians. This saves visits to the out-patient clinic and still allows early detection of health related problems.

Denmark has moved a long way in terms of IT support for clinical work. All major public hospitals and 95% of general practitioners (GPs) are using electronic health record systems. However, connecting the home or individual patient to this infrastructure is challenging. There have been numerous telemedicine projects but generally the developed software architectures can be classified as "stovepipe systems" as each project typically develops their own dedicated client system for the home, proprietary databases and storage formats, and a dedicated application for clinicians. The result is a lack of integration with other clinical systems, missed opportunities for reuse, and generally the systems are not supported once the project funding ceases. To remedy this situation, the five Danish Regions (public institutions that govern Danish public hospitals which are by far the most important health care providers in Denmark) have decided to develop a common infrastructure.

In this paper, we report central issues and experience regarding defining a common data format for storing telemedical measurements. The Danish Regions have decided to localize the Personal Healthcare Monitoring Report (PHMR) [1], a HL7 Clinical Document Architecture (CDA) [2] template, for use in Denmark. While the localization process is still ongoing and our focus is a Danish context the lessons learned so far will be valuable for other countries adopting PHMR.

1. Methods

The process leading up to the decision for adopting the PHMR format and localizing it for Denmark has been a long one. In Denmark, MedCom, a publicly funded non-profit organization, controls standardization of clinical information systems. Since 1995 it has had success in establishing electronic exchange formats. These formats have not been based upon HL7 standards but mostly on Danish OIOXML formats (a nationally developed XML dialect initially created for exchanging information between public authorities) partly because the HL7 formats were much less mature when MedCom started. As the use of PHMR has been discussed by various stakeholders, including regional and national authorities for healthcare IT, research groups at universities, as well as commercial companies, MedCom formed a *PHMR Localization Committee* (PLC) [3] during November 2013 with the mandate to draft a first release of a Danish PHMR localization.

A main technical contributor to the process is the Net4Care project [4, 5], which was a research project based on an action research agenda [6]. From 2010 onwards, Net4Care developed and still maintains an open-source software framework based upon software ecosystem principles. The focus was on supporting rapid development of home monitoring applications by small-medium sized businesses (SMB)—and the project hypothesized a future where clinical systems migrated to PHMR and XDS.b. The Net4Care framework became widely used for experimentation and learning by SMBs and numerous presentations were made for Danish Regions and healthcare providers. Its demonstration of how these standards could be used in practice and the technical insights gained in the project thus strengthened the argumentation to move towards international standards.

2. Results

The PHMR draft [1] dictates to great detail how to use HL7's Clinical Document Architecture (CDA) to represent measurements of vital signs. Still, there are several open issues that must be handled before two IT systems can unambiguously understand a PHMR document. Below we discuss the central issues that any national or regional use of PHMR must consider. A premise of this work is the choice to require CDA level 3 [2,§3.4] which makes the PHMR machine processable as opposed to only supporting human readable contents.

2.1. Establish Unique OIDs

A central way that HL7 assigns unique meaning to entities is through the use of ISO/IEC Object Identifiers (OID), a sequence of non-negative integers separated by periods. For instance, the OID to identify HL7 itself is 2.16.840.1.113883. OIDs are essentially a tree, and one may request a unique root OID from a registration authority and define branches and leaves by adding subnodes.

As a PHMR document must identify many objects, like national and regional organizations (e.g. hospitals, GPs, etc.), and registers and standards (e.g. Danish National Register of Persons which assigns unique identities to all citizens), a Danish authority must identify and maintain such a list of OIDs and register a root OID.

In Denmark, it was decided to register the root OID at HL7's OID registry [7] as PHMR is a HL7 standard. Furthermore, MedCom is responsible for defining and maintaining the OID list in collaboration with National standards to avoid duplicated OIDs.

2.2. Clinical Code System

The CDA standard defines structure and contents of a data format for storing clinical data but has wisely refrained from dictating clinical semantics. Semantics, instead, is defined by *codes and vocabularies* [2, §8].

For instance, a measurement of a weight is represented by a *physical quantity* in HL7 (value, unit), such as 72.6 kg, but to uniquely identify it as a body weight measurement, a reference is made to a *code in a vocabulary*. Thus, in

```
<observation classCode="OBS" moodCode="EVN">
  <templateId root="2.16.840.1.113883.10.20.1.31"/>
  <templateId root="2.16.840.1.113883.10.20.9.8"/>
  <code code="8341-0" codeSystem="2.16.840.1.113883.6.1"
    displayName="Dry body weight Measured"/>
  <value unit="kg" value="72.6" xsi:type="PQ"/>
</observation>
```

the measured value is 72.6 kg and the code identifying the actual type of measurement is 8341-0 in vocabulary 2.16.840.1.113883.6.1. Looking up the latter OID you will find the LOINC [8] system. Again, by going to the search.loinc.org web site, you can lookup the 8341-0 code to find that it is indeed a weight measurement. In Denmark, it has been decided to use the Danish NPU terminology as this is www.labterm.dk hosted by the Danish Sundhedsstyrelse (health care authority).

2.3. Context of Measurement

The aspect of reviewing measurements made by a patient without any supervision by clinical trained personnel raises concerns for the clinicians responsible for the treatment. The question is how to judge the credibility of measurements made by the patient. This has in a Danish setting prompted a wish to add *context* to measurements. The required context includes how data has been *provisioned*, specifically whether scalar values like weight has been recorded either through electronic transmission or by manual entering of values, as well as how the *authoring context* was, specifically whether a patient made the measurements all by himself, aided by a home caregiver, or made by a trained clinician. The PHMR has entries that cover some aspects. The `Author` field [1, §2.13.2] represents the creator of the document, and the dataEnterer field [1, §2.13.3] represents the person who transferred the information from other sources into the document, while the Informant field [1, §2.13.4] is the source of the information. Thus, with a more precise definition of what is meant by these fields specifically in a Danish telemedical setting would enable the context to be deduced. As an example if Mr. Hansen measures his blood pressure aided by his home caregiver Miss Jensen using a device of type X—the Author could be device X, dataEnterer Miss Jensen, and Informant Mr. Hansen.

However, these fields cannot be used for defining the other dimension, how data is provisioned. Furthermore, these fields are global for all contained measurements in the PHMR document. And finally, the actual understanding of the context hinges on specific interpretations of more general fields in the PHMR, which is a very volatile proposal: Odds are that different systems will interpret the fields differently.

Therefore, the PLC has decided to use another feature of the CDA specification, the methodCode. According to IHE [9]: The methodCode element may be the specific method used to make an observation when this information is not already pre-coordinated with the observation code.

The PLC is presently working on a proposal with defining branch OIDs for two dimensions of methodCodes: One for author context (who was involved in making the measurement), and one for the data provision (which means were used to transfer the value to the document), and define a code system for each dimension. This entails the values as well as the codes. At present the envisioned values are: Author context (by patient himself/herself; aided by home nurse; by clinician)—Data provision (by electronic trans- mission; manually entered). As an example of the use of methodCode, the XML below shows a weight measurement using codes to define the context as *measured by the citizen* ("Målt af borger"), and *automatically provisioned* ("Måling overført automatisk").

```
<observation classCode="OBS" moodCode="EVN">
  <templateId root="2.16.840.1.113883.10.20.1.31"/>
  <templateId root="2.16.840.1.113883.10.20.9.8"/>
  <code code="NPU03804" codeSystem="2.16.840.1.113883.3.4208.100.1"
    codeSystemName="NPU terminologien"
    displayName="Legeme masse; Pt"/>
  <value unit="kg" value="77.5" xsi:type="PQ"/>
  <methodCode code="POT" codeSystem="2.16.840.1.113883.3.4208.100.6"
    codeSystemName="MedCom Message Codes"
    displayName="Målt af borger"/>
  <methodCode code="AUT" codeSystem="2.16.840.1.113883.3.4208.100.6"
    codeSystemName="MedCom Message Codes"
    displayName="Måling overført automatisk"/>
</observation>
```

One may note that this is not in strict accordance with the PHMR V1.1 DSTU's CONF-414 which states only one methodCode may be present in an observation section. A potential solution is to combine the two dimensions into a single set of codes, but this obviously scales poorly. We have adopted to keep this small deviation as the official XSD schemas for CDA and POCD MT000040 that we can find all allow an unbounded set of methodCodes.

2.4. Other Issues

Several other issues have been discussed in the PLC. One issue is regarding the interpretation of the Author field. In [1, §2.13.2] the author element is defined as: The author element represents the creator of the clinical document.

The question, however, is *who* is the author for a document containing medical measurements made in the home by a patient? At least three interpretations are viable: the measuring device, the patient, or a physician involved in the prescription or authenticating. The PLC has decided that the person finalizing the document (typically a disease management professional) will be viewed as the author in a telemedicine setting.

Another issue regards device information. The Regions (representing the clinicians) express this information as important with regards to interpretation of measured values. For instance, a sudden change in mean glucose level for a patient may simply be due to a change from one device to another that is slightly differently calibrated. Also, the date of last calibration is important information. However, the PHMR for- mat is relatively weak in structuring these data. Basically, only two tags are provided, manufacturerModelName and softwareName, which just contain unstructured text. Thus

the PHMR document structure has no means to enforce the presence of calibration information.

3. Discussion

A recent study of semantic interoperability [10] exemplified that real-world CDA documents are often still only semi-structured. In Denmark, the Regions aim at fully machine processable documents and strive for a common format for telemedical data after years of telemedicine projects that ended in proprietary formats. Also a decision has been made to depart from the line of national standards in favor of an international standard. This decision is mostly economically grounded: The Regions want to allow bids from all of Europe for greater competitions, and it actually is also a wish expressed by Danish providers as building software systems using international standards opens for a broader international market.

In parallel with the PLC work, our research group has developed an open source Java component, inspired by Green CDA, to allow quickly constructing proper Danish PHMR. It is available on BitBucket: https://bitbucket.org/4s/net4care-phmr-builder.

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References

[1] Health Level Seven. Implementation Guide for CDA Release 2.0 Personal Healthcare Monitoring Report (PHMR) (International Realm) Draft Standard for Trial Use Release 1.1; 2010.
[2] Boone KW. The CDA Book. Springer Verlag; 2011.
[3] MedCom Personal Health Monitoring Report Project; 2014. http://www.medcom.dk/wm112683.
[4] The Net4Care Site: http://www.net4care.org/.
[5] Christensen HB, Hansen KM. Net4Care : Towards a Mission-Critical Software Ecosystem. In: Joint Working IEEE/IFIP Conference on Software Architecture (WICSA) and European Conference on Software Architecture (ECSA), 2012. Helsinki, Finland: IEEE Communications Society; 2012. p. 224–228.
[6] Sjøberg D, Dyba T, Jørgensen M. The future of empirical methods in software engineering research. International Conference on Software Engineering. 2007; p. 358–378.
[7] HL7 OID Registry;. http://www.hl7.org/oid/index.cfm.
[8] Regenstrief Institute I. Logical Observation Identifiers Names and Codes;. http://loinc.org/.
[9] IHE Wiki. http://wiki.ihe.net/index.php?title=1.3.6.1.4.1.19376.1.5.3.1.4.13.
[10] Franz B, Schuler A, Helm E. Analysis of Clinical Documents to Enable Semantic Interoperability. In: Proceedings of 24th International Conference on Database and Expert Systems Applications. vol. 8056 of Lecture Notes in Computer Science. Prague, Czech Republic; 2013.

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Interoperability Standards enabling cross-border Patient Summary Exchange

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Abstract. In an increasingly mobile world, many citizens and professionals are frequent travellers. Access during unplanned care to their patient summary, their most essential health information in a form physicians in another country can understand can impact not only their safety, but also the quality and effectiveness of care. International health information technology (HIT) standards such as HL7 CDA have been developed to advance interoperability. Implementation guides (IG) and IHE profiles constrain standards and make them fit for the purpose of specific use cases. A joint effort between HL7, IHE, and HealthStory created Consolidated CDA (C-CDA), a set of harmonized CDA IGs for the US that is cited in the Meaning Use II (MU-II) regulation. In the EU, the Patient Summary (PS) Guideline recently adopted, cites the epSOS IG also based on HL7 CDA, to support cross-border care in the EU and inform national eHealth programs. Trillium Bridge project supports international standards development by extending the EU PS Guideline and MU-II in the transatlantic setting. This paper presents preliminary findings from comparing patient summaries in the EU and US and reflects on the challenge of implementing interoperable eHealth systems in the cross-border or transatlantic setting.

Keywords. Patient summaries, eHealth interoperability, Meaningful Use, HL7 CDA

Introduction

Interoperability has been part of national eHealth strategies for many years. Initially the focus was on technical interoperability and frequently limited to the in-hospital setting. Recently semantic and organizational interoperability are recognized as equally important as attention shifts toward patient empowerment and integrated care. In 2010, the Memorandum of Understanding on eHealth Cooperation between the European Commission and the United States Department of Health and Human Services recognized cooperation to advance eHealth/HIT as a driver for improved health and health care, economic growth, and innovation. The MoU highlighted HIT standards as a shared goal: *"Development of internationally recognized and utilized interoperability standards and interoperability implementation specifications for electronic health record systems that meet high standards for security and privacy protection."*[1]. In the

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US, the Meaningful use program that has revolutionised healthcare by defining standards, IGs, certification criteria for Electronic Health Record technology and providing incentives for its use, cites HL7 CDA (see Table 1).

Table 1. HL7 CDA content exchange standards under Meaningful Use Stage II [2].

§ 170.205 Content exchange standards and implementation specifications for exchanging electronic health information.	
170.205(a)(3)	Consolidated CDA (C-CDA): Standardized representation of the Consult Note, Diagnostic Imaging Report, Discharge Summary, History and Physical, Operative Note, Procedure Note, Progress Note, and Continuity of Care Document (CCD).
170.205(h)	CDA Guide for Quality Reporting Document Architecture, Category I (QRDA-I): Standardized representation of quality data for an individual patient. Data in a QRDA-I report can be consumed by a calculation engine to determine if the patient met the numerator or denominator criteria for a given quality measure.
170.205(i)	CDA Guide for Reporting to Central Cancer Registries: Standardized cancer registry reporting format.
170.205(k)	CDA Guide for Quality Reporting Document Architecture, Category III (QRDA-III): Standardized representation of aggregate quality data (e.g. number of patients meeting the numerator criteria for a given quality measure).

On the 19th November 2013, the eHealth Network (eHN) established under article 14 of the EU Directive on patient's rights in cross-border care [3] approved the guidelines on minimum/non-exhaustive patient summary (PS) dataset [4]. The aim of this guideline is primarily to support continuity of care and patient safety across borders focusing on emergency or unplanned care, but also to serve as a common baseline for patient summaries at national level. Patient summary is defined as the "*minimum set of information needed to assure healthcare coordination and continuity of care*" [4]. Emergency or unplanned care refers to "*the range of healthcare services available to people who need medical advice, diagnosis and/or treatment quickly and unexpectedly*" [4]. The guideline presents the *basic* dataset defined as the set of *essential* information from a clinical point of view that needs to be exchanged to deliver safe care to the patient, in the context of unplanned care. This information must be always available. In contrast, the *extended* dataset is defined as the minimum amount of *recommended* information that needs to be exchanged from a clinical point of view and should be completed whenever possible. Although the guideline serves as non-binding recommendation to the EU Member States (MS), it provides for the first time the technical, semantic and organizational framework for cross-border care noting the implications and responsibilities of the MS. The epSOS LSP (www.epsos.eu) designed, built, and evaluated a service infrastructure that demonstrated cross-border interoperability between electronic health record systems and provided the background and practical experience for the PS guideline. Trillium Bridge (www.trilliumbridge.eu) carries out a feasibility study for the EU/US electronic exchange of patient summaries. Starting with the gap analysis, it compares the C-CDA Continuity of Care Document (CCD) specification cited in MU-II [5] and the epSOS PS IG cited in the PS Guideline. Methodology and preliminary findings are presented and discussed below.

1. Methods

Trillium Bridge has adopted a five step strategy (shown in Figure 1) in its effort to establish an interoperability bridge across the Atlantic. Its findings intend to inform

international standardization efforts, promote high standards of quality and safety in cross-border care, and contribute to health system sustainability and economic growth:

- *Selecting the grounds*: Mobilize people and resources creating a forum of collaboration and knowledge sharing to select and analyse key use cases and to carry out gap analysis i.e. compare patient summary specifications and associated policies including eIdentification, authorisation, privacy & security.
- *Building the Bridge*: Assemble interoperability assets to align structure and terminology i.e. clinical document structures and semantic mappings for value sets published by the National Library of Medicine & epSOS.
- *Testing the Bridge*: Develop testing tools strategy and validate PS exchange.
- *Paving the Bridge*: Contribute to Policy Alignment, Standardization and Future Sustainability by *informing* development of PS IGs and template libraries in liaison with Standards Development Organizations to reduce the cost of standards and by *delivering* policy briefs in seven areas identified for policy alignment: cross-vendor integration, incentives, standardization, innovative business models, education, clinical research, security & privacy.

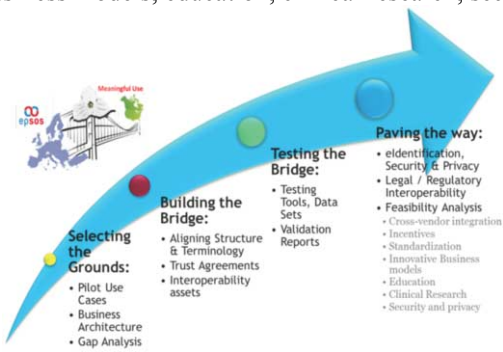


Figure 1: Trillium Bridge adopts a five step strategy in the feasibility study of transatlantic PS exchange.

2. Results

2.1. Selecting the Grounds

After establishing its community of knowledge, Trillium Bridge set out to collect user stories that reflect the need of patient summary exchange in the transatlantic setting: a woman that is a cancer survivor, a college student with known allergies, a retired businessman with hypertension and so on. All come down to a citizen crossing the Atlantic, who has access to his/her patient summary for unplanned care. Key questions are: "*Is it feasible to accurately communicate an EU patient summary or US C-CDA/CCD to physicians on the other side of the Atlantic?"* and *"Is it feasible to receive a report from a healthcare encounter on the other side of the Atlantic in a format that can be understood and incorporated in the health system back home?*" The Digital Agenda for Europe sets 2015 as the deadline for giving patients online access to their medical data (Key action 13) and epSOS pilots the Patient Access (PAC) service [7]. In the US, the BlueButton+ drives citizen's access to their EHR data (http://bluebuttonplus.org). TheEU PS Guideline cites the epSOS PS IG that uses HL7 CDA and has been designed as a dataset of "*essential and understandable health*

information" that is made "*available at the point of care to deliver safe patient care."* On the other hand, C-CDA/CCD is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare, covering one or more healthcare encounters. It provides a means for one healthcare practitioner or system to aggregate all of the pertinent data about a patient and forward it to another practitioner or system to support continuity of care. The primary use case for the C-CDA/CCD is thus, to provide a snapshot in time containing the pertinent clinical, demographic, and administrative data for a specific patient. Mindful of the slightly different purpose, we compared the two specifications and associated terminologies in the clinical context of unplanned care. Figure 2 presents the common patient summary sections as reflected in Europe and the US. The coded section shared in the two documents are: medications, allergies, immunizations (vaccinations), problems, medical devices and implants. Several elements are richer in content in CCD (social history observation, results, vital signs, procedures, plan of care, and functional status. The EU PS guideline changed the optionality to mandatory in a few coded sections: surgeries past 6 months, treatment (plan of care), and autonomy (functional status).

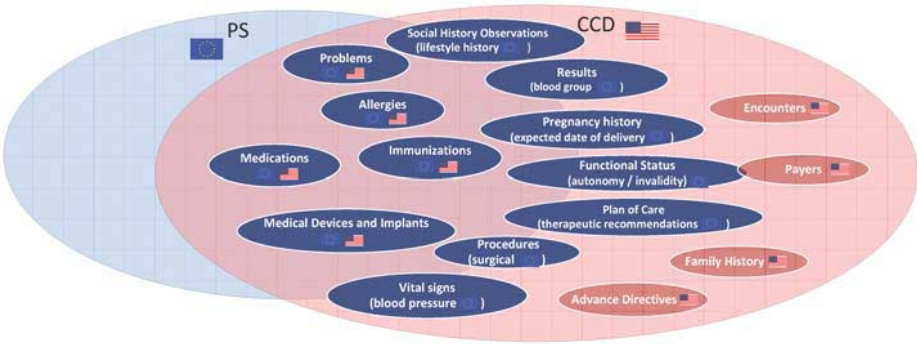


Figure 2: Intersection of coded sections between EU PS Guideline and US C-CDA/CCD (clinical view point).

Significant aspect of this comparison relates to the value sets used in each coded section. Table 2 presents a subset of the equivalence mappings identified so far.

Table 2. Indicative equivalence mappings of value sets in selected coded sections.

Coded Section	C-CDA terminology		epSOS terminology
Allergies			
Allergy/Adverse Event Type	SNOMED CT	epSOSAdverseEventType/ epSOSReactionAllergy	SNOMED CT
Medication Clinical Drug Name Value Set	RxNORM	epSOSActiveIngredient	ATC
Immunizations/Vaccinations			
Vaccine Admin Value Set	CDC Vaccine Code (CVX)	epSOSVaccine	SNOMED CT
Problem			
Problem	SNOMED CT	epSOSIllnessesandDisorders	ICD-10
Medical Equipment			
N/A		epSOSMEdicalDevices	SNOMED CT
Medications			
Medication Route FDA	FDA RouteofAdministration	epSOSRouteofAdministration	EDQM
UnitsofMeasureCaseSensitive	UCUM	epSOSUnits	UCUM
Vital Signs			
Vital Sign Result	LOINC	epSOSBloodPressure	LOINC

3. Discussion

There has always been tension between general purpose and highly constrained standards or IGs in eHealth. The less constrained a standard is, the more susceptible it is to local extensions, and inconsistent implementation. The proliferation of various types of templates does not make things any easier and the need for implementation guidance and pre-production interoperability testing is only partly met by IHE profiles and connectathons. Our early experience with Trillium Bridge confirms that a lot of ground work is needed to lower cost of implementation advancing interoperability in the widening space covered by eHealth. Only part of the effort to meet clinical needs and enable patient safety and high standards of care is technical. An infrastructure needs to be set up to facilitate service provision including translation, mapping and transcoding of terminologies, supported by a legal framework that acts as an enabler rather than inhibitor for cross-border care addressing security and privacy. According to the PS Guideline "*semantic mapping is a shared cross-border responsibility between respective Member States managed at the cross-border level and is part of its trust-building framework."* Last but not least, there are cultural differences to be addressed across the board with education, training awareness raising and patient empowerment.

For the next steps, Trillium Bridge aims to define interoperability assets that are well-understood and fit for the purpose of validating the key use cases of presented a PS in the patient's or the provider's device transformed and transcoded in the language and format of the country of treatment. Findings of the gap analysis, interoperability assets and the results of the validation exercise will provide practical input to the feasibility study of Trillium Bridge, which aims to lower standards development costs accelerating convergence towards global standards. If successful, Trillium Bridge will be pivotal in lowering costs/barriers of transatlantic business engagement, but more importantly in supporting the fundamental right of citizens to their health information.

References

[1] Memorandum of Understanding between the United States Department of Health and Human Services and the European Commission on Cooperation surrounding health related information and communication technologies (ICT): http://ec.europa.eu/information_society/activities/health/docs/policy/eu-usa-mou-ehealth-signed2010.pdf

[2] Federal Register, Part II HHS, 45 CFR Part 170, 42 CFR Parts 412, 413, and 495; Electronic Health Record Incentive Program—Stage 2; HIT: Standards, Implementation Specifications, and Certification Criteria for EHR Technology, 2014 Ed; Revisions to the Permanent Certification Program for HIT; Final Rules September 2012, http://www.gpo.gov/fdsys/pkg/FR-2012-09-04/pdf/2012-21050.pdf

[3] Guideline on Minimum/non-exhaustive patient summary dataset for electronic exchange in accordance with the cross-border directive 2011/24/EU, 2013, http://ec.europa.eu/health/ehealth/docs/ guidelines_ patient_summary_en.pdf

[4] European Parliament and the Council of the European Union, Directive 2011/24/EU of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare, 9 March 2011 http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2011:088:0045:0065:en:PDF

[5] HL7 Implementation Guide for CDA® Release 2: IHE Health Story Consolidation, DSTU Release 1.1 (US Realm), Draft Standard for Trial Use, July 2012 https://www.hl7.org/implement/standards/product_brief. cfm?product_id=258

[6] epSOS D3.2.2 Final definition of functional service requirements- Patient Summary, Oct 29, 2012. http://www.epsos.eu/uploads/tx_epsosfileshare/D3.2.2_Final_Definition_Functional_Service_Req_Patient_Summary.pdf

[7] epSOS D1.4.3 EED Services including specifications for all services. http://www.epsos.eu/uploads/tx_epsosfileshare/D1.4.3_EED_Services_including_specifications_for_all_services_01.pdf

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Towards a global IT system for personalized medicine: the Medicine Safety Code initiative

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Abstract. The availability of pharmacogenomic data of individual patients can significantly improve physicians' prescribing behavior, lead to a reduced incidence of adverse drug events and an improvement of effectiveness of treatment. The Medicine Safety Code (MSC) initiative is an effort to improve the ability of clinicians and patients to share pharmacogenomic data and to use it at the point of care. The MSC is a standardized two-dimensional barcode that captures individual pharmacogenomic data. The system is backed by a web service that allows the decoding and interpretation of anonymous MSCs without requiring the installation of dedicated software. The system is based on a curated, ontology-based knowledge base representing pharmacogenomic definitions and clinical guidelines. The MSC system performed well in preliminary tests. To evaluate the system in realistic health care settings and to translate it into practical applications, the future participation of stakeholders in clinical institutions, researchers, pharmaceutical companies, genetic testing providers, health IT companies and health insurance organizations will be essential.

Keywords. Personalized medicine, pharmacogenetics, biological ontologies, medical informatics, clinical decision support systems

Introduction

The availability of pharmacogenomic data of individual patients can significantly improve physicians' prescribing behavior, lead to a reduced incidence of adverse drug events and an improvement of effectiveness of treatment. Unfortunately, major barriers to the wide-spread implementation of pharmacogenomics in clinical practice remain. Even though genetic testing is constantly becoming cheaper and faster, the financial cost and turnaround time remain a hindrance to wide-spread implementation. Furthermore, the practical application of insights from pharmacogenomic tests is hindered by difficulties in the storage, exchange, and interpretation of pharmacogenomic data. In particular, interoperable electronic health record systems capable of storing structured genetic test results and transmitting those results to other care providers are needed, but such infrastructures are still unavailable in most parts of

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the world. Finally, most institutions lack easily accessible computer-based clinical decision support systems that can assist clinicians with the interpretation of pharmacogenomic data – a vital component to the use of these data at the point of care.

To make patient's genotype data on essential pharmacogenes globally available to routine medical care, simple and intuitive systems are required to minimize the need for specialized infrastructure, software, and knowledge. The Medicine Safety Code initiative is an effort to improve the ability of clinicians and patients to share pharmacogenomic data and to use it at the point of care.

1. Methods

The Medicine Safety Code (MSC) was implemented as a two-dimensional (2D) barcode that captures data about genetic variants in essential pharmacogenes of an individual patient (Figure 1). The 2D barcode is based on the Quick Response (QR) code standard, which has become widely popular in recent years because it can be decoded quickly and reliably, has relatively high information density and can encode hyperlinks to pages on the World Wide Web. In addition to the QR code representation, MSC data can also be embedded into electronic health records.



Figure 1. A Medicine Safety Code printed on a card carried by the patient is decoded with a smartphone to display drug dosing recommendations.

The data contained in each MSC is a standardized string consisting of a base-URL, a version number and a compressed representation of the pharmacogenomic markers of the patient, e.g.:

http://safety-code.org/v0.2/QXGqrLF2h8xuqzIyCGJE2hzPzVzrND... (truncated)

This string does not only contain anonymous, compressed genetic data, but also double-acts as a URL that leads to a web page for decoding and interpreting these data. This means that common mobile devices can be used for interpreting the pharmacogenomic data contained in MSCs without requiring the installation of dedicated software. The system presents recommendations for all medications where pharmacogenomic guidelines for the specific patient apply, and medical professionals can quickly select information about a specific medication (e.g., a medication that is considered for prescription).

The system is backed by a curated knowledge base that contains information about essential pharmacogenes, including haplotype definitions, phenotype translations and clinical guidelines. Haplotype definitions were adapted from the Pharmacogenomics Knowledge Base (PharmGKB) [1], while phenotype translations and clinical guidelines were taken from the Clinical Pharmacogenomics Implementation consortium (CPIC) [2], the Dutch Pharmacogenomics Working Group [3] or the American College of Rheumatology [4]. The knowledge base was implemented as an OWL 2 DL ontology called *Genomic CDS*. We used TrOWL [5], a highly scalable OWL 2 DL reasoner, for all reasoning tasks, such as providing the decision support service, analyzing aggregated data and checking the consistency and coherence of the knowledge base.

The MSC system was tested by printing, scanning and interpreting exemplary MSC QR codes.

2. Results

The project website and demos of the decision support service are available at http://safety-code.org/ . The source code of the software and the Genomic CDS ontology are available from the Google Code project website at [6].

The current version of the MSC (version 0.2) is capable of representing data on 385 genetic markers in 58 important pharmacogenes. The curated knowledge base contains 299 pharmacogenomic decision support rules curated from the Clinical Pharmacogenomics Implementation consortium, the Dutch Pharmacogenomics Working Group or American College of Rheumatology, covering 62 pharmaceutical compounds (Table 1).

Table 1. Overview of pharmaceutical compounds for which guidelines have been curated and added to the Genomic CDS knowledge base (ordered by number of prescriptions per year in Germany).

Pantoprazole, simvastatin, metoprolol, omeprazole, phenprocoumon, allopurinol, glimepiride, citalopram, estrogen-containing oral contraceptives, clomipramine, clopidogrel, mirtazapine, venlafaxine, carvedilol, amitriptyline, tramadol, esomeprazole, glibenclamide, sertraline, doxepin, carbamazepine, duloxetine, paroxetine, escitalopram, risperidone, trimipramine, olanzapine, oxycodone, tamoxifen, lansoprazole, azathioprine, codeine, haloperidol, clozapine, flecainide, flupenthixol, aripiprazole, phenytoin, propafenone, tacrolimus, zuclopenthixol, warfarin, rabeprazole, nortriptyline, imipramine, atomoxetine, capecitabine, abacavir, moclobemide, peginterferon alfa-2a, ribavirin, mercaptopurine, acenocoumarol, desipramine, fluorouracil, gliclazide, irinotecan, peginterferon alfa-2b, tegafur, thioguanine, tolbutamide, voriconazole

To yield an overview of the potential influence that the MSC could have on clinical care, we analyzed prescription statistics of drugs containing substances listed in Table 1. Based on data from general practitioners and medical specialists in private practice in Germany [7], these compounds were associated with 123,12 million drug prescriptions in the year 2011; amounting to costs of 3,76 billion Euros (drug dispensation inside

hospitals is not included in these statistics). New guidelines for other drugs are constantly issued, so the set of pharmacogenes represented by the MSC might cover an even larger fraction of prescribed medications in the future.

We found that the TrOWL reasoner [5] offered excellent reasoning performance with the Genomic CDS ontology, returning results within 3-4 seconds (system specifications: Intel Xeon E3-1230, 3,30 GHz, 16 GB RAM). Even though the response time of TrOWL is vastly superior to other reasoning systems, it is still not optimal for use in busy medical routine. This issue is mitigated by the fact that the MSC system includes a caching functionality, so that results are available without delay for MSCs that have already been processed and cached by the system once. With cached results, the entire process of using an MSC (i.e., picking up a card with an MSC, scanning the QR code, selecting a medication, reading the associated decision support message) can be accomplished within 15 seconds.

3. Discussion

The MSC could act as an enabling technology for the widespread dissemination and clinical implementation of pharmacogenomic data and decision support for several reasons. It is easily implementable, since the MSC is based on technology that is low-cost and widely available and requires minimal integration with existing clinical infrastructure. The 2D barcodes used by the MSC can be printed on personalized cards that patients can carry in their wallets, or they can be incorporated in paper-based lab reports. The 2D barcodes can be quickly decoded using common smartphone devices to yield clinical decision support messages that are pertinent to the individual's genetic profile. If a customized implementation is desired, the MSC can be deployed locally. The system specifications and source code are made openly available.

The MSC system makes it possible to provide access to up-to-date decision support, anywhere. This includes outpatient and emergency situations, regardless of whether the care facility has implemented a genome-enabled electronic medical record and local clinical decision support algorithms. The infrastructure also allows patients to opt-in or opt-out of the system at any time, since they can always choose whether they want to make their MSCs available to healthcare providers.

The Genomic CDS ontology we developed as a backend for the MSC system can be used to represent, organize and reason over the growing wealth of pharmacogenomic knowledge, as well as to identify errors, inconsistencies and lacking definitions in source data sets or individual patient data.

To succeed, the establishment of a network of stakeholders in clinical institutions, researchers, pharmaceutical companies, genetic testing providers, health IT companies and health insurance organizations is essential. Persons interested in participating in the Medicine Safety Code initiative are welcome to visit http://safety-code.org/ and to subscribe to the mailing list of the initiative.

3.1. Related work

While the MSC system is unique in its focus on providing pharmacogenomic data and decision support in a decentralized setting, some systems have been described that implement pharmacogenomic CDS in local institutions or regional infrastructures.

Swen *et al.* reported on the implementation of pharmacogenomic decision support rules in a computerized drug prescription system in the Netherlands [8]. Pulley *et al.* reported encouraging results about using pharmacogenomic CDS for optimizing anticoagulant therapy at the Vanderbilt University Medical Center [9]. Lærum *et al.* recently reported good feedback from clinicians when testing a prototype of a pharmacogenomic decision support application for immunosuppressant dosing [10].

3.2. Future work

As an important next step towards practical application, we are preparing for user tests with medical professionals to optimize the system for use in realistic clinical settings.

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References

[1] Hewett M, Oliver DE, Rubin DL, Easton KL, Stuart JM, Altman RB, et al. PharmGKB: the Pharmacogenetics Knowledge Base. Nucleic Acids Res. 2002 Jan 1;30(1):163–5.
[2] CPIC: Clinical Pharmacogenetics Implementation Consortium [PharmGKB] [Internet]. [cited 2013 Jul 26]. Available from: http://www.pharmgkb.org/page/cpic
[3] DPWG: Dutch Pharmacogenetics Working Group [Internet]. [cited 2014 Jan 27]. Available from: https://www.pharmgkb.org/page/dpwg
[4] American College of Rheumatology [Internet]. [cited 2014 Jan 27]. Available from: http://www.rheumatology.org/
[5] Thomas E, Pan JZ, Ren Y. TrOWL: Tractable OWL 2 Reasoning Infrastructure. the Proc of the Extended Semantic Web Conference (ESWC2010). 2010.
[6] genomic-cds - Knowledge Bases and Clinical Decision Support Systems for Realizing Personalized Medicine - Google Project Hosting [Internet]. [cited 2014 Jan 27]. Available from: https://code.google.com/p/genomic-cds/
[7] Schwabe U, Paffrath D. Arzneiverordnungs-Report 2012 aktuelle Daten, Kosten, Trends und Kommentare. Berlin: Springer; 2012.
[8] Swen JJ, Nijenhuis M, Boer A de, Grandia L, Zee AHM der, Mulder H, et al. Pharmacogenetics: From Bench to Byte - An Update of Guidelines. Clin Pharmacol Ther. 2011 Mar 16;89(5):662–73.
[9] Pulley JM, Denny JC, Peterson JF, Bernard GR, Vnencak-Jones CL, Ramirez AH, et al. Operational Implementation of Prospective Genotyping for Personalized Medicine: The Design of the Vanderbilt PREDICT Project. Clin Pharmacol Ther. 2012;92(1):87–95.
[10] Lærum H, Bremer S, Bergan S, Grünfeld T. A taste of individualized medicine: physicians' reactions to automated genetic interpretations. J Am Med Inform Assoc. 2013 Sep 3;amiajnl–2012–001587.

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Using Design Science Research to develop Online Enhanced Pharmaceutical Care Services

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Abstract. The *ePharmaCare* project aims at assessing the potential of eHealth services for the provision of pharmaceutical services interacting actively with patients. The results presented here focus on the first three steps of Design Science Research Methodology. A mixed methods approach was used with an online survey to collect data on use of information technologies in community pharmacy, followed by an exploratory observational time and business processes study, which use the shadowing method to identify and assess the opportunity to lunch online services. Combining this with the Service Experiment Blueprint and the Dáder method an enhanced pharmaceutical service was designed. Next, an artifact is developed and a prototype is implemented to demonstrate the value of online pharmaceutical services' delivery. This new service could represent a new perspective for pharmaceutical services integration within the health system.

Keywords. eHealth, pharmaceutical care services, design science research methodology, community pharmacy, service experience blueprint.

Introduction

The *ePharmaCare* project aims at assessing measurable health gains in efficiency and in quality from the development of online pharmaceutical services (PS); and estimating the potential of eHealth in the provision of PS by actively interacting with patients. The easy accessibility and the perceived affordability that positions pharmacists at the first line of contact within the healthcare system are important advantages [1].

A clear demographic and epidemiological transition in Europe is leading to a growing burden on chronic diseases. The orientation towards the patient is the new paradigm of pharmacy practice, and has led to the PS concept and a higher role for patients, as devised by the Dáder method [2]. It can be considered very valuable due to economic savings, to larger service efficiency and better patient's health outcomes [3].

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Costa et al. [4] have described the status and outlined the trends of community pharmacy (CP) services in Portugal. Investing in information technologies (IT) and modernizing the architecture of pharmacies was envisioned as a necessary step. Recent political changes seem to reinforce the need to expand to a wider range of services, but this process has been very slow [5]. There is a need for IT to support the extended role of CPs to include the interaction with patients [6]. Calabretto et al.[7] found out that CPs are still in the "infancy" of IT usage. Gregório & Lapão [8] explored different scenarios for the future of CPs, and eHealth emerges as one approach that may develop in next years to harvest the full potential of these professionals. eHealth uses "IT to support health service provision, complying with the needs of citizens, patients, health professionals and other providers" [9]. It promises a better access to information by patients and providers leading to a safer health [10]. The main problem addressed by this research is to understand how online PS could improve patient management and how to improve PS's quality, thus establishing its feasibility and sustainability.

1. Methods

A mixed method approach is used. A literature review was performed using MEDLINE and Google Scholar for searching strings like "pharmaceutical services", "pharmacist role", etc. The online survey was sent to 323 pharmacies associated with the Portuguese Association of Pharmacies to collect data on PS and to diagnose IT usage in CP.

The Design Science Research Methodology (DSRM) was used to link between research and professional practice by designing and evaluating artifacts that address a specific need. Hevner et al.[11] established the DSRM rules in the form of guidelines with six main activities. Here, the first three activities of the DSRM are studied: identify the problem relevance and solution aims, design and develop an artifact. To design the online service the *Service Experience Blueprint* (SEB) [12] was applied (combined with Dáder method [2]) to ensure a customer driven design perspective through actual service experience [13]. Dáder method was used as a reference to create an operative procedure that allow for pharmacotherapy follow-up to be carried out on any type of patient, in any setting and by any pharmacist [2]. These procedures include activities like monitoring response to therapy, etc., according to patients' individual needs.

A set of four CPs (serving the population at high-street) was selected by convenience to study the patterns of PS provided to evaluate clinical services value [14]. An exploratory observational time and motion study (weekday full 8hour shift) was done using the shadowing method [15]. Informed consent was formally obtained. An Excel database (Microsoft Corporation®) spreadsheet on a laptop PC and a stopwatch were used to record the duration of each activity, as well by who, where and how it was performed. To apply SEB a set of 50 qualitative interviews was performed in health-centers and hospitals. These interviews sought information regarding the current service concept offered by CPs but also what desired outcomes customers would enjoy to see implemented within existing or new services. The prototype was implemented using *rubi-on-rails* open-source software. The *Trello* was used to manage implementation and the website was SSL certificated. Data and Statistical analysis was conducted in Excel® and SPSS® Software Package for Social Sciences; Version 20.0. All data were kept anonymous and confidential. This study was performed in strict accordance with the good research practices and code of ethics of Instituto de Higiene e Medicina Tropical, and approved by the Committee on the Ethics (Permit Number: 7-2012-PN).

2. Results

2.1. Online Survey

The online survey (with response rate of 4.76%, comparable with other pharmacy research surveys [3]), from which the following results can be highlighted:

- The installed information system (IS) is mainly used for dispensing medicines and administrative tasks (stock management, reimbursement activities, etc.);
- All pharmacies claim to check their email daily, although only 15% use it to answer to patients' queries, and do so less than 5 times a month;
- 23% of the pharmacies have a website and 38% use a social network.

The dispensing of medicines and the collection of used medicines are the only services that all the pharmacies provided. 38.5% of the pharmacies refer that about 60% of the customers have chronic conditions. The services related with the provision of information (SMS alerts, etc.) were the ones that pharmacies are more open to provide in the future. Most CPs use SIFARMA IS, provided by pharmacy owners' Association. Patients' data is located in each pharmacy, and only information regarding the national prescription system is shared with the Ministry of Health.

2.2. Observational Study

The observational study took place in four pharmacies, with 108 hours of working time (and 894 tasks) recorded. The average total aggregated time observed per pharmacy was 27h10min. Pharmacist performed 85% of the tasks (65% of total time). An average of 481 min./pharmacy (76 min./employee) was not used in any tasks. Almost 50% of pharmacists' time is used in interaction with customers and 38% is used in administrative tasks, including ordering and storage of medicines and checking for errors in the dispensed prescriptions. Since 20% of the idle time is considered socialization, an average of 38min. of available time per pharmacist was estimated. In 44.6% of the observed dispenses, at least one chronic use medicine was dispensed. The pharmacy's IS was used in 95.6% of medicine dispensing processes, in 80.4% of patients queries about medicine availability and in 27.2% of administrative tasks.

2.3. Qualitative research

The SEB qualitative research was undertaken in the hospitals and health centers. The interviews involved 24 males and 26 females (mean age: 44.4 years). The interviewees reported an average interval of 45 days between visits. 46% of the participants admitted that they sought healthcare provision within the CP for minor issues before going to a doctor. The main service failures identified were the lack of medicines, lack of professionalism and an overall dissatisfaction with the service provided. The SEB highlights the guidelines responsible for the service theater identifying the various actors and the flow of possible actions throughout the service. It is also defined where the service takes place and how is the customer interacting with the service provider, as well as possible waiting points and fail points.

2.4. ePharmaCare Prototype design and implementation

The 3rd step of DSRM addresses the design of an artifact. This artifact resulted from 5 months of work with people from various backgrounds. The prototype aims at helping to capture patients' commitment and to teach them how to be content generators. This will support pharmacies' work on patients' monitoring and assistance. Trello assured a better fitting between the online service design requirements and the implementation. The patient's unique therapeutic profile is made from all medicines taken by each patient (validated throughout the process). The prototype is able to calculate the therapeutic profile's end date and warn the pharmacist when the date is approaching. In cases such as diabetes, missing a medicine dose can create very serious problems.



Figure 1. 'Maria Lopes' (non-real name) therapeutic profile view at ePharmaCare.

In figure 1, one can see patient *Maria Lopes*' therapeutic profile with 3 different medicines, each one has its own dose and regime, and therefore duration (until new prescription is needed). Each medicine is tagged as chronic or not. This ability is useful for pharmacies to be aware of the medicines that a patient needs to continue to take even when medicines do not strictly belong to the therapeutic profiles. This information could be also helpful when trying to detect conflicts between medicines.

3. Discussion

The results show thus far allow for a good characterization of today's PS' provision. The pharmacists' available time we have accounted for is an indication that there may be an opportunity to develop PS. This challenges the usual barriers pointed out by pharmacist to this development, which is "*lack of time*" [15, 16]. This is probably due to miss perception on the use of time.

The observational study also points out the eventual necessity to reorganize the internal functioning of pharmacies, with more clear roles for each of the professionals. The social abilities that these professionals do have may be used as complementary tools to better interact with patients in a new web-based service. There is the necessity to rethink the CP business model in order to effectively and coherently integrate it into

future health system models. Currently, the *ePharmaCare* is on the 4th phase of DSRM, demonstrating the platform usage and educating patients and pharmacist on interacting with each other, collecting data on the value of services for patients and health system. To validate patient data completeness patients should visit their community pharmacist monthly. However, pharmacist can also inquire patients about it interactively.

We believe that *ePharmaCar* prototype is offering participating pharmacies a way to better monitor their patients. By bringing to life a useful tool it fulfills the detected need for IT and opens to patients a way to interact with their data and actively contribute to their own therapy. These first interactions with patients show that *ePharmaCare* prototype is also facilitating patients to learn how to better manage their medications. More comprehensible results will be presented at the end of the project, which will also address other issues like security, data privacy, and incentives.

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References

[1] M.A. Chisholm-Burns, J.S. Graff Zivin, J.K. Lee, et al., Economic effects of pharmacists on health outcomes in the United States: A systematic review, *AmJ Health Syst Pharm* **67** (2010), 1624-34.
[2] Pharmaceutical Care Research Group. Pharmacotherapy follow-up: The Dader method (3rd revision: 2005). *Pharmacy Practice* 4.1 (2006): 44-53.
[3] W.R. Doucette, D.H. Kreling, J.C. Schommer, et al., Evaluation of Community Pharmacy Service Mix: Evidence From 2004 National Pharmacist Workforce Study, *J Am Pharm Assoc.* **46** (2006), 348-355.
[4] S. Costa, C. Santos & J. Silveira, Community pharmacy services in Portugal, *Ann Pharmacother,* **40** (2006**),** 2228-34.
[5] R.M. Gallagher & H.C. Gallagher. Improving the working relationship between doctors and pharmacists: is inter-professional education the answer? *Adv Health Sci Educ Theory Pract,* **17.2** (2012): 247-257.
[6] P.P. George, J.A.D. Molina, J. Cheah, S.C. Chan, B.P. Lim, Evolving Roles of the Community Pharmacist – A Literature Review, *Annals Academy of Medicine Singapore* **39** (2010), 861-867.
[7] J.P. Calabretto, J. Warren, K.. Darzanos & B. Fry, Building common ground for communication between patients and community pharmacists with an internet medicine cabinet. *In: 35th Hawaii International Conference on System Sciences* (2002), 2087-2094.
[8] J. Gregório & L.V. Lapão, Uso de cenários estratégicos para planeamento de recursos humanos em saúde: o caso dos farmacêuticos comunitários em Portugal 2010-2020, *Revista Portuguesa de Saúde Pública,* **30** (2012), 125-142.
[9] S. Callens, *The EU legal framework on ehealth.* In *Health Systems Governance in Europe: The Role of EU Law and Policy*, Edited by E. Mossialos, G. Permanand, R. Baeten and T.K. Hervey, Cambridge University Press, Cambridge, 2010.
[10] D.W. Bates, A.A. Gawande, Improving safety with information technology, *N Engl J Med* **348** (2003), 2526-2534.
[11] A.R. Hevner, S.T. March, J. Park, S. Ram, Design Science in Information Systems Research, *MIS Quarterly* **28** (2004), 75-105.
[12] L. Patrício, R.P. Fisk & J. Falcão e Cunha, Designing Multi-Interface Service Experiences: The Service Experience Blueprint, *Journal of Service Research,* **10** (2008), 318-334.
[13] R. Normann, *Reframing Business - When the Map Changes the Landscape*. Chichester John Wiley & Sons, 2001.
[14] S. Mache, C. Scutaru, K. Vitzthum, D Quarcoo, N Schöffel, T Welte, Does type of hospital ownership influence physicians' daily workschedules? An observational real-time study in German hospital departments, *Hum Resour Health* **7** (2009), 41-48.
[15] L.V. Lapão, J. Gregório, A. Cavaco, M. Mira da Silva and C. Lovis, Implementing eHealth Services for Enhanced Pharmaceutical Care Provision: Opportunities and Challenges. *Advances in Information Systems and Technologies (2013), 433-443.*
[16] M.A. Gastelurrutia, S. I. Charlie Benrimoj, C. C. Castrillon et al., Facilitators for practice change in Spanish community pharmacy, *Pharmacy world & science* **31** (2009), 32-39.

3. Improved Healthcare Through Informatics

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An Approach for Utilizing Clinical Statements in HL7 RIM to Evaluate Eligibility Criteria

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Abstract. The HL7 RIM (Reference Information Model) is a commonly used standard for the exchange of clinical data and can be employed for integrating the patient care and clinical research domains. Yet it is not sufficiently well specified to ensure a canonical representation of structured clinical data when used for the automated evaluation of eligibility criteria from a clinical trial protocol. We present an approach to further constrain the RIM to create a common information model to hold clinical data. In order to demonstrate our approach, we identified 132 distinct data elements from 10 rich clinical trails. We then defined a taxonomy to (i) identify the types of data elements that would need to be stored and (ii) define the types of predicate that would be used to evaluate them. This informed the definition of a pattern used to represent the data, which was shown to be sufficient for storing and evaluating the clinical statements required by the trials.

Keywords. HL7 RIM, Electronic Healthcare Records, Clinical Trials, Eligibility Criteria

Introduction

A major barrier to repurposing clinical data from Electronic Healthcare Record (EHR) systems or Clinical Data Warehouses (CDWs) to support clinical trial design and execution is that the information systems in patient care and clinical research domains represent data differently. The collective international efforts of multiple standard development organizations (such as ISO, HL7, CDISC, etc.) currently focus on defining the various standards required to achieve computable semantic interoperability and may help to bridge the gap between clinical research and patient care by enabling a scalable semantic interoperability framework [1].

Various initiatives and standards have been documented [2-5] that aim to define a shared set of semantically unambiguous and context-neutral common *data elements*.

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This affords dynamic mappings between data structures and semantics of varying data sources and ensures that queries are defined using centrally managed common data elements. These features codify a shared Common Information Model (CIM) and can be mapped to the individual EHR or CDW models. The Electronic Healthcare Records for Clinical Research (EHR4CR) project has developed a platform for researchers to define eligibility criteria to identify eligible patients in clinical trials using controlled access to data held securely at clinical sites [6,7]. The set of eligibility criteria is formally defined as a query that is evaluated using purely structured patient data (i.e. not free text, images etc.) drawn from hospital EHR systems. Given that the HL7 RIM (Reference Information Model) was used to construct the repository of patient data, the question we address is how this data can, hailing from multiple and diverse EHR systems, be represented and queried canonically. We describe here how we defined a pattern for achieving this end. This was then used to implement a data warehouse as a relational. Eligibility criteria were evaluated automatically on data extracted from multiple warehouse instances from heterogeneous hospital EHR systems.

1. Methods

In the domain of patient care, several large-scale efforts have been underway for over a decade with the goal of specifying both the structure and semantics of patient clinical information in a manner that enables computable semantic interoperability between diverse systems. Two major contributions to the interoperability of clinical information currently dominate internationally: ISO EN 13606, with its implementation in the openEHR Foundation [8,9], and HL7 RIM, which became an ISO standard in 2003 and its implementations such as the Clinical Document Architecture (CDA), based on the Clinical Statement Message Pattern (CSPM) [10].

The HL7 RIM is a widely used clinical information exchange standard, which was adopted by the EHR4CR project for querying heterogeneous EHRs through a standard interface. Common data elements were defined in order to specify additional constraints on the high-level EHR4CR Constrained Information Model (CIM) and to represent the fine-grained clinical information required to evaluate eligibility criteria.

In order to devise a pattern for the storage and use of those clinical statements, which were required to evaluate eligibility criteria, we selected ten rich evaluative clinical trial protocols to cover the range of clinical areas covered by the project, specifically: cancer, cardiovascular disease (especially arrhythmias), and neurology. From analysis of these, we then devised a pattern that would support the data elements and corresponding criteria that were amenable to automatic evaluation.

The set of ten clinical trials was selected by EFPIA (European Federation of Pharmaceutical Industries and Associations) partners within EHR4CR. Each of these clinical trials was running in more than one of the participating university hospitals. From the 269 free text eligibility criteria from the ten clinical trials, 99 computable eligibility criteria that were relevant in the context of feasibility were manually pre-processed by the EFPIA partners. This yielded 132 data elements and their corresponding value sets, of which there are 32, representing the fine-grained clinical information included in eligibility criteria constructs.

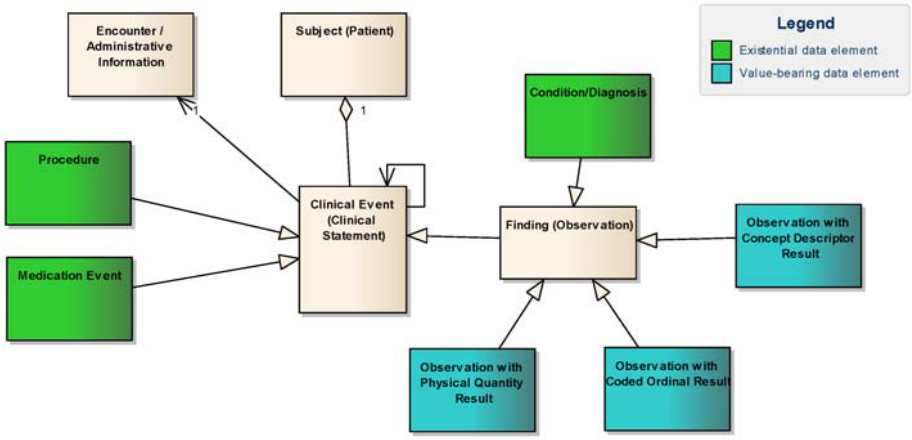


Figure 1: Object Model of Part of the EHR4CR Constrained Information Model, showing data element classification used in EHR4CR

2. Results

The 132 data elements correspond to different types of data elements, and these types were classified by the EHR4CR project: demographic statements (gender, birth date), diagnoses, clinical observations, lab test results, anatomic pathology observations, procedures and medications. Figure 1 shows a diagram of the relevant part of the CIM.

Any data element in the CIM may be further classified as being either *value bearing* or *existential*. A *value-bearing* element records the value of some measurement, score or categorisation. This value may be represented as either a number, usually with a unit of measurement, e.g. an HbA1c test, or a concept defined in some medical terminology e.g. male. An *existential* element denotes the recording of an event without any value being associated with it. *Existential* is used here in the mathematical rather than philosophical sense. In the EHR4CR CIM, procedures, medications, diagnoses and certain observations such as pregnancy and drug abuse are existential data elements; note that dosage of medications is currently ignored since it was not found in the eligibility criteria analysed. Diagnoses are considered existential because coding systems such as ICD-10 give a single code to represent a condition; there is no numeric or categorical qualifier. A key distinction between value-bearing and existential data elements is that the former form a series and the latter do not. A new observation of an HbA1c test adds to and in some senses updates a previous result of the same type. A diagnosis of a broken wrist cannot add to or update a diagnosis of lung cancer.

Date of birth and administrative gender, which are demographic statements, are represented as attributes of the HL7 *Living Subject* class. So, in keeping faithful to HL7, there are date of birth, administrative gender, deceased indicator and date of death fields. Mechanisms for recording procedure and medication statements in HL7, which are always existential, are well defined using the *Procedure* and *Substance Administration* classes respectively. For a procedure, a coded concept is used to specify the procedure described using the ISO21090 data type CD meaning a "concept descriptor". Similarly, a substance administration instance uses a coded concept to

describe the relevant medication consumed. The *Observation* class, however, caters for a broad range of clinical facts and encompasses diagnoses and clinical findings such as vital signs, laboratory tests and assessments. An observation instance is described by a pair: a 'code' field recording the nature of the observation and a 'value' field. According to HL7, the former is of type CD and the latter may be of any data type (structured or unstructured). To define our pattern effectively, a further restriction was needed.

HL7 already provides a mechanism for representing a diagnosis. Here, the 'code' attribute is set to a CD for the concept of 'diagnosis' and the value attribute is also of type CD and is used to hold the actual diagnosis in some medical terminology e.g. ICD-10. It was therefore natural to represent existential findings in the same fashion, so that the 'code' attribute is set to a CD meaning 'finding' and the actual finding, also a CD is held in the 'value'. For value-bearing observations, the 'code' field holds the CD for measurement or assessment type (e.g. fasting blood glucose) in some terminology and the 'value' field holds the result of the recorded value. Only three types of value were found in the trials analysed:

- Physical quantity (ISO21090 type PQ) where there is a numeric quantity and a unit of measurement. Vital signs and many laboratory tests fall into this category;
- Coded Ordinal (ISO21090 type CO) where there is an ordinal scale of values to which both a numeric value and a meaning (as a code) is also assigned. An example is the ECOG score of ambulatory status in cancer patients;
- Coded Value (ISO21090 type CD) where there is no numeric value or order over the range of values; the value is itself a concept e.g. HIV status, which can be 'positive' or 'negative'.

An EHR4CR Eligibility Criteria Model (ECM) was defined to support the querying for the full range of eligibility criteria deemed necessary by the project. A description of the ECM is contained elsewhere [11]. The part of the model relevant to the pattern proposed here is the form of predicates. Each criterion entered by a user contains exactly one predicate that evaluates to be *true* or *false* for a given patient. From a relevant clinical statement relating to that patient it is possible to determine whether the criterion includes or excludes him. Three types of predicate are supported:

- Existential – the predicate is deemed true if at least one instance of the data element has been recorded. This is used for existential elements.
- Numerical range – the predicate is deemed true if the numerical value for the data element lies within a specified range. This is used for physical quantities (PQ) and coded ordinals (CO).
- Finite set of non-numeric values – the predicate is deemed true if the value lies in this set and is used for coded ordinals (CO) and concept descriptors (CD).

Coded ordinals may be used in two types of predicates since either the (usually integer) numeric or coded value can be used.

The EHR4CR clinical data warehouse schema is based on the EHR4CR CIM. Tables exist for the major classes such as the Procedure, Substance Administration and Observation and their dimensions: Subject, Encounter and Participation. Some ISO 21090 data types, which would normally be given their own table, were de-normalised and placed directly in the Observation table, such as physical quantities (with their units) and coded ordinal values. With few exceptions, all coded concepts were placed within a single table for better management. The data warehouse is a core component

of a larger platform that allows the automatic evaluation of eligibility criteria. Further details are given elsewhere [7]. This implementation was found to be sufficient to store and evaluate all data elements found in any of the computable criteria from the 10 trials.

3. Discussion

Since the eligibility criteria evaluated by the EHR4CR platform require to be computed precisely and without human intervention, we record only clinical statements that may be expressed as structured data. Since any clinical statement will either be existential or value bearing (i.e. scalar, ordinal and categorical data), the pattern should support all future data elements since it is difficult to imagine how structured clinical data could be represented otherwise. Certainly, all the data elements identified in the ten clinical trial protocols analysed to date are representable in this form. The EHR4CR platform does also access legacy i2b2 [12] databases. However mapping of the CD and CO elements is problematic since this system was not designed with these data types in mind.

The proposed pattern provides a comprehensive means for expressing clinical statements used in both patient care and clinical research that uses structured data. The constrained pattern has been demonstrated as an effective way of recording clinical observations and affording reasoning about them. Potentially this could be extended beyond the evaluation of eligibility criteria, for example for storing data that is used for epidemiological research where data is subjected to statistical analysis.

References

[1] Hammond WE, Jaffe C, Kush RD. Healthcare Standards Development. The Value of Nurturing Collaboration. J. Ahima Am. Heal. Inf. Manag. Assoc. 2009 Jul; 80(7):44–50;

[2] Komatsoulis GA, Warzel DB, Hartel FW, Shanbhag K, Chilukuri R, Fragoso G, et al. caCORE version 3: Implementation of a model driven, service-oriented architecture for semantic interoperability. J. Biomed. Inform. 2008 Feb;41(1):106–23.

[3] Warzel DB, Andonaydis C, McCurry B, Chilukuri R, Ishmukhamedov S, Covitz P. Common Data Element (CDE) Management and Deployment in Clinical Trials. Amia Annu. Symp. Proc. 2003;1048.

[4] Jiang G, Solbrig HR, Iberson-Hurst D, Kush RD, Chute CG. A Collaborative Framework for Representation and Harmonization of Clinical Study Data Elements Using Semantic MediaWiki, Amia Summits Transl. Sci. Proc. 2010 Mar 1;2010:11–5.

[5] ISO/IEC 11179, Home Page for ISO/IEC 11179 Information Technology - Metadata registries [Internet]. 2014 Feb 9 [cited 2014 May 6]. Available from: http://metadata-standards.org/11179/

[6] EHR4CR: Electronic Health Records for Clinical Research [Homepage on the Internet] [cited 6 May 2014]. Available from: http://www.ehr4cr.eu/

[7] Chen Y, Bache R, Miles S, Cuggia M, Soto-Rey I, Taweel A, A SOA-based Platform for Automating Clinical Trial Feasibility Study, In Macedo M Editor, Proceedings of the IADIS International conference e-Health 2013, 2013: 84-94

[8] Kalra D, Singleton P, Milan J, Mackay J, Detmer D, Rector A, et al., Security and Confidentiality Approach for the Clinical E-Science Framework (CLEF). Methods Inf. Med. 2005;44(2):193–7.

[9] OpenEHR. OpenEHR [Homepage on the Internet]. 2014 [cited 6 May 2014] Available from: http://www.openehr.org/

[10] HL7. Health Level Seven International - Homepage [Homepage on the Internet]. 2014 [cited 29 Mar 2013]. Available from: http://www.hl7.org/

[11] Bache R, Taweel A Miles S, Delaney B , An Eligibility Criteria Query Language for Heterogeneous Data Warehouses, Methods Inf. Med. to appear.

[12] i2b2-Informatics for Integrating Biology & the Beside: [Homepage on the Internet] 2014 [cited 6 May 2014]. Available from http://www.i2b2.org/

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A conceptual Framework to Design a Dimensional Model Based on the HL7 Clinical Document Architecture

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Abstract. This paper proposes a conceptual framework to design a dimensional model based on the HL7 Clinical Document Architecture (CDA) standard. The adoption of this framework can represent a possible solution to facilitate the integration of heterogeneous information systems in a clinical data warehouse. This can simplify the Extract, Transform and Load (ETL) procedures that are considered the most time-consuming and expensive part of the data warehouse development process. The paper describes the main activities to be carried out to design the dimensional model outlining the main advantages in the application of the proposed framework. The feasibility of our approach is also demonstrated providing a case study to define clinical indicators for quality assessment.

Keywords. Data Warehouse, Extract, Transform and Load, Dimensional Model, HL7, Clinical Document Architecture, Electronic Health Record.

Introduction

Enterprise data warehouses are increasingly adopted in the healthcare domain to improve decision-making, business processes as well as to discover new treatments and improve patient care [1]. Their development makes it necessary to integrate data provided by heterogeneous information systems (e.g. Laboratory Information Systems, Electronic Health Records, Radiology Information Systems), developed for different specialties, by different organizations and for different purposes [2]. In data warehouse implementation and maintenance process this integration is called Extract, Transform and Load (ETL), that is considered the most time-consuming and expensive activity (around 70% of the resources used) [3]. This implies the adoption of transformation procedures to convert data from source systems in a common data model to be loaded in the target system (i.e. data warehouse and/or data marts).

In the healthcare domain Health Level 7 (HL7) plays an important role to improve interoperability providing a set of standards for the exchange, integration, sharing and retrieval of healthcare information. These standards are based on the Reference Information Model (RIM) [4], which represents a conceptual model covering both clinical and administrative aspects. One of the most widely adopted implementation of the RIM is the Clinical Document Architecture (CDA) [5] that specifies the structure and semantics of a document (e.g. discharge summary, continuity of care document).

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The aim of this paper is to propose a conceptual framework to map the dimensional model primitives with the HL7 CDA classes in order to facilitate the definition and implementation of ETL tools developed in a data warehouse architecture. This study is part of the Smart Health 2.0 national project that aims to develop a regional healthcare infrastructure based on HL7 standards. It also intends to explore the use of Electronic Health Record (EHR) for secondary purposes in a clinical governance framework to assess the quality of care from the structural, organizational, financial and professional points of view [6]. The framework proposed in this paper facilitates the identification of clinical indicators for quality assessment to be calculated from data contained in CDA documents stored in a regional EHR.

1. Conceptual framework based on the dimensional model developing life cycle

The approach proposed in this paper is described considering the 4-step process described by Kimball and Ross in [7]. The feasibility of our approach is demonstrated providing a case study based on the Continuity of Care Document (CCD) [8] to define clinical outcome indicators for quality assessment, such as percentage of patients with a vital sign parameter within a specific threshold (e.g. glycated hemoglobin under 7%).

1.1. Choose the business process and declare the grain

The determination of a business process can be based on the HL7 RIM Act class that represents "an intentional action that can be either executed, ordered, planned and must be documented". For this reason it is important to identify which Act is a feasible representation of the event taking into account also the level of granularity to be represented. In this perspective, the CDA is mainly described by three Acts: 1) ClinicalDocument that provides an high level description of the document; 2) Section that aggregates in a single "narrative block" core patient-specific data based on common clinical conventions (e.g. laboratory test results, medications, problems, procures); 3) clinicalStatement a choice structure that represents the content of a specific action (e.g. observation, procedure, substance administration).

In particular, in the CCD implementation the class Section through the attribute code is a standardized identifier to classify clinical business processes coded using the LOINC (Logical Observation Identifiers Names and Codes) nomenclature, such as functional status, family and social history, medical equipment and encounters. In this paper the attention is posed on the vital sign section that contains individual's clinical findings, such as blood pressure, heart rate, body mass index and glycated hemoglobin.

1.2. Identify the dimensions

In our approach dimensions are determined on the basis of the Zachman framework [9] that provides a systematic information representation starting from the following questions related with the investigated event: who (persons), what (the fact), when (the time), where (the place), why (the reason) and how (the manner). Each Participation included in the CDA model represents a suitable candidate element to derive a dimension table, given that it "captures the functions of subjects and objects involved in a specific process, identifying who performed it (i.e. performer), for whom it was done (i.e. recordTarget), where it was done (i.e. location), etc.". For instance, the Act

Observation that represents an action in the CDA, can be associated with the following Participations: a) performer to identify the "person who actually and principally carries out or will carry out the action"; b) consumable to determine the "substance that is taken up or consumed as part of the substance administration"; c) subject to define the "principle target that the service acts on". For each applicable Participation a dimension table can be determined collapsing the hierarchy represented by the 4-ple <$Entity_{player}$, $Entity_{scoper}$, Role, Participation> in a single denormalized table. This process that introduces data redundancy with a less complex queries is particularly suitable for one-to-many relationships between the fact and the relevant dimension. For instance the Act ClinicalDocument is related with only one Participation recordTarget. Thus, the hierarchy can be mapped in a single dimension table composed by relevant attributes of both Role (i.e. PatientRole) and related Entities (i.e. Patient and Organization), as shown in figure 1. However, some requirements need to be represented with a many-to-many relationship in the dimensional model to be modeled using a bridge table as proposed in [10]. For instance, when different practitioners deliver care to an individual over different distinct time intervals.

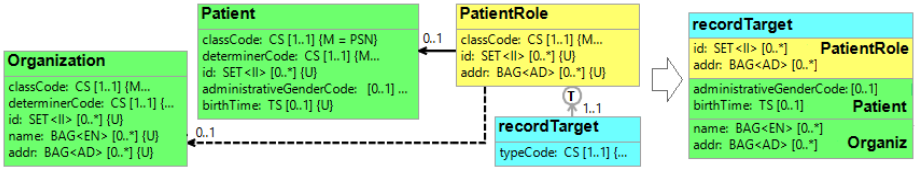


Figure 1. recordTarget dimension defined through the denormalization of the RIM 4-ple hierarchy.

Table 1. Example of dimensions derived from the HL7 RIM stereotypes and CDA features

Question	RIM stereotype	CDA feature	Example
Who	Participation	recordTarget	The patient involved in the event
		performer	Physician/Practitioner that carried out the event
		responsibleParty	Participant with legal responsibility
Where	Participation	location	Healthcare facility where the event occurred
What	Participation	consumable	Material consumed during the event
		product	Material dispensed during the event
	Act	Act.code	Type of event performed
	ActRelationship	referenceRange	Range of values for the measured parameter
When	Act	Act.effectiveTime	Time when the event has been performed
How	Act	Act.methodCode	Technique used to establish the event
Why	ActRelationship	entryRelationship	A principal cause of an event

Table 1 highlights some examples of possible mapping between HL7 stereotypes and dimensional model primitives. The attribute *typecode* of the stereotype Participation can be also used to define who/whom is involved in the business process, where the event has been carried out (i.e. location) and what are the equipment involved to perform the event (i.e. substance consumed or product dispensed). Other information describing the event can be captured through the Act that describes the event under investigation and its related Act described by the stereotype ActRelationship. Moreover, there are different attributes of the stereotype Act and its specialization in the CDA model that can describe the business process, such as time when the event took place (i.e. *effectiveTime*) and type of the event observed (i.e. *code*). Considering the ActRelationship class, in the CDA model there are two main specializations: 1) entryRelationship that links two clinicalStatements of the same Section to identify, for instance, a principal cause of an event (e.g. an allergy reaction

to penicillin that causes hives or rashes); 2) referenceRange that shows the thresholds of a specific parameter (e.g. blood pressure). The mapping of the ActRelationship class in a dimension can require the adoption of a bridge table to be associated with the fact.

The dimensions detected to describe the vital sign business process based on the CCD are described as follows and depicted in figure 2: recordTarget and performer using the denormalization approach described previously including the Entity Organization that identifies the location where the service has been performed. Moreover, type of clinical test (vitalSignObservation), the technique used to determine it (method) and the time when it has been performed (Time_Date) are defined using, respectively, the attribute *code*, *methodCode* and *effectiveTime* of the Act Observation.

1.3. Identify the Fact

A fact table contains qualitative and quantitative measures to represent the performance of the business process. In the RIM these information are collected in specific attributes of the stereotype Act representing "measurement of healthcare business processes". Data to be collected strictly depend on the event under investigation. For instance, the vital sign section of the CCD includes two attributes: 1) *value* to capture a physical quantity (i.e. weight) and its unit of measure (i.e. kg); 2) *interpretationCode* to provide a qualitative interpretation of the measure (e.g. normal, low). Both attributes have been included in the fact table of the dimensional model shown in figure 2.

1.4. Modelling the HL7 RIM Data Types

Most of the attributes of the CDA are modelled using complex data types that need to be transformed in a database data type. A possible solution to represent of a complex data type is to store each property in a single column of the relevant table. For instance a Physical Quantity (PQ) can be mapped into two distinct attributes: value and unit. However, different attributes of the RIM can assume multiple values. For instance, the Act Observation captures a set of *interpretationCode* (e.g. the value is decreased, is below lower alert threshold, is moderately susceptible, etc.). These data types can be modelled either creating a separate table to store each multiple valued attribute or revising the model to have only a single value for each attribute.

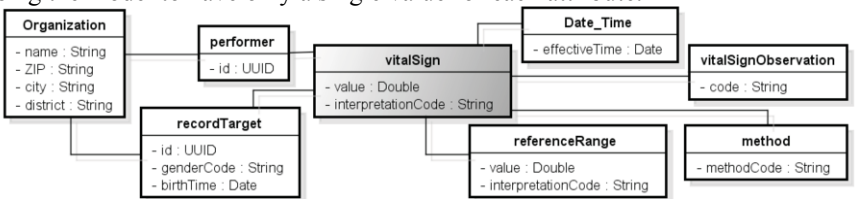


Figure 2. Dimensional model with complex data types normalized

Starting from the specification defined in the previous paragraph attributes with complex data types have been normalized and a dimensional model is proposed in figure 2. In particular: 1) in the vitalSign and referenceRange tables the unit of measure of the attribute value has been removed and only the measurement reported using a double data type (*value*); 2) *address* of the sub-dimension organization has been exploded in three distinct attributes: ZIP, city and district; 3) coded attribute (*interpretationCode*, *methodCode*, *code*, *administrativeGenderCode*) are stored as a

string attribute based on the relevant vocabulary. Finally, *birthTime* and *effectiveTime* are mapped in a Date column.

2. Discussion

In this paper we demonstrated the feasibility of a conceptual framework to define the primitives of a dimensional model based on the HL7 CDA entities with the purpose of developing a clinical data warehouse supporting clinical quality assessment. The adoption of this approach can lead to different advantages both at the design and execution phases of the data warehouse implementation process. At the design level, a dimensional model based on HL7 CDA can simplify the definition of the business process to be analysed as well as the dimensional model primitives that describe it. This makes data transformation a simplified straightforward process thus reducing the resources to be invested to implement ETL tools and procedures. From the implementation point of view, information collected in HL7 CDA messages can be loaded in the target data warehouse without implementing tools to transform source data models to the destination dimensional model. This makes the integration of heterogeneous systems more robust limiting the ambiguity in the semantics of messages and avoiding the proliferation of dialects. Moreover, as highlighted in our previous paper focused on the database model [11], this approach can also facilitate end-users in interpreting and defining query in the data warehouse. From the architectural point of view this approach enhances the extensibility of the data warehouse architecture facilitating the integration of other systems in the future given that: 1) rules and parsing procedures are standardized in a common framework and 2) clinical information are coded using international nomenclatures and dictionaries, such as LOINC. This approach is going to be tested within the Smart Health 2.0 project.

References

[1] T.R. Sahama, P.R. Croll, A data warehouse architecture for clinical data warehousing, *Fifth Australasian symposium on ACSW frontiers* **68** (2007).
[2] N. Wickramasinghe, J.L. Schaffer, Creating knowledge-driven healthcare processes with the intelligence continuum, *Int J Electron Healthc*, **2(2)** (2006), 164-174.
[3] R. Kimball, J. Caserta, *The Data Warehouse ETL Toolkit*, Wiley, Indianapolis, USA, 2006.
[4] G. Schadow, C.N. Mead, D. M. Walker, The HL7 Reference Information Model under scrutiny, *Stud Health Tech Informat*, **124** (2006), 151-156.
[5] R.H. Dolin, L. Alschuler, S. Boyer, C. Beebe, F.M. Behlen, P.V. Biron, A. Shabo, HL7 Clinical Document Architecture, Release 2, *J Am Med Inform Assoc* **13** (2006), 30-39.
[6] F. Pecoraro, D. Luzi, F.L. Ricci, Secondary uses of EHR systems: a feasibility study. *IEEE E-Health and Bioengineering Conference (EHB)* (2013).
[7] R. Kimball, M. Ross, The Data Warehouse Toolkit Second Edition: The Complete Guide to Dimensional Modelling, Wiley Computing Publishing, 2002.
[8] O. Lupse, M. Vida, L. Stoicu-Tivadar, V. Stoicu-Tivadar, Using HL7 CDA and CCD standards to improve communication between healthcare information systems, *IEEE 9th International Symposium on Intelligent Systems and Informatics (SISY)* (2011), 453-457.
[9] W.H. Inmon, J.A. Zachman, J.G. Geiger, Data Stores, Data Warehousing, and the Zachman Framework: Managing Enterprise Knowledge, McGraw-Hill, New York, NY, 1997.
[10] T.J. Eggebraaten, J.W. Tenner, J.C. Dubbels, A health-care data model based on the HL7 Reference Information Model. *IBM Journal of Research and Development* **46** (2006), 5-18.
[11] F. Pecoraro, M. Contenti, D. Luzi, Clinical Investigation on Medical Device: A data model based on HL7 Reference Information Model, *IADIS MCCSIS* 2010.

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Formalizing Mappings to Optimize Automated Schema Alignment: Application to Rare Diseases

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Abstract. In the era of data sharing and systems interoperability, the automation of data schema alignment has become a priority. Discovering data mappings is the aim of many alignment approaches that have been described in the literature and the effectiveness of which depends on data specifications. In this context, we propose a method for mappings formalization that allows automated data integration processes optimization. This method, involving both data element level and value element level, allows an automated inference of mappings expressed by rules. In this paper, we start by describing the methods used to achieve this mappings formalization. Then, we explain how it has been validated by characterizing data from two use cases. We end up by discussing the objectives of the proposed formalization.

Keywords. Data integration, schema alignment, interoperability, mappings formalization, medical informatics

Introduction

Building a French Database for Rare Diseases (BNDMR) that identifies patients suffering from rare diseases at a national level is an ambitious ongoing project [1]. This database should allow institutions to evaluate the adequacy between the healthcare supply and demand, but should also allow researchers to identify eligible patients for clinical trials or rare diseases cohorts. The project deals with 7000 [2] different diseases and the data is collected at a national scale from multiple sources. Data sources are 131 Rare Disease Reference Centers and 501 Competence Centers that cover 30 rare disease groups.

Connecting all these sources to the target database requires huge efforts in order to deal with data heterogeneity. All the sources do not collect the same data, and even if they share similar data elements [3], syntactic and semantic heterogeneity may persist.

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As a first effort to deal with the interoperability issue, BaMaRa, a communicating application, was designed to collect a Rare Disease Minimum Data Set (MDS) [4]. Standardized elements were used to build the MDS and mappings[2] have to be set to connect the databases that don't use those standards.

Automated schema alignment[3] approaches have been released to avoid spending time on manual alignment to detect similarity between data elements building different data schemas (e.g. database schemas, xml schemas, ontologies…). The way to classify these alignment approaches may differ in the literature [5,6]. However, we can notice the existence of four major classes: linguistic approaches, structure level approaches, approaches based on constraints and instance level approaches.

As analyzed in some evaluation studies [5,7,8] on alignment techniques, the effectiveness of the different approaches depends on the inherent characteristics of data, schemas and coding. In this paper, we propose a methodology for characterizing mappings that will allow a data pre-analysis, and optimize the appliance of each automatic alignment approach. We thus investigated the nature of the experimental mappings using a heuristic approach to derive the characterization.

1. Methods

1.1. First attempt of a mappings' classification

Our first experimentation was to integrate data coming from the National Alzheimer Database [9] (BNA). After a manual alignment, we obtained less than 50% of recovery rate. A study of the results allowed the identification of five different mappings linking the source (BNA) and target (BaMaRa) data elements:

- *Exact match:* the source element was mapped to the target element and their domains values matched perfectly.
  E.g. the source element "birth name" was mapped to the target element "patronymic name", there was no coding transformation.
- *Partial match:* the source element was mapped to the target element but the domains values matched only partially.
  E.g. the source element "patient sent by" was mapped to the target element "patient addressed by" but their coding lists just overlapped.
- *Conditional match:* the source element could be mapped to the target element only if a condition was verified.
  E.g. the source element "name of use" could be mapped to the target element "marital name" only if it was different from "birth name".
- *Aggregation:* Two or more source elements were mapped to the target element.
  E.g. the source elements "department code" and "commune code" were aggregated to give the target element "birth country code".
- *Split-up:* the source element was mapped to two or more target elements.

[2] Mapping = the relationship indicating a similarity according to a given measure between two elements of two data schemas.

[3] Alignment = (also called matching) the process of detecting mappings between elements of different data schemas.

E.g. the source element "type of act" was mapped to three target elements "activity context", "activity objective" and "profession of the personnel performing the activity".

All the mappings obtained after the BNA and BaMaRa schema alignment fitted into the previous classification. This classification was similar to the one described in [10] and provided an overview on the relations linking the source data elements to the target data elements and the involved cardinalities.

The classes defined above were not always disjoint: a mapping between source and target elements could be a split-up matching with a condition.

Our main contribution is to propose a new formalization of mappings processable by the machine and operating at a value elements level. Being given a source schema description, the objective is to fulfill the maximum of the target schema elements. It is a one-way process: to integrate the source data in the target data model. However, with this approach, the reverse path can be used to get a bidirectional alignment.

1.2. Mappings formalization

In the proposed method for characterizing mappings, formalization considers the data elements, the value elements and the exact relation that links the source and the target elements which is described below:

Let $S=\{E^S_i;i=1..n;n=card(S)\}$ be the *source* dataset and $T=\{E^T_j;j=1..m;m=card(T)\}$ the *target* dataset, with E^S_i and E^T_j their constitutive *data elements*. E^S_i and E^T_j domain values can be either finite (e.g. a predefined list of values) or infinite (e.g. a textual or an integer entry). We note e^S_{ik} and e^T_{jl} the respective *value elements* of E^S_i *and* E^T_j. A value element can represent one item from the finite value domain (e.g. for e^S_{ik}, k=1..p with p=card(E^S_i)) or the different possible values of the infinite domain (e.g. for e^S_{ik}, we set k=0 and e^S_{i0} is treated regardless of the value it takes).

E^S_i can be mapped to E^T_j by one or more binary relations e^S_{ik}-e^T_{jl}. Each binary relation e^S_{ik}-e^T_{jl} is defined by one or more rules r. A mapping is then defined for each value element pair and not for each data element pair.

To summarize, a mapping from *S* to *T* can be characterized by the triplet $\{E^S_i$-E^T_j; e^S_{ik}-e^T_{jl}; $r\}$:

- A binary relation E^S_i-E^T_j between a source data element and a target data element.
- A binary relation e^S_{ik}-e^T_{jl} between a source value element of E^S_i and a target value element of E^T_j.
- A rule *r* expressed in the " if … then …" format.

2. Results

The mappings formalization described above is a result that we validated by characterizing a set of mappings from two use cases. As a first use case, we chose to characterize data from CEMARA [11], a database that collects data of about 240,000 patients suffering from rare diseases. CEMARA and BaMaRa schemas are not too different and share some of their data elements. The triplet data elements pair, value elements pair and rule was relevant for each mapping obtained after schema alignment.

Our second use case was to align BNA schema (1.1) and BaMaRa schema and we could also characterize all the mappings by the proposed formalization (see Table 1).

Table 1. Examples of triplet mappings from the two use cases

E^S_i - E^T_j	e^S_{ik} - e^T_{jl}	r
"Death" – "Vital status"	"Y" - "Y"	If $\mathbf{e^S_{ik}}$ ="Y" then $\mathbf{e^T_{jl}}$ ="Y"
"Death" – "Vital status"	"N" - "N"	If $\mathbf{e^S_{ik}}$ ="N" then $\mathbf{e^T_{jl}}$ ="N"
"Coming CPC" – "Patient addressed by"	"Y" - "CPC"	If $\mathbf{e^S_{ik}}$ ="Y" then $\mathbf{e^T_{jl}}$ ="CPC"
"Name of use" – "Marital name"	String - String	If $\mathbf{e^S_{i0}} \neq \mathbf{e^S_{c0}}$ then $\mathbf{e^T_{j0}} = \mathbf{e^S_{i0}}$ (E^S_c= "Birth name")

The mappings formalization allowed the definition of automatic alignment processes where the two first pairs of the triplet (data elements and data values) were inputs and the third element, which was the rule describing the exact relation between them, was the output. The methodology was the following:

- Data pre-analyses: Getting the source and target schema description and identifying data elements (E^S_i, E^T_j) and corresponding value elements (e^S_{ik}, e^T_{jl}). Homogeneous data groups' creation according to data types and domain values.
- Processes definition: Defining the strategies (processes or algorithms involving one or more schema alignment approaches) to come along for each group of data, and route the data to the suitable treatment.

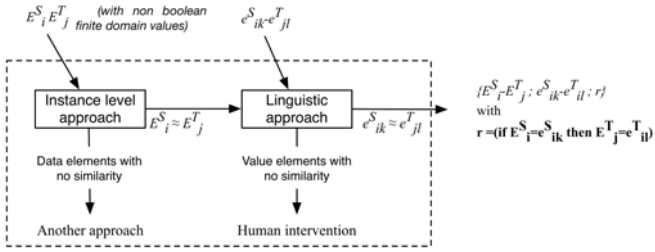


Figure 1. Example of an optimized alignment process.

An example (see figure 1) of an optimized process of schema alignment might be the following:

- As input process, consider subsets of $\{E^S_i\}$ and $\{E^T_j\}$ data elements that have a finite and non-Boolean domain of values.
- Apply an instance level approach on the two sets of data elements $\{E^S_i\}$ and $\{E^T_j\}$ in order to detect similarity based on instance redundancy.
- For the similar pairs E^S_i-E^T_j, a linguistic approach will be applied to the corresponding value sets $\{e^S_{ik}\}$ and $\{e^T_{jl}\}$ to detect the e^S_{ik}-e^T_{jl} pairs.
- The output mappings can be characterized by the triplet $\{E^S_i$-$E^T_j ; e^S_{ik}$-$e^T_{jl} ; r\}$ with: r = (if E^S_i=e^S_{ik} then E^T_j=e^T_{jl}).

3. Discussion

To summarize, the methodology we describe in this paper is based on:

- Data pre-analysis and the importance of the dualities: source data/target data and data element level/value element level. This will allow the construction of homogeneous data groups.

- Possibility of proposing reliable automated data integration processes for each data group that will infer the third element of the triplet presented in section 1.2: the rule that specify the mapping.

Adopting this new methodology will not improve the effectiveness of the automated approaches that are applied on data. We do not introduce a new approach or a new algorithm that will infer mappings that were previously undetectable without human intervention because of semantic issues. Indeed, this proposition aims to optimize the use of alignment approaches and to limit human intervention.

In a real data integration experience, aligning schemas using automated alignment tools remains a human supervised task, not only to validate the inferred mappings but also to make a decision toward the "good" result. In fact, different approaches, that proved their effectiveness in previous schemas alignments, used to be applied on all data then the obtained results are compared and weighted according to data specificities. Following the methodology that we propose in this paper and standardizing the minimal data description would allow the reusability of effective processes, for each suitable data group and would introduce some confidence in the previous works and reliance on the proposed results.

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References

[1] Banque Nationale de Données Maladies Rares [Internet]. 2014 [cited 2014 Jan 14]. Available from: http://www.bndmr.fr/
[2] Orphanet [Internet]. 2012 [cited 2014 Jan 14]. Available from: http://www.orpha.net/
[3] ISO, IEC. ISO/IEC 11179-3. 2013.
[4] Choquet R, Messiaen C, Priouzeau A, de Carrara A, Landais P. Un jeu de données minimum pour faciliter l'interopérabilité des bases de données pour les maladies rares. Paris; 2012. p. 1–6.
[5] Rahm E, Bernstein PA. A survey of approaches to automatic schema matching. VLDB J. 2001 Dec 1;10(4):334–50.
[6] Euzenat J, Shvaiko P. Classifications of Ontology Matching Techniques. Ontology Matching. Springer Berlin Heidelberg; 2013. p. 73–84.
[7] Euzenat J, Shvaiko P. Evaluation of Matching Systems. Ontology Matching. Springer Berlin Heidelberg; 2013. p. 285–317.
[8] Kaza S, Chen H. Evaluating Ontology Mapping Techniques: An Experiment in Public Safety Information Sharing. Decis Support Syst. 2008 Nov;45(4):714–28.
[9] Le Duff F, Duport N, Gonfrier S, Lafay P, Texier N, Schück S, et al. Plan national Alzheimer 2008-2012 - Mesure 34 Mise en place du recueil épidémiologique national et premières tendances. Rev Gériatrie. 2010;35(8):575–82.
[10] Savasere A, Sheth A, Gala S, Navathe S, Marcus H. On applying classification to schema integration. , First International Workshop on Interoperability in Multidatabase Systems, 1991 IMS '91 Proceedings. 1991. p. 258–61.
[11] Messiaen C, Le Mignot L, Rath A, Richard J-B, Dufour E, Ben Said M, et al. CEMARA: a Web dynamic application within a N-tier architecture for rare diseases. Stud Health Technol Inform. 2008;136:51–6.

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Estimating the Impact of Prevention Action: A simulation Model of Cervical Cancer Progression

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Abstract. Cervical cancer is one of the highest occurring cancers for women in East Africa. Many studies have shown that disease occurrences and particularly the number of deaths due to the disease can be reduced significantly by screening and vaccination. East Africa and Kenya in particular are undergoing change and taking actions to reduce disease levels. However, up until today disease level in the different districts in Kenya is not known nor what be the prevalence of disease when prevention actions take place. In this paper we propose a novel Bayesian model for estimating disease levels based on available partial reports and demographic information. The result is a simulation engine that provides estimations of the impact of various potential prevention actions.

Keywords. Disease prevalence, Bayesian Model, Cervical Caner

Introduction

Cervical cancer remains one of the strongest threats to female reproductive health; it is the second most common cancer worldwide and in the Sub-Saharan African region, and is the leading cause of cancer related death among women in developing countries. The human papillomavirus (HPV) is known to be the causative agent of a vast majority of cervical cancers. Early detection of the virus by screening and removal of the precancerous cells, as well as vaccination against (most of) the HPV strains that cause the cancer have reduced the level of disease in more developed countries. Current screening tests include the Pap test that explores changes in the cells of the cervix, the HPV test that detects the existence of the high risk strains of the HPV virus in the cells, visual inspection with acetic acid (VIA), and visual inspection with Lugol's iodine

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(VILI). Not only is the cost of VIA and VILI significantly lower than the PAP test and HPV test but these visual inspection methods also allow for treating of any detected abnormal cells during the same visit as the screening. These 'see and treat' tests are a better fit for countries with fewer resources and have become common in Kenya in recent years.

Vaccinations, screening tests and appropriate treatment have become part of national policies and guidelines formulation in many countries. The Kenyan Ministry of Health adopted guidelines developed by the Department of Reproductive Health and partners as a standard approach to be used by all cadres of health care workers in the country; these guidelines address screening, diagnosis and palliative care for cervical cancer patients. However, they have been only partially adopted and with a large variation between different districts in Kenya due to constraint resources. Moreover the information on such actions is not centrally gathered and it is a challenge to estimate the current and expected disease levels. We propose a system that is based on an innovative Bayesian model [1] that utilizes the unique freely available dataset of Kenya called Open Kenya Data [2] and provides district level estimates of disease prevalence.

1. Methods

In this work we leverage existing models for cervical cancer progression that have been used to estimate disease level and cost effectiveness of vaccination and screening, and extend the models to include demographic information that in turn enables more accurate estimates of current disease level. We infer the dependencies and values of the parameters and random variables in the Bayesian model by performing a meta-analysis study. To the best of our knowledge this is the first time a Bayesian model is introduced to tie between rich demographic information and disease status using meta-analysis in general and the first to be used for modeling Cervical Cancer prevalence and progression.

Bayesian models are statistical models represented by acyclic graphs that capture dependencies between random variables. In this paper we used the convention that random variables are represented by circles, arrows stand for dependency and shaded circles stand for random variables for which the value is considered observed. In this paper we propose a model that stands for different characteristics of a woman in Kenya, her particular district, whether she lives in rural or urban area, likelihood of her having cervical cancer and so on. The random variables in this model are those characteristic and take values from a finite set of values (also the age variable is categorized into a few age groups). Figure 1 illustrates the model.

A number of Bayesian models have been introduced to model the progression from HPV infection to a cervical cancer. One of the most commonly used models is the Markov model introduced by Mayers et al[3] that captures the different stages from infectious by the virus where the woman state is 'well' to the presence of a Low-grade Squamous Intraepithelial Lesion ('LSIL') (cervical intraepithelial lesion 1). Such state might progress to High-grade SIL ('HSIL') (cervical intraepithelial lesion 2-3, including carcinoma in situ). The woman might progress to have local than regional than distant cancer. In Figure 1, the insert illustrates the model for such natural progression. The model we propose captures the likelihood for a woman to be screened, and treated given that pre-cancerous cells or cancer is detected.

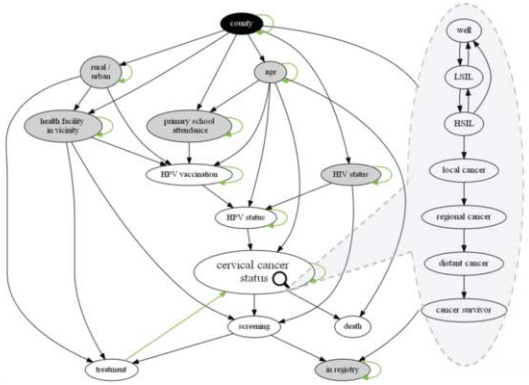


Figure 1: Dynamic Bayesian model of cervical cancer progression and monitoring

The likelihood for a screening depends on availability and accessibility of the screening as represented by the information whether the woman has access to a healthcare facility nearby. The likelihood for a woman living in a city to have a healthcare facility nearby is larger than those who leave in rural areas. This is one way by which the demographic information plays a role in the estimations of disease prevalence. Similarly, as vaccination typically is offered to girls in school, as according to guidelines the vaccine is most effective while administered before getting engaged in sexual activity, information regarding school attendance can serve as a predictor of whether or not a woman is vaccinated, and thus the likelihood of contracting the disease. This information is also captured in our proposed model, Figure 1.

Dynamic Bayesian models [4] allowing the state space to be represented in factored form, instead of as a single discrete random variable. A given hypothetical state of a woman is characterized by her age group, where she lives (in rural or urban area), whether she is infected by HPV, if she has a cancer, and if yes in what state and so on. The development of the state of the woman over the years is depicted by a dynamic Bayesian model, where in Figure 1 gray arrows depict dependencies between different variables within the same timeframe and green arrows depict the dependency between the states in one year to the following one.

We used this innovative dynamic model by extracting real information from Open Kenya data with respect to the demographic information on women in Kenya. We learned dependencies between the random variables by exploiting standard meta-analysis. The model than can serve to simulate different scenarios such as what happens in terms of disease prevalence five and ten years ahead if a portion of the woman are vaccinated and / or screening policy is applied.

Finally, we used existing references and meta-analysis method [5] for evaluating the Bayesian model results with respect to current disease prevalence and prevention actions. Search of PUBMED with the keyword “cervical cancer AND Kenya” produced 99 related articles on which we applied our inclusion and exclusion strategy. In addition we performed a few discussions with local nonprofit organizations and obtained links to reports of disease status and associated studies that are not covered by PUBMED, The initial strategy was a quick review of the abstracts/reports for a description of the study on desired data of interest. The inclusion or exclusion of published articles where only abstracts were accessible was based solely on whether

data of interest are reported in the abstracts or not. This way, the initial search result list was filtered to 24 articles. A detailed review of these articles (reading the entire paper) revealed that some data of interest are only partially reported.

2. Results

The meta-analysis study yielded a few but significant references such as [6],[7],[8]. These reports where used to confirm the Bayesian model analysis at the country level. The estimates we have performed where per district. There are close to 13 Million women at age 14 and higher out of a total population of around 44 Million.

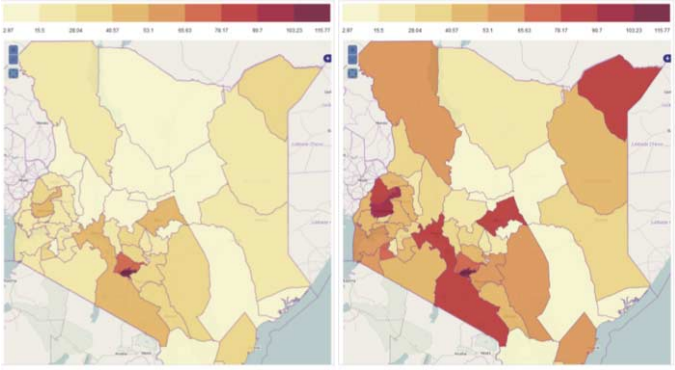


Figure 2: Nunber of women (x1000) aged 35-40 (left) and 9-12 (right) per distrcit

We used the Bayesian model to simulate an estimate of mortality rate for 35-40 year old women in 10 years in three different conditions; status quo, screening and treating as necessary 90% of all women in current year and the same but only for those living near a health facility. Figure 3 shows these scenarios. The redder the color, the higher the number.

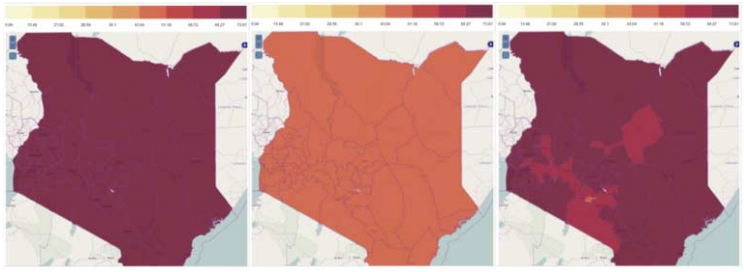


Figure 3 mortality rate per 100K women aged 35-40 in 10 years. Left: status quo. Middle: screen & treat 90% this year. Right: screen & treat 90% who live near health facility

Table 1 compares cost effectiveness of the mentioned scenarios (assuming pricing similar to Goldie et al [9]). While vaccination of all 9-12 yo is relatively expensive and has no immediate effects, it saves the most lives and life-years in the long run.

Table 1: Cost-effectiveness of simulated scenarios

solution	cost ($K)	cost per life-year-saved ($ / yr)	healthcare savings in later 10 years (dollars)	lives saved (10-yr pd) (women)	lives saved (30-yr pd) (women)	life-years saved (30-yr pd) (years)	life-years saved (10-yr pd) (years)	cancer incidence rate in 10 years (women per 100K)	cancer incidence rate in 30 years (women per 100K)	population (1000 women)
9-12 year olds: status quo	0	0	0	0	0	0	0	30.29	80.37	2090.6
9-12 year olds: vaccinate	21845.98	368.54	13786.55	262.77	6526.99	59276.55	624.52	18.57	50.25	2090.6
35-40 year olds: status quo	0	0	0	0	0	0	0	103.32	158.13	1194.74
35-40 year olds: screen and treat all	15522.75	221.15	25130.88	1439.6	4817.01	70190.06	5047.17	78.43	154.38	1194.74
35-40 year olds: screen and treat near HF	2825.78	134.31	17542.26	435.39	1436.44	21039.24	1528.95	95.89	157.06	1194.74

3. Discussion

Our proposed system can serve agencies in making informed decisions with respect to planned programs to launch. At the moment, health records in Kenya are very limited, and yet they indicate a high prevalence of cervical cancer, low level of awareness of the disease and limited access to screening among women in Kenya. A coordinated effort is performed between different agencies to raise the awareness for the disease, increase level of screenings, and apply vaccination programs. The system we developed can easily integrate further information, at the form of evidence in the Bayesian model and to provide more accurate results when more information is collected with respect to disease level. We are working with these forces and aim at supporting further coordinating the effort that hopefully will lead to a significant decrease of the number of women suffering from cervical cancer in Kenya. This system can be easily extended for usage in other disease areas.

References

[1] J Pearl, Probabilistic Reasoning in Intelligent Systems: Networks of Plausible Inference. Morgan Kauffman , San Francisco (1988)
[2] Kenya open Data, https://opendata.go.ke/ accessed on 14th of August 2013
[3] ER Myers, DC McCrory, K Nanda, L Bastian , and D Matchar (2000). Mathematical Model for the Natural History of Human Papillomavirus Infection and Cervical Carcinogenesis. Am. J. Epidemiol. 151 (12): 1158-1171
[4] KP Murphy, Dynamic Bayesian Networks: Representation, Inference and Learning. Dissertation. Univ. of California (2002)
[5] D F Stroup, J A Berlin, S C Morton, et al. (2000). Meta-analysis of observational studies in epidemiology: a proposal for reporting. Meta-analysis Of Observational Studies in Epidemiology (MOOSE) group. JAMA : the journal of the American Medical Association, 283(15), 2008-2012
[6] J S Smith, S Moses, M G Hudgens, et al. Increased Risk of HIV Acquisition among Kenyan Men with Human Papillomavirus Infection. J Infect Dis 2010; 201(11):1677–1685
[7] "Kenya first country to protect girls against cervical cancer with GAVI support, GAVI Alliance", 14 May 2013, (http://www.gavialliance.org/library/news/press-releases/2013/kenya-first-country-to-protect-girls-against-cervical-cancer-with-gavi-support/#sthash.6XwVgnka.dpuf)
[8] WHO/ICO Information Centre on HPV and Cervical Cancer (HPV Information Centre). Human Papillomavirus and Related Cancers in World. Summary Report 2010.
[9] Goldie, S. J., Kuhn, L., Denny, L., Mmed, O., Pollack, A., & Wright, T. C. Policy Analysis of Cervical Cancer Screening Strategies in Low-Resource Settings, JAMA 2010, *285*(24), 3107–3116.

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A Concept of a MIABIS based Register of Biosample Collections at the Medical University of Innsbruck

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Abstract. The knowledge about the quality of samples and associated clinical data in biospecimen collections is a premise of clinical research. An electronic biosample register aims to facilitate the discovery of information about biosample collections in a hospital. Moreover, it might improve scientific collaboration and research quality through a shared access to harmonized sample collection description data. The aim of this paper is to present a concept of a web-based biosample register of the existing biosample collections at the Medical University of Innsbruck. A uniform description model is built based on an analysis of the sample collection data of independent sample management systems from two departments within the hospital. An extended set of attributes of the minimum dataset used by the Swedish sample collection register (MIABIS) has been applied to all biosample collections as a common description model. The results of the analysis and the data model are presented together with a first concept of a sample collection search register.

Keywords. Biosample register, Biosample collection, Minimum data set, MIABIS, BBMRI

Introduction

Quality indicators of biosample collections like pre-analytical sample processing, long term storage and the availability of clinical data have a significant impact on medical research [1][2].

Biospecimen collections at the Medical University of Innsbruck are managed by their respective departments which often use individual in-house sample management software, sample description terminologies and operating procedures. Currently, there exists no common sample management system. Due to this heterogeneity, many researchers are unaware of existing biospecimen repositories outside their departments.

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A common biosample register shall not only facilitate the access of information to collections available but also improve collaboration and research quality through the exchange of harmonized data about sample quality and processing standards.

This paper presents a concept of a hospital-wide biosample register which enables queries for existing biosample collections at the Medical University of Innsbruck.

The register will be accessible through a web-interface from any workstation with an internet/intranet connection and a standard browser.

The biosample register should facilitate researchers to find out which samples can be used within the scope of their study using a set of quantitative/qualitative query parameters. Quantitative parameters can be for example the number of aliquots contained in a collection or the sample collections that exist from patients with a certain diagnosis. Examples of quality indicators might be the preprocessing and long-term storage of samples in a collection. Such information has a significant influence on the outcome of research projects and should be kept in the register for each sample collection. A set of attributes for describing biosample collections is provided by the MIABIS [3] dataset. A main objective is to integrate MIABIS elements into the local biosample register. Primarily, the system is intended to be used by clinical researchers and clinicians within the hospital. Moreover, it might be used to share information about biosample collections across clinical boundaries in the future.

The integration of an additional interface allowing a connection of the local sample register with a future Austrian biobank register had also to be considered in the requirements specifications.

1. Methods

First, an overall system analysis of existing collections of biomaterials at all departments was conducted to obtain a detailed overview of the current sample collections, databases and IT-infrastructures. The departments of Gynaecology and Urology were selected as pilot clinics. Therefore, comparisons of the amount and the level of granularity of the clinical data and sample data were made between the departments observed. The communication processes between the different information systems were investigated and the bottlenecks identified. A graphical visualisation of the data communication between the different IT-based systems within each department was made using the 3LGM model [4].

Next, data representations from different departments were harmonized to obtain a unified model of all sample collections. Therefore attributes from the MIABIS dataset were mapped to semantically equal data elements used by the different sample management systems.

Finally, a list of functionalities of the biosample register was created based on the harmonized data model and the definition of the functional and non-functional requirements that were identified during the preceding analysis.

2. Results

2.1. Current situation

We identified 50 biosample collections at the Medical University of Innsbruck. All of the biospecimen collections are disease-oriented, i.e. they consist of samples that are collected continuously from patients during disease courses. Usually, these kinds of biosample collections are not associated with one particular study. There are no automated mechanisms or processes for the storage and retrieval of samples. The department of Gynaecology run both a biochemical and a morphological laboratory which are both ISO/IEC 9001 certified. A locally developed LIMS[2] PGS-IT [5] and Microsoft Access is currently used at the department of Gynaecology to manage the data associated with collected tissues and body fluids. The laboratory at the Department of Urology uses the proprietary database system Filemaker [6] which keeps sample data and clinical data together in a single system. The data is entered manually into the LIMS by the laboratory members at each department.

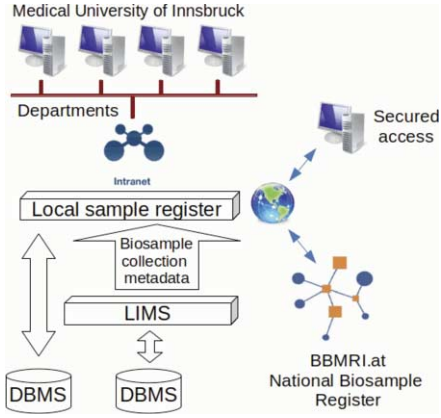


Figure 1. Integration of a local biosample register within the hospital and BBMRI.at

2.2. Definition of the MIABIS use cases

Four query examples identified in cooperation with several department members shall demonstrate some typical search activities of a user who is logged in to the register:

a) Find all collections of body fluids at the department of Gynaecology.
b) How many tissue sample collections exist with ICD-10 diagnosis “neoplasm of..”?
c) How many collections with more than 1000 samples exist at the department of Urology?
d) Find all collections of fresh frozen tissues or FFPE tissue samples from the prostate.

[2] Laboratory information system

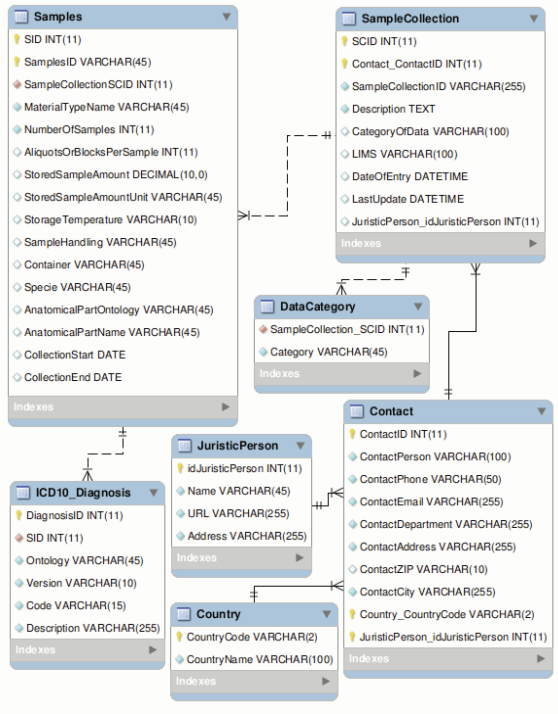


Figure 2. E/R model of the extended MIABIS database schema

Use case a) implies that the system performs a search based on material type values within the body fluid domain (serum, blood, plasma, ascites, etc.). Therefore, information about the material type must be stored for each sample collection.

To fulfil use case b), the register needs to hold information about the disease code and material type of each collection. For use case c), the system performs a search based on the number of samples contained in the collections and a specific department name. To fulfil use case d), the system requires information about the anatomical position and the material type of the sample collections.

2.3. MIABIS based data model

A department-wide biobank register with shared access to uniform biosample collection information requires a set of common description elements. Such a "minimum dataset" was developed during the preparatory phase of the BBMRI[3] project and includes 21 meta-level attributes. MIABIS has emerged as an enhanced version of the BBMRI Minimum dataset during implementation of the Swedish biobank register [7]. Tables from the MIABIS database schema have been adapted and extended with a set of attributes describing common properties of all sample collections (Figure 2).

[3] Biobanking and Biomolecular Resources Research Infrastructure

2.4. Requirement specifications of a MIABIS based biosample register

A document with all functional, non-functional and technical requirements was created based on the IT-analysis and the user needs that were collected during interviews with department members. An interface between the LIMS and the register will allow for automated updates of aggregated sample collection data. Since there will be no donor information stored in the biosample register there is no concern about donor privacy.

3. Discussion

A biosample register should enable an easy and quick access for researchers to aggregated data about existing biosample collections. Privacy issues are addressed by the anonymization during the aggregation of the data. The usage of MIABIS will enable international access to the register. However some limitations in the level of detail of the register data must be considered: For instance, as a consequence of data aggregation, no detailed information about individual samples or clinical data associated is available. This information is currently kept in the local department databases and the hospital information system (HIS) and it is not planned to be integrated in the biosample register without a formalized access policy. Possibly, the detailed data will be managed by a hospital-wide LIMS in the near future.
Currently the prototype implementation of the biosample register based on the requirements specification document is running. Further activities will concentrate on the integration of a BBMRI.AT interface (Figure 1) and the full ICD-10 disease catalogue [8].

Acknowledgements

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References

[1] Simeon-Dubach D, Better Provenance for Biobank Samples, *Nature* **475** (2011), 454–455.
[2] Simeon-Dubach D, Quality really matters: The need to improve specimen quality in biomedical research, *Journal of Pathology* **228** (2012), 431-433.
[3] Norlin L, A Minimum Data Set for Sharing Biobank Samples, Information, and Data: MIABIS, *Biopreservation and Biobanking*, **10(4)** (2012), 343-348.
[4] Wendt T, Modeling Hospital Information Systems (Part 2): Using the 3LGM2 Tool for Modeling Patient Record Management, *Methods Inf. Med* **45** (2006), 216-224.
[5] PGS IT-Systems [Internet]. PGS-IT: Home, PGS-IT Ges.m.b.H.; [updated 2013 Jun 13; cited 2014 Apr 11]. Available from: http://www.pgs-it.at
[6] Filemaker [Internet]. Custom Business Solutions | Filemaker, FileMaker GmbH; [updated 2013 Dec 30; cited 2014 Apr 11]. Available from: http://www.filemaker.at
[7] Swedish Sample Collection Register [Internet]. Sample Collection Register - BBMRI.se, BBMRI.se; [updated 2012 Oct 8; cited 2013 Dec 10]. Available from: http://bbmri.se/en/find-samples-and-data/Sample-Collection-Register
[8] ICD10Data.com [Internet]. The Web's Free 2014 ICD-10-CM Medical Coding Reference; [updated 2014 Feb 8; cited 2014 Jan 10]. Available from: http://www.icd10data.com

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How Google Glass Could Support Patients with Diabetes Mellitus in Daily Life

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Abstract. Even long before it was published, many people regarded Google Glass as a Swiss army knife for nearly every task. There are some fields of application in which the best known wearable device could simplify daily life, such as car navigation or reading recipes. But does this also apply for medicine and health care? This paper will at first explain what Google Glass is and how it works. Afterwards, diabetes mellitus (DM), is discussed. Moreover, we try to answer the question whether a Glass-like device could support and improve people with DM. Therefore, several use cases for Glass-enabled chronic disease care are outlined.

Keywords. Google Glass, Wearable Devices, Mobile Health, Patient Empowerment, Medical Informatics

Introduction

In 2012, Google announced at their developer conference "Google I/O" a new category of technology, a wearable device called "Google Glass". Moreover, Gartner predicts that in 2017, companies using Glass could annually save up to $1 billion due to hands-free access to the Internet, cameras, conferencing and phone calls. Additionally, Gartner mentions that health care industry could also benefit from the ability to practice telemedicine and teleconsultation. But does this also apply for patients with chronic diseases such as diabetes mellitus (DM)?

1. Methods & Material

1.1. Google Glass – What's inside?

Google Glass is a smart glasses device, comprising a lightweight, flexible frame, a camera and a small head-mounted display. According to Google, the display resolution can be compared to a 25" HD screen from 8 feet away, which is roughly 2.5 meters. The camera has 5MP and is able to capture 720p videos. In its first version, audio was solely transmitted by a bone conduction transducer. The capacity in terms of storage is

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16GB of which 12GB are usable and 4GB are used by the OS and system software. Furthermore, Glass provides built-in Wi-Fi and Bluetooth connectivity.

1.2. Diabetes Mellitus

DM is a chronic disease, which shows an alarming increase in terms of people affected [1]. The International Diabetes Federation states in the 6th edition of their "Diabetes Atlas" that as of 2013, 382 million people worldwide live with DM. Even worse, another 175 million people suffer from undiagnosed diabetes [2].Within the next 20 years, the amount of diabetics will globally increase further by 55% to about 592 million people. For this reason, it is important to prevent or delay the onset of DM as it can have serious long-term complications, including damage to the heart, kidneys, nerves and blood vessels. Moreover, diabetics are exposed to an at least doubled risk for death compared to people without this disease.

As diabetes is a disease with severe comorbidities, awareness and diabetes-specific education are crucial. This also reflects in several national and international programs like the German national plan for diabetes [3] and the UN Resolution "unite for diabetes" [4] respectively.

2. Results

As diabetics need to cope with their disease, we examine several solution ideas whether and how Google Glass could enhance their daily life.

In this context, one must differentiate between at least two typical groups of diabetics. Group *A* includes patients who have recently been diagnosed with DM, whereas group *B* comprises patients that struggle with this disease for a long time. However, there are factors that strongly affect both groups likewise, such as changes in their diet, physical activity and the need to perform regular checks of their blood glucose value. According to Chomutare et al., we focused on five out of the ten most important features for diabetes self-management: Education and personalized feedback, diet management, physical activity, insulin and medication management and other therapeutics (foot, eye care) [5].

2.1. Solution Ideas – Group A

Recently diagnosed patients are confronted with a large amount of DM related information. Hence, it is crucial to provide them with educational support during early stages of DM. Thus, patients can be enabled to adjust to their diagnosed disease.

2.1.1. Reminder and Visual Alerting

As outlined in Section 2, it is essential for diabetics to pay attention to a regular food intake and measurement of blood glucose levels to avoid hypoglycemia[2]. Recently diagnosed diabetics, especially young adults, often tend to skip meals, forget measurements and are not aware of resulting consequences.

[2] http://www.ncbi.nlm.nih.gov/mesh/68007003

In this context visual alerts and reminders triggered by a Glass application are easily recognized as they are projected directly in the user's field of view. For this reason, reminders could reduce the risk of hypoglycemic events by increasing adherence to their treatment [6].

2.1.2. Awareness & Education

One of the major issues in diabetes treatment is low health literacy, i.e., the ability to read, understand and act according to health information. Health literacy in general is not bound to socioeconomic status. Besides, low health literacy contributes to poor adherence and therefore lowers health outcomes [7].

Chomutare et al. have found that personalized education is "an underrepresented feature in diabetes mobile applications" [5]. Glass could raise awareness and improve the user's disease-specific education level by, e.g., showing useful tips or clarify misconceptions of common nutrition myths ("Did you know…?"). Moreover, a diabetes quiz, that playfully imparts knowledge about the disease, could be a valuable feature. Disease related awareness could therefore be increased if such application features would provide individualized DM lectures.

Increased disease related information provision does not raise the education level. It can even cause information overload. Laymen friendly language seems to be a vital factor to raise health literacy in general. A Glass application could suggest individually tailored content such as proposed by [8] in a similar context.

2.1.3. Context-Sensitive Nutrition Facts & Advice

As Diabetics have to change their eating habits, they need to intensively deal with nutrition and contained ingredients. Sadly, many groceries do not provide information on carbohydrates and other nutrition facts, and even then, these facts are frequently printed in a rather small font size. This time consuming and mentally challenging task of reading and comprehending can pose a barrier for many patients affected.

With Glass, a user could just scan a barcode and receive nutrition facts in an instant. Additionally, a corresponding service could check for harmfulness, e.g., if a diabetic is also allergic to nuts. Thereby, this service provides context-based decision support and informs the user whether the desired product contains a lot of hidden sugar. Given data stored in a medical record, another feature might be a bread units and insulin bolus calculator. The advantages of this solution are obvious: A Glass user could interact hands-free with such a device, which is an important prerequisite in grocery stores. This allows to check whether a product is harmful according to several diabetes-specific parameters, such as the current blood glucose value or HbA1c[3], retrieved from the electronic medical record. With respect to the personal medical diabetes history, a Glass-based software solution would trigger an alert if a product violates nutrition or treatment plans. To realize this scenario, nutrition information for a wide range of products needs to be available.

2.1.4. Interactive Guide for Blood Glucose Measurement

In particular, recently diagnosed diabetics have to memorize about 20 steps of a correct measurement process and therefore need training. In this context, it is important to

[3] http://www.ncbi.nlm.nih.gov/mesh/68006442

notice, that a measurement should be performed on the side of a fingertip to prevent sore spots. Moreover, hygiene aspects have to be taken into account. Therefore, an interactive guide can support a diabetic to internalize the measurement process to become a daily routine.

Glass could alleviate such measurement steps by showing a recipe-like instruction what action has to be fulfilled within a certain step. As a basic requirement, a software solution should show a short textural description of every step. Addressing the health literacy problem, an application needs to make sure that these descriptions have a high degree of laymen friendliness for every diabetic. To further improve comprehensibility, pictograms or audio-guided instead of merely textual information might be even more beneficial.

2.2. Solution Ideas – Group B

Long-term diabetics have different needs, as they are already accustomed to this disease. In particular, such patients already changed their daily life according to treatment plans provided by a diabetes specialist. Yet, some patients lose interest in strict adherence to a therapy or treatment plan [6]. For this reason, there is a need for mental support of patients, i.e., to sustain their motivation [9]. Moreover, documentation of diabetes-related complications is a special need of elderly patients. This can avoid exacerbation and potentially slow down a further decrease of a patient's quality of life.

2.2.1. Digital Wound Documentation

In a patient context, a diabetic takes care of his/her wounds and the documentation at home. This mainly applies to people suffering from diabetic foot syndrome, who face a high risk of amputation. Furthermore, patients tend to lose interest in regularly taking pictures, even though they do not have to travel and see a diabetes specialist.

By contrast, a caregiver documents wound progression on a regular basis, i.e., this is performed in a professional manner a part of a medical routine, it can have a large influence on future treatment options. Therefore, motivational aspects are not the major issue. Yet, both groups struggle to take high quality images while holding a leg or foot. Moreover, surrounding ambient light might have negative effects on image acquisition.

The advantages of Glass in this scenario are hands-free use and voice triggered commands to take photos. In the current software release, there is also the opportunity to take a photo by blinking. However, Glass does not have a flash and therefore insufficient ambient light needs to be compensated for as well. Nevertheless, we assume that this will be a minor issue of future wearable devices.

2.2.2. Motivation to Move

Physical activity is important and can positively influence daily life [10], but people today tend to use their car instead of walking. For this reason, they need to be encouraged to be more active by equipping them with a pedometer and giving them a specific goal. Despite buying a stand-alone pedometer, steps can also be measured with an accelerometer, which is included in nearly every smartphone. This also applies to Google Glass, which has the necessary hardware already built-in [11], although this functionality is not activated so far. Therefore, the hardware facilitates the creation of an app using a gamification approach, i.e., the app is designed as a game in which users

can achieve badges or levels, collect points and break their personal records. Thus, to strive for personal high-scores could lead to personal ambitions. This might improve a patient's state of health and could reduce risk for long-term complications of DM, either.

3. Discussion & Future Trends

In this paper we introduced Google Glass as one device of a new class of assistive technology. We presented several use case scenarios, in which Google Glass could improve daily life of diabetics. In addition, we identified two groups of diabetics, which have different user needs in terms of wearable devices. Recently diagnosed patients are confronted with a large amount of DM-related information and need educational support during the early stages of the disease. By contrast, long-term diabetics are already accustomed to this disease and need mental support to sustain their motivation and level of adherence. Moreover, documentation of diabetes-related complications can avoid exacerbation and thereby sustain a patient's quality of life.

Despite many opportunities Glass can offer, social issues and legal aspects need to be considered. For instance, there are still open questions regarding responsibility for decisions based on insulin or bread unit calculations. Moreover, many people fear that health-related data could be misused or even sold. But even in a general context, concerns with the built-in camera and being recorded without prior permission exist. Such ethical and legal issues provide tremendous potential for future research.

As diabetes mellitus is still a disease that mainly affects elderly people - referred to as digital immigrants - we assume that the acceptance of Glass-like devices will be low in the nearby future, but this will change over the next decade.

References

[1] World Health Organization. Diabetes and statistics. [Online].; 2013 [cited 2013-12-17]. Available from: http://www.euro.who.int/en/health-topics/noncommunicable-diseases/diabetes/data-and-statistics .
[2] International Diabetes Federation. IDF Diabetes Atlas, 6th edn. Brussels: International Diabetes Federation; 2013.
[3] United Nations. Resolution adopted by the General Assembly on 20 December 2006. In ; 2006.
[4] diabetesDE - Deutsche Diabetes-Hilfe. Deutscher Gesundheitsbericht Diabetes 2013 Mainz: Kirchheim + Co GmbH; 2013.
[5] Chomutare T, Fernandez-Luque L, Årsand E, Hartvigsen G. Features of Mobile Diabetes Applications: Review of the Literature and Analysis of Current Applications Compared Against Evidence-Based Guidelines. Journal of Medicine Internet Research. 2011 Sep 22.
[6] Wood B. Medication Adherence: The Real Problem When Treating Chronic Conditions. US Pharmacist. 2012; 37: p. http://www.uspharmacist.com/content/s/200/c/33457/.
[7] Office of the Surgeon General (US); Office of Disease Prevention and Health Promotion (US).. Proceedings of the Surgeon General's Workshop on Improving Health Literacy: September 7, 2006 National Institutes of Health, Bethesda, MD. Rockville (MD): Office of the Surgeon General (US); 2006.
[8] Wiesner M, Yilmaz A, Pfeifer D. Satisfying Health Information Needs: A German Health Exhibition Example. In Proceedings of Computer-Based Medcial Systems (CBMS); 2012; Rome, Italy.
[9] Rubin RR. Diabetes and Quality of Life. Diabetes Spectrum. 2000; 13(1): p. 21.
[10] American Diabetes Association. Physical Activity is Important. [Online].; 2013 [cited 2014-01-29]. Available from: http://www.diabetes.org/food-and-fitness/fitness/physical-activity-is-important.html .
[11] V S C. Sensors on Google Glass. [Online].; 2013 [cited 2014-01-26]. Available from: http://thecodeartist.blogspot.de/2013/05/sensors-on-google-glass.html .

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Shared Decision Making: Using Theories and Technology to Engage the Patient in Their Health Journey

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Abstract. Shared decision making is considered the cornerstone of patient-centred care but transpires in only 10% of face-to-face consultative encounters. Technology interventions have rampantly sought to fill the shared decision making gap but fall short in patient engagement. Recent studies indicate that combining multiple approaches could lead to greater commitment towards achieving positive health outcomes. Consequently, this study combines and embeds the I-Change behavioural theory with choice architecture within a technology-based aid to facilitate shared health decision making for hypertension reduction. An ontology knowledge model combining the behavioural and choice methods forms the core framework that will inform the technical solution. The model is both scalable and patient-centric. A pilot study will trial the solution, solicit feedback and propose refinements for future clinical use.

Keywords. Shared Decision Making, Patient Empowerment, Technology Intervention, I-Change Model, Behavioural Theory, Choice Architecture

Introduction

Shared decision making (SDM) empowers patients to be more informed and to actively participate in their own health. It is a meeting of the experts in which the physician is the expert in medicine and the patient is the expert in his or her own life, values and circumstances [1]. SDM can improve the patient's quality of life [2], quality of care and safety [3] while lowering healthcare costs [4].

Despite its benefits and being touted as the cornerstone of patient-centred care [5], literature shows that only 10% of face-to-face clinical consultations involve shared decision making [3]. Consequently, technology interventions (decision aids) are a well-studied method for filling the SDM gap [6]. Decision aids can improve decision quality; reduce decisional conflict and increase choices consistent with the patient's values [7].

Use of behavioural theories improves the success rate of health interventions [8]. For instance, theory-driven behavioural strategies can reduce the risk of cardiovascular disease through lifestyle change rather than increasing patient medication [9]. Choice architecture (CA) is recommended as a complimentary technique for improving health behaviour and decisions [10]. Reinforcement through multiple methods may increase

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motivation and adherence [11]. Hence, this research envisions a technology intervention employing behavioural theory and choice architecture to reduce a cardiovascular risk factor (hypertension) using SDM.

1. Methods

This research study develops a web-based technology application integrating behavioural theory and choice architecture to facilitate SDM. A conceptual process flow (Figure 1) and an ontology knowledge model (Figure 2) informs the computerization of the technology intervention.

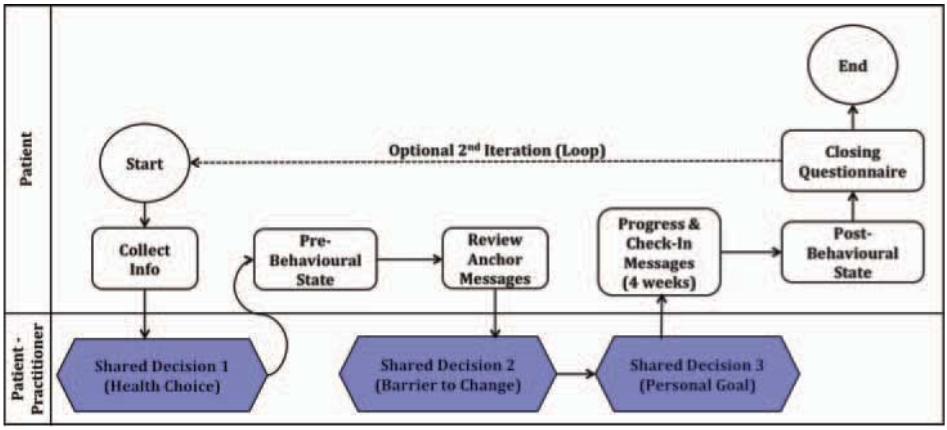


Figure 1. Process flow

The steps in the process flow are:

Information Collection: Demographics along with health markers for current exercise, smoking and sodium intake are collected for use in the subsequent choice architecture.

Shared Decision 1 (Health Choice): A health choice (lifestyle intervention) is the first shared decision towards reducing hypertension.

Pre-Behavioural State: A validated questionnaire captures the initial behavioural state using the Integrated Change (I-Change) behavioural model [12]. I-Change has three states: awareness, motivation and action.

Anchor Messages: CA anchor messages motivate behaviour change by framing the importance of the intervention and setting expectations without impacting preferences.

Shared Decision 2 (Identify Main Barrier to Change): Identifying and overcoming inhibiting psychological barriers is essential for altering lifestyles successfully [13].

Shared Decision 3 (Personal Goal Setting): A shared decision sets a realistic personal goal for the intervention.

Progress and Check-In Messages: Systolic and diastolic blood pressure measurements are entered in the system while receiving a concurrent motivational check-in message.

Post-Behavioural State: The behavioural state is measured again for comparison.
Closing Questionnaire: Evaluates the participant experience with the intervention.
Second Iteration (Optional Loop): A second iteration reduces the possibility that external factors interfered with the first attempt (if unsuccessful).

The theory and shared decision making steps from the conceptual process were represented in an ontology knowledge model using Protégé 3.5. The ontology model in Figure 2 contains the behavioural, choice and domain specific content.

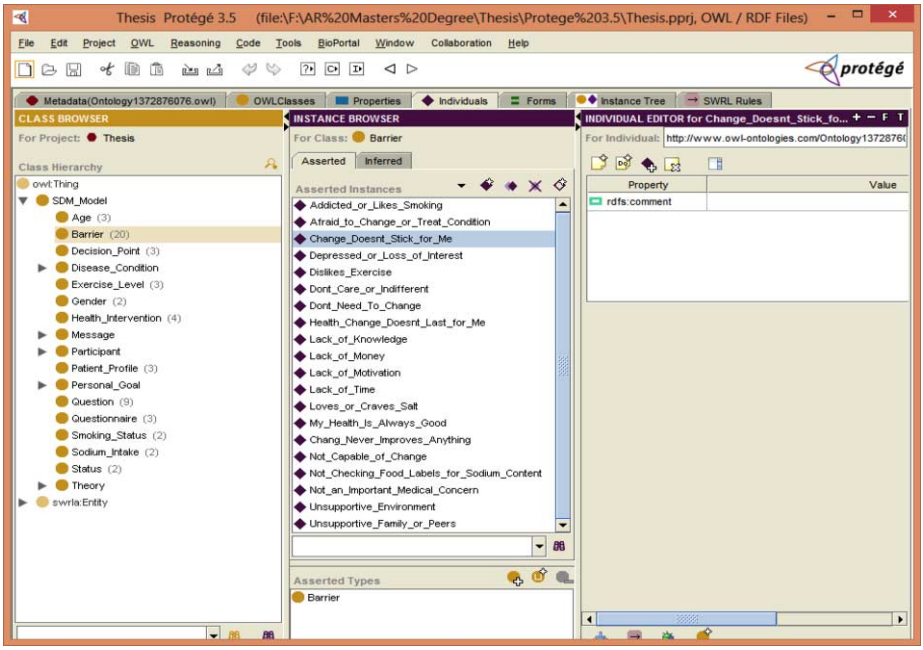


Figure 2. Ontology knowledge model

For instance, identifying the barrier to change is a behavioural construct and making the decision on how to overcome it is a shared decision. Thus, the ontology model contains a class for "barrier" with Protégé individuals representing the common obstacles for change derived from psychological evidence [13].

The model also contains a class for "messages" which contains the various CA message techniques that could be employed. Anchor messages and check-in messages are examples of sub-classes. Within each sub-class, the specific messages for display appear as Protégé individuals and the message content is captured using an "app_message" datatype property.

The model was built to be scalable and flexible and can accommodate any disease condition, multiple participants, the selection of different theories for behaviour change and also different choice architecture concepts. The ontology model is patient-centric and contains the core constructs, relationships, and description logic that form the foundation upon which the technical solution will draw its elements and processing logic.

The technology solution envisioned will be a web-based interface storing information on a centralized server within a secure relational database. The Vaadin open source web application framework will be used to produce a rich internet

application. Vaadin contains a plug-in for chat sessions to enable online shared decision making. The technical solution will utilize the ontology model constructs to present the behavioural theory, choice and domain content as a seamless process flow.

2. Evaluation and Results

The research design is a usability pilot study of 8-10 participants. Each participant will use the technology intervention for a minimum period of four weeks. The technology intervention has been validated by two domain experts in medicine and further reviewed by two individuals with hypertension for patient input.

Evaluation will be achieved by capturing both quantitative and qualitative information. Quantitative pre and post-behaviour states will be obtained by automated scoring of an embedded I-Change behavioural state questionnaire. Daily measures of systolic and diastolic blood pressure using digital monitors, along with the health intervention progress (i.e. quantity of cigarettes smoked) will be tracked for quantitative analysis. This information will be used to determine whether the lifestyle change was actualized.

A post-study questionnaire will solicit the usability and shared decision making experience of both participants and healthcare provider through questions scored using a 5-point Likert scale for quantitative analysis in conjunction with open ended questions for qualitative analysis. The post-study questionnaire will determine the value and success of the technology intervention.

Statistical software such as SAS or R will be used to calculate mean scores for blood pressure and health progress measures. Moreover, mean scores will be calculated within each section of the post-study survey. Chi-square will be used to evaluate both the question and section level information and Cronbach's alpha will be used to evaluate response consistency within each survey section. The combined study data and post-study questionnaire will be reported as general/aggregate findings.

3. Discussion

The research study will show whether a multi-faceted intervention based on an ontology model can be an effective tool to reduce hypertension.

3.1. Limitations

Finding hypertensive participants in the local area is a pragmatic challenge that impacts the study size. Hence, the evaluation will focus on the usability, benefits, challenges and value of the online shared decision making intervention.

3.2. Conclusion

This study contributes to new knowledge by assessing whether technology can be used as a successful medium for sharing decisions informed by an ontology model combining behavioural theory and choice architecture. The solution is designed to be

generalizable and can be used for any disease or condition. Hence, the SDM model could be expanded in future research for other specialties or disease conditions.

References

[1] Tuckett D, Boulton M, Olson C, Williams A. Meetings between experts. An approach to sharing ideas in medical consultations, New York: Routledge; 1986. 264 p.

[2] Ashraf AA, Colakoglu S, Nguyen JT, Anastasopulos AJ, Ibrahim AM, Yueh JH, et al. Patient involvement in the decision-making process improves satisfaction and quality of life in postmastectomy breast reconstruction, *J Surg Res* [Internet]. 2013 Sep [cited 2014 Apr 22];184(1):665-70. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23706394

[3] Godolphin W. Shared decision making, *Healthc Q* [Internet]. 2009 Special Issue [cited 2014 Apr 22]*;12:*e186-90. Available from: http://www.ncbi.nlm.nih.gov/pubmed/19667767

[4] Veroff D, Marr A, Wennberg DE. Enhanced support for shared decision making reduced costs of care for patients with preference-sensitive conditions, *Health Aff (Millwood)* [Internet]. 2013 Feb [cited 2014 Apr 22];32(2):285-93. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23381521

[5] Barry MJ, Edgman-Levitan S. Shared decision making – the pinnacle of patient centred care, *N Engl J Med*. 2012 Mar 1 [cited 2014 Feb 6]; 366:780-81. Available from: http://www.nejm.org/doi/full/10.1056/NEJMp1109283

[6] Ozanne EM, Annis C, Adduci K, Showstack J, Esserman L. Pilot trial of a computerized decision aid for breast cancer prevention, *Breast J* [Internet]. 2007 Mar-Apr [cited 2014 Feb 6];13(2):147-54. Available from: http://www.ncbi.nlm.nih.gov/pubmed/17319855

[7] Ng C.Y., Lee Y.K., Lee P.Y., Abdullah K.L. Health Innovations in Patient Decision Support: Bridging the Gaps and Challenges, *Australas Med J* [Internet]. 2013 Feb 28 [cited 2014 Feb 6]; 6 (2): 95-9. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23483776

[8] E-Source [Internet]. New England: National Institutes of Health; Social and behavioural theories; [sections2-8]. Available from: http://www.esourceresearch.org/eSourceBook/SocialandBehavioralTheories/1LearningObjectives/tabid/724/Default.aspx

[9] Cox JL, Vallis TM, Pfammatter A, Szpilfogel C, Carr B, O'Neill. A Novel Approach to Cardiovascular Health by Optimizing Risk Management (ANCHOR): behavioural modification in primary care effectively reduces global risk, *Can J Cardiol* [Internet]. 2013 Nov [cited 2014 Feb 6];29(11):1400-07. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23796526

[10] Nease RF, Frazee SG, Zarin L, Miller SB. Choice architecture is a better strategy than engaging patients to spur behavior change. *Health Aff (Millwood)* [Internet]. 2013 Feb [cited 2014 Feb 6];32(2):242-49. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23381516

[11] Leddy MA, Anderson BL, Schulkin J. Cognitive-behavioral therapy and decision science, *New Ideas Psychol* [Internet]. Dec 2013 [cited 2014 Feb 6]; 31(3):173-83. Available from: http://yadda.icm.edu.pl/yadda/element/bwmeta1.element.elsevier-d837f335-13c7-3d8a-bb97-6794f77cb9b4

[12] de Vries H, Mesters I, Van de Steeg H, Honing C. The general public's information needs and perceptions regarding hereditary cancer: an application of the integrated change model. *Patient Educ Couns* [Internet]. 2005 Feb [cited 2014 Feb 6];56(2):154-65. Available from: http://www.ncbi.nlm.nih.gov/pubmed/15653244

[13] Olson JM. Psychological barriers to behaviour change, *Can Fam Physician* [Internet]. Feb 1992 [cited 2014 Feb 6]; 38: 309–319. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2145450/

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Knowledge Representations in Ambient Assisted Living - Context Awareness in Smart Homes

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Abstract. This paper introduces a knowledge representation for smart home rules and scenarios. We have created a rule base based on the rules found during a literature review. Following this, a general rule concept was derived from the identified categories. Furthermore, subcategories for certain contexts in the smart home environment were identified and illustrated in the results by means of an extract of the rules found in the literature. Based on this information, a hierarchically structured nomenclature with four axes has been developed and evaluated.

Keywords. Smart home, rules, knowledge representation, context awareness

Introduction

Smart Homes have already been used for several years as a tool for self-determination in old age, but also as a facilitation of life at home. According to [1], 1.06 million smart homes have been used in Europe since 2012. Among them are 150.000 of multifunctional use. A considerable number of activities of daily living can be simplified or even automated to a certain degree by using versatile technologies. Be it the sensors which sense the water tap running water, the stove being on or off, or the microwave scanning the barcode to take over the cooking process [2]. Moreover, safety aspects like RFID to replace the door key and gas sensors to protect people from gas explosions or fires are used to protect the people living in the smart home [3]. Therefore, physically or mentally disabled people can be given the possibility to maintain their quality of life in a domestic environment as long as possible. This is especially important for old people as the quality of life affect the personal wellbeing, meaning and appreciation of life positively or negatively [4].

The final conception of smart homes requires a high degree of planning though. At first, the decision of which type of smart home shall be constructed must be taken. Basically, smart hopes can be categorized into the aspects of safety, eldercare, healthcare, childcare, energy efficiency and a better life [5]. Dependant on the persons to be supported, the smart home is equipped specifically. As the behaviour of humans in their homely environment is highly individual and above all unstructured, sensors are required to sense behaviour patterns of several persons and adapt to them properly [5]. In spite of having many possibilities to implement these scenarios, the

system constantly has to consider current circumstances in the smart home [6]. Thus, it acts context-aware in the situations of daily living. In a more general sense, it triggers one or more actions under certain conditions.

The implementation of rules in smart homes is done either a priori, if possible, done by the user himself, or supplemented by the manufacturer after another consultation with the client. Not seldom are users overwhelmed by the mass of functionality, so the full potential of the smart home cannot be utilized very often [8]. Therefore, a well thought-out concept is essential.

As of this writing, an official representation format to describe such rules in a generic environment has not been developed yet. In spite of individual adaptations realised in smart homes up to this point, there are scenarios whose characteristics are quite similar. With that said, a possibility to develop a more general purpose system is desirable.

1. Methods

To get an overview over related works and the implementation of rule-based systems in general, a literature review was condcuted. In order to do this, PubMed, IEEEXplore, SCOPUS and DIMDI were searched for different articles, including articles covering general and concrete smart home scenarios, classifications, rule-based frameworks and architectures, ontologies, multi-agent systems, simulations, decision support systems, management platforms and data analyses. Based on the results of this research, every rule mentioned or derived from a scenario was inserted into a table with general categories. The categories listed below are covered in most rules and therefore are chosen to be part of a general rule.

- Person: Describes Key characteristics of a person in the smart home and gives information about its current status including activity, posture, used object and desire of effects.
- Parameter: Represents Environmental and physiological parameters as well as deduced conditions and their value.
- Inference: Gives information about deduced situations in the smart home.
- Activity: Gives information about the persons' activities in the smart home.
- Action: The action that is done in the smart home. This generally includes smart devices or robots as well as the smart home system itself.

As most contexts are not identical, the rules found in the research consist of different parts and cover different contexts. To include every rule in one list, the table was extended by additional categories when a rule did not fit into the current version. In case one or more rules were too specific, for example by evaluating certain variables or proportions, generalisation was done. Having classified all rules, a general construct was derived from the rule base to describe every rule with an abstract one. Moreover, abstract rules for certain subcategories of context were identified.

Based on the previously found categories to classify rules in smart homes, a representation format was developed and evaluated by domain experts.

2. Results

A repository of 221 concrete rules in smart home context was created. Based on its information, a general scheme for the definition of rules can be derived. It follows the categories used in the rule table and can be described as follows:

(person OR parameter) → (inference OR activity OR action) (1)

Both the head and the body of the formula above (1) consist of a set of 1, 2, ..., n elements. The reasoning behind this is that a rule following the ECA-rule conventions has to have at least one event or condition and at least one action to form an ECA-, EA-, or CA-rule (IF-THEN-rule). Furthermore, the elements within the sets can be connected with predicate logic.

The general scheme can further be used to identify subcategories of rules with a specific function. The first subcategory is a simple construct which reacts to changes in the environment with an action.

(parameter) → (action) (2)

The formula (3) describes a rule scheme to control the environment and alarm systems based on parameters. By its means devices can be controlled with uncomplicated structures and thus already provide a certain comfort and safety, which can be illustrated by the rule no. 1 in table 1 (carbon monoxide concentration → window) [9].

Table 1. Extract from the rule base containing examples for every subcategory of the general rule scheme.

No.	Person	Parameter	Inference	Activity	Action
1	-	Carbon monoxide concentration is high	-	-	Open all windows
2	-	Smoke sensor is active	-	-	Trigger home / fire alarm
3	-	Luminance is below optimum	Room is dark	-	-
4	-	Breathing rate is more than 30 times per minute	Breathing rate is high	-	-
5	Enters the bedroom	-	-	-	Switch the lights in the bedroom on
6	Is in the kitchen	Stove is on	-	Cooking	-
7	Is outside OR	Telephone in the kitchen rings and the music in the adjacent room is on	-	-	-

Moreover, using the same syntax rules to trigger the alarm system can be described. Context parameters which could be hazardous to health immediately or in the longer term are important in this context. A rule representing this concept is rule no. 2 (smoke sensor leads to fire alarm) [7].

The rule pattern used so far is also useful for the inference of context situation.

(parameter) → (inference) (3)

The syntax in (3) describes a general scheme for inference rules based on parameters. An example for this is rule no. 3 in table 1 where a dark room is inferred from a brightness value below the optimum [10].

Aside from environmental parameters sensed by the sensors, there are a number of situations which can be described by the characteristics and actions of persons and which create causal relationships in the intelligent environment. Taking up the last points made before, the usage of vital parameters of person in combination with the syntax given in (3) provides a supplement to the alarm system of a smart home. Rule no. 4 in table 1 (vital parameter leads to health) [11].

(person) → *(inference)* (4)

The rule scheme for inference based on characteristics of person in (4) provides inference to trigger alarms. High blood pressure for example can be caused by an unusual situation, whereupon a warning or alarm is sent to the monitoring centre or another contact person. However, alarms can also be caused by activities like falling or by the identification in the smart home like burglars. Moreover, they show that personal aspects like localisation and activity can be used to control the environment. A proper example for this context is no. 5 in table 1 (activity leads to light) [12]. The corresponding rule syntax is shown in (5).

(person) → *(action)* (5)

By using both environmental parameters and characteristics of persons, contexts which give information about the activity of every person in the smart home can be described.

(person OR parameter) → *(activity)* (6)

The rule syntax (6) is used in rule no. 6 in table 1 (localisation and device status leads to activity) illustrates well, how to combine both aspects to describe a context.

As every atom of (1) can be a set, the rules' complexity is dependent on the size of every set. Whereas low complexity rules possibly address only one subsystem in one room and one device, rules with a higher complexity address more than one subsystem and are able to extend their conditions and actions to other rooms as rule no. 7 shows (device status in the kitchen and person is outside or music in the adjacent room is on) [12].

Based on this information, a nomenclature with four axes (Person, Condition, Action, Features) which is able to represent the rules of the literature research was developed.

3. Discussion

Searching for smart home related articles led to relevant hits in every database. Therefore, context awareness in smart homes might have been investigated for a longer time. However, research done on knowledge representations in smart home is not very elaborated. Knowledge representations found in the literature cover possible contexts from only one developed smart home system each. Furthermore, they are limited to the

given equipment. Our knowledge representation include a general scheme that can be replaced by any other smart home conditions, so it can be used to classify either non-implemented smart home scenarios or implemented smart home rules. Therefore, it stands out in terms of context coverage.

Nevertheless, the idea of creating categories based on rules found in the literature might be too narrow focused as scientific research does not necessarily cover every single rule possible. The majority of the most established rules in smart home systems is represented though. The same argument applies to the evaluation of the knowledge representation as it was done locally and therefore does not include experiences from other domain experts. Furthermore, the developed knowledge representation cannot be simply deployed to a smart home system as it does not implement it directly. Therefore, additional efforts would be needed for the adaptation. Another limitation is that some of the rules found during the literature review were too specific to include them in our knowledge representation as they originally were. Therefore, these rules were generalised, so that the identified categories in the table were applicable to the rules. Not knowing the extent of such rules, this might imply that a generalisation of smart home contexts is not possible.

In the end, with increasing knowledge about trends in smart home systems and significance of homecare, a general knowledge representation can be extended even further and might help to systematize the state of the art.

References

[1] L. Kurkinen, *Smart Homes and Home Automation*, http://www.berginsight.com/ReportPDF/Summary/bi-sh2-sum.pdf , 2013.

[2] J.C. Augusto, J. Liu, P. McCullagh, H. Wang, Management of uncertainty and spationtemporal aspects for monitoring and diagnosis in a Smart Home, *International Journal of Computational Intelligence Systems* **1** (2007), 361-378.

[3] D.M. Han, J.H. Lim, Design and Implementation of Smart Home Energy Management Systems based on ZigBee, *IEEE Transactions on Consumer Electronics* **56** (2010), 1417-1425.

[4] A. Sarvimaki, B. Stenbock-Hult, Quality of life in old age described as a sense of wellbeing, meaning and value, *Journal of Advanced Nursing* **32** (2000), 1025-1033.

[5] C.D.S. Liyanage, M. Chamin, M.P. Iskandar, State of the art of smart homes, *Engineering Applications of Artifical Intelligence* **25** (2012), 1313-1321.

[6] C. Röcker, M.D. Janse, N. Portolan, N. Streitz. User Requirements for Intelligent Home Environments: A Scenario-Driven Approach and Empirical Cross-Cultural Study, *sOc-EUSAI '05. Proceedings of the 2005 joint conference on Smart objects and ambient intelligence: innovative context-aware services: usages and technologies*, New York: ACM, 2005 ,111-116.

[7] C.Y. Leong, A.R. Ramali, T. Perumal, A Rule-Based Framework for Heterogeneous Subsystems Management in Smart Home Environment, *IEEE Transactions on Consumer Electronics* **55** (2009), 1208-1213.

[8] C. Reinisch, W. Kastner, Agent based Control in the Smart Home, In: Proceedings of the IECON 2011-37th Annual Conference on IEEE Industrial Electronics Society, 2011, 334-339.

[9] U. Bischoff, V. Sundramoorthy, G. Kortuem, In: 3rd IET International Conference on Intelligent Enviroments (IE 07), 2007, 554-555.

[10] Y.G. Cheong, Y.J. Kim, S.Y. Yoo, H. Lee, S. Lee, S.C. Chae, H.J. Choi, An ontology-based reasoning approach towards energy-aware smart homes. In: *Consumer Communications and Networking Conference (CCNC)*, 2011, 850-854.

[11] M. Popescu, A. Mahnot, Early illness recognition using in-home monitoring sensors and multiple instance learning, *Methods of information in medicine* **51** (2012), 359-367.

[12] A.K. Dey, T. Sohn, S. Streng, J. Kodama, iCAP: Interactive Prozotyping of Context-Aware Applications, *In: Pervasive Computing, 4th International Conference, PERVASIVE, Proceedings,* 2006, 254-271.

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Rule-based Interface Generation on Mobile Devices for Structured Documentation

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Abstract. In many software systems to date, interactive graphical user interfaces (GUIs) are represented implicitly in the source code, together with the application logic. Hence, the re-use, development, and modification of these interfaces is often very laborious. Flexible adjustments of GUIs for various platforms and devices as well as individual user preferences are furthermore difficult to realize. These problems motivate a software-based separation of content and GUI models on the one hand, and application logic on the other. In this project, a software solution for structured reporting on mobile devices is developed. Clinical content archetypes developed in a previous project serve as the content model while the Android SDK provides the GUI model. The necessary bindings between the models are specified using the Jess Rule Language.

Keywords. Archetype, structured documentation, GUI, rule-based, Android

Introduction

Structured data entry (SDE) should be used as often as possible in medical documentation to ensure a high level of data quality and processability. For various reasons structured data entry is not popular with most physicians. In addition to a feeling of restriction and laboriousness due to missing individual adaption to special needs, inconvenient user interfaces are to blame for this lack of acceptance. Nonetheless, the time consuming process of design and generation of SDE forms should not be underestimated. The data entry forms in existing documentation systems are internally represented in a proprietary format without conformance to available standards. Thus, the forms are hardly verifiable or reusable; and do not contribute to achieving semantics. There is, however, a great need for changing and individually modifying the forms. Towards the aim of an automatic interface generation, a content model repository has to be built. Many research projects are working on that, including the TMF Metadata Repository, the OpenEHR in parallel to the EN 13606 and the Operational Data Models. A promising approach was proposed by Schuler et al. [1] who used Archetypes to design templates.

In this paper, a standard-based approach for the automatic generation of graphical user interfaces (GUIs) is presented. A fast and flexible generation of GUIs is achieved by separating clinical content models (e. g. EN 13606 archetypes) and GUI models,

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and linking both by suitable bindings. Using a formal rule language increases the adaptability of the binding over a static mapping.

1. Methods

The approach proposed in this paper is divided into two steps: Firstly, we built the necessary content and GUI models. Secondly, we defined a suitable binding between both models by means of a rule language. The content models use coded values, which refer to terminologies to ensure semantic interoperability. To enhance the interoperability the documented forms are further transformed into HL7 CDA. An overview of the implemented architecture is provided in figure 1. The implementation is based on a two-level approach, the coordinated use of separate schema information at content and presentation level.

At the level of clinical content, EN 13606 Archetypes are used. The use of these content models facilitates machine interpretability and increases the reusability of already defined structured content. The Archetype model supplies textual descriptions for the user. In an Archetype's ELEMENT class, different types of instance data can be stored, such as a calendrical date or a boolean value. An input screen for a value of boolean type can be presented to the user, for example, as a radio button or a drop-down menu. In contrast to a hard-coded layout description inside the Archetype, this methodology of declarative GUI specification reduces the definition effort [2] and increases flexibility. The binding between both content and GUI models is implemented by means of a rule engine.

The requirement of a mobile documentation is met by the implementation using the Android SDK. This framework provides GUI elements that can easily be integrated into the proposed architecture. The mobile application calls for reconstructing the documentation workflow. For example, due to the limited display size it is not always possible or useful to show the complete forms on the display. We tested several alternative display options.

Content models: Standards like HL7 Version 3, ISO 11179 on Metadata Registries, and archetypes provide standardized content models. In this project, the use of EN 13606 archetypes is most suitable.

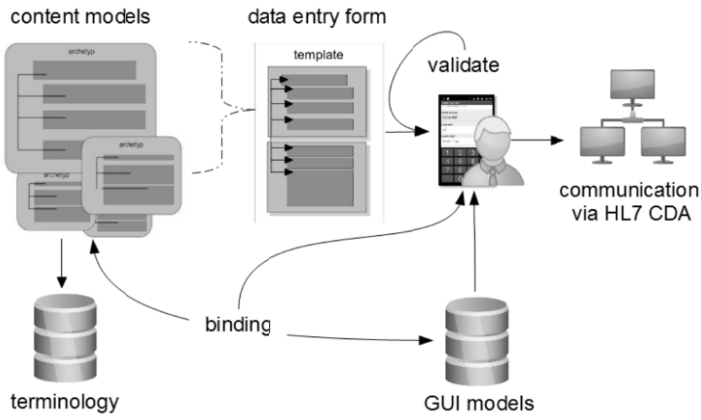


Figure 1. Overview of the implemented architecture.

For the construction of a content model repository, several steps were necessary: Firstly the documentation items had to be identified. For this reason, the original forms were analyzed and atomic documentation items were extracted [3]. In a second step, these items were implemented as primitive EN 13606 archetypes. To ensure compliance to the standard and to simplify the transformation, the Template Editor developed by Medical-Objects was used. Subsequently, we combined multiple atomic documentation items by reassembling our primitive ENTRY archetypes to SECTIONs and those in turn to COMPOSITIONs. The whole data entry form is then modeled as an EHR template, which is a combination of different archetypes. We chose the XML format to represent these entry form templates in order to simplify transformation [3].

GUI models: The aim of a mobile documentation is met by an exemplary implementation for tablet computers and smart phones using the Android SDK. This library provides predefined layouts and GUI widgets, which can easily be integrated into the proposed architecture. The widgets are platform-independent GUI elements that are organized in views. These views are responsible for the correct rendering process on different devices.

Binding: The binding of GUI and content models is essential to our two-level approach. It is separated from the application logic source code and largely independent of the device's display size. But to enhance the functionality and the user acceptance, it became necessary to substitute the mapping table with a more dynamic and flexible binding solution [4]. We thus moved on to using a rule language that offers functional adaptability.

Using a rule language to bind content and GUI models enables the re-use and adaption of the binding, which has high priority. It will allow for adapting the interface not only to user preferences and computer hardware, but also to relevant context information in an intelligent way. The rules on how to display the graphical user interface are kept separate from the application logic to ensure the highest possible amount of flexibility. They are stored outside the source code similar to a configuration file and are evaluated at runtime, not during compilation. As the amount of users increases, having individual rule files reduces the computation time.

In our implementation, the rules are defined using Jess, a rule language suitable for the Java framework [5]. The rules are defined and stored in an XML file employing the Jess XML Rule Language (JessML). This XML file is validated by a provided schema to check as to whether the rule expressions are well-formed. Using XML provides the advantage of simple convertibility using XSLT.

Building on the latest Jess version 8, it is possible to import the Jess library locally on the Android device. This version, however, is still under active development and only accessible for licensed user. The prior version 7 requires JavaBeans, which is not supported by the Android OS. Until version 8 will be open to academic use, we are building on version 7.1p2 of the engine running on a remote server in a client-server-architecture (see figure 2):

The selected Archetype is send to the server, the server further process the archetype and generates following the defined rules the Archetype specific binding. Therefore it is necessary to specify the Jess "archetype" template containing all relevant attributes, e.g. data type, visibility and obligation.

Not only the template needs to be established but also the rules. Therefore a pool of rules needed to be set up. An example of a simple rule is given in figure 3: If the concerning primitive Archetype is of type *boolean* and the condition is *mandatory*, then it is bound to the GUI widget *checkbox* with the background color *red*.

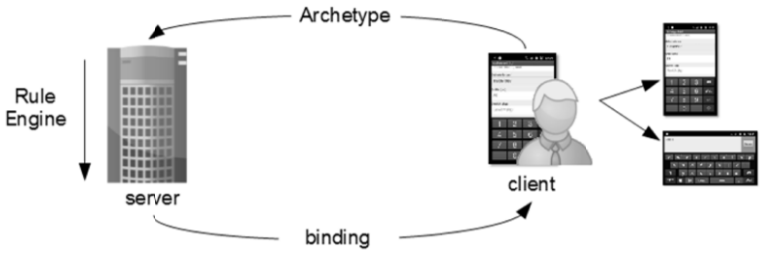


Figure 2. Generation of the binding in a client-server-architecture.

```
(deftemplate archetype (slot datatype) (slot visibility) (slot obligation))

(defrule boolean-mandatory
    "Defines a boolean datatype with the obligation mandatory"
    (archetype (datatype == boolean && obligation == mandatory))
    =>
    (bind ?widget checkbox)(bind ?color red)
```

Figure 3. Simple pseudo example of a Jess Archetype template (deftemplate) and Jess rule (defrule).

Through this rule-based binding, each Archetype item is assigned a specific GUI element (see figure 4). The output is an XML file containing the specific mapping of the archetype ID to a GUI widget including all visual information such as color and size. This XML binding file is returned to the client system and the graphical interface is rendered to the according display size and layout.

Benefitting from the flexibility of a rule language, the binding can be adjusted to individual user preferences, to device settings, or to context information. Furthermore, dependencies that are not defined in the Archetype itself can be added here to enhance the functionality or imply additional constraints on the data entry form, for example only to ask for the daily amount of cigarettes if the patient is smoker.

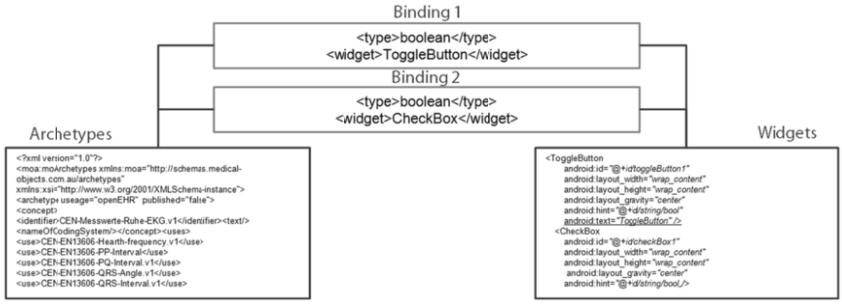


Figure 4. Binding between the content and GUI model.

2. Results

Within the scope of this project, we developed a prototype for mobile, structured documentation for the Android operating system. Our major focus was on separating

the interface description and the content model and dynamically connecting them through a rule-based binding when displayed. This separation of GUI and content models was completely implemented; it is no longer necessary to determine the appearance and positions of the individual elements in advance. Designing an own interface for each entry form is therefore obsolete, as the widgets are automatically arranged. Furthermore, this approach allows the form to be adapted to the user's personal preferences by choosing their favorite widgets.

It was possible to render the documentation application on different devices and to apply changes quickly. The binding between content and GUI elements is kept separate from the actual program code and is mostly independent of the display size. It has been shown that a sequential display of entry elements is most suitable [4], as it avoids scrolling by automatically switching to the next input element after the value is entered.

The proposed method provides the possibility of a context-aware creation of SDE applications from the design of forms to their utilization. This approach constitutes a proof of concept. However, the evaluation process is in the making but more applications need to be considered to figure out its cost-benefit ratio.

3. Discussion

The archetypes we designed comply with the EN 13606 standard. Opposed to the openEHR project, it is approved as an official standard and used in several European projects including the "Smart Open Services for European Patients" (epSOS). The necessary archetypes for this project were redesigned, as they needed to be atomic and simple to achieve the highest amount of flexibility.

It was possible to export the defined archetypes and templates as an XML file, which is beneficial for routine usage and enables validation against a schema.

The process of gradual replacement of proprietary data entry forms by archetype-based templates was initiated in order to take advantage of the automated generation of template-based entry forms. This work is part of a pilot study and will be expanded to support alternative display and clinical content models. It is thus far implemented only for the mobile use. A mobile and desktop solution with the same look-and-feel would leverage its benefits. In addition, the implementation of a web-based approach is being investigated.

References

[1] Schuler T, Garde S, Heard S, Beale T. Towards automatically generating graphical user interfaces from openEHR archetypes. Stud Health Technol Inform. 2006;124:221–226.

[2] Linden, Jan T. Helma van der: Generic screen representationd for future-proof systems, is it possible? Computer Methods and Programs in Biomedicine. 2009;95:213-226.

[3] Kock A-K, Ingenerf J, Halkaliev S, Handels H. Migration Path for Structured Documentation Systems including Standardized Medical Device Data. *Stud Health Technol Inform*. 2012;180:43-7.

[4] Kock A-K, Andersen B, Ingenerf J, Handels H Archetype-basierte strukturierte Dokumentation auf mobilen Geräten. 58. Jahrestagung der Deutschen Gesellschaft für Medizinische Informatik, Biometrie und Epidemiologie (GMDS) . :ID184:322-323. 2013

[5] Jess® the Rule Engine for the Java™ Platform. [Online] Available from: http://www.jessrules.com/ [Accessed 25 Jan 2014].

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Learning from an Ambient Assisted Living Lab: the case of the Intelligent Bed

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Abstract. This paper presents methodological lessons learned from an Ambient Assisted Living (AAL) lab exploring the use of intelligent beds in a nursing home. The living lab study was conducted over a period of three month. 20 intelligent beds were installed. Data was collected via self-registration, diaries, observations, interviews and workshops with residents, nurses, nursing assistants, management, building officers, and purchasers from the Municipality. The paper presents an analysis within the overall themes of technology, use, and care, which is discussed by use of the SWOT framework presenting strengths, weaknesses, opportunities, and threats identified in the living lab of the intelligent bed. The paper concludes by emphasizing the need for mature technology, long-term studies, clarification of role and tasks of different stakeholders, and attention on methods used for living lab evaluations.

Keywords. Living Labs, Ambient Assisted Living, Intelligent bed, SWOT analysis.

Introduction

This paper presents methodological lessons learned from an Ambient Assisted Living Lab exploring the use of intelligent beds in a nursing home. Ambient Assisted Living (AAL) is defined as "services based on informatic tools that systematically process data information or knowledge about the state of health of elderly people in their natural environment, aiming to preserve or enhance their state of health or to reduce the negative consequences of a disease" [1]. The ambition to design technology that interacts closely with the use environment is depending on innovations carried out in co-operations with users in order to understand and develop the complex practice of AAL. A living laboratory is an ideal approach to support such co-operative technology innovation in real life environments.

Living labs are technological installations in (semi)-naturalistic settings with the objective to conduct medium- or long-term technological studies and innovations in co-operation with users "living" in the environment. Living labs are "semi" naturalistic in the sense that they are set up in real life "living" environments like cities [2] [3] or as in this case in a nursing home. These environments are turned into "labs" by the installation of new technology that will possibly affect the everyday life of people living in the "lab". In this case the intelligent bed affects health care professionals' and residents. Living lab research is occupied with studies of how people react, change, and integrate the new technology into their everyday lives [4]. Data collection often

includes a mix of unobtrusive and obtrusive methods like observations, instructions for users' self-documentation, interviews, and workshops [5]. The medium- and long-term aspect distinguish living labs from usability labs and simulation labs [6] which have been proven successful for quick findings of many usability issues but often miss aspects related to in-situ use of the technology [7] [8]. Innovation is the primary ambition of living labs [5], [9], [10] and user participation integrated in technology innovation distinguish living labs from merely technological tests. Though some living labs are presented as "test beds" they do emphasize that "benefits or usefulness for people in everyday life must be proven before technology or services can be said to be a success" [11].

The ambition of this paper is to extract methodological lessons learned from an AAL lab. Recent research has highlighted the complexity of living labs and a need to learn from and develop the living lab methodology [12]. The living lab concept is still novel and "requires substantial research to optimize its operations and methods although already promising" [5]. Experiences from long-term living lab studies are presented as "rewarding, though often inefficient" [13] and as "expensive to run" while "expectations are high as to what they will provide" [4]. Consequently "There needs to be more explication of the benefits and costs" of these "wild" and "living" lab studies [4]. Several methodological concerns related to living labs are found in the literature. These include dilemmas of how artificial to make the naturalistic setting in order to enable the right level of control to conduct evaluation and keeping sense of the real life practice [14]. It is acknowledged, that understanding the "living" practice does not happen *per se* just by setting up technology in a real life setting, which calls for development of catalogues or taxonomies of AAL lab methods. Additionally, there is a call for methods that focus on challenges of keeping users motivated during the lab period [12], facilitating participatory innovations among various interests and stakeholders [5], and the importance of maturing the technical set-up since unpredictable technical problems, device errors and other technical influencing factors are barriers disturbing the "living" aspect of the lab [12].

The research presented in this paper supports the call for methodological explication of living labs with specific emphasis on AAL labs. The work presented is part of a project, LabX that is a platform for public private partnerships on innovation of ambient assisted living technologies. The intelligent bed case, presented in this paper, is the first in a series of living labs working towards methodological models for AAL labs. In this paper we first present the case. Second, methods used in the AAL lab of the intelligent bed are presented. Third, central themes derived from data analysis are presented. The SWOT framework is used to point out and discus the strengths, weaknesses, opportunities and threats identified in the AAL lab of the intelligent bed and the consequences for future AAL lab methods.

1. The case of the intelligent bed

The case of the intelligent bed is the first in a series of AAL lab set up in the LabX as co-operative product innovations between technology providers (engineering enterprises, in this case the producer of the intelligent bed), users (in this case a variety of stakeholders including nurses, nurse assistants, residents, nursing home management, and purchasers from the Municipality), and researchers (responsible for coordinating and facilitating the living lab, partnerships, data collection and analysis).

The primary technology of the intelligent bed is sensors in the mattress sending alarms to staff's mobile phones when residents leave the bed, if residents are not in bed for a certain period of time, if the sheet is vet, if the breaks are not turned on properly. Additionally, the bed turn on a light placed under the bed for the purpose of safeguarding the resident's way to e.g. the lavatory. The Nursing home where the living lab was set up has 30 residents living in their own apartment consisting of a combined living- and bedroom and a bathroom. Initially 20 residents agreed to try the new intelligent bed, but three had second thought in the very first days of the living lab period and got their old bed back. Thus 17 beds were actually in use for a period of three months. Seven of the employees were selected as super users. The super users received a thorough introduction to the functionality of the intelligent bed before installation of the beds, given by the company. The intelligent beds were installed and turned off again within the first 24 hours due to technical problems. After a couple of weeks the intelligent bed was re-installed and tested in 3 month during summer 2013.

2. Methods

The overall aim of the LabX project is to develop a methodological model for supporting innovation of ambient assistant living technologies. This includes product innovation and practice innovations, respectively. The case of the intelligent bed focused on adjusting the AAL technology and on understanding functionality, workflow and utility issues. Thus, potentials for innovation concerned these matters.

During the test period of the intelligent bed data was collected through a) observations recorded via field notes and video, b) interviews (before and after installation) with employees at the nursing home, management at the nursing home, residents and focus group interview with building officers and management, c) manual registration of types of notifications received from the bed and of amounts of washings of vet sheets, and d) log books made by staff on a regular daily basis. After the test period e) a workshop was conducted facilitated by researchers and with participants representing nurses and nursing assistants, management, building officers, and a purchaser from the Municipality. At the workshop videos from observations in the living lab were presented and discussed.

The analysis in this paper is primarily based on data from the interviews, supported by the manual registration of types of notification received from the bed. In total 18 interviews were conducted. Before the implementation 7 employees were interviewed and 6 of them were interviewed again in the end of the implementation period; two residents were interviewed before and one of them again after; and the manager of the nursing home was interviewed before and after the implementation of the intelligent beds. The overall themes for the interviews were expectations and experiences, respectively. Interviews were audio recorded and transcribed. Data was coded in order to identify core themes from the living lab. During this process three main themes came to light concerned with 1) technology, 2) use, and 3) care issues.

3. Lessons learned

Technology: The technical implementation of the bed beame a much bigger challenge than expected. Especially in the beginning of the living lab there were problems with a

large amount of alarms from the beds and it was almost impossible to turn them of, the switch off bottom being placed under the bed. Some alarms were send because the breaks were not put on and the staff learned to do an extra push to ensure that brakes were actually on. Also switching off the bed became possible from one of the three remote controls belonging to each bed. The main technical problem, however, was that the alarm systems of the intelligent beds could not be integrated properly with the alarm system already in use at the nursing home.

Use: The alarms most valued by the staff were the "out of bed" alarm and the "wet alarm". Several examples of the benefits of these functionalities were mentioned e.g. that the "wet alarm" meant that the pad of some residents could be changed in time before the whole bed got wet and that the "out of bed" alarm ensured that residents did not loose their way in he middle of the night. Furthermore it was noticed during the test that the wet sheet was to small and also perhaps to easy to ruin or wear out, and that the bed itself could not fit into the normal procedure of washing beds.

Care: As for the question of what the implementation of the intelligent bed would mean for the care of residents several issues were considered, e.g. that the beds would mean a better (uninterrupted) sleep for the residents, and that the resident perhaps would feel more safe e.g. to visit the bathroom by themselves knowing that if something went wrong the alarm would go. However during the three-month evaluation period issues in understanding the technology in itself played a dominating role and issues in use and care remained on a more speculative level.

In order to contribute to methodological development of AAL labs and inspired by related living lab evaluations [15] we discuss these lessons learned in terms of the SWOT framework to emphasize the identified strengths, weaknesses, opportunities, and threats observed during the study.

Strengths: The nursing home living lab provided a natural setting to explore the complex relation between the intelligent beds, the residents, and the working routines. Although the major problems were due to the integration of different alarm systems the consequences of this were only fully realized when the 17 beds were switched on in the nursing home.

Weaknesses: One of the weaknesses of living lab is that it requires lot of resources. In this case it involved 17 beds, the residents, the staff at the nursing home, people from the municipality, the company developing the intelligent beds and the researchers. To identify the roles and task of all these people involved and to manage the project is a big challenge.

Opportunities: An obvious opportunity in living lab is to activate users innovative thinking on both uses and value of technology for care. I our case this innovative potential was not realized due to problems with the technology.

Threats: The immaturity and fragility of the technology combined with limited time frame makes it difficult to provide room for co-operative innovation processes.

In conclusion the living lab of the intelligent beds add to existing living lab literature in emphasize the importance of mature technology, long-term studies and clear roles for involved stakeholders.

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4. References

[1] W. Ludwig, K.-H. Wolf, C. Duwenkamp, N. Gusew, N. Hellrung, M. Marschollek, M. Wagner, and R. Haux, "Health-enabling technologies for the elderly–an overview of services based on a literature review," *Comput. Methods Programs Biomed.*, vol. 106, no. 2, pp. 70–78, 2012.

[2] E. Almirall and J. Wareham, "Living Labs and open innovation: roles and applicability," *Electron. J. Virtual Organ. Netw.*, vol. 10, no. 3, pp. 21–46, 2008.

[3] A. M. Kanstrup, K. Bjerge, and J. E. Kristensen, "A living laboratory exploring mobile support for everyday life with diabetes," *Wirel. Pers. Commun.*, vol. 53, no. 3, pp. 395–408, 2010.

[4] A. Crabtree, A. Chamberlain, R. E. Grinter, M. Jones, T. Rodden, and Y. Rogers, "Introduction to the special issue of 'The Turn to The Wild,'" *ACM Trans. Comput.-Hum. Interact. TOCHI*, vol. 20, no. 3, p. 13, 2013.

[5] M. Eriksson, V.-P. Niitamo, and S. Kulkki, "State-of-the-art in utilizing Living Labs approach to user-centric ICT innovation-a European approach," *Lulea Cent. Distance-Spanning Technol. Lulea Univ. Technol. Swed. Lulea Online Httpwww Cdt Ltu Semain PhpSOALivingLabs Pdf*, 2005.

[6] A. Kushniruk, C. Nohr, S. Jensen, and E. M. Borycki, "From Usability Testing to Clinical Simulations: Bringing Context into the Design and Evaluation of Usable and Safe Health Information Technologies," *Yearb Med Inf.*, vol. 78, p. 85, 2013.

[7] J. Kjeldskov, M. B. Skov, B. S. Als, and R. T. Høegh, "Is it worth the hassle? Exploring the added value of evaluating the usability of context-aware mobile systems in the field," in *Mobile Human-Computer Interaction-MobileHCI 2004*, Springer, 2004, pp. 61–73.

[8] Y. Rogers, K. Connelly, L. Tedesco, W. Hazlewood, A. Kurtz, R. E. Hall, J. Hursey, and T. Toscos, "Why it's worth the hassle: The value of in-situ studies when designing UbiComp," in *UbiComp 2007: Ubiquitous Computing*, Springer, 2007, pp. 336–353.

[9] A. Følstad, "LIVING LABS FOR INNOVATION AND DEVELOPMENT OF INFORMATION AND COMMUNICATION TECHNOLOGY: A LITERATURE REVIEW.," *EJOV Electron. J. Virtual Organ. Netw.*, vol. 10, 2008.

[10] B. Bergvall-K\aareborn, C. Ihlström Eriksson, A. St\aahlbröst, and J. Svensson, "A milieu for innovation–defining living labs," in *2nd ISPIM Innovation Symposium, New York*, 2009.

[11] M. Ponce de Leon, M. Eriksson, S. Balasubramaniam, and W. Donnelly, "Creating a distributed mobile networking testbed environment-through the living labs approach," in *Testbeds and Research Infrastructures for the Development of Networks and Communities, 2006. TRIDENTCOM 2006. 2nd International Conference on*, 2006, p. 5–pp.

[12] C. Ogonowski, B. Ley, J. Hess, L. Wan, and V. Wulf, "Designing for the living room: long-term user involvement in a living lab," in *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 2013, pp. 1539–1548.

[13] J. M. Carroll and M. B. Rosson, "Wild at Home: The Neighborhood as a Living Laboratory for HCI," *ACM Trans. Comput.-Hum. Interact. TOCHI*, vol. 20, no. 3, p. 16, 2013.

[14] Y. Rogers, J. Preece, and H. Sharp, *Interaction Design: Beyond Human-Computer Interaction*, vol. 3rd edition. John Wiley & sons Ltd, 2011.

[15] D. Schuurman, K. De Moor, L. De Marez, and T. Evens, "A Living Lab research approach for mobile TV," *Telemat. Inform.*, vol. 28, no. 4, pp. 271–282, Nov. 2011.

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Improving Health Care Service Delivery with A National Code Service

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Abstract. An implementation of eHealth services including a national code service is ongoing in Finland. The code service shares and maintains all common codes and data structures used in electronic patient records. In this paper, we describe the code service process and the challenges of developing the process as a part of national eHealth services.

Keywords. Health care, codes, structured data, interoperability, code service.

Introduction

In Finland, an implementation of national information system services (Figure 1) is ongoing phase by phase in health services as a general paradigm shift from passive services towards active and proactive services. The information system services include a centralized patient information archiving and electronic prescription with added services, such as, patient summary for health care professionals and patient information access for citizens. Patent consent releases archived information for use also in additional health care organizations than where the information was first documented. Standardized documentation of patient data is essential to share patient information between health care professionals in multi-disciplinary care teams, between organizations in distributed and specialized health care, and between various patient information systems provided by different vendors [3, 8]. In Finland, the main specifications are based on HL7 clinical document archiving (CDA release 2), messaging and medical records standards.

To improve health care service delivery as planned at the national level, HL7 CDA R2 structured entries require common codes and structures. National Institute of Health and Welfare (THL) maintains Code Service for Social and Health care. THL manages the preparation, distribution and maintenance of nationally uniform social and health care code sets, classifications, terminologies and specified form structures. All code sets are downloadable free of charge and used by all social and health care providers. Furthermore, the coded data can be utilized for statistics and registers and, for example, in organisation's own enterprise resource planning or in research. Besides national delivery, Code Service provides codes for national participation in pilot of European patient smart open services (epSOS).

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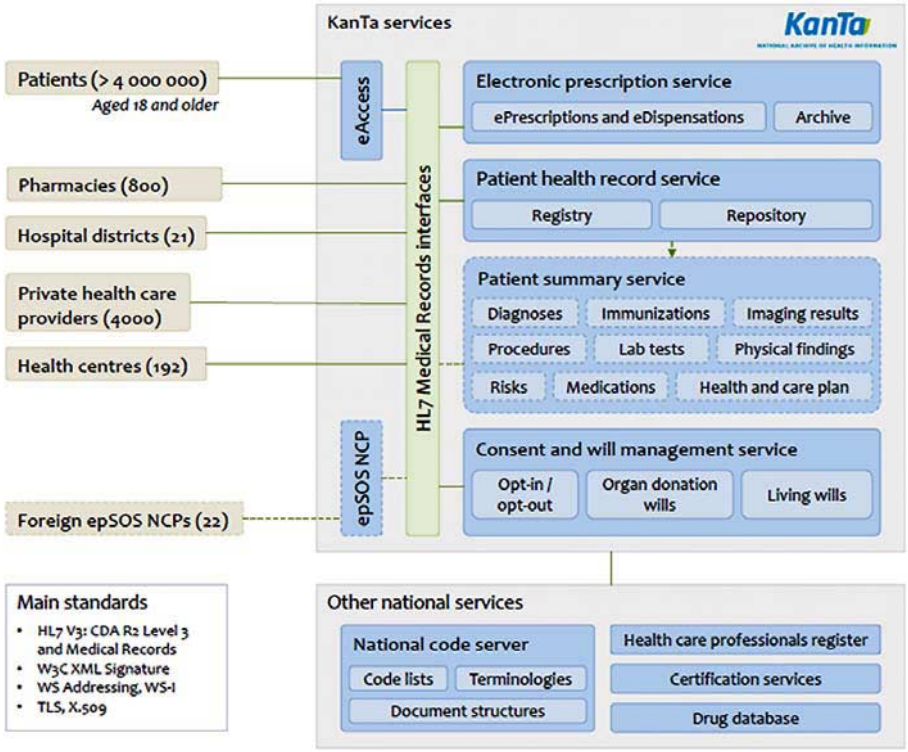


Figure 1. National information services in health care in Finland.

At present, over 300 code sets have been published in Code Service. As the implementation of national electronic services continues, the number of code sets is expected to rise during next several years. The amount of code sets and structures as well as the various needs from service providers and customers manifest as challenges in preparing the code sets. In this paper, we describe national code service process and argue how to develop the process with lean thinking to better answer the needs of service providers and customers. We also discuss the merits of national Code Service in improving health service deliverance with standardised documenting and messaging.

1. Methods

The Code Service process was systematically modelled in 2013 [6]. The process description was triggered by recurrent challenges and customer feedback. Additionally, the process constitutes a part of the public enterprise architecture in social and health care. Thus, we chose to utilize already validated and standardized modelling methods [e.g. 5] that cover both public enterprise architecture principals and BPMN[2] modelling as required by Finnish public administration guidelines.

First step to improve efficiency of a process is to understand how the process works and what it delivers [2, 4]. Therefore, our first goal was to model the Code

[2] Business Process Modelling Notation.

Service process and identify crucial phases and issues in it. The description includes code set life cycle from a need for a particular code set or data structure to preparation, publication and maintenance as well as to termination or recycling. The process participants consist of multidisciplinary team of health care professionals and administration as well as information system experts. Additionally, the Code Service has several appointed expert groups. To maintain a critical view, the roles and responsibilities of the participants and expert groups were examined as a part of the process description [cf. 1].

To further develop the process, we included a discussion of process value, added value and process waste based on lean thinking applied in health care. Lean tools have been applied in health care process improvement, but resulting gains, such as, improved productivity or service deliverance have not been accounted for [7] or remain as ongoing articulation and negotiation [10]. In short, the lean principles are: specifying customer values, identifying the desired value in products or services and challenging non-value adding action, making the product or service flow smoothly without delays, identifying specific demands and trigger events, and lastly, developing the process flow so that non-value adding activity is removed from the value chain to decrease the amount of time and information needed in the process [11]. The lean principles have later been summarized as attitude of continuous improvement, value creation, and unity of purpose, respect for workers, visual tracking and flexible steering [9].

In contrast to lean tools, the nature of the Code Service as a law based action seems to create constrains for process development. We defined non-value adding but necessary activity as activity that the customer is not ready to pay for but which is based on statutory regulations or the law and, thus, cannot be removed. Non-value adding action contributes to process waste by increasing production costs and slowing down the process without creating added value to the customer. An example of a non-value adding but necessary action is the Code Service administrative process.

2. Results

The Code Service core processes include the development and maintenance of codes, classifications and structured data specifications in health care. Its operation is based on the tasks set by law, and its purpose is to meet customer needs with nationally uniform codes. The need for a new code set can arise from various sources, such as, end users, regional or national bodies in health care or patient information system providers. The need for a new code set can also arise from changes in legislation.

The Code Service process begins with the Code Service Management Group evaluating a code set proposal according to necessity criteria. When the proposal meets the criteria, preparation begins within the process. Besides reasoning the need, the proposal requires an account of financing and resourcing. This account is made by the preparer, and if necessary, THL Code Service team will assist in this as in all other phases of code set preparation. During the preparation, person or body preparing the proposal needs also to establish the following: the purpose of the code set in relation to the national functions and the area of use; the relation and interoperability of the code set with the other code sets in the same area.

When the Management Group for preparation has approved a code set, the group will appoint a responsible preparation team, an owner candidate for the code set and a contact person at the Code Service. The preparation team is responsible for the

production of the code set for the approval processing in the Management Group, for requesting necessary statements from the Code Service expert groups and for organising an external round of comments when necessary. In the approval processing, the Management Group appoints the final owner of the code set, usually the body or expert group responsible for the maintenance of the code set. In the second processing, statements and suggested amendments by expert groups are also presented. When the Management Group approves a code set for publication, it means that the data content and maintenance plan of the code set have been accepted and that an expert group or owner responsible for its maintenance and monitoring has been appointed.

When the Management Group has approved a code set, it will be converted to code server format. During this phase, the code set undergoes a technical inspection, and also concluding comments on the code contents are requested from Code Service's own social and health care experts and terminologist. The terminologist evaluates the interoperability of the code set with other code sets on semantic level, suggests necessary harmonisation of terminology and revises the language. Then Code Service Quality Group processes the code set for publication by inspecting the contents and technical functionality of the code set. Lastly, an official decision is made on the publication of the code set.

As each published code set requires maintenance, an expert groups or a responsible body needs to be named during the preparation. Some code sets are updated annually after publication and other are updated according to their maintenance plan and user feedback if necessary. The Code Service updating process includes different actions, such as, replacing a single code with a new one, adding a new code or larger update of several codes. Updating also includes correcting any technical flaws detected in the code sets and preparing necessary translations. All code sets should be available in Finnish and in Swedish.

Acting on national level requires administrative steering and quality checking the process outcome. Thus, all code sets and related structure specifications are processed in the Code Service administrative process inseparable of the preparation process as well as in various expert groups. During the process modelling, also the resource binding administrative process to publish codes and the functioning of expert groups were described. During the modelling, the Code Service had two administrative groups, 25 social and health care expert groups, four expert groups for statistics and registers and four external expert groups. Over 100 experts from different fields of social and health care participate altogether in these groups.

Time spent in the Code Service process from a proposal to a published code set was generally assessed to be a critical issue. Therefore, a 3-scaled urgency rating as a new feature in the process was implemented. All codes in preparation are now rated according to the necessity criteria and given an urgency rating to monitor the time used in the process. The administrative process was another crucial issue that was apprehended as process waste creating, for example, in creating waiting times, overproduction and over-processing. To enable more efficient administration and process steering, also a requirements analysis for process administration and steering system was conducted. The Code Service process modelling resulted in implementing an administrative information system. The implementation and training phase is still undergoing, but the next step of intensifying the Code Service process is related to the system efficiency in monitoring the process and quality indicators. The process and quality indicators for Code Service were specified during the process modelling but still need clarification and further development. At the moment, the main indicators are

described as the quality of published code sets and as the time used in Code Service process.

3. Discussion

By developing the Code Service process, besides increasing the efficiency of the process, our goal was to move from quality assurance of process outcome to quality control during the process. This will better support the preparer's tasks and emphasize the significance of expert groups. The preparation is administratively complex and takes a lot of resources, which is why the definition of roles and tasks is expected to decrease process waste and costs. The process description was published to serve as a guideline for preparing teams with new necessity and process criteria for code sets.

The modelling of Code Service process was prompted by customer feedback. Customers wished for more agile and profit responsible publishing of new code sets and updating of published code sets. The resulting Code Service process description identifies customer needs more accurately and describes actions to react to those needs more efficiently than before. Focusing on the process flow and steering intensifies the administration process, as the code set proposals and maintenance will be more systematically prepared in the new system. It is expected to decrease the number of non-value adding action and process waste. Better process steering and resource usage is expected to shorten the time used in the preparation process.

We continued to develop Code Service process with lean tools to increase the efficiency and to decrease the production time as a part of national eHealth service. The development is ongoing with Code Service internal development projects, but outcome quality and efficiency of publishing national code sets remain as the overall goal.

References

[1] D. Allen, E. Gillen and L. Rixson, Systematic review of the effectiveness of integrated care pathways: what works, for whom, in which circumstances? *International Journal of Evidence Based Healthcare* **7**(2009), 61-74.

[2] T. Beale and S. Heard, An Ontology-based Model of Clinical Information, In K. Kuhn et al. (Eds.), *MEDINFO 2007*, IOS Press, 2007, 760-764.

[3] S. Heard, The use of standard content specifications in a national health interoperability framework, *Electronic Journal of Health Informatics* **5**(2010).

[4] G.T. Jun, J. Ward, Z. Morris and J. Clarkson, Health care process modelling: which method when? *International Journal for Quality in Health Care* **21**(2009), 214-224.

[5] R.K.L. Ko, S.S.G. Lee and E.W. Lee, Business process management (BPM) standards: a survey, *Business Process Management Journal* **15**(2009), 774-791.

[6] P. Mäkelä-Bengs and R. Vuokko, Code Service in Social and Health Care. Process description of the THL Code Service. Directions 19, THL, Helsinki, 2013.

[7] Z.J. Radnor, M. Holweg and J. Waring, Lean in healthcare: The unfilled promise? *Social Science and Medicine* **74**(2012), 364-371.

[8] P. Schloeffel, T. Beale, G. Hayworth, S. Heard and H. Leslie, The relationship between CEN 13606, HL7. and openEHR, *Proceedings of Health Informatics Conference* **7**(2006), 24-28.

[9] J.S. Toussaint and L.L. Berry, The Promise of Lean in Health Care, *Mayo Clinic Proceedings* **88**(2012, 74-82.

[10] J.J. Waring and S. Bishop, Lean healthcare: Rhetoric, ritual and resistance, *Social Science and Medicine* **71**(2010), 1332-1340.

[11] J.P. Womack and D.T. Jones, Beyond Toyota: how to root out waste and pursue perfection, *Harvard Business Review* **74**(1996), 140-158.

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Mining Level of Control in Medical Organizations

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Abstract. In literature of strategic management, there are three layers of control defined in organizational structures. These layers are strategic, tactical and operational, in which resides senior, medium level and low level managers respectively. In strategic level, institutional strategies are determined according to senior managers' perceived state of organization. In tactical level, this strategy is processed into methods and activities of a business management plan. Operational level embodies actions and functions to sustain specified business management plan. An acknowledged lead organization in Turkish medical area is examined using case study and data mining method in the scope of this paper. The level of decisions regarded in managerial purposes evaluated through chosen organization's business intelligence event logs report. Hence specification of management level importance of medical organizations is made. Case study, data mining and descriptive statistical method of taken case's reports present that positions of "Chief Executive Officer", "Outpatient Center Manager", "General Manager", monitored and analyzed functions of operational level management more frequently than strategic and tactical level. Absence of strategic management decision level research in medical area distinguishes this paper and consequently substantiates its significant contribution.

Keywords. Strategic Management, management pyramid, data mining, tactical, strategic, operational, medical organizations, hospital, business intelligence

1. Introduction

Strategic management in organizations becomes vital amid the rapid changes of technology and competing environment. As every technology correlated area perpetual developments introduce new devices in medical sector and along with the population growth; medical organizations are burdened with vast amounts of information. Analyzing, organizing and making remarks with information become a crucial issue. Business intelligence concept commits to resolve the issues also further enhancements of the structure adapted to support all strategic management levels. Hence business intelligence utilization for strategic management is increasing inevitably [1]. This paper aims to reveal the level of management in medical organizations by analyzing outcome reports of a business intelligence tool that belongs to a lead organization, which has thousands of employees and tens of divisions. Firstly, the brief definitions of the concepts used in the paper are given. Then in the methodology section the case is introduced and the case study is discussed. Lastly, the results of the study are illustrated and the paper is concluded by potential research fields.

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2. Conceptual Framework

Organizational layers are defined as strategic, tactical and operational in the literature as shown by Figure 1. Strategic level generates guiding mechanisms and institutional strategies. In this level, initiatives are determined by asking "At which state must organization reside?", "Which area of business must be chosen?".

Tactical level is the transition of strategic ideas into actions that are identified by answering queries like "How to compete?", "How to succeed in this competition?". Resulting answers are gathered to form a business management plan.

Operational level carries out the functional actions and supportive activities to substantiate determined strategies. Through these actions and activities tangible results are taken. This level endeavors to make operational decisions [2].

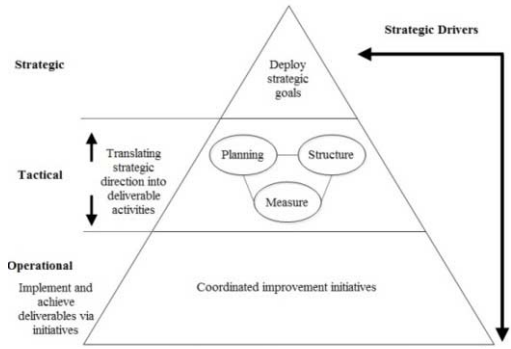


Figure 1. Management Pyramid (Source: Leonard and McAdam [2] page:23)

In their researches Türkeli et al. [3], Türkeli and Erçek [4] defined 3 strategy (strategic level), 21 strategic target (business management, operational level) and 223 criteria on operational level for an educational and research hospital. Thus, these researches are coherent to the Management Pyramid as shown by Figure 1; amount of strategies diminishes when ascending to higher levels.

In every layer of strategic management, determination of right strategies and decisions is related to a reliable decision making process. Fountas et al. [5] separated the decision making process into 3 parts; gathering data, correlating data into information, making further connections with this information, which concludes to a decision. March and Hevner [6] identify first phase of this process as intelligence, in which information is gathered in order to be processed for management decisions. Business intelligence (BI) defined as an aggregation of the remaining parts, where decision is achieved after performing analytical operations. In a rapidly changing environment hence growing data, it is vital to perform these analytical operations by the aid of BI tools. Inevitable demand of BI tools in decision making process resulted into vast amount of different software tools, which enhance and specialize ceaselessly by adapting to environmental changes [7]. Through these amendments BI identifications are altered so that tools become the core of the definition and new perspectives are emerged [7]. Sahay and Ranjan [7] approached BI from two angles, in which process and technological perspectives reside. They clarified BI as an analytic process, that evolves the acquired data into decisions and strategic goals need to be adapted in order to prevail among the competitive environment. As their second

approach, they claimed BI as the cluster of technological concepts like data mining, online analytical processing (OLAP) that BI tools hold whereby analytical operations occurred. Türkeli [8] identified BI as "Applications that are capable of providing the desired information to the required site in an appropriate time".

Significance of decision making process is apparent as every organization encounter a dynamic environment shaped within the nature of business competition [7]. As this technology dependent process determines the survival of organizations, various kinds of researches discussed the thriving BI systems and benefits of BI tools. Türkeli [8] indicated the significance of BI by implicating Gartner Company's survey on information technology (IT) managers, and it pointed out that BI investment is acknowledged as the most important and privileged IT investment. Murphy and Simon [9] discussed the complexity of benefit evaluation in BI tools, as BI tools provide mainly intangible benefits which are not directly visible through cost analysis. They summarized intangible benefits under five topics; operational, managerial, strategic, IT infrastructure, organizational.

We can now apply BI and management concepts to the healthcare domain. Information management using BI tools are important for hospitals because each hospital has to plan its own hospital information system in order to direct, monitor and measure its operations that based on planned objectives and strategies [15].

3. Methods

Due to the nature of study area and scantiness in number of organizations that hold BI tools, firstly a qualitative research method case study is adopted. Yin [10] remarked on the utility of case study, as it generally used in researches that ask "why" and "how" questions and about contemporary phenomena in practical life [11]. This research investigates the reason of management level regarded in medical organizations. After initial discussions with a number of expert groups including: three private hospitals' chief information officer and software group leaders, four different business intelligence software consultants, medical doctors and nurses; it was decided that this study should focus on the H1 described in table 1. In Turkey there are 5 types of hospital. H1 private and multi branch, H2 private unique branch, H3 private, multi branch and foundation supported, H4 public hospital, H5 university hospital [12]. Based upon being a lead actor in Turkish medical sector and along with the BI tools utilization that enables to measure management level significance through quantitative data, H1 hospital is approved as a sample.

Table 1. H1 Hospital in the in-depth Case Study

Case H1	Hospital 1
Medical Care Provider	H1 Health Care Group
Established	1991
Employees	2200 doctor, 3500 nurse, in total 13000
Number of Facility	17 hospitals and 13 medical centers

This paper aims to extract knowledge from the event logs which are recorded by business intelligence software. Event logs generally used for detect process, control, organizational and social structures [13].

Table 2. Structure of event logs

Position	Report	Date	Frequency
Chief Executive Officer	Survey number	12.01.2014	2

After analyzing H1 hospital in-depth case study, data mining techniques are applied in order to understand relations (information), patterns (knowledge) and finally principles (wisdom). In this study, after determining that there are clusters raised among positions and level of control, data are tried to be grouped by cluster algorithms. Cluster methods aggregate similar or interrelated data into same cluster [14]. Cluster methods are generally classified in 4 groups: partitioning methods, hierarchical methods, denisty-base methods, model-base methods. In the scope of this study, model-base methods are chosen based upon the target of forming data groups according to appropriate management levels. This method reckons every cluster as to be pertaining to a model, hence data are grouped with respect to the related models [14].

4. Results

Event logs data acquired from BI tool belonging to sample hospital contains 455 days. In this study it is identified that in total of 1595 reports are examined by managers from different position levels. Within these dates positions of "Outpatient Center Manager", "Chief Executive Officer", "General Manager", etc. are examined regarding management level of functions used in BI tool. Frequency of BI tool use regarding the positions in hospital shown below:

Table 3. Number of Reports Examined Regarding Positions

Level of Control/ Position	Strategic Level	Tactical Level	Operational Level	Total Number of Reports Sighted
Outpatient Center Manager	0	24	26	50
Chief Executive Officer	77	137	519	733
General Manager	1	20	42	63
Director of Business Management (Doctor)	21	85	476	582
Managers of Nursing Services	0	16	4	20
Director of Business Management	0	20	33	53
Director of Business Management (Finance)	0	5	70	75
Medical Center Manager	0	6	10	16
Total	**99**	**316**	**1180**	**1595**

Number of functions used in "Chief Executive Officer" position are 733 in which reside 214 strategic and tactical level functions hence the number of operational functions are 519. "Director of Business Management (Doctor)" position sighted 582 functions in 455 days and the number of strategic and tactical level functions are 106 which implicate that the number of operational level functions are 476. Position of "Management Director" looked into 53 functions, 20 of them are in tactical level while 33 of them are in operational level. "General Manager" level sighted 63 functions of which the number of strategic and tactical functions are 21 consequently the number of operational level functions are 42. "Managers of Nursing Services" position used BI

tool only twice in 455 days and sighted 16 of them are in tactical level, 4 functions that are all in operational level.

5. Discussion and Conclusion

In consequence of the abundant operational (functional) tasks in health sector, constituted strategic management tools cannot be completely utilized. This paper concluded that most of the data sighted regarding positions in health organizations are not in strategic level. Human life concern of the operational level tasks caused the operational level to be regarded as significant. Furthermore, alterations in laws and regulations by Ministry of Health and rapid changing nature of the sector obstruct the generation of a strategy. In general, the level of management in health sector is operational hence the comprehension and concern of tactical and strategic levels become inconvenient. Managers, whose profession is in a medical related area, may conclude in giving priority to operational level problems.

References

[1] Baars, H. and Kemper, H. G., "Management Support with Structured and Unstructured Data -An Integrated Business Intelligence Framework," *Information Systems Management,* pp. 132-148, 2008.

[2] Leonard, D. and McAdam, R., "The Role of the Business Excellence Model in operational and Strategic Decision Making," *Management Decision,* pp. 17-25, 2002.

[3] Türkeli, S., Akal, U., Baş, S., Özalp, H. and Egeli, Ü., "Sağlık Sektöründe Stratejik Yönetim Modeli Olarak Kurumsal Karne Uygulaması: Vakıf Gureba Hastanesi Örneği," in *6. Ulusal Sağlık Kuruluşları Yönetim Kongresi*, Bodrum, 2008.

[4] Türkeli, S. and Erçek, M., "Designing a Capability-Focused Strategic Management Model for a Turkish Public Hospital: Learning From Failure," *Systemic Practice and Action Research,* pp. 353-370, 2009.

[5] Fountas, S., Wulfsohn, D., Blackmore, B., Jacobsen, H. and Pedersen, S., "A model of decision-making and information flows for information-intensive agriculture," *Agricultural Systems,* pp. 192-210, 2006.

[6] Hevner, A. R. and March, S., "Integrated Decision Support Systems: A Data Warehousing Perspective," *Decision Support Systems,* pp. 1031-1043, 2007.

[7] Sahay, B. S. and Ranjan, J., "Real Time Business Intelligence in Supply Chain Analytics," *Decision Support Systems,* pp. 1031-1043, 2007.

[8] Türkeli, S., "Sağlık Sektöründe Karar Destek Sistemi Olarak İş Zekası Uygulaması ve Model Önerisi," in *5th TurkMIA Congress*, Antalya, 2008.

[9] Murphy, K. E. and Simon, S. J., "Intangible Benefits Valuation in ERP Projects," *Info Systems,* pp. 301-320, 2002.

[10] Yin, R. K.-Z., Case Study Research: Design and Methods, Thousand Oaks, CA: Sage Publishing, 1994.

[11] Samanlı, M., "Kalite ödüllerinin şirket performansına etkisi: Türkiye özelinde TÜSİAD-KALDER ulusal kalite ödülü örneği," ITU Graduate School of Science Engineering and Technology Master's Thesis, 2009.

[12] Türkeli, S. and Şahin, H., "How Can We Improve the Communication Quality between Doctor and Foreign Patient?," in *EFMI Special Topic Conference*, Antalya, 2009.

[13] Van der Aalst W., Weijters, T. and Maruster L., "Workflow Mining: Discovering process models from event logs," *Knowledge and Data Engineering, IEEE Transactions,* pp. 1128-1142, 2004.

[14] Han J, Kamber M Data mining: concepts and techniques, 2nd edn. Morgan Kaufmann,2006

[15] Winter, A, Haux, R,Ammenwerth, E, Brigl, B,Hellrung, N,Jahn, F. Health Information Systems, Springer, 2011

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Using an Iconic Language to Improve Access to Electronic Medical Records in General Medicine

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Abstract. Physicians have difficulties to access and analyse information in a medical record. In a previous work on drug databanks, we have shown that with an iconic language as VCM, an icon-based presentation can help physicians to access medical information. Our objective, herein, is to study whether VCM can be used in an electronic medical record for facilitating physician access in general practice. We identify the data and the functionalities of an electronic medical record that could benefit from VCM icons representing clinical findings, patient history, etc. We also present a preliminary evaluation of this new icon-focused interface. We conclude by discussing the results like the assessment of the user's satisfaction and pointing out the importance of coding data.

Keywords. Electronic Medical Record, Family medicine, Icon-based language

Introduction

The use of electronic medical records in general practice is increasing [1] and has become vital for patient follow-up. This is generally done over a long period and involves the management of acute conditions, repeated episodic outbreaks and chronic diseases, thus requiring the coordination of healthcare programmes. The records can often be complex due to the plethora of conditions that can affect different organs or functions, and the wealth of patient information (patient examination, minutes, prescription, etc.).

Furthermore, care management makes it incumbent on the medical practitioner to work as a member of a team [2]. For instance, a doctor may need to refer to a record that he or she had not drafted. It must therefore be possible for a doctor, who may not necessarily be the case manager, to quickly find all the relevant information on a patient from the electronic medical record. However, given the complexity and diverse

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nature of the data and data sources, a joint analysis of the record by the doctor and others is often difficult.

To address this problem and thus facilitate the analysis of patient record, several graphical solutions with interface capabilities have been evaluated in the context of their benefits and limitations (lifeline [3], visualisation methods [4], etc...).

The research laboratory LIM & BIO/LIMICS has developed an icon-based language called VCM (Visualisation of Medical Concepts) [5]. VCM icons can represent disorders, physiological states, patient history, risks, drug and non-drug treatments, follow-up procedures, health professionals, etc. This icon-focused approach has been successfully applied to the SPCs (Summaries of Product Characteristics) of medical drugs, leading to faster analysis and synthesis of information [6].VCM is different from previous approaches insofar that it describes medical information and can be integrated with existing interfaces to enhance their effectiveness rather than replace them.

Our study seeks to establish whether VCM can be adapted for use in an electronic medical record, e.g. for representing patient disorders, with the view to improving the overall management of the process while enhancing response times and quality in the selection of information and documentation during a consultation process [7].

This study was conducted in the framework of L3IM project by a consortium of several research laboratories, industrial firms and a learned society in general practice. As a first step, it was vital to identify the functionalities of a general medicine software that would benefit from icon-based representation. The next challenge was to implement these functionalities in an electronic medical record. Then we present the results of the evaluation in terms of time for reading patient records, the amount of relevant information found in the records and perceived user-satisfaction. We conclude by discussing perspectives for icon-based representations in health records.

1. Methods

The VCM language consists of icons depicting medical concepts and associated information from a combination of different basic concepts. Each icon consists of a colour that represents the temporality of the information (history, current problem or risk), a basic shape indicating the status as either "normal/physiological" or "abnormal/pathological", a main pictogram indicating the organ or the function involved, and optionally shape modifiers to specify a problem as a viral infection, a haemorrhage, etc.. M. VCM is an interactive interface that can present summarised information by organising VCM icons according to anatomy and aetiology on a graphical representation of a human body. More information is available on the VCM web site: http://vcm.univ-paris13.fr.

éO Médecin is a French medical software that captures all the information produced or collected by a doctor, and is used to structure information with SOAP contacts flagged up as problems. Within SOAP (Subjective, Objective, Assessment, Plan), each problem encountered during consultation is apportioned across four categories: the reasons given for the visit by the patient in narrative form, the objective and traceable facts identified by the practitioner, the conclusions or diagnoses and what the health care provider has done to treat the patient in terms of procedures and prescriptions.

1.1. The identification of areas of information suitable for graphical visualisation

Several steps have been taken to identify the information that may benefit from VCM graphical visualisation.

First, a focus group was organised by the Evalab laboratory involving doctors from SFTG, a general practice learned society. Six doctors worked on two clinical cases including 2 paper-based patient records (8 and 20 pages) and on one computerised record with the view to solving medical problems. The Evalab team provided the impetus for the production of results in order to highlight the key areas on which the doctors focus their attention, for helping in the articulation of the difficulties related to information management, and for recording the exchanges with respect to navigation within the record [8]. Finally, the doctors stuck VCM icons on parts of the record that they viewed as suitable candidates for visualisation and drew some VCM summaries. These iconised records and summaries were analysed by ergonomists.

Second, the éO software was analysed and stress-tested over several sessions with the help of the General Practitioners, with the view to identifying the functionalities of the software that could be enhanced by the use of icons and would meet users' expectations. The list of functionalities that would benefit from VCM was used to identify both the data that need to be represented by icons and the medical terminologies that can be used for coding these data.

1.2. User-centered assessment

A representative sample by age and by sex of 20 GPs was established with users at their doctors' offices using the éO software (without VCM icons).

Two anonymous medical records were extracted from a General Practitioner's database. Physicians were asked to read the records in éO, either with or without VCM functionalities, and to identify the important information items to prepare care management for the patient. Several parameters were assessed: (1) the number of items identified by the physician, (2) the relevance of these items assessed against a list drawn up by the doctors from the consortium and corresponding to relevant information to establish a diagnosis or a prescription for this patient, (3) the time taken by the GP to consult and analyse the record and (4) the time per item ratio.

After using the system, each GP completed a usability scale questionnaire with the aim of measuring the perceived usability of the system. The SUS (Standard Usability Scale[9]) questionnaire, consisting of 10 questions to be rated on a scale of 1 to 5 corresponding to "Strongly disagree" to "Strongly agree", was used.

Finally, the GPs had the opportunity to discuss freely the positive or negative aspects of the use of VCM and its incorporation within the software.

2. Results

The focus groups highlighted the challenges faced by the GPs when consulting and analysing patient records.

This study has enabled the identification of the key functionalities and information in a patient record that would benefit from VCM; these include: the patient's current disorders, history (Figure. 1), reasons for and diagnoses from consultations, medical specialties associated to medical reports, prescription drugs, dashboard summaries as

well as VCM pictograms to filter the information or to illustrate an interactive patient timeline. The study has highlighted that the lack of structured information [10] and common language is a limitations when implementing a support system. In a previous work, ICD-10, one of the most used terminologies [11], has been mapped to VCM. Furthermore, we used mapping between ICPC-2 and ICD-10 to perform transcoding of ICPC-2 and VCM. In addition, we have extended VCM with new icons to respond to GP requirements, such as illustrating the impact of social factors on health.

During evaluation, the number of relevant information items retrieved by GPs in both test records is a little higher without VCM functionalities. However, the Wilcoxon test does not demonstrate statistically significant differences (P = 0.54 and 0.73). For the first record, GPs took less time using VCM but this difference is not significant. For the second record, we found that the GPs took significantly more time when using VCM (439 secs without VCM on average against 675 secs with VCM, p=0.0312). The subjective evaluation in the SUS questionnaire returned a 65 out of 100 satisfaction score, thus demonstrating a positive assessment of this implementation. To improve this SUS result, a majority of users suggested they needed more time to explore and practice all the VCM-based functions. However, they believe that these functions have not been complicated by VCM and are in fact easy to use but should be further simplified. With no additional training, they would be well-placed to take over the system. The users are comfortable with the information displayed by the VCM icons and, in the main, have expressed the desire to use it. They appreciate the ability to filter information by clicking on an icon, and the M. VCM visual summary which provide "a quick overview of the patient case" and the highlighting of key information.

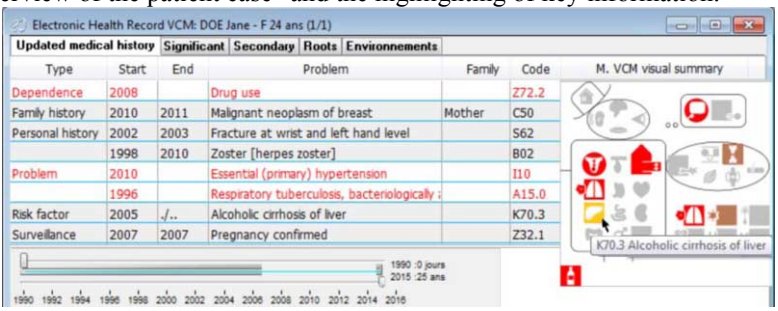


Figure 1. M. VCM based on patient history and problems

3. Discussion

In this study, we have shown that icons representing disorders, drug treatments, procedure, etc., can be used to enhance medical records. This study has highlighted the system's benefits to users, particularly with respect to complex records of multi-pathological patients followed up over a long period of time. The evaluation provided contradictory results on the impact of VCM on consultation time. This may be due to the complexity of the second record changing the behaviour of the GPs via a two-fold discovery of the record: in the first instance, they seem to return to their old habits without paying much attention to VCM; in the second instance during the record's journey, they seem to focus their attention on the information displayed by the VCM icons. This can probably be explained by the GPs discovering the VCM language, with

their attention focused on the analysis of the icons and the instruction on how to use the language. This focus on the use of the icons may have diverted their attention to other cognitive tasks. The sample size of GP-evaluators was reduced. It would be interesting to conduct a more extensive evaluation to remove the effects of playful discovery and of learning the VCM language while analysing factors such as the complexity of a record that can influence the behaviour of medicines and the impact of results.

The coding of medical information is necessary to enable the display of the information in iconic form. However, the actual practice shows that very few medical data are encoded in France. Further work is needed to improve the interfaces for data entry and to propose new methods of capturing standardised information (structured and coded information based on recognised terminology and classification) with minimal user intervention. This led us to start a new research project, SiFaDo (*Saisie Facile des Données Médicales*, Easy Entry of Medical Data).

After a phase of improved processes, VCM in éO can be handed over to users for evaluation at the doctor's office. This will provide an evaluation of user acceptance and of the benefits delivered in the context of a more sustained ownership. It will enable the assessment of the benefits delivered to other medicine stakeholders such as trainees and locum replacements who do not have as full a picture of the patient's history.

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References

[1] Xierali IM, Hsiao CJ, Puffer JC, Green LA, Rinaldo JCB, Bazemore AW, et al. The Rise of Electronic Health Record Adoption Among Family Physicians. Ann Fam Med. 2013 Jan-Feb;11:14-19.

[2] Gill JM. EMRs for Improving Quality of Care: Promise and Pitfalls. Fam Med. 2009 Jul-Aug;41(7):513-51.

[3] Plaisant C, Milash B, Rose A, Widoff S, Shneiderman B. LifeLines: visualizing personal histories. Proceedings of the SIGCHI conference on Human Factors in Computing Systems; 1996 apr 13-18; Vancouver:Canada.

[4] Kosara R, Miksch S. Visualization methods for data analysis and planning in medical applications. Int J Med Inform. 2002 Dec 18;68(1):141-153.

[5] Lamy JB, Duclos C, Bar-Hen A, Ouvrard P, Venot A. An iconic language for the graphical representation of medical concepts. BMC Med Inform Decis Mak. 2008 Apr 24;8:16.

[6] Lamy JB, Venot A, Bar-Hen A, Ouvrard P, Duclos C. Design of a graphical and interactive interface for facilitating access to drug contraindications, cautions for use, interactions and adverse effects. BMC Med Inform Decis Mak. 2008 Jun 2; 8:21.

[7] Poissant L, Pereira J, Tamblyn R, Kawasumi Y. The impact of electronic health records on time efficiency of physicians and nurses: a systematic review. J Am Med Inform Assoc. 2005 Sep-Oct;12(5):505-516.

[8] Beuscart-Zéphir MC, Elkin P, Pelayo S, Beuscart R. The Human Factors Engineering approach to biomedical informatics projects: state of the art, results, benefits and challenges. Yearb Med Inform. 2007;109-27.

[9] Bangor A, Kortum P, Miller J. Determining What Individual SUS Scores Mean: Adding an Adjective Rating Scale. Journal of usability studies. 2009 May; 4(3):114-123

[10] Tate AR, Martin AGR, Ali A, Cassell JA. Using free text information to explore how and when GPs code a diagnosis of ovarian cancer: an observational study using primary care records of patients with ovarian cancer. BMJ Open. 2011 Feb 23;1(1):e000025.

[11] Ahmadian L, van Engen-Verheul M, Bakhshi-Raiez F, Peek N, Cornet R, de Keinser N. The role of standardized data and terminological systems in computerized clinical decision support systems: Litterature review and survey. Int J Med Inform. 2011 Feb;80(2): 81-93.

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A Workflow Model to Analyse Pediatric Emergency Overcrowding

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Abstract. The greatest source of delay in patient flow is the waiting time from the health care request, and especially the bed request to exit from the Pediatric Emergency Department (PED) for hospital admission. It represents 70% of the time that these patients occupied in the PED waiting rooms. Our objective in this study is to identify tension indicators and bottlenecks that contribute to over-crowding. Patient flow mapping through the PED was carried out in a continuous 2 years period from January 2011 to December 2012. Our method is to use the collected real data, basing on accurate visits made in the PED of the Regional University Hospital Center (CHRU) of Lille (France), in order to construct an accurate and complete representation of the PED processes. The result of this representation is a Workflow model of the patient journey in the PED representing most faithfully possible the reality of the PED of CHRU of Lille. This model allowed us to identify sources of delay in patient flow and aspects of the PED activity that could be improved. It must be enough retailed to produce an analysis allowing to identify the dysfunctions of the PED and also to propose and to estimate prevention indicators of tensions. Our survey is integrated into the French National Research Agency project, titled: "Hospital: optimization, simulation and avoidance of strain" (ANR HOST).

Keywords. Workflow, workload, hospital emergency service, pediatrics, information systems, modelling, peak of activity, crowding indicators.

Introduction

In many countries, Emergency Departments are facing problems associated with increased demand in their services (1, 2). The arrival patient flow to the emergency department is stochastic and keeps increasing. This rise has generated a strategic interest in optimizing the technical and human resources while mastering the costs. This situation creates a set of unique challenges for the patient, family, and care providers (3).

This problematic is the main challenge of the HOST ANR French project. The objective is to elaborate an innovative methodological approach for the anticipation of the tensions of the complex care production system and more especially of the emergency paths in the Pediatric Emergency Department (PED) of the CHRU of Lille in France. The problematic of strategy, the performance assessment and traceability of the patient course are integrated into the suggested approaches.

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The objective of this paper is to provide a complete picture of the PED delivery processes and detailed data on all aspects of the patient journey in order to identify bottlenecks that potentially contribute to overcrowding.

1. Methods

We used a structured method research design which comprised five major steps:

1. Several visits were piloted in the PED of CHR of Lille with researchers and physicians (the HOST ANR project partners) to build a model of the patient path and PED treatment processes as the basis for a patient mapping form to collect data;
2. Each Research Assistant (RA) partner of the project spent a continuous 10 days mapping exercise during which they independently observed and manually recorded patient journeys through the PED for a sample of presentations;
3. In order to validate an all-day observations, a PED staff meets the research assistant regarding their observations of patient flow;
4. The analysis of data obtained during steps 1-3 to construct dynamic models of the process. This model is constructed with the Business Process Management Notation (BPMN) which is an international standard.
5. Model simulation and its comparison with the real scenarios of patient path. The goal of this step is to optimize the model.

The first design characteristic lead on the use uses an observational tool, done by EVALAB partner of our HOST ANR project which is in compliance with the ISO standard EN 9241-210: "Process of human-centred design for interactive systems".

The second design characteristic lead on the use of a Workflow approach. The Workflow produces a model that describes precisely the activities flow in the patient path using an internationally standardized language: the BPMN (4).

2. Results

2.1. Background

Our work represents the first step of the national ANR HOST project realization and discusses the emergency handling system. Modeling patients' paths at PED is faced with a high amount of complexity. This complexity stems from the inherent dynamics of the processes and the distributed organization structure of hospitals, as they are divided into several autonomous wards and ancillary units. For treatment, patients visit different units according to their illness. However, the pathway of the patients through the PED is confronted with uncertainties. Because it is in the nature of diagnostics to gain additional information about the patients' diseases, the necessary medical treatments are often not completely determined at the beginning of the treatment process. Further, the duration of the examinations and treatments are stochastic, due to the individuality of the patients. Additional problems for the patient-modeling in PED arise from complications and emergencies. The immediate need of treatment for emergency patients causes disturbances in the schedule. Complications, which may

occur during a treatment, result in waiting times and changed pathways for other patients. This results in variable pathways and stochastic processing times.

2.2. The Workflow model and the patient mapping form

The Workflow model (Figure 1) shows the major stages, activities and actions of the patient journey in the PED as identified by the workshop participants managed by EVALAB partner. There are three major stages: Stage 1, (Patient Arrival and Initial Assessment), Stage 2, (Patient (re)orientation and treatment) and Stage 3 (Patient Destinations). The patient can be orientated or reoriented to one of these units knowing that some of them are represented by a sub-process in the global process Workflow model. The decision points, at which the patient journey is dependent on a combination of treatment characteristics and the availability of physical resources, are represented by gateways in the global model.

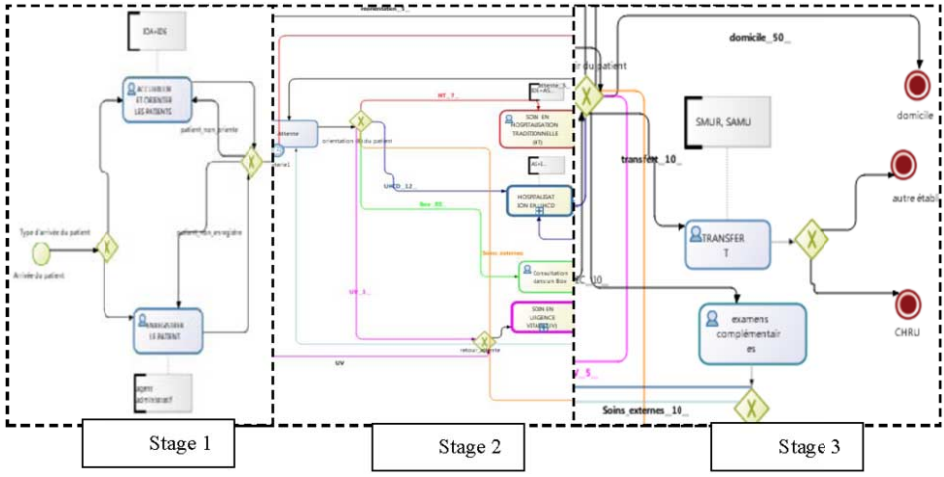


Figure 1. Global Workflow model for the PED

Due to the 2-years data collection in the PED of the CHRU of Lille, we have anonymous information about 23150 patients' admissions in 2011 and 24039 in 2012. They were used to determine qualitative and quantitative patterns to adjust the Workflow model. We have identified three profiles: summer profile (Figure 2), winter profile (Figure 3) and crisis profile (Figure 4) knowing that we used the same simulation parameters (time slots) for all these profiles.

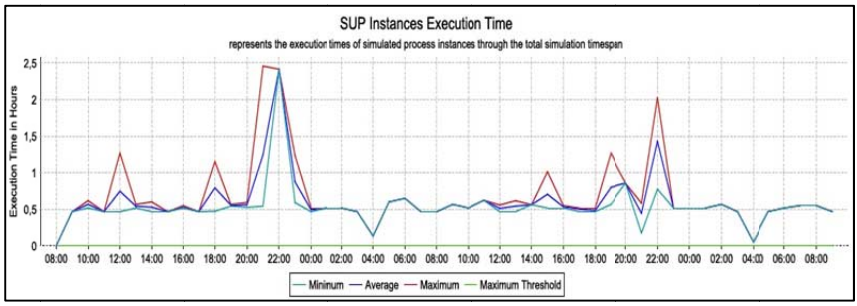


Figure 2. Average waiting time (summer profile)

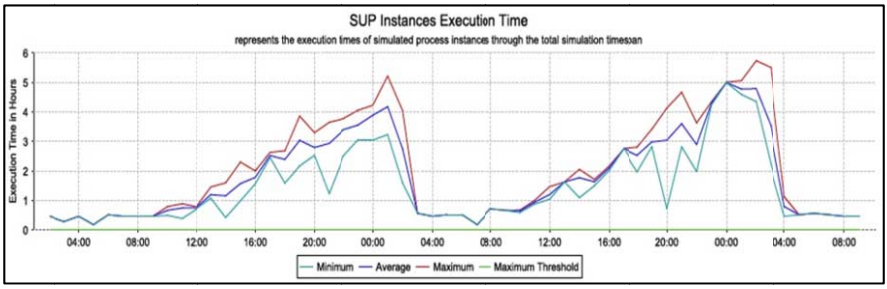
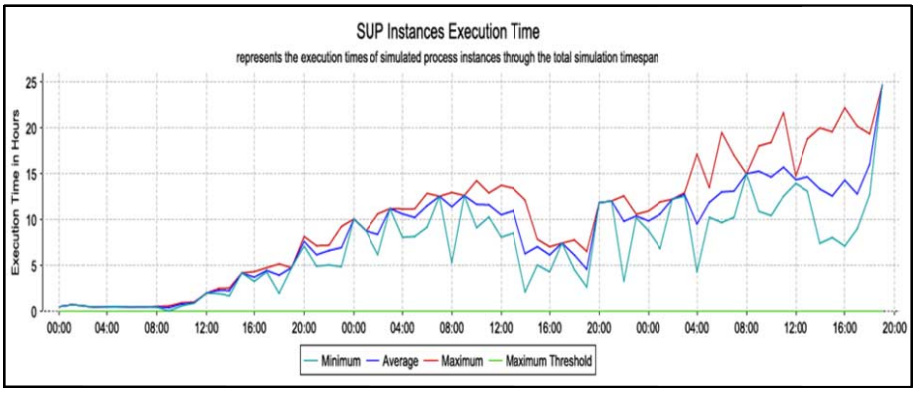


Figure 3. Average waiting time (winter profile)

For each step of the patient journey, expressed within the Workflow model, we developed the correspondent interface form to minimize the possibility of recording errors. So the data record can be done in real time according to the progress of the patient path process in the PED. The Workflow model is connected to a real data base. The collected data is useful for future analyses which are displayed in output simulation interfaces. Patient flow mapping through the PED was carried out in a continuous 2 years period from January 2011 to December 2012. The dataset obtained from the data collection exercise (after improvement) is injected in the simulation module of our Workflow tool. Simulation parameters can be chosen according to a special load profile: Injection period (time window of the staff medical activity) and number of the instances (number of patient cases distributed with a repartition type). There are 2 kinds of repartition: The constant repartition which dispatches instances injection in a constant way along the period and the direct repartition which dispatches instances injection in the start of the period. Thanks to this simulation tool, we can measure the waiting time, each resource's consumption, and at any time, we can find the service states for each patient process for the entire patient journey in the PED.



3. Discussion

The Workflow mapping model was limited to the PED itself. Therefore, the outcomes are valuable, primarily, for internal PED management. Nevertheless, the mapping process does shed light on the impact of external factors such as inpatient bed

availability (first tension indicator) and on the impact of internal factors such as the sudden increasing of patient flow (second tension indicator). This latter generates a peak of activity of medical staff then a bottleneck (third tension indicator). The data used to adjust the model were collected during two years (2011-2012) within a specific PED and is limited in its general application to other time periods and departments. There were some patients for whom admission was sought, but inpatient beds were unavailable. The patients were eventually discharged after stays in excess of ten hours, having been treated in the PED. The statistical impact was to increase mean time in the PED for discharged patients. On the other hand the mean time interval from bed request to bed availability was artificially reduced due to the removal of the data for these patients from the admitted patients list.

Another limitation is the connection of the Workflow model with the database which is not already established to automate the simulations. In fact, for the moment, we inject manually data in the simulation module in order to generate graphs.

Some other ED projects to reduce patient waiting time exist. For example, in Canada, a four-year project is aimed at bringing ED wait times to zero, and improving patient experiences as they move through the health care system (http://www.health.gov.sk.ca/patient-flow). The goal of this project is "by 2017, no waiting and better patient experiences". In UK, a similar project exists (http://www.ncuh.nhs.uk/about-us/trust-board/2012/september/trust-board-resentation-July-2012.pdf). Indeed, these projects don't model processes corresponding to PED. Adopted methods in these projects don't focus on the crowding aspect within the PED.

4. Conclusion

The use of Workflow approach to design the patient journey through the PED of CHRU of Lille was effective in facilitating the application of a combination of qualitative and quantitative data to depict and analyze the entire PED activity spectrum. This work will contribute for the re-designing and resourcing the PED. The goal is to develop an intelligent business system which aim to the timely identification of impending access block so that action can be taken to alleviate serious PED over-crowding.

References

[1] Aalst Wvd, Dongen Bv, Herbst J, Maruster L, Schimm G, Weijters T. Workflow mining: A survey of issues and approaches. Data & Knowledge Engineering. 2003;47(2):237–67.

[2] Sinclair D. Emergency department overcrowding – implications for paediatric emergency medicine. Paediatr Child Health. 2007 Jul 2007;12(6):491–4.

[3] Gausche-Hill M, Schmitz C, Lewis RJ. Pediatric Preparedness of US Emergency Departments: A 2003 Survey. Pediatrics. 2007;120(6).

[4] Bonitasoft. Open Source Workflow Managment System. Available from: http://community.bonitasoft.com/.

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The Data Model for Social Welfare in Finland

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Abstract. A client data model for social welfare was gradually developed in the National Project of IT in Social Services in Finland. The client data model describes the nationally uniformed data structures and relationships between the data elements needed in production of social services. It contains the structures of social care client records, unique core components and distinct classifications. The modeling method guaranteed the coverage, integrity, flexibility and device independency of the model. The model is maintained and developed by the National Institute for Health and Welfare (THL) together with the social workers and other experts of social welfare. It forms the basis of the electronic information management of the social services. Implementation of the data model in information systems enables the availability of the client data where and when ever a client has to be helped.

Keywords. Data model, client data, client record, social welfare

Introduction

A client of social services may use different human services in various agencies. Every agency records the client data of its own. Often the identical data is saved in several local repositories. The stored data of the client, his needs and the services should be available where and when ever he's been helped. In order to share client data between the agencies interoperability of information systems is needed. [1, 2]

In the last decade political initiatives in promoting interoperability among public administrations has been taken in Europe [3]. In Finland the interoperability between the systems used in the public services is patterned after an overall enterprise architecture concept [4]. Information architecture is one of the four fields of the enterprise architecture framework. It contains standardization of terminologies and data structures etc.

There are no international or widely recognized standards focused on social welfare informatics. In order to achieve the interoperability standardization of the contents of the client data used in social welfare is required. Thus a client data model supporting social services processes is at the core of the social services information architecture.

This article presents a modeling process of the client data model and the data model developed for the needs of the social services in Finland. The analysis focuses particularly on the quality properties of the data modeling instead of analysing the actual data model. Traditionally, when the quality assessment has been limited to an existing data model, the errors can be found and fixed afterwards. When the quality has

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been controlled already on the modeling process stage, many errors will be avoided and prevented in advance. [5]

In this article main steps in constructing the client data model and some characteristics of the model are described. Thereafter a structure of the data model is presented and the quality properties of the model are examined considering the appropriate literature. Finally a few outlooks of using the data model are discussed.

1. Methods

The client data model was developed step by step in the National Project of IT in Social Services during 2008-2011 [6, 7]. Data requirements were defined in dialogical teamwork in which both social welfare specialists and information technology experts were involved [8]. As far as is known a similar data model to this extent has never been created in social welfare in Finland nor in other countries. Main stages of the development process of the client data model are presented in Figure 1.

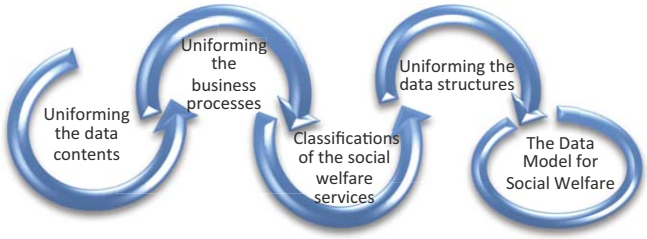


Figure 1. Main stages in developing the client data model for social welfare services.

In Finland, the organizing and delivery of social services are strongly legislated. Despite the regulatory control the ways local governments are organizing and producing various social services differ from each other. The essential characteristics of social welfare, the scope of field and diversity of customer needs brought their own challenges to the development of data model. Due to these challenges generic solutions were sought concerning data specifications. The data contents were defined in such a way that they were usable in as many social services as possible.

Method and guiding principles of modeling evolved when specifications proceeded. When a content of a single specification was developed, the means of description were improving meanwhile. In practice, several specifications became iteratively and incrementally more precise.

Several social services are produced alongside health care services. For example substance abuse services, child and family counseling and disability services employ professionals with social care and health care expertise. Where possible, the national data structures used in health care has been utilized when creating the social welfare client data model. Similarly, other useful recommendations and suitable principles used in public administration are appropriately applied.

The data definitions were based on reports of social services information requirements carried out by the THL in 2006 - 2011. The information needed in the production of every particular social service was described. The examinations were carried out in cooperation with experts and professionals from each field of social

services. The information needs collected could later be used to form the structures of client records and technical specifications. [7, 8]

In order to create a high-quality data model, business processes of the social services have to be understood and described, too [9]. In 2008-2011 target states of social welfare key business processes were described as part of modeling of the national business architecture for social welfare. Particular attention was paid to mechanisms in which the data and structured client records are generated during the client processes. Also the client data transfer between those involved in the process was studied. Cooperation between the process modeling and the data modeling was found to be mutually beneficial, and it improved the quality of all specifications.

Nationally unified and terminologically harmonious classifications describing social welfare functions and social care services were created in 2009-2010 From an information management point of view, the classifications serve as a nationally unified structure for client records, metadata, data retrieval and compilation of statistics.

Options of technical standard and principles of constructing the client documents were examined and evaluated since 2007. Finally, in 2010, the technical specifications were started based on the inventories of social services information requirements. Henceforth generic and shared data requirements and uniform data structures replaced the particular data needs of a specific service as a focus of modeling. Alternative modeling frameworks were studied and finally CCTS model (Core Component Technical Specification) was chosen to ensure the harmonized formation of the components [10].

The client records play a key role when documenting the client information in social welfare. There are for example administrative decisions drawn up by the social welfare authority and documents describing the services provided for a client. In 2010-2012 structures of social welfare electronic client records were modeled for different service tasks, such as social assistance and child protection, as well as for a number of services to support social care processes. The service-specific data descriptions were the key sources of document structures, which were composed of the data components [7, 11].

The first compilation of the social welfare client data model was completed and released in 2011. The client data model is maintained and developed by the THL in close co-operation with the social workers and other experts of social welfare.

2. Results

The literature [12-14] describes a variety of quality-related features of data models, such as the coverage, simplicity and flexibility of the model. In evaluating the coverage of the data model you can study how well the model corresponds to the needs described by the users. When evaluating the simplicity of the data model you focus on how many entities and the relationships between the entities data model includes. The flexibility refers to how well the data model takes into account the needs for change.

The client data model of Finnish social welfare describes the nationally uniformed data structures and relationships between the elements of the data needed when providing social services. It contains structures of over 250 different social care client records, over 150 unique core components and about 100 distinct classifications. [7] An example of the structure of data model is presented in Figure 2.

The client data model can be considered as a logical data model because it captures the requirements of social welfare, but does not take a stand on technical solutions. The model is limited only to describe the data structures of social service user. Thus it does not describe for example data structures used in human resource management or financial management, even if occasionally those have connections with the client data. Thus far no mapping between the data elements of the data model and other data models, such as the UMLS, has been done.

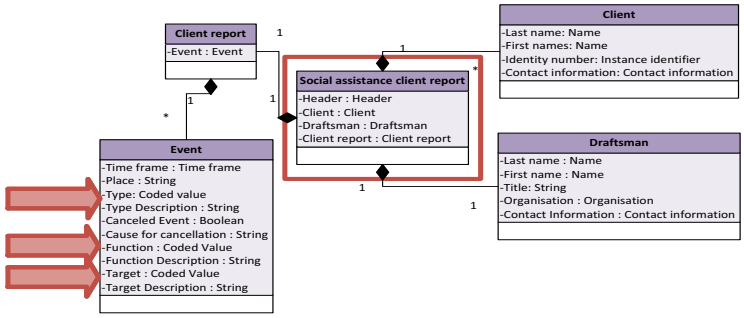


Figure 2. An UML-diagram of a client report as an example of the data model for social welfare.

The coverage of the client data model is almost one hundred percent, but it does not yet cover every field of social services, such as services of employment of persons with disabilities. The data model represents not only the information needs the social workers recognize today but it also tries to capture the information needs of the future.

The selected modeling method of the data components and the records enables the description of a data field name, a data representation, a definition, a note related to the definition, an example, repeatability and mandatority. Diversity of the needs and variety of the circumstances of the social welfare service users make demands on flexibility of the data model. The flexibility can be acquired for example by defining data structures optional and repeatable.

Data modeling gives a formal process to learn how a specific field operates. Also the client data model structures social welfare and helps the communication between different stakeholders. Understandability is defined as the ease with which the data model can be understood. Different stakeholders, such as developers of applications, must be able to understand the model in order to verify if it meets their requirements and to implement it correctly. [14] Understandability of the client data model was increased by means of the terminological work.

3. Discussion

Flexibility is one of the most important quality factors of the data model. It describes how the data model can cope with changes, for instance changes in the legislation. [5] The client data specifications will remain feasible, usable, consistent and up to date by way of a management model. In the model sources of needs to change individual client data specifications have been identified and the client data model management process has been planned. The management model has been gradually introduced.

Before an implementation the quality of the client data model is reviewed by the social workers. The goal of the reviews is to remove unnecessary client document

structures, add missing structures and clarify inaccurately defined structures in the data model. With the help of the reviews it is possible to prevent rework and added cost after the implementation. Also the users will probably be more satisfied. [7]

The implementation of the data model to the operational systems will be taking gradually place when the Finnish social welfare organizations are preparing to use a National Client Data Repository for Social Services [15]. The implementation will need strong support and co-operation of the various stakeholders. Eventually the high-quality data model enables the availability of the client data and lays out the foundation for the information management of the social services [16]. The basis affords also an opportunity to discuss the integration of social and health care delivery [17].

References

[1] Hämäläinen P, Reponen J, Winblad I, Kärki J, Laaksonen M, Hyppönen H, et al. eHealth and eWelfare of Finland - Checkpoint 2011. National Institute for Health and Welfare and University of Oulu; Report 5, 2013.

[2] Kärki J, Laaksonen M, Hyppönen H. Use of ICT in Finnish social welfare - Situation in 2011. IARIA SOTICS. 2012 Oct 21; 91-95.

[3] European Commission. Towards interoperability for European public services - Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee of the Regions. European Commission; 2010.

[4] Act on information management governance in public administration, 634/2011 (June 10, 2011). Available in English from [cited 2014 Feb 7]. http://www.vm.fi/vm/en/04_publications_and_documents/03_documents/20110902ActonI/Tietohallintolaki_englanniksi.pdf

[5] Moody DL, Shanks GG. Improving the quality of data models: empirical validation of a quality management framework. Inf Syst. 2003; 28: 619–650.

[6] Mykkänen J, Hyppönen K, Kortelainen P, Lehmuskoski A, Hotti V, Paakkanen E, et al. National interoperability approach for social services information management in Finland. In: Charalabidis Y, editor. Interoperability in digital public services and administration.1st ed. Information science reference; 2009. p. 254-278.

[7] Laaksonen M, Kärki J, Ailio E. Uniforming information management in Finnish social welfare. In: Mantas J, et al, editors. Quality of life through quality of information. European Federation for Medical Informatics and IOS Press 180; 2012. p. 922-926.

[8] Kärki J. Defining requirements of information used in social services in Finland. Paper presented at Joint World Conference on Social Work and Social Development; 2010; Hong Kong: Abstract book p. 626.

[9] Miettinen A, Mykkänen J, Laaksonen M. Method for modeling social care processes for national information exchange. In: Mantas J, et al, editors. Quality of life through quality of information. European Federation for Medical Informatics and IOS Press 180; 2012. p. 906-910.

[10] United Nations Centre for Trade Facilitation and Electronic Business [Internet]. Core Components Technical Specification. Version 3.0; [updated 2009 Sept 29; cited 2014 Jan 17]. Available from: http://www.unece.org/fileadmin/DAM/cefact/codesfortrade/CCTS/CCTS-Version3.pdf

[11] Lehmuskoski A. New structures of social care records. Paper presented at Joint World Conference on Social Work and Social Development; 2010; Hong Kong: China, Abstract book p. 631.

[12] Levitin A, Redman T. Quality dimensions of a conceptual view. Inf Process Manag. 1995; 31(1):81-88.

[13] Kesh S. Evaluating the quality of entity relationship models. Information and Software Technology. 1995;37(12):681-689.

[14] Moody DL. Metrics for evaluating the quality of entity relationship models. In: Ling TW, Ram S, Lee ML, editors. ER'98, LNCS. 1998; 1507. p. 211−225.

[15] Laaksonen M, Suhonen M, Paakkanen E, Mykkänen J, Satama R. National client data repository for social services (KanSa) – Summary of implementation options and policies. National Institute for Health and Welfare. Discussionpaper 5, 2013.

[16] Rigby M, Hill P, Koch S, Keeling D. Social care informatics as an essential part of holistic health care: A call for action. Int J of Med Inform. 2011; 80:544 -554.

[17] OECD ICTs and the Health Sector. Towards smarter health and wellness models. OECD Publishing; 2013.

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Integrating Personalized Health Information from MedlinePlus in a Patient Portal

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Abstract. The objective of this paper is to describe the implementation and use of context aware information in Spanish from MedlinePlus embedded in a Patient Portal. Personalized information can help patients solve problems, make treatment decisions, gain confidence in their ability to care for themselves and communicate with providers. To integrate MedlinePlus information in our institutional PHR we used the HL7 Context-Aware Knowledge Retrieval Standard, also known as the Infobutton Standard. After analysing one year of use, patients accessed MedlinePlus information in Spanish in a similar rate to other personalized information generated locally. Infobuttons associated to laboratory test results were used in approximately 10% of patients portal sessions when reviewing lab results.

Keywords. Health Information, Patient Portal, Personal Health Record (PHR), Infobuttons, MedlinePlus

Introduction

Personal health records (PHRs) are 'healthcare-related online applications that allow consumers to interact with their health care information in one place.' [1] There are two main PHR architecture implementations. The first one is linked directly to the physician's practice-based electronic health record (EHR), and these are known as tethered PHRs or "Patient Portals". The other is a stand-alone implementation, without linkages to any EHR. The first architecture offers advantages because it can include specific information imported directly from the patient's medical record. Functions available in these tethered PHRs include: reminders for preventive practices, the ability for patients to securely e-mail their clinicians, make an appointment, or ask for a new prescription. [2] From tethered PHRs, patients can have access to their problem list, medication list, laboratory test results, and links to personalized health information. Evidence that patient portals improve health outcomes, cost, or utilization is insufficient, [3] however the use of these kinds of systems is also spurred by financial

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incentives and outlined in the USA Meaningful Use incentive program, which aims at disseminating EHR adoption. [4]

Infobuttons can be defined as context-specific links embedded in EHR or PHR systems and that provide seamless access to relevant online health information resources. [5] While investigators have studied the use and impact of Infobuttons on clinicians' information needs and information-seeking behaviour, little has been done to investigate the use of infobuttons by health care consumers.

MedlinePlus, from the US National Library of Medicine (NLM), is a freely available consumer health information resource that offers information about diseases, conditions, and wellness issues in laymen terms. MedlinePlus information is offered in English and Spanish. MedlinePlus Connect is a free service that allows health organizations and health IT providers to link patient portals and electronic health record (EHR) systems to MedlinePlus via Infobuttons. [6] MedlinePlus Connect accepts requests for information on diagnoses (problem codes), medications, and laboratory tests, and returns related MedlinePlus information.

This paper describes the implementation process of infobuttons within a PHR system as well as the use of MedlinePlus information in Spanish through these infobutton links.

1. Methods

The study took place at Hospital Italiano de Buenos Aires (HIBA) in Argentina. HIBA is a non-profit academic medical center with over 2,000 physicians and 6,000 employees. In 1998, HIBA began to implement a Healthcare Information System (HIS) that was completely developed in-house. Within the HIS, there is a Terminology Server that supports standard medical vocabularies including SNOMED-CT. [7] The HIBA information infrastructure includes a patient portal, which was launched in 2007. In October 2013 approximately 80,000 patients were enrolled representing more than 50% of enrolment rate.

The core functions of HIBA´s portal are similar to those of other patient portals and include: Secure messaging, access to limited electronic health record (EHR) data, delivery of personalized health information, appointment scheduling and bill management

In 2008, access to personalized consumer health information was added as a new functionality in the portal, but all the information offered was developed in-house. As developing healthcare information it is not an easy task, in 2012 we decided to integrate HIBA's PHR with MedlinePlus information in Spanish via infobutton using the two implementation strategies offered by the NLM.

In order to understand if patients read the information offered, we used audit log information of the interaction of the patients with the portal on MedlinePlus general information and lab test results. In this paper we describe the use of this new information source.

2. Results

We started the implementation process in July 2012, following the indications available at the MedlinePlus Connect website, we decided to show the information from

MedlinePlus in two different modules of the PHR, the home screen and the laboratory test results module. The first one was implemented as "push" mechanism, where information related to a patient's diseases is automatically displayed when the patient is logged into the system. The other format, offered in the laboratory test results module, is a "pull" approach, in which patients actively click on a specific button (infobutton) located next to each test result to access explanatory information from MedlinePlus. Two software developers from our department worked half time in this project, and took them approximately 20 days to have the first version of the solution available for patients.

The two alternatives were implemented using the Health Level Seven (HL7) Context-Aware Knowledge Retrieval (Infobutton) Standard. The Infobutton Standard supports two implementation approaches that were used in the HIBA PHR. Specifically, the pull approach described above uses the HL7 URL-based implementation guide and the push approach uses the HL7 services-oriented architecture (SOA) implementation guide. The sections below describe how these strategies were implemented and how patients used them.

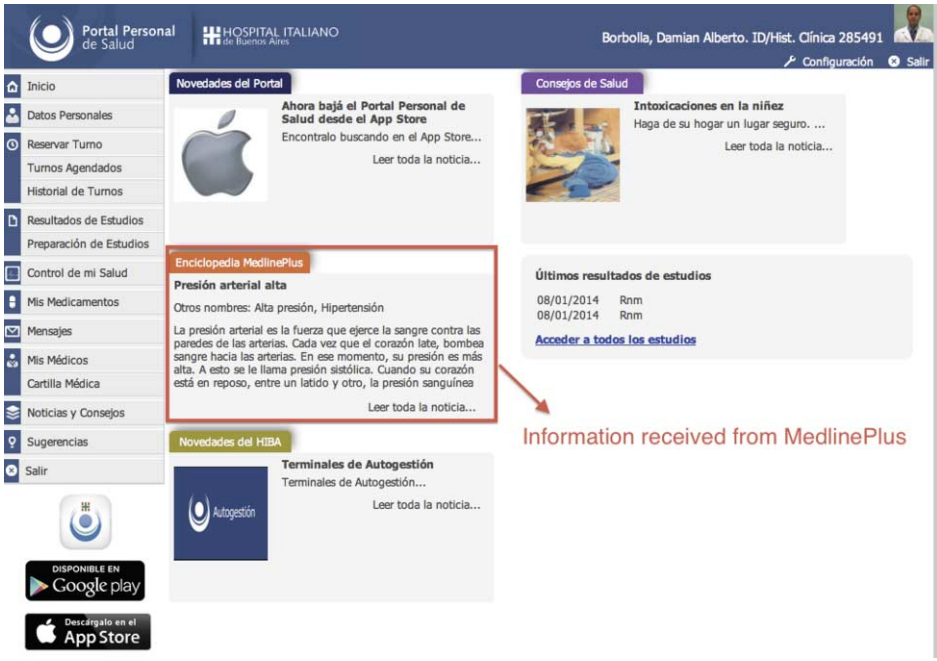


Figure 1. Personalized information at HIBA's PHR

2.1. Disease-specific information for patients

After logging into HIBA's PHR, all users were presented with information specific to their health conditions and demographic profile in the main screen. This information is derived from the SNOMED-CT diagnostic and problems list section of HIBA´s EHR. All terms in the problem list are auto-codified with the terminology server and a SNOMED-CT code is linked to each of these terms. When users access their home page in the PHR, a knowledge request is sent to MedlinePlus Connect including the

patient's problems (SNOMED-CT codes), age, gender, and language. When the information is received, the Web service provided by the NLM generates a standard XML knowledge response with relevant content, which is received and parsed by the PHR in Argentina. Figure 1 shows how information coming from MedlinePlus is integrated with the information produced locally.

2.2. Infobuttons in the lab results

Every time patients access their laboratory results, they can click on infobuttons located next to each of the results displayed. When an infobutton is clicked, the test's LOINC code provided by the terminology server at HIBA is encoded in a URL-based knowledge request. This knowledge request is sent to MedlinePlus Connect, which responds with relevant content in HTML format. This content is then displayed to the user in a browser window independent form the PHR

2.3. Infobuttons Use

Both Infobutton approaches were released to users in August 2012. The information provided by MedlinePlus Connect on the portal's home screen was accessed on average 1,000 times per month, compared to 1,500 times for local information and 500 times for food recipes.

Reviewing laboratory results is the functionality patients use the most in the portal. On average, patients access laboratory results in 50% of their portal sessions. Between September 2012 and September 2013, patients accessed explanatory information from MedlinePlus via infobuttons in 10% of the sessions in which patients accessed their lab results. The lab test that triggered most of the infobutton uses was CBC, with a total of 11,682 clicks, followed by urine culture, with 5,236, both in one year period. Trends of the use of the two functionalities implemented are shown in Figure 2

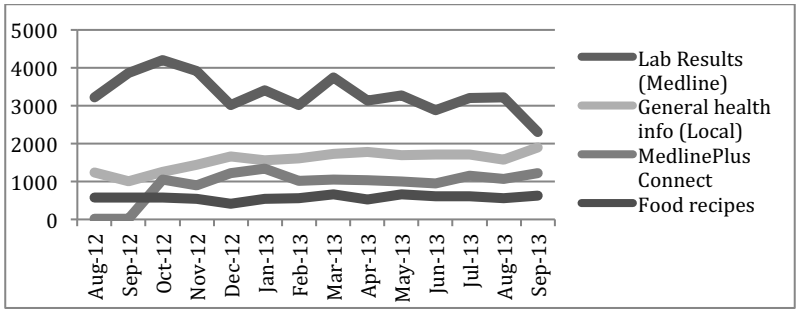


Figure 2. Comparison of access to MedlinePlus and locally produced information

3. Discussion

As the demand for patient portals increases, understanding the functionalities available, use and impact of these portals becomes critical. Other studies described functionalities of PHRs. [8-10] In this study, we have described the implementation process and investigated the use of personalized consumer health information in Spanish provided

by MedlinePlus Connect and accessible via infobuttons in a PHR for patients in Argentina. We have observed strong use of both functionalities provided in the patient portal, especially by the personalized information provided in the main screen linked to patients' problem lists. This concept of accessing personalized information is a relatively new. Similar approaches to tailored information for patients have been described by Weiner and Pfeifer [11]. They proposed "Recommender Systems" as a potential approach to suggest items of interest to users. While there has been research with recommender systems aimed at helping clinicians' decision making [12], to our knowledge there are no publications describing such experience with patients, even though, according to the NLM, there are approximately 13 healthcare institutions and more than 30 EHR systems using MedlinePlus Connect. [13]

The main limitation of this study is that we were unable to determine details such as the value and impact of the information accessed by patients; and whether value and impact differ between MedlinePlus and locally produced content.

Given the high use of MedlinePlus information through our PHR, we believe that other health organizations could benefit from a similar standards-based implementation approach. Future research will assess the value and impact of the information accessed on patients.

References

[1] Bates DW, Wells S. Personal health records and health care utilization. *JAMA*. **19** (2012), 2034–6

[2] Archer N, Fevrier-Thomas U, Lokker C, McKibbon KA, Straus SE. Personal health records: a scoping review. *J Am Med Inform Assoc*. **4** (2011), 515–22

[3] Goldzweig CL, Orshansky G, Paige NM, Towfigh AA, Haggstrom DA, Miake-Lye I, et al. Electronic patient portals: evidence on health outcomes, satisfaction, efficiency, and attitudes: a systematic review. *Ann. Intern. Med*. **10** (2013), 677–87

[4] American Recovery and Reinvestment Act of 2009. Section A, Title XIII, Health Information Technology. [Internet]. Available from: http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/hitechact.pdf

[5] Del Fiol G, Huser V, Strasberg HR, Maviglia SM, Curtis C, Cimino JJ. Implementations of the HL7 Context-Aware Knowledge Retrieval ("Infobutton") Standard: challenges, strengths, limitations, and uptake. *J Biomed Inform*. **4** (2012), 726–35

[6] MedlinePlus Connect: Linking Patient Portals and Electronic Health Records to Health Information [Internet]. [cited 2014 Feb 5]. Available from: http://www.nlm.nih.gov/medlineplus/connect/overview.html

[7] Osornio AL, Luna D, Gambarte ML, Gomez A, Reynoso G, De Quirós FGB. Creation of a local interface terminology to SNOMED CT. *Stud Health Technol Inform*. (2007), 765–9

[8] Osborn CY, Rosenbloom ST, Stenner SP, Anders S, Muse S, Johnson KB, et al. MyHealthAtVanderbilt: policies and procedures governing patient portal functionality. *J Am Med Inform Assoc*. **18** (2011), 18–23

[9] Grant RW, Wald JS, Poon EG, Schnipper JL, Gandhi TK, Volk LA, et al. Design and implementation of a web-based patient portal linked to an ambulatory care electronic health record: patient gateway for diabetes collaborative care. *Diabetes Technol. Ther*. **5** (2006), 576–86

[10] Bourgeois FC, Mandl KD, Shaw D, Flemming D, Nigrin DJ. Mychildren's: integration of a personally controlled health record with a tethered patient portal for a pediatric and adolescent population. *AMIA Annu Symp Proc*. (2009) 65–9

[11] Wiesner M, Pfeifer D. Health recommender systems: concepts, requirements, technical basics and challenges. Int J Environ Res Public Health. 2014 Mar 3;11(3):2580-607

[12] Del Fiol G, Haug PJ. Classification models for the prediction of clinicians'information needs. J Biomed Inform. 2009 Feb;42(1):82-9

[13] MedlinePlus Connect in Use [Internet]. [cited 2014 Feb 5]. Available from: http://www.nlm.nih.gov/medlineplus/connect/users.html

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Telehealth for "the Digital Illiterate" – Elderly Heart Failure Patients' Experiences

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Abstract. Telehealth solutions should be available also for elderly patients with no interest in using, or capacity to use, computers and smartphones. Fourteen elderly, severely ill heart failure patients in home care participated in a telehealth study and used digital pens for daily reporting of their health state—a technology never used before by this patient group. After the study seven patients and two spouses were interviewed face-to-face. A qualitative content analysis of the interview material was performed. The informants had no experience of computers or the Internet and no interest in learning. Still, patients found the digital pen and the health diary form easy to use, thus effortlessly adopting to changes in care provision. They experienced an improved contact with the caregivers and had a sense of increased security despite a multimorbid state. Our study shows that, given that technologies are tailored to specific patient groups, even "the digital illiterate" may use the Internet.

Keywords. Telemedicine, digital pen, heart failure, home care services

Introduction

Using a computer or a smartphone is a matter of course for most of us. Still this is not for all, especially if you are of old age [1] and suffer from one or more severe health conditions.

The prevalence for heart failure (HF) is >= 10 % among those 70 years and older [2]. It is associated with comorbidities, poor quality of life, and high mortality [3]. HF patients receiving non-hospital care are geographically separated from the healthcare-providing organisation, making symptom control more difficult.

Telehealth programmes for HF home care patients [e.g. 4-6] are suggested to have positive impact on both mortality and morbidity [4, 7]. However, most often programmes require that patients use a computer, a tablet or a mobile phone together with other medical equipment. In order to also let patients who have never used such technologies or the Internet, i.e. "the digital illiterate", to be included in a telehealth clinical trial, we developed a telemonitoring system, *the Health Diary*, for elderly HF home care patients, based on digital pen technology. Here, Internet use comprise of not only browsing or sending emails, but any use of Internet-connected networks. Digital pen technology has been tried and evaluated with cancer patients [8-9] but, to our knowledge, never by HF patients—a patient group with high mean age [10]. We

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implemented the system in clinical use in a 13 months long study between November 2010 and December 2011 at the hospital-based home care (HBHC) clinic, Linköping University Hospital.

The aim of this paper was to explore and describe the patients' and spouses' experiences in using the system.

1. Methods

Permission to carry out the study was given by *The Regional Ethical Review Board in Linköping*. The digital pen technology (www.anoto.com) comprises the pen and ordinary paper with a printed close-to-invisible pattern read by a camera inside the digital pen. The pen is used as an ordinary ball-point pen, but the strokes made by the pen are recorded and transferred via mobile internet to a server [11].

The Health Diary system supported daily reports on shortness of breath, intake of p.r.n. medications, weight and other measurements by use of the digital pen and a health diary form (see Figure 1). The diary also allowed free text messages to the care provider. The system generated alarms if patient-reported values were below/above certain limits [10]. Inclusion criteria comprised Swedish-speaking patients with HF, not being cognitively impaired, able to perform the assessments with or without help from a spouse. Written consent was collected from all participating patients. A nurse instructed the patients on how to handle the equipment. The patients performed daily assessments and measurements which were immediately reported by filling in the health diary. The system was monitored by health professionals.

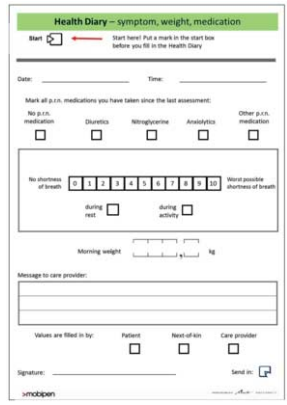


Figure 1. Health Diary Form

Fourteen home care patients (11 men, mean/median age 84/83 years at inclusion) diagnosed with HF, NYHA class II-IV, with a median of two previous hospital admissions during the last 12 months were included in the study. Five patients died during or shortly after the study, one was in a too poor condition to be interviewed, and one left the study shortly after inclusion. Seven patients and two spouses gave their consent to be interviewed face-to-face in their homes by one of the authors (LL). An interview guide was used and concerned, e.g., experiences from using the technology and method, the patients' health status during the study, and, possible changes in contact with the care provider and care participation. The interview guide served as support for the interviewer's memory and to trigger the discussions [12-13]. In order to explore patients' and spouses' experiences in using the system a qualitative content analysis of the interview material was accomplished by four researchers. Content analysis focuses on the subject and context, and it points out differences and similarities between and within categories [14].

2. Results

Four sub-categories showing patients' experiences of using the digital pen technology and health diary for daily assessments were identified and described in the two

categories *Difficult seeing one's own change* and *Multimorbid, but with a sense of security and trust*. Selected original quotations, translated into English, from each category are presented to illuminate the patients'/spouses' experiences.

Difficult seeing one's own change, with the sub-categories: *Technology acceptance and new daily routines despite the indifference to technology in general* and *Difficult seeing one's own gain in health insights and increased care participation*.

Technology in general, including computers and mobile phones, was regarded as "not interesting" and "a bit scaring". None of the informants had experiences from using computers. They expressed that they *did not have use* for computers and the Internet – and did not want to learn *how to use* them – still, they realised that they were going to miss a lot of information this way.

> "Technology and things? No, I know nothing about such things!" (Patient 14)
> "We got a DVD from our daughter but we haven't tried it. And then one is afraid of pushing the buttons" (Patient 11)
> "There are still some older people without computers, so it [Internet access] shouldn't be taken for granted [that everyone can] 'go in there and have a look'" (Spouse 04)

During the study the patients began using new daily routines for the reporting of assessments and measurements, and they thought that handling the digital pen was an easy task.

> "I can manage, 'cause that's nothing special, as long as I can read and hold the pen" *(Patient 14)*

Two patients needed help from a spouse when reporting but believed that they could manage themselves. The informants did not notice the change from being non-users to users of Internet services; neither patients nor spouses reflected over the fact that they were using the Internet when reporting with the digital pen.

Both patients and spouses expressed that they now kept track of the patient's symptoms and signs, and that the care provider's advice was better followed. However, especially the patients had difficulties seeing their own gain in health insights and that they had increased their own care participation.

> "[Before inclusion] I thought 'what's the *use* of measuring?'" *(Patient 05)*
> "I take the medicine I'm prescribed, that I do." *(Patient 09)*
> "Perhaps I listen to the body more, and listen to what *they* [the care providers] say" *(Patient 11)*

Multimorbid, but with a sense of security and trust, with the sub-categories: *A sense of increased security and closer contact with the care provider due to trust* and *A sense of stability despite the multimorbidity*.

None of the patients were admitted to hospital care due to HF deterioration. Issues related to HF were detected by care providers via the system allowing patients to be cared for at home. The informants trusted that the care provider checked and used the reported assessments, and this resulted in a sense of increased security and of being in a "closer" contact with the care provider. Both patients and spouses had this feeling of being closer to the HBHC clinic even when they didn't get home visits or had telephone contact with the care providers.

> "It [the digital pen] is a…security." *(Patient 08)*

The patients described that they had one or more comorbidities which affected their overall health status. Despite their multimorbid state a few patients expressed a sense of a less unstable heart during the study inclusion, compared to before inclusion. This sense was expressed as being closely connected to the sense of a greater security.

"It's always good to have them [the care providers] come *here*, to avoid going to the hospital, and not have to chase a doctor" *(Patient 08)*
"[Interviewer:] Has the health diary reporting affected your health in some way?
[Informant:] Absolutely! I feel much more secure." *(Patient 12)*
"I have felt so healthy a while now…it's so different!" *(Patient 12)*

3. Discussion

The frailty of elderly patients with severe HF, and one or more comorbidities, can be comparable to elderly palliative cancer patients [15]. This is not a point in life when a person easily learns how to use new technologies. In two earlier studies palliative cancer patients in the end of their lives effortlessly used digital pen technology for reporting of symptoms and intake of pain medications. Study results, as in this study, showed that also these patients and their spouses participated more in the care and had a sense of increased security by the method used [8].

Common use of the Internet started about 20 years ago and has rapidly spread among the population. In Sweden, around 90 % are Internet users and the so called digital divide is shrinking, albeit at a progressively slower rate now leaving the majority of older people "outside" of the growing information society. The most common reasons for not using the Internet are "no interest" and "complicated technology" [1]. This is not unique for Sweden [16-18]. Many countries in Europe are now implementing telehealth and eHealth services targeted at citizens, such as patient access to health records [19]. Citizens, including many elderly, are also increasingly using the Internet for their health information needs [20]. We live longer – nearly every fifth person in high-income countries is over 65 years of age [21] – and the risk of contracting diseases increases when the later stages of life approach [22]. This implies a need for alternative technologies and solutions, in order not to exclude the old and severely ill "digital illiterates" when developing telehealth systems.

The HF patients in our study had no experiences of using the Internet but quickly accepted and managed to handle the digital pen technology for daily reporting of their health status, making them more empowered and increased their own participation. In conclusion, our study shows that, given that technologies are tailored to specific patient groups, even "the digital illiterate" may use the Internet.

The Health Diary project is now being evaluated in a larger (three years) intervention study in which elderly patients with severe HF and/or chronic obstructive pulmonary disease (COPD) participate and use the same technology and method for assessment and reporting. This study will be evaluated according to quality of care, participation, perceived control, technology acceptance and usability, self-care, and health-economic efficiency.

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References

[1] O. Findahl, *Swedes and the Internet 2012*. The Internet Infrastructure Foundation, 2012, .SE. ISBN: 978-91-979411-7-4

[2] ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2012. *Eur J Heart Fail* (2012), 14(8): 803-869.

[3] T. Thorvaldsen, L. Benson, M. Ståhlberg, U. Dahlström, M Edner, L.H. Lund, Triage of Patients with Moderate to Severe Heart Failure: Who Should be Referred to a Heart Failure Center?, *J Am Coll Cardiol* (2013), doi: 10.1016/j.jacc.2013.10.017.

[4] S.C. Inglis, R.A. Clark, F.A. McAlister, J. Ball, C. Lewinter, D. Cullington, S. Stewart, J.G. Cleland. Structured telephone support or telemonitoring programmes for patients with chronic heart failure. *Cochrane Database Syst Rev*. (2010) Aug 4;(8):CD007228.

[5] A. Giordano, E. Zanelli, S. Scalvini. Home-based telemanagement in chronic heart failure: an 8-year single-site experience. *J Telemed Telecare*. (2011), 17(7):382-6.

[6] A. Steventon, M. Bardsley, J. Billings, J. Dixon, H. Doll, S. Hirani, M. Cartwright, L. Rixon, M. Knapp, C. Henderson, A. Rogers, R. Fitzpatrick, J. Hendy, S. Newman; Whole System Demonstrator Evaluation Team. Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial. *BMJ*. (2012) Jun 21;344:e3874.

[7] J. Polisena, K. Tran, K. Cimon, B. Hutton, S. McGill, K. Palmer, R.E. Scott. Home telemonitoring for congestive heart failure: a systematic review and meta-analysis. *J Telemed Telecare*. (2010),16(2):68-76.

[8] L. Lind, D. Karlsson, B. Fridlund. Patients' use of digital pens for pain assessment in advanced palliative home healthcare. *Int J Med Inform*, (2008) Feb;77(2):129-36.

[9] L. Lind & D. Karlsson. Electronic patient-reported symptom assessment in palliative end-of-life home care. *Health Systems*, (2013) 2, 171–180.

[10] L. Lind & D. Karlsson. Digital pen-based telemonitoring of elderly heart failure patients. *Stud Health Technol Inform*. (2013), 192:1062.

[11] L. Lind & D. Karlsson. A system for symptom assessment in advanced palliative home healthcare using digital pens. *Med Inform Internet Med*, (2004) Sep-Dec;29(3-4):199-210.

[12] M.Q. Patton. *Qualitative research and evaluation methods*. 3rd ed. ISBN: 0-7619-1971-6. Thousand Oaks, CA: Sage; 2002

[13] S. Kvale. InterViews: An Introduction to Qualitative Research Interviewing. Thousand Oaks, CA: Sage; 1996

[14] U.H. Graneheim & B. Lundman. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. (2004) Feb;24(2):105-12. Review

[15] M. Brännström & K. Boman. A new model for integrated heart failure and palliative advanced homecare--rationale and design of a prospective randomized study. *Eur J Cardiovasc Nurs*. (2013) Jun;12(3):269-75.

[16] World Internet Project, *International Report 2013*. Can be downloaded from the internet web site: www.worldinternetproject.net (accessed 2014-02-05)

[17] V. Hanson. Technology skill and age: what will be the same 20 years from now? *Univ Access Inf Soc* (2011), 10:443–452

[18] E. Neter & E. Brainin. eHealth literacy: extending the digital divide to the realm of health information. *J Med Internet Res*, (2012), *14*(1).

[19] S. de Lusignan, P. Ross, M. Shifrin, M. Hercigonja-Szekeres, B. Seroussi. A Comparison of Approaches to Providing Patients Access to Summary Care Records Across Old and New Europe: An Exploration of Facilitators and Barriers to Implementation. In *MEDINFO 2013: Proceedings of the 14th World Congress on Medical and Health Informatics* (Vol. 192, p. 397). IOS Press, 2013.

[20] H.K. Andreassen, M.M. Bujnowska-Fedak, C.E. Chronaki, R.C. Dumitru, I. Pudule, S. Santana, V. Henning, R. Wynn. European citizens' use of E-health services: a study of seven countries. *BMC Public Health*, (2007), 7(1), 53.

[21] The World Bank. Internet web site: http://data.worldbank.org/indicator/SP.POP.65UP.TO.ZS (accessed 2014-02-05)

[22] E. Davies & I.J. Higginson (Editors) *Better Palliative Care for Older People*. 2004. ISBN 9289010924. Available from http://www.euro.who.int/ (accessed 2014-02-05)

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An Open-Source, Mobile-Friendly Search Engine for Public Medical Knowledge

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Abstract. The World Wide Web has become an important source of information for medical practitioners. To complement the capabilities of currently available web search engines we developed FindMeEvidence, an open-source, mobile-friendly medical search engine. In a preliminary evaluation, the quality of results from FindMeEvidence proved to be competitive with those from TRIP Database, an established, closed-source search engine for evidence-based medicine.

Keywords. Information retrieval; medical care; World Wide Web; clinical decision support

Introduction

It has been shown that web-based search engines such as Google can aid the diagnostic process (1) and that the availability of an online information retrieval system increased the percentage of correctly answered medical questions from 21% to 50% in a group of 75 clinicians (2). In a recent study we conducted, medical professionals were shown to frequently use general-purpose search engines such as Google, medical research databases and – perhaps surprisingly – Wikipedia to answer medical questions online (3). A potential problem with these resources is that most of them either return large amounts of clinically irrelevant or untrustworthy content (e.g., Google), or that they are mainly focused on primary scientific literature that makes selection of clinically relevant publications very time-consuming (e.g., PubMed).

Here we report on our development of FindMeEvidence, an open-source, mobile-friendly web search engine optimized for medical information needs. The goal of the FindMeEvidence project is to improve efficient access to medical evidence on the web by providing a free, easily customizable, light-weight solution for medical information retrieval.

[1] Corresponding Author.

1. Methods

FindMeEvidence was built around the open-source Apache Solr 4.4. information retrieval system. Server-side scripts were written in PHP 5. An overview of the system architecture is shown in Figure 1.

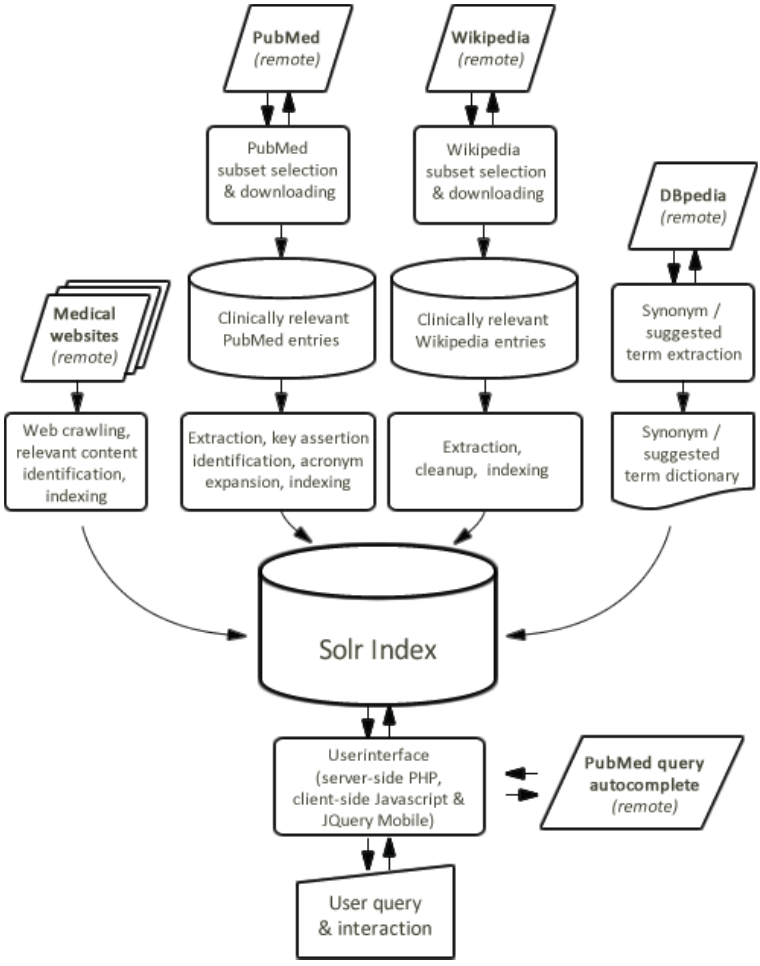


Figure 1: FindMeEvidence system components

The selection of medical data sources was based on scientific studies of digital information needs of medical professionals (3), as well as a review of popular and trustworthy web resources providing medical evidence. Only datasets in English were included. Based on these criteria, the following datasets were integrated into FindMeEvidence: A clinically relevant subset of PubMed and Wikipedia, Merck Manual (4), Medscape (5), NICE Clinical Knowledge Summaries (6), Guideline.gov (7), BestBETs (8) and ATTRACT (9). Wikipedia was among the included datasets because it was reported as an important tool for medical professionals (3). Wikipedia can be used to get a quick overview of a novel subject matter as well as to retrieve term

definitions (10), even though the quality of detailed medical and pharmacological information in Wikipedia was found to be modest (11).

One author (MS) conducted a simple, preliminary evaluation of the quality of search results returned by the system based on a list of 36 medical queries that were derived from a 24-hour sample of the query logs of the PubMed search engine (12) and a sample query log of the TRIP database. The queries consisted of simple Boolean queries with a length of one to five words. For each query, the likely information need behind the query was written down. Then, it was checked whether FindMeEvidence and TRIP database (as a control) returned relevant information within the first 5 query results each, without using any result filters available in the search engines.

2. Results

The search engine is accessible at http://FindMeEvidence.org/, the source code repository is accessible at (13). Figure 2 shows a screenshot of the user interface of the software.

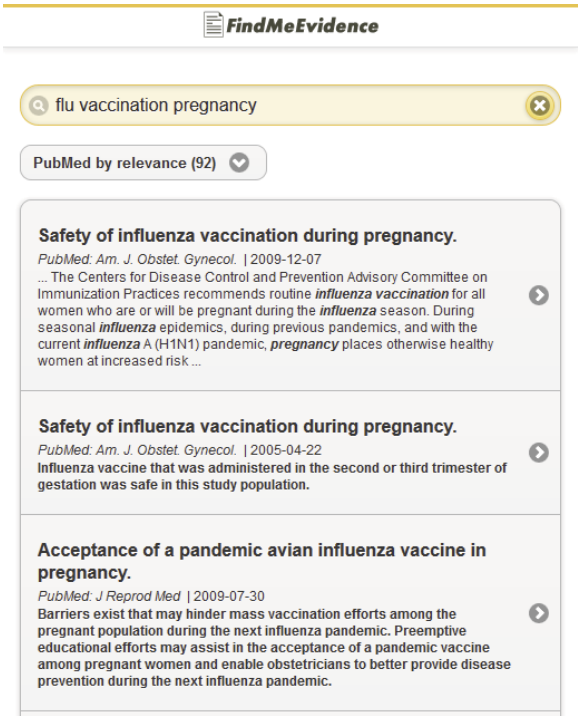


Figure 2: Screenshot of a FindMeEvidence result list containing clinically relevant research results. In the second and third result, key findings were identified in the abstracts and are shown in the result previews.

Out of all test queries (N = 36), FindMeEvidence results met success criteria for 25 (69,4%) of the queries, while TRIP Database results met criteria for 17 (47,2%) of the queries. It should be noted that both the results of FindMeEvidence and TRIP Database could have been further improved by making use of their result filter functionalities –

this is especially relevant for TRIP Database, which offers sophisticaed functionalities for result filtering based on different types of evidence.

3. Discussion

The first public release of FindMeEvidence we present here was able to provide useful answers to a variety of realistic medical queries and could compete with systems that are the state-of-the-art in medical information search. The evaluation results allow us to further optimize data source selection and ranking. A common reason for failure of both FindMeEvidence and TRIP database was that for some general queries, very specific results – such as results from very specific clinical studies reported in PubMed abstracts – were returned first. Although users can potentially exclude these specific results by selecting an appropriate search facet, this problem should be better addressed in future versions of the software.

An objective evaluation of modern search engines is very difficult, since many relevant aspects of the overall user experience cannot be captured by the simple assessment of precision and recall of document retrieval (14). Furthermore, the needs of different medical user groups vary significantly, and different search engines might fit the preferences of different groups. An important goal of FindMeEvidence is to complement the qualities of existing solutions by providing a light-weight, focused entry point to the most relevant openly available medical content.

Since FindMeEvidence is open-source software, local institutions can easily create their own versions of the software that are tailored to their specific needs, such as including descriptions of institutional standard operating procedures.

A major next step in the evaluation and further improvement of FindMeEvidence is to test it with medical professionals in their daily routine. The preliminary evaluation results presented in this paper suggest that FindMeEvidence has already reached a level of maturity that makes such an evaluation feasible.

3.1. Related Work

Several systems geared towards providing medical information retrieval capabilities in clinical settings have been described in the literature. To our knowledge, FindMeEvidence is the only currently available system that is open-source, built on an industry-strength information retrieval engine, and optimized for cross-platform and mobile web access. Some examples of related systems are listed below.

The TRIP Database (15) is a publicly available, closed-source search engine for evidence-based medicine and was used as a comparison for our evaluation. TRIP Database has a large user base and has processed over 100 million user queries.

One of the earliest systems with goals comparable to FindMeEvidence was Quick Clinical, a federated medical search system developed by Coiera *et al.* (16). Quick Clinical introduced sophisticated meta-search filters that allow users to optimize query results by explicitly stating the types of their information needs (e.g., diagnosis, etiology) in addition to a free text query. Quick Clinical was extensively evaluated and was shown to improve clinical question answering (2). To our best knowledge, the Quick Clinical system is currently not publicly available.

Khresmoi (17) is a large European research project developing a medical search engine platform around the GATE Framework and semantic technologies. Compared to

FindMeEvidence, the Khresmoi system is more geared towards large-scale data processing and the support of machine translation, and its system requirements are significantly higher.

3.2. Conclusion

FindMeEvidence demonstrated its potential to become a useful addition to the digital toolset available to medical professionals. Still, there is a lot of room for potential improvements and we invite interested parties to contact us and join the future development and dissemination of the system.

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References

[1] Tang H, Ng JHK. Googling for a diagnosis—use of Google as a diagnostic aid: internet based study. BMJ. 2006 Dec 2;333(7579):1143 –1145.
[2] Westbrook JI, Coiera EW, Gosling AS. Do Online Information Retrieval Systems Help Experienced Clinicians Answer Clinical Questions? J Am Med Inform Assoc JAMIA. 2005;12(3):315–21.
[3] Kritz M, Gschwandtner M, Stefanov V, Hanbury A, Samwald M. Utilization and Perceived Problems of Online Medical Resources and Search Tools Among Different Groups of European Physicians. J Med Internet Res. 2013;15(6):e122.
[4] THE MERCK MANUALS - Trusted Medical and Scientific Information [Internet]. [cited 2013 Oct 15]. Available from: http://www.merckmanuals.com/
[5] Diseases & Conditions - Medscape Reference [Internet]. [cited 2013 Oct 15]. Available from: http://emedicine.medscape.com/
[6] NICE Clinical Knowledge Summaries (CKS) [Internet]. [cited 2013 Oct 15]. Available from: http://cks.nice.org.uk/
[7] National Guideline Clearinghouse | Home [Internet]. [cited 2013 Oct 15]. Available from: http://www.guideline.gov/
[8] Welcome to BestBETs [Internet]. [cited 2013 Oct 15]. Available from: http://bestbets.org/
[9] ATTRACT | Home [Internet]. [cited 2013 Oct 15]. Available from: http://www.attract.wales.nhs.uk/
[10] Heilman JM, Kemmann E, Bonert M, Chatterjee A, Ragar B, Beards GM, et al. Wikipedia: a key tool for global public health promotion. J Med Internet Res. 2011;13(1):e14.
[11] Clauson KA, Polen HH, Boulos MNK, Dzenowagis JH. Scope, Completeness, and Accuracy of Drug Information in Wikipedia. Ann Pharmacother. 2008 Jan 12;42(12):1814–21.
[12] Herskovic JR, Tanaka LY, Hersh W, Bernstam EV. A Day in the Life of PubMed: Analysis of a Typical Day's Query Log. J Am Med Inform Assoc JAMIA. 2007;14(2):212–20.
[13] bricoleur-fast-medical-search - Building a highly efficient search engine for medical professionals - Google Project Hosting [Internet]. [cited 2013 Nov 26]. Available from: https://code.google.com/p/bricoleur-fast-medical-search/
[14] Jouis C, Biskri I, Ganascia J-G, Roux M, editors. Next Generation Search Engines: Advanced Models for Information Retrieval [Internet]. IGI Global; 2012 [cited 2013 Oct 28]. Available from: http://www.igi-global.com/chapter/framework-evaluating-retrieval-effectiveness-search/64437
[15] Trip Database [Internet]. [cited 2013 Oct 15]. Available from: http://www.tripdatabase.com/
[16] Coiera E, Walther M, Nguyen K, Lovell NH. Architecture for Knowledge-Based and Federated Search of Online Clinical Evidence. J Med Internet Res. 2005 Oct 24;7(5):e52.
[17] Khresmoi - Medical Information Analysis and Retrieval [Internet]. [cited 2010 Dec 6]. Available from: http://khresmoi.eu/

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A Mobile Logbook to Diagnose Masked Hypertension: a Pilot Application

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Abstract. In the last years, there has been a growing interest in health mobile applications. Great benefits could be gained by seemingly "simple" solutions if these were designed to build a bridge between doctors and patients. In this paper, we describe a mobile health solution for patients allowing them to measure and record accurately their blood pressure at home, helping doctors to diagnose hypertension. An accurate measurement of the blood pressure, in fact, is a prerequisite for appropriate management of hypertension, a condition causing many serious diseases. The peculiarity of the hypertension kit is that the system requires interaction between the patients and their general practitioner. Finally, we present a pilot study carried out to evaluate the acceptability of the technologies, the compliance of patient to the self-monitoring procedure and the perceived benefits and disadvantages of both doctor and patients in using this kit.

Keywords. M-health, hypertension, Personal Health Record, NFC.

Introduction

In the last years, there has been a bloom of health related mobile applications. This relatively new market has been hailed by many as a potential game changer in the relationships among health institutions and patients, providing the latter with the tools for empowerment and self-management. The large success of mobile health applications, though, is now mostly limited to the self-care practices with only limited connections to the clinical processes. This is partly due to the gap existing between the relative easiness in designing of health applications for patients and the complexities of rethinking clinical processes in which to embed new technical solutions. This gap is a major problem to be addresses to fully exploit the potential of m-health applications and to explore new forms of technologically enhanced patienthood characterized, among other things, by the increasing availability of easy-to-use and affordable patient-oriented medical devices [1].

In this work, we argue that great benefits could be gained also by seemingly "simple" applications if these were designed to build a bridge between doctors and patients. In the following pages, we shall describe an m-health solution designed to help doctors diagnosing hypertension. We shall start providing a short introduction about the clinical problem and then we shall describe the solution adopted.

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1. The clinical problem

High blood pressure (BP) is a major risk factor for stroke (ischemic and haemorrhagic), myocardial infarction, heart failure, chronic renal failure, peripheral vascular disease, cognitive impairment and premature death [2,3,4,5]. Untreated hypertension is associated with a progressive increase in blood pressure, a condition often resistant to any treatment because of associated vascular and renal damage.

An accurate measurement of blood pressure is a prerequisite for appropriate management of hypertension. This is generally done through Conventional Blood Pressure Measurement (CBPM), where a doctor measures BP using mercury, aneroid or electronic sphygmomanometers. The most recent guidelines on the treatment and management of hypertension, however, have shown a sharp appreciation of Home Blood Pressure Monitoring (HBPM), with the patient checking the blood pressure at home by herself, using an automatic blood pressure machine. [5]. HBPM is able to provide BP values relating to extended periods of time, it has lower costs, it is easily repeatable and generally well accepted by the patient. For these reasons, HBPM offers a better measurement, reducing the so-called "white coat effect" or "masked hypertension" [6] and allowing a better assessment of the usual blood pressure of the patient [7]. Despite these positive features, the HBPM is not yet considered a trustworthy method to diagnose hypertension. The main hindrance is that reliable HBPM measures need to be taken following a simple but strict protocol (two consecutive measures at one minute interval; always at the same time). This process cannot be controlled by doctors, who need to rely entirely on patients. Moreover, evidence suggests that transcribing measurements from the BP meter leads to errors and that these are more frequent in people with hypertension [8].

2. Methods

2.1. The technical solution

The “hypertension diagnostic kit” (Hyper-kit) is a tool devised by Fondazione Bruno Kessler (FBK). The aim is to allow patients to manage BP measurements taken at home and to ensure doctors about the reliability of the process. It is made of an off-the-shelf NFC (Near Field Communication)-enabled electronic BP monitor and a logbook application (Hyper-Logbook) for Android-based smartphones. The patient acquires BP data from the BP meter, simply touching the device with the smartphone, thus facilitating the error-prone data entry operation.

Unlike many other systems on the market, Hyper-kit requires interaction between patients and their general practitioners. Physicians instruct patients about the correct use of the BP meter and configure the logbook, i.e., the scheduling of the measurements, which the patient cannot change. Hyper-Logbook is visually organized as a paper-based agenda, with a calendar that automatically opens on the current day. The physician can set the advanced features of the application, which are:

- The configuration of the Hyper-Logbook: for each patient the doctor can insert a new plan for BP recording, setting different parameters: the duration of the measurement period; the frequency of the measurements (e.g., two daily measurements, one every n days, etc.); the time in which the patient has to

measure BP in a typical day. As the time for the measurement approaches, an automatic notification reminds the patient to measure the pressure.
- The display of a report of BP values entered in the logbook so far, with the description of the measurement plan and the averages of the diastolic ad systolic pressure, calculated from the values entered in the indicated period;
- The synchronization of the BP data with TreC, a citizen-controlled Personal Health Record [9]. All data in the Hyper-Logbook, in fact, are stored in a local database on the smartphone. On user's request, the application can connect with the central TreC platform to upload the BP data in the PHR database. This operation, in any cases, is proposed each time the user exits from the application, to guarantee an updated central backup of the local database.

Doctors can visualize the data collected in the Hyper-Logbook by their patients and uploaded to the central TreC in a web-based dashboard accessible through a web browser, after entering their login credentials.

2.2. Design of the study

To test the functionality and the portability of the application in a real General Practitioner (GP) ambulatory setting, we carried out a pilot study to evaluate the acceptability of the technologies, the compliance of patients to the self-monitoring procedure and the perceived benefits and disadvantages of both doctors and patients. In the period from August to October 2013, we provided the Hyper-kit (NFC equipped BP meters and smartphones with the Hyper-Logbook preinstalled) to three GPs. The GPs recruited 15 patients, according to the following criteria:
- subjects able to use a smartphone technology;
- patients with clinical suspicion of arterial hypertension, for whom the GP needed to confirm the diagnosis; or
- subjects with known diagnosis of hypertension whose blood pressure was out of range despite the therapy.

The only exclusion criterion was the presence of arrhythmias that affect the use of automatic BP meter. Each GP was in charge of programming the configuration of the Hyper-kit, in accordance with the criteria set out in the NICE Guidelines [10], namely:
- 7 consecutive days of BP measurements;
- 2 daily measurements sessions characterized by two measurements each (at a distance of 1 minute one from the other), one in the morning and the second in the evening at regular times indicated by patients.

At the end of the cycle of measurements, we administered to patients a satisfaction questionnaire and collected the opinions of the physicians.

3. Results

Of the 15 patients recruited for the study, 12 accomplished the entire cycle of measurements of the BP, while three stopped early for the malfunctioning of the application, namely software errors that blocked the application, without compromising the reliability of the data collected through the BP meter. The majority of patients (13) had previously high levels of BP and were already receiving at least one antihypertensive medication, enrolled because their BP values were not targeted. All

patients returned the filled questionnaires. The majority of them were male (male/female ratio of 4:1), with age between 52 and 67 years (mean age 59), and medium - high literacy. Most of them (14) already had a smartphone and judged their computer skills sufficient or good.

All patients measured BP at home with electronic devices; in addition, four patients used ABPM; i.e., home monitoring of the BP during 24 hours through holter.

3.1. Patients' opinions

The majority of patients were satisfied with the Hyper-kit and did not experience any problem in completing the cycle of measurements.

Among the difficulties reported by patients there were too short shutdown time of the application at the time of data transmission, the invasiveness of the audible alarm activated by the reminder, and the rigidity of the setting time for the measurements. One patient, in particular, emphasized that during the weekend he had to follow the same rhythms as the working days, although tolerable for him.

These difficulties, however, did not affect the smooth running of the recordings. The majority of patients (14) considered this tool useful to confirm or refute the diagnosis of hypertension. Compared to the measurement mode they used before the study, patients who had previously performed ABPM preferred the Hyper-kit, since all of them considered ABPM particularly annoying during the night; in the group of 11 patients that traditionally used HBPM, however, only six preferred the Hyper-kit respect to the traditional method.

3.2. Doctors' opinion

All doctors agreed that the "hypertension diagnostic kit" is less invasive, compared to ABPM, since it does not require measurements at night that heavily interfere with patients' sleep. Another reported advantage of this method was that the BP values measured are not editable, since the BP meter transfers them automatically to the phone via NFC technology. With traditional registration, doctors believe that patients often tend to adjust the values according to their needs. Two GPs, finally, envisaged the opportunity to educate patients through the app. By using these tools, in fact, not only patients become familiar with the concept of long-term follow-up, but they also understand that the goal of antihypertensive therapy is to achieve a stable target BP.

4. Discussion and conclusions

The result of the pilot study provides some indications both for the fine-tuning of the application and for reflecting more broadly on m-health diagnostic tools.

The Hyper-kit is highly appreciated by both doctors and patients. It combines the need for reliable information and controlled data acquisition process of the doctors with the easiness of use perceived by patients, who can also smoothly accommodate the measurements' routines in their daily life. However, the experimentation revealed some open issues to address before the deployment of the system. Apart from some minor bugs fixing and some problems related to the battery duration of the smartphone, the major limit of the applications is its scarce customizability. As a patient noted, for instance, the daily routines change during the weekend but the apps does not allow

modifying the measurements timing accordingly. Another complain regarded the "intrusiveness of the remainder" and the impossibility to disable it. Finally, while the use of the kit required only a few-minutes training during the consultation, some doctors considered this extra-time hard to find when working on a tight schedule.

The study offers some food for thought about m-health applications and their potential, reflecting on some peculiarities that distinguish it from other tools available on the market. In the case analyzed here, the devices with their technical features provide the prerequisite for success. However, their setup and combination guarantee it. On the one hand, measuring devices (e.g., the BP meter) are becoming more and more user-friendly, reliable, and affordable, offering the possibility to monitor parameters outside surgeries and with no need of professional assistance. On the other hand, though, these tools can be used in many different ways while the diagnostic process requires standardized and controllable procedures. Some of these procedures can be delegated to other tools (in our case the Hyper-Logbook) to ensure their correctness and consistency. Only with this combination, it is possible to delegate safely to patients or caregivers some tasks of the diagnostic process with reliable results.

In the future, we plan to perform a cost-effectiveness analysis to compare this method with others, with particular reference to HBPM.

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References

[1] Danholt P, Piras EM, Storni C, Zanutto A. The Shaping of Patient 2.0: Exploring Agencies, Technologies and Discourses in New Healthcare Practices. Science & Technology Studies 26 (2), 3-13
[2] Lewington S, Clarke R, Qizilbash N, Peto R, Collins R. Age-specific relevance of usual blood pressure to vascular mortality: a meta-analysis of individual data for one million adults in 61 prospective studies. Lancet 2002;360:1903–1913.
[3] Britton KA, Gaziano JM, Djousse L. Normal systolic blood pressure and risk of heart failure in US male physicians. Eur J Heart Fail 2009;11:1129–1134.
[4] Kalaitzidis RG, Bakris GL. Prehypertension: is it relevant for nephrologists? Kidney Int 2010;77:194–200.
[5] Brown DW, Giles WH, Greenlund KJ. Blood pressure parameters and risk of fatal stroke, NHANES II mortality study. Am J Hypertens 2007;20:338–341.
[6] Mancia G, Bertinieri G, Grassi G, Parati G, Pomidossi G, Ferrari A, Gregorini L, Zanchetti A. Effects of blood-pressure measurement by the doctor on patient's blood pressure and heart rate. Lancet 1983;2:695–698.
[7] Hodgkinson J, Mant J, Martin U, Guo B, Hobbs FDR, Deeks JJ, Heneghan C, Roberts N, McManus RJ. Relative effectiveness of clinic and home blood pressure monitoring compared with ambulatory blood pressure monitoring in diagnosis of hypertension: systematic review. BMJ. 2011; 342:d3621
[8] Johnson KA, Partsch DJ, Rippole LL, McVey DM. Reliability of self-reported blood pressure measurements. Archives of Internal Medicine. 1999; 159(22):2689-2693.
[9] Eccher C, Piras EM, Stenico M. TreC - a REST-based regional PHR. In: Anne Moen, Stig Kjær Andersen, Jos Aarts, Petter Hurlen (eds.) User Centred Networked Health Care - Proceedings of MIE 2011, Oslo Norway, Stud Health Technol Inform. 2011; 169:108-12.
[10] Ritchie LD, Campbell NC, Murchie P. New NICE guidelines for hypertension. BMJ 2011;343:d5644.

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A Reference Data Model of a Metadata Registry Preserving Semantics and Representations of Data Elements

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Abstract. Integration and analysis of clinical data collected in multiple data sources over a long period of time is a major challenge even when data warehouses and metadata registries are used. Since most metadata registries focus on describing data elements to establish domain consistent data definition and providing item libraries, hierarchical and temporal dependencies cannot be mapped. Therefore we developed and validated a reference data model, based on ISO/IEC 11179, which allows revision and branching control of conceptually similar data elements with heterogeneous definitions and representations.

Keywords. metadata registry, reference data model, heterogeneous data collection systems, data integration

Introduction

The integration and analysis of clinical data collected in various systems and over a long period of time has become a major challenge in medical care and research [1, 2]. The increased use of data warehouses simplifies this process by aggregating current and historical data into a central data repository [3]. However, data recorded in different systems, relational databases and spreadsheets is likely to be heterogeneous in its structure, inconsistent in its definition and often described insufficiently, which makes data integration a complex and time consuming task.

Metadata registries (MDR) can help to define the characteristics of data elements like their meaning and system-specific representation. Within *ISO/IEC 11179, Information Technology -- Metadata registries (MDR)* the structure of an MDR is described in detail, but it does not address the characteristics of metadata [4]. Thus, several solutions emerged, implementing ISO/IEC 11179 according to their specific purpose [5, 6]. Since all of these solutions focus on describing data elements to establish domain consistent data definitions, they are limited in representing variations of heterogeneous data elements across multiple data sources and over time. This makes it impossible to track a single data element, recorded e.g., for decades in various definitions and systems, with its modified semantics and representation. As an example,

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the documentation of the data element "diagnosis" changes when the classification renews, diagnostic procedures improve or simply the number of included diagnoses extends. Managing and mapping complex and heterogeneous data elements like "diagnosis", without a tool that supports the harmonization process, is even with modest-sized datasets almost impossible [5].

The main objective of this paper is to find a reference data model, based on ISO/IEC 11179, which allows generalizing data elements, preserving their semantics and representations, and identifying hierarchical and temporal dependencies. According to this specification we developed an MDR and validated it by entering all data elements recorded over two decades in multiple data collection systems in the Department of Multiple Myeloma, Heidelberg University Hospital. The data elements result from clinical routine care, observational and interventional studies of diagnosed and treated patients with multiple myeloma.

1. Methods

The data model of our MDR is based on open-source tools and on *ISO/IEC 11179, Information Technology -- Metadata registries (MDR)*, published by the International Organization for Standardization (ISO).

1.1. ISO/IEC 11179, Information Technology -- Metadata registries (MDR)

ISO/IEC 11179 defines a conceptual model to describe metadata, but does not specify an implementation. Metadata is regarded as data that defines and describes other data. A *Data Element*, which is the atomic unit of data that exists in a data collection system, is associated with a so-called *Data Element Concept* and a *Value Domain* according to the ISO/IEC standard. While the *Data Element* corresponds to a particular object described by its identifier, name, definition and other attributes, the *Data Element Concept* represents its semantic component and the *Value Domain* its representational component. A *Data Element Concept* is an abstract unit of knowledge, described independently of any representation that can be associated with multiple data elements. For example, certain conditions may require linking the data element "blood sugar" and "blood glucose level" to the same concept. The *Value Domain*, includes the data type (e.g., number, character, or date), unit of measure, permissible values, and permissible length (e.g., number of characters). In case of an enumerated list, the *Value Domain* is extended by a *Conceptual Domain*, which provides the permissible values of the enumeration.

1.2. Development Tools

For implementation of our MDR we used Valentina Studio as a visual database design tool, and PostgreSQL as a relational database management system because both are specific suited in their functionality to develop and edit a reference data model in a flexible manner and to convert it to a relational database for validation purposes. Both tools can be replaced by products with similar functions.

1.3. Verification datasets

The Department of Multiple Myeloma, Heidelberg University Hospital, has established a documentation system for recording myeloma-specific clinical data since 1992. Over these years, one of the most comprehensive and detailed clinical dataset for diagnosis and therapy of multiple myeloma has emerged. The dataset is used for scientific evaluations and enhanced by cytogenetic, imaging, or molecular data. Datasets exist in various file formats, were recorded with different purposes and guidelines, and are heterogeneous in data structure, definition, and quality. Therefore data have to be generalized and harmonized carefully before integration into a data warehouse.

2. Results

2.1. Reference data model of a metadata registry

The reference data model of our MDR is shown in Figure 1. It consists of five tables, with *DataElement*, *DataElementConcept* and *ValueDomain* as the most important ones.

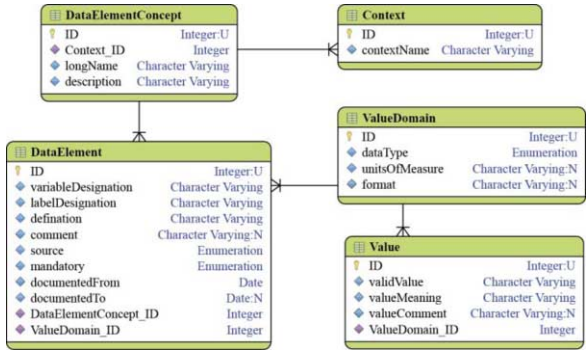


Figure 1. Reference data model of a metadata registry preserving semantics and representations.

All tables are identified with a numeric and unique **ID**. The remaining attributes describing a data element in table *DataElement* are:

- **variableDesignation:** symbolic name or designation of a data element used in the source code; normally only known by the administrator
- **labelDesignation:** refers to the data element´s name as it is visible on the graphical user interface
- **definition:** text field to describe meaning and semantics of a data element
- **comment:** text field in case of additional information, that is not part of the definition but critical to know
- **source:** a selection list, created by the administrator of the MDR, consisting of all possible data collection systems from which data elements are registered
- **mandatory:** three-valued logic (yes, no, unknown) to indicate that the data element is mandatory
- **documentedFrom:** date of recording the data element
- **documentedTo:** date up to which the data element has been recorded; if documentation is still ongoing, the unknown end date can be left blank

The characteristics of a data element concept, which can be associated with multiple data elements, in table *DataElementConcept* are the following:

- **Context_ID:** to assign multiple concepts to a single domain, we use a table named *Context*, which consists of a unique identifier and a name, to serve as a selection list, created and managed by the user of the MDR; the context is thereby on a more abstract level than the concept
- **longName:** abstract designation related to the corresponding data elements; in case a concept is only associated with a single data element, the concept's name corresponds to the data element's label
- **description:** abstract description related to the corresponding data elements; in case a concept is only associated with a single data element, the concept's description corresponds to the data element's definition

The representational component of a data element, in terms of its system-specific view, is described by table *ValueDomain*, which consists of these fields:

- **dataType:** selection list, created by the administrator of the MDR, consisting of all possible data types to which a data element can be assigned
- **unitsOfMeasure:** selection list, created by the administrator of the MDR, or a text field of the units of measurement. Whether a selection list or a free text is more appropriate should be decided depending on the expected number of different units and the level of standardization.
- **format:** to specify the permissible length of characters and of the number of decimal places; wildcards such as ?, * and # and decimal marks are used

If the value domain comprises a list of enumerated or ordinal items, the permissible values are specified in the table *Value*. The fields are described as follows:

- **validValue:** designation of the permissible value or the value itself; since values are often coded by an integer in data collection systems, and only the integer is stored instead of the value itself, both are accepted
- **valueMeaning:** a text field to describe meaning and semantics of a valid value
- **comment:** a text field in case of additional information, that is not part of the meaning but critical to know

2.2. Verification of the reference data model

For verification of the reference data model we entered all data elements from seven data collection systems used over the last two decades in the Department of Multiple Myeloma, Heidelberg University Hospital. Upon completion we obtained 660 data elements, assigned to 450 data element concepts with 500 value domains.

As an example, the data element "diagnosis" was recorded continuously in all data sources. Over the time it was expanded from Boolean to an enumeration list with three permitted values, later with five values, and was modified by adding the cancer stage to the diagnosis and lastly changed in 2013 from ICD-10 to ICD-11.

The different versions of the similar data elements were mapped in our reference data model by adding all seven data elements individually with their specific attributes and representations, and then linked to the data element concept "diagnosis" and described as "relevant diagnoses to be documented". Evaluation of the "diagnosis" data

can easily be achieved by comparing the different representations, and deciding if mapping and integration is appropriate.

3. Discussion

We successfully developed a reference data model that preserves semantics and representation and still performs a generalization by mapping to a conceptual level, to identify hierarchical and temporal dependencies. The advantage is that changes in metadata can be tracked across data source and over time. This provides a revision control of data elements, in terms of replacing a data element by its new version in one source, as well as branching, meaning that two or more conceptually similar data elements exist parallel in multiple sources. Analyzing revisions and branches of a data element can support harmonization, mapping and finally integration.

We used the conceptual model of ISO/IEC 11179 that describes the structure of metadata, but does not specify its characteristics and attributes. Our focus was preserving semantics and representations we deviated from the standard by not considering the relationship between Conceptual Domain and Date Element Concept. According to ISO/IEC this connection is used for Data Elements that share the same Data Element Concept, so that the conceptually related representations are shared as well. This was not necessary in our specification.

In many other groups implementing ISO/IEC 11179 an MDR is used as description tool to establish consistent data definitions and to provide an item library for setting up data collection forms for clinical trials [5, 6]. Since we did not want to cover an entire domain, but to depict the existing elements in an extensive and comprehensible way, our implementation differs. Our data scheme can be used in other domains as introduced above.

The distinctive feature of our implementation is that multiple revisions and branches of conceptually similar data elements with heterogeneous definitions and representations, can be managed, stored and overviewed.

Next, we plan to extend the data reference model to include validation rules to ensure logical integrity between different data elements and their values. This will allow us not only to represent semantic and representational dependencies within a data element concept, but also dependencies within the content.

References

[1] B. Louie, P. Mork, F. Martin-Sanchez, A. Halevy, P. Tarczy-Hornoch, Data integration and genomic medicine. *Journal of Biomedical Informatics* **40** (2007), 5–16.

[2] W. Sujansky, Heterogeneous Database Integration in Biomedicine. *Journal of Biomedical Informatics* **34** (2001), 285–298.

[3] S.N. Murphy, M.E. Mendis, D.A. Berkowitz, I. Kohane, H.C. Chueh, Integration of clinical and genetic data in the i2b2 architecture. *AMIA Annu Symp Proc* (2006), 1040.

[4] International Standards OrganizationISO/IEC 111179, Information Technology -- Metadata Registries. Available from URL:http://metadata-stds.org/11179/

[5] P.M. Nadkarni, C.A. Brandt, The Common Data Elements for cancer research: remarks on functions and structure. *Methods Inf Med* **45** (2006), 594–601.

[6] J. Stausberg, M. Löbe, P. Verplancke, J. Drepper, H. Herre, M. Löffler, Foundations of a metadata repository for databases of registers and trials. *Stud Health Technol Inform* **150** (2009), 409–413.

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Longitudinal Data Driven Study Design

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Abstract. In this paper we present a method for processing EHR data into a longitudinal data model and examples for using this model to identify patients cross-sectionally and longitudinally as well as testing study designs retrospectively. Our data model describes measurements on four dimensions: the associated patient, observed feature, data source and time of survey. The transformation of structured source data into our model is defined by rules written in XML. To showcase the flexibility of the proposed longitudinal data model, we present an evolution of a retrospective study design as well as an example for interpreting biomarkers in emergency situations. With the proposed longitudinal data model complex queries can be performed, study designs tested and optimized.

Keywords. Longitudinal Data, Entity-Attribute-Value Model, EHR, Secondary Use, Data Driven Study Design, Power Analysis

Introduction

Looking at patients cross-sectionally is a physician's daily work as well as the basis for prevalence-, intervention result- and other studies. However the progressive nature of many diseases typically requires a longitudinal examination. This means looking at a research subject at different points of time.

Longitudinal examinations at the Department of Cardiology, University Hospital Heidelberg, Germany often focus on progressive heart diseases with recurrence of symptoms during a follow-up period of multiple years. On the other hand, diagnosis of acute diseases requires biomarker changes within a few hours, a typical example being rule-in or rule-out of acute myocardial infarction. While some of the studies must be conducted prospectively, others are based on retrospective analysis of patient documentation, either written exams or structured data sources.

To reduce the amount of time spent on reading written exams for the purpose of research, the Research Warehouse project (RWH) was created with the goal of providing a platform for analysing structured patient data already existing in the department [1]. This platform is being used to perform retrospective studies: cross-sectional or longitudinal and to define cohorts based on a specific phenotype for genetic analysis. Sample size planning and power analysis can also be supported by providing access to observed values while simulating a prospective study design.

In this paper we present a method for processing structured data into a longitudinal data model and examples for the usage of this model to identify patients cross-sectionally and longitudinally as well as testing study designs retrospectively.

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1. Methods

Our data model describes measurements, events and other patient information on four dimensions: the associated patient, observed feature, data source and time of survey. This model is based on the Entity-Attribute-Value (EAV) paradigm and is used to store information from different sources in a single data table. The EAV model has been used in a number of different clinical applications [2],[3],[4]. Our model focuses on a single entity: The Patient.

A patient is distinguished by two pseudonyms based on identifiers from the hospital's master patient index: PSN1 and PSN2 respectively. These identifiers represent patient and case-based contexts.

By the use of a key-string, the feature or attribute of a stored value is described in a second metadata table with name, description and data type, an example being: *key: diagnostics.lab.hstnt; display-name: HSTNT; description: High sensitive cardiac Troponin T; value-type: Double*. The keys are split into five major groups: demographic-information, events, diagnostic procedures, non-pharmacological interventions and pharmaceutical therapies.

For each particular value, additional tracking information is stored. This meta-information associates each data point with the source system and position in the import data file: *SrcColumn*, *SrcRow* and *SrcJob*. Information on successfully or unsuccessfully imported data is stored in an additional database.

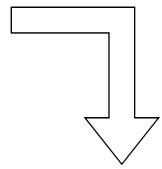
The fourth dimension stores the *time of survey* for every value. This information is derived from the data provided by the source system and varies in accuracy. The time of survey is stored as either *date only* or *date and time*.

The longitudinal data model is implemented, using a PostgreSQL database running on a virtualized Ubuntu 12.04. Data source integration, format normalization and patient identifier pseudonymization are handled by the RWH architecture [1],[5]. This architecture provides a fully automatic import process with monthly or weekly data deliveries. Currently structured information from cardiac catheterization results, MRI results, echocardiogram results, laboratory results, bio bank entries, Chest-Pain-Unit physician letters as well as ICD-10 and OPS codes are integrated.

The source data is processed by transformation rules written in XML. These rules define which columns are being used for patient identifiers, date / time and value. The attribute key-string is defined per rule by a constant or a switch-case over a source column value. These rules are used to provide a timeline of all known events and examination results for each patient. Figure 1 shows the transformation of laboratory

PSN1	PSN2	Identifier	Value	SpecimenReceivedDate
P11	P12	HSTNT	15	2014-01-06 12:45:30
P11	P12	KREA	0,93	2014-01-06 12:45:30
P11	P12	HSTNT	40	2014-01-06 15:50:12

Example Source Import Job with ID 1234



Transformation

PSN1	PSN2	Date	Time	Attribute	Value	SrcColumn	SrcRow	SrcJob
P11	P12	2014-01-06	12:45:30	diagnostics.lab.hstnt	15	Value	1	1234
P11	P12	2014-01-06	12:45:30	diagnostics.lab.krea	0,93	Value	2	1234
P11	P12	2014-01-06	15:50:12	diagnostics.lab.hstnt	40	Value	3	1234

Figure 1. Transformation of example lab values into the proposed longitudinal data model.

results into our data model as defined by the rule depicted in Figure 2. No filtering is performed during the import process.

```
<rules psn1-source="PSN1" psn2-source="PSN2">
  <entry source="Value">
    <timestamp source="SpecimenReceivedDate" pattern="yyyy-MM-dd HH:mm:ss"/>
    <attribute source="Identifier">
      <case key="HSTNT" value="diagnostics.lab.hstnt"/>
      <case key="KREA" value="diagnostics.lab.krea"/>
    </attribute>
  </entry>
</rules>
```

Figure 2. XML-Listing: Rule for transforming lab values.

As of May 2014, nine commercial and non-commercial information systems, for patient care or research are integrated into the longitudinal data model. These systems contain structured data in 59 relational tables with a total of 1217 columns. About one third of the data-volume is currently transformed by the use of 678 rules into 18,7 million data points. These values are covering an observation period of close to ten years.

2. Results

2.1. Retrospective data driven study design

To showcase the flexibility of the proposed longitudinal data model, we present the evolution of an analysis performed for the EU Inheritance project [6]. This project focuses on dilated cardiomyopathies (DCM)[2] and related genotype expression.

To identify patients diagnosed with DCM within our local cohort, we initially defined the main diagnosis DCM and a DNA sample available in our biorepository as inclusion criteria. The relational algebra statement (1) shows a transformation of the criteria onto our model.

$$S1 = (\pi_{psn1}(\sigma_{attribute = diagnostics.maindiagnosis \wedge value = DCM}(db)) \wedge \pi_{psn1}(\sigma_{attribute = diagnostics.maindiagnosis.icd \wedge value = I42.0}(db))) \cap \pi_{psn1}(\sigma_{attribute = procedures.biorepository.unique\_code}(db)) \quad (1)$$

To further substantiate the diagnosis, we extended statement (1) with additional inclusion criteria as follows: severely impaired cardiac function (LV EF <= 35 %) and dilated left ventricle (LV EDD > 55 mm), quantified by echocardiography or cardiac MRI as well as coronary artery stenosis, greater than 50 %, quantified by cardiac catheterization as an exclusion criteria, resulting in statement (2).

$$S2 = (S1 \cap \pi_{psn1}(\sigma_{(attribute = diagnostics.echo.lv\_ef \vee attribute = diagnostics.mri.lv\_ef) \wedge value <= 35}(db)) \cap \pi_{psn1}(\sigma_{(attribute = diagnostics.echo.lv\_edd \vee attribute = diagnostics.mri.lv\_edd) \wedge value > 55}(db))) \setminus \pi_{psn1}(\sigma_{attribute = diagnostics.cc.stenosis \wedge value >= 50}(db)) \quad (2)$$

[2] http://www.ncbi.nlm.nih.gov/mesh/?term=Cardiomyopathy,+Dilated

By ignoring the time of survey for all selected values, the result of statement (2) can be based on values observed at different times in the course of the disease especially if a patient had more than one echocardiogram, cardiac MRI or cardiac catheterization. This can be resolved by defining a timeframe of two weeks between the survey of the cardiac function / left ventricle diameter and cardiac catheterization, resulting in statement (3). For the purpose of clarity we define $\delta(d_x, d_y)$ as the number of days between date d_x and date d_y.

$$
\begin{aligned}
S3 = S1 \cap \rho_{psn1/ef\text{-}psn1} (\pi_{ef\text{-}psn1} (\sigma_{stenosis\text{-}psn1 = null} (\\
\rho_{ef\text{-}psn1/psn1,ef\text{-}date/date} (\pi_{psn1,\ date} (\sigma_{(attribute = diagnostics.echo.lv\_ef \vee attribute = diagnostics.mri.lv\_ef) \wedge \\
value <= 35} (db))) \\
\quad \bowtie_{ef\text{-}psn1 = edd\text{-}psn1 \wedge ef\text{-}date = edd\text{-}date} \\
\rho_{edd\text{-}psn1/psn1,edd\text{-}date/date} (\pi_{psn1,date} (\sigma_{(attribute = diagnostics.echo.lv\_edd \vee attribute = diagnostics.mri.lv\_edd) \wedge \\
value > 55} (db))) \\
\quad \bowtie_{ef\text{-}psn1= stenosis\text{-}psn1 \wedge \delta(ef\text{-}date, stenosis\text{-}date) <= 14} \\
\rho_{stenosis\text{-}psn1/psn1,stenosis\text{-}date/date} (\pi_{psn1,date} (\sigma_{attribute = diagnostics.cc.stenosis \wedge value >= 50} (db)))))) \qquad (3)
\end{aligned}
$$

Statement (3) can subsequently be used as an inclusion criterion for a prospective study. To determine changes in the cardiac function we can simulate follow up evaluations by adding additional measurements using self-joined sub-queries. These additional measurements are then transformed to *SELECT* statements and the time interval is determined by selecting join criteria based on the patient identifier and a relative time interval between the first and related follow up measurements.

2.2. Biomarker evaluation in emergency care

By defining a narrow timeframe we can adapt the evaluation schema for biomarkers in emergency situations. This example is based on the diagnosis of acute coronary syndromes using a set of subsequent Troponin T[3] assays three hours apart [7]. To account for deviations from this guideline in practice, we define a time window of 3 ± 1 hour. Statement (4) shows a transformation onto our data model using the function $\theta\,(d_x, t_x, d_y, t_y)$ to evaluate the number of hours between two date and time tuples $d_x\,t_x$ and $d_y\,t_y$.

$$
\begin{aligned}
S4 = \rho_{tnt1\text{-}psn1/psn1,tnt1\text{-}date/date,tnt1\text{-}time/time} (\pi_{psn1,date,time} (\sigma_{attribute = diagnostics.lab.hstnt} (db))) \\
\quad \bowtie_{tnt1\text{-}psn1 = tnt2\text{-}psn1 \wedge 2 \leq \theta(tnt1\text{-}date, tnt1\text{-}time, tnt2\text{-}date, tnt2\text{-}time) \geq 4} \\
\rho_{tnt2\text{-}psn1/psn1,tnt2\text{-}date/date,tnt2\text{-}time/time} (\pi_{psn1,date,time} (\sigma_{attribute = diagnostics.lab.hstnt} (db))) \\
\quad \bowtie_{tnt2\text{-}psn1 = tnt3\text{-}psn1 \wedge 2 \leq \theta(tnt2\text{-}date, tnt2\text{-}time, tnt3\text{-}date, tnt3\text{-}time) \geq 4} \\
\rho_{tnt3\text{-}psn1/psn1,tnt3\text{-}date/date,tnt3\text{-}time/time} (\pi_{psn1,date,time} (\sigma_{attribute = diagnostics.lab.hstnt} (db))) \qquad (4)
\end{aligned}
$$

3. Discussion

In this paper we present a data model for storing measurements, events and other patient-information in a longitudinal manner. This data model allows querying a data warehouse cross-sectionally, while using patient or case contexts provided by identifiers as well as longitudinally by defining arbitrary observation times. The

[3] http://www.ncbi.nlm.nih.gov/mesh/68020107

proposed data model is based on a simplified EAV model as it stores values only in relation to a patient entity. The addition of the *time of survey* as part of the value description allows for fast longitudinal queries.

The data model is used to store structured data from a variety of information system sources. Our implementation uses rules written in XML, to transform source data into the longitudinal model. No filtering of values is performed during the import process. A filtering of invalid values needs to be performed on a query by query basis; this retains the flexibility to reject values in certain situations or to include them in others.

Assessing the data quality and applicability is still a manual process and usually requires an in-depth discussion between computer- and medical scientists. Moreover a sufficient and robust assessment typically also requires knowledge about the processes leading to the acquisition of the measurements. With our data model every value can be associated with the data source and time of import. This information is indispensable in tracking systematic errors.

In conventional EHR systems data structures are motivated by administrative reasons. These patterns often do not reflect the natural course of a disease especially in continuously proceeding illnesses. Monitoring of such illnesses requires a long-term observation independent of accounting periods. In this context flexible observation periods can be defined and adapted for individual parameters with the proposed data model.

In summary the RWH and this longitudinal data model should enable us to design prospective studies by retrospectively testing inclusion criteria, and characterizing expected cohort sizes and compositions. This analysis could also enable a better estimation of the significance and variance of each individual biomarkers used for the inclusion and observation of patients during the course of the study. Not at least this might lead to optimized study designs and more precise data driven power-analysis.

While our data model has already been evaluated for defining cohorts retrospectively using cross-sectional and longitudinal examinations as well as extracting measurements for already defined cohorts, the potential for optimizing prospective study designs is work in progress.

References

[1] Hund H, Gerth S, Loßnitzer D, Fegeler C. Erschließung von klinischen Routinedaten für die medizinische Forschung, *Proceedings of 56. Jahrestagung der GMDS* (2011). German.

[2] Friedman C, Hripcsak G, Johnson SB, Cimino JJ, Clayton PD. A Generalized Relational Schema for an Integrated Clinical Patient Database, *Proceedings of Annual Symposium on Computer Application in Medical Care* (1990), 335–339.

[3] Huff SM, Haug PJ, Stevens LE, Dupont RC, Pryor TA. HELP The Next Generation: A new Client-Server Architecture, *Proceedings of Annual Symposium on Computer Application in Medical Care* (1994), 271-275.

[4] Nadkarni PM, Marenco L, Chen R, Skoufos E, Shepherd G, Miller P. Organization of Heterogeneous Scientific Data Using the EAV/CR Representation, *Journal of the American Medical Informatics Association* **6** (1999), 478-493.

[5] Hund H, Graupner H, Gerth S, Loßnitzer D, Fegeler C. Webservice zur sicheren Pseudonymisierung durch Datentreuhänder, *Proceedings of 57. Jahrestagung der GMDS* (2012). German.

[6] Arbustini E. The INHERITANCE Project, http://www.inheritanceproject.eu, last accessed 12.07.2014

[7] Thygesen K, Alpert JS, Jaffe AS, Simoons ML, Chaitman BR, White HD. Third universal definition of myocardial infarction, *European Heart Journal* **33** (2012), 2551–2567

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End Users Transforming Experiences into Formal Information and Process Models for Personalised Health Interventions

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Abstract. Five physiotherapists organised a user-centric design process of a knowledge-based support system for promoting exercise and preventing falls. The process integrated focus group studies with 17 older adults and prototyping. The transformation of informal medical and rehabilitation expertise and older adults' experiences into formal information and process models during the development was studied. As tool they used ACKTUS, a development platform for knowledge-based applications. The process became agile and incremental, partly due to the diversity of expectations and preferences among both older adults and physiotherapists, and the participatory approach to design and development. In addition, there was a need to develop the knowledge content alongside with the formal models and their presentations, which allowed the participants to test hands-on and evaluate the ideas, content and design. The resulting application is modular, extendable, flexible and adaptable to the individual end user. Moreover, the physiotherapists are able to modify the information and process models, and in this way further develop the application. The main constraint was found to be the lack of support for the initial phase of concept modelling, which lead to a re-designed user interface and functionality of ACKTUS.

Keywords. Physiotherapy, Intervention, Fall prevention, End-user development, Socio-technical systems, Participatory action design

Introduction

There is a common understanding that future users of a computer system should be involved in the design and development process as early as possible. Methodologies such as human factors engineering [1], socio-technical frameworks [2], participatory design [3], participatory action research [4], and user-centred development all aim at involving future users to different extent. The role of the users differs, from being an active stakeholder, to contributing in evaluation studies with their perspective. Typically, they contribute with their experiences, knowledge and preferences, which are transformed by knowledge engineers and designers from informal into formal representations integrated in working prototypes and systems. This knowledge bottleneck is well-known and research efforts have aimed at bridging the divide between the two (e.g., [5]).

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Another obstacle is visible when knowledge-based systems are developed for improving patients' and clients' health. For improving health, changes in behaviour are often strived for, e.g., increasing physical activity and changing food intake aiming at healthier habits (e.g., [6]). For accomplishing this, motivational structures are essential, which also need to be considered and integrated in the design and content of a health application. Such knowledge can also be collected during a design process, which involves end-users. However, regardless type of knowledge or its source, it needs to be integrated into formal structures to be computable by a supporting system.

The aim for the work presented in this paper was to study a design process where a group of end-users who are experts in a particular domain, however, not experienced in knowledge engineering, are given the opportunity to collaboratively formalise the content related to the knowledge domain and design the interaction with the content, i.e., as a *sociotechnical innovation system* as described in [7]. The end-user development process is described, analysed, and a model of the emerging design process was created. The model was discussed together with factors, which functioned as facilitators and constraints in the process.

1. Methods

We identified two end user groups in our sociotechnical innovation system. One group consisted of 17 older adults, which was divided into two groups in meetings, and one group of five physiotherapists specialised on fall prevention. Both groups were also considered as stakeholders. Ten focus groups meetings were held with different content, all containing both older adults and physiotherapists.

We identified also two design processes both aiming to develop an application for promoting exercise and preventing fall incidents. The first process was organised by physiotherapists following the method Participatory and Appreciative Action and Reflexion (PAAR), which focuses on the end users' successful experiences and builds on these in the creation of new technology [8]. The second design process, supplementing the PAAR process, focused on the knowledge content, and the potential learning and behaviour change effects of the use of the resulting application. The second design process took the form of an end-user development process where the group of physiotherapists transformed their knowledge, experiences and expertise into formal models leading to interactive prototypes, which were evaluated with the older adults in an iterative process. Consequently, results of the first design process were fed into the second design process. In our study we take particular interest in the second process.

ACKTUS was used by the physiotherapists as a platform for knowledge engineering and prototyping [9]. ACKTUS integrates a generic semantic model, based on models of human activity, the International Classification of Functioning, Ability and Health (ICF) and other medical terminologies, which can be expanded into higher granularity specific for a knowledge domain. None of the physiotherapists had prior experience in knowledge engineering, but were guided by a knowledge engineer in the process.

These design processes and their outcomes were analysed from a socio-technical perspective with a focus on the transformation of informal knowledge, expertise and experience into formal information and process models.

2. Results

The results are divided into the process of identifying the categories of relevant entities, which are key for representing *factual* knowledge, and the modelling, visualisation and evaluation of flows, actions and decisions, i.e., *process knowledge*.

2.1. Identifying and modeling relevant entities

After eight workshop sessions with the older adults, a range of information and ideas had been identified, discussed and prioritized. The participants had created a perception of how a system supporting fall-preventive exercises could be designed and function. However, a common model had not yet been formed. At this point, the physiotherapists had a meeting with the knowledge engineer and began to structure the content and the flow of interaction. The knowledge engineer guided the physiotherapists in the organization of the potential content. This was done by reflecting on their proposals and visions, which they based on both the older adults experiences and on their own expertise. This was also done by drawing a map with key concepts and their relations. At this point, the physiotherapists began to organize the concepts into categories along different axes. These different axes became different perspectives on the knowledge domain, for example, one axis represented different environments, another physiological functions and processes and a third different levels of strain, which a physical exercise may cause. Examples of key elements that were identified were *instructions, movies with instructions, questions with answer alternatives, decisions* and *advice*. Key categories, which represent or involve groups of elements were also identified, e.g., *categories of exercises* following a theme or concept. ACKTUS provided tools for the creation, re-arrangement of entities and concepts, but was considered insufficient in providing overview in the initial collaborative sketching. As a consequence, whiteboards were used as supplement.

After another two workshops with the end users, the physiotherapists' knowledge engineering focus was broadened to include also different additional perspectives on the knowledge about risks, e.g., research on the topic. The physiotherapists also envisioned additional sources of assessment information, e.g., from sensor-based tests or traditional assessments. Moreover, during the workshops different aspects on a potentially proactive behavior in the application, such as reminders were discussed, leading to identifying additional elements such as *reminders, advice, schedules, accomplishments, routines* and *feedback*.

The two groups' contributions to the application were visible also in the different everyday exercises, which they had suggested, and which the physiotherapists had recorded and implemented.

2.2. Modeling flows and decisions

During the initial meeting with the knowledge engineer the potential behaviors of the system was outlined by the physiotherapists. The physiotherapists' key goals were *personalized services* (e.g., tailored exercises and advice), *educational* benefits and *motivational* benefits. As a consequence of the tailoring requirement, the physiotherapists began to discuss how *assessment of function and ability in a user* could be accomplished through the use of the system. This was perceived as necessary

to build a base for personalization. The concept of an *interactive guide* leading to an assessment and tailored exercise program was formed.

The different categorizations of objects implemented in the system became instruments for modeling the *assessment* as a procedure. The categorization of *preferences* was selected as the structure at the highest level in the model. This preference level regarded the *context of exercises* (e.g., location). The second level was structured by a categorization of *physiological motives for exercises*, e.g., gaining strength and balance. One goal of the assessment was to find the most suitable exercise targeting each of the purposes for each individual. The second goal was to generate a tailored set of exercises for each user, which forms the base for a personalized exercise program. The baseline assessment could then be used for following up the outcome of exercises. This set was to be extended with additional preferred exercises by the user.

The physiotherapists composed sets of objects representing exercises with different *levels of demand* for each category of exercise motives. The purpose was to guide the user towards a suitable level by comparing different exercises. The level of demand was represented differently in different versions, in the final version simply by a number in an ordered list within a category.

The physiotherapists created questions with a set of answer alternatives, which were used in the assessments for the user to value an exercise. For accomplishing the adaptation to the user, the physiotherapists also modeled decision-nodes. Based on what the user answered, they could either be presented alternative more suitable exercises, an advice or a confirmation that the exercise was suitable and added to the user's exercise program.

A significant observation made during the workshop sessions was the wide variety of opinions and suggestions for change, which was expressed, where the participants often had contradictory opinions. In particular, there were different opinions about tailored support and to which degree the application should guide and propose exercises and advice. As a consequence, a large degree of flexibility was strived for.

3. Discussion

Five physiotherapists organised a user-centric design process of a knowledge-based support system for promoting exercise and preventing falls, which included a group of end users. This study focussed the transformation of informal medical and rehabilitation expertise and older adults' experiences into formal information and process models during the development. It was found that the process became agile and incremental, when the process was organised and driven by the physiotherapists. This was partly due to the diversity of expectations and preferences among both older adults and physiotherapists and the participatory approach to design and development. There was a need to develop the knowledge content alongside with the formal models and their presentations. As tool they used ACKTUS for modelling the content and designing the interaction, which allowed the participants to test hands-on and iteratively evaluate the ideas, content and design. The lack of directly applicable domain knowledge constituted the major challenge and difference compared to earlier work on formalising knowledge in the medical and health domain, which has focused on domains where there are clinical practice guidelines and treatment protocols available (e.g., [5, 10]). This puts demands on both the design process model and the

tools for knowledge modelling, which need to allow loosely conceptual models to be revised and refined into more firm constructs.

The physiotherapists had no prior experiences in knowledge engineering, however, some in user interface design. The knowledge modeling system ACKTUS functioned as a tool for achieving the goal of developing a working prototype, and as such it functioned as the main facilitator for bridging the gap between informal results from applying participatory design methods and the formal requirements specifications necessary for realizing a working prototype. Even if the health professionals needed guidance to initiate the knowledge engineering in terms of organizing their information and making use of the building blocks in the system, they managed to transform their knowledge into computable formal models. Primarily, since it allowed the physiotherapists model the content and behavior of the system following their ambitions, experience and understanding of what the participating older adults need and desire. However, ACKTUS provided insufficient overview of entities in the initial phase of concept development, which lead to a redesign of the user interface and the implementation of additional functionality as a part of the design and development process.

The resulting application is modular, extendable, flexible and adaptable to the individual end user. Moreover, the physiotherapists are able to modify the information and process models, and in this way further develop the application. The application will be used in intervention studies for the purpose to study its effects on the end user's activity, motivation and health.

References

[1] Beuscart-Zéphir MC, Elkin P, Pelayo S, Beuscart R. The Human Factors Engineering Approach to Biomedical Informatics Projects: State of the Art, Results, Benefits and Challenges. Yearb Med Inform. 2007:109-27.

[2] Coiera E. Putting the technical back into socio-technical systems research, Int J med Inf 2002;76(S1):98-103.

[3] Häkkinen H, Korpela M. A participatory assessment of IS integration needs in maternity clinics using activity theory. Int J Med Inform. 2007;76(11-12):843-9.

[4] Simonsen J, Hertzum M. Iterative Participatory Design. In: Simonsen J, Bærenholdt JO, Büscher M, Scheuer JD, editors. Design Research: Synergies from Interdisciplinary Perspectives. London, UK: Routledge; 2010. p. 16-32.

[5] Seyfang A, Miksch S, Marcos M, Wittenberg J, Polo-Conde C, Rosenbrand K. Bridging the Gap between Informal and Formal Guideline Representations. In: Brewka G, Coradeschi S, Perini A, Traverso P, editors. ECAI 2006. Frontiers in Artificial Intelligence and Applications, vol. 141. Amsterdam: IOS Press; 2006. p. 447–51.

[6] Colineau A, Paris C. Motivating reflection about health within the family: the use of goal setting and tailored feedback. UMUAI 2011;21(4-5):341-76.

[7] Lindgren H. Sociotechnical Systems as Innovation Systems in the Medical and Health Domain. Stud Health Technol Inform. 2013;194:35-40.

[8] Gaye T, Melander-Wikman A, Kisare M, Chanbers P, Bergmark U, Kostenius C, et al. Participatory and appreciative action and reflection (PAAR) – democratizing reflective practices, Reflective Practice: International and Multidisciplinary Perspectives. 2013;9(4):361-97.

[9] Lindgren H, Nilsson I. Towards User-Authored Agent Dialogues for Assessment in Personalised Ambient Assisted Living. Int J of Web Engineering and Technology, 2013;8(2):154-76.

[10] Hatsek A, Shahar Y, Taieb-Maimon M, Shalom E, Klimov D, Lunenfeld E. A Scalable Architecture for Incremental Specification and Maintenance of Procedural and Declarative Clinical Decision-Support Knowledge. Open Med Inform J. 2010;4:255-77.

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Towards IHE Profiles for e-Supply in the Healthcare Domain

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Abstract. Procurement and supply belong to the crucial supporting processes in hospitals. By providing the right products at the right time in the right quantity in the right place, these processes are of major importance for patient safety and the success of the primary hospital process *cure and care*. Though of such an importance, the hospital's internal and external procurement and supply processes are still not performed seamlessly by information systems, due to a variety of electronic standards for procurement and supply. These different standards and missing guidelines for electronic procurement and supply in the healthcare domain lead to little or no interoperability between the participating procurement and supply systems. Consequences can be delayed or wrong supply, and increased costs. To overcome this deficiency this work describes the derivation of a common guideline for the implementation of electronically enabled supply processes in the healthcare domain based upon the identification of commonly used electronic standards and detailed specifications of procurement processes in hospital facilities.

Keywords. e-procurement, e-supply, healthcare, IHE, standardization, interoperability

Introduction

Integrating the Healthcare Enterprise (IHE) [1] is an initiative of healthcare professionals and system vendors focused on streamlining the way computer systems share information. It does not provide additional standards, but frameworks, guidance and best practices on implementing existing standards. IHE is focused on real-life integration problems, and provides a validated way to establish guidance for system architectures in several clinical domains – from radiology to laboratory - and in the IT infrastructure, covering aspects from security to privacy and data exchange across different institutions.

One pervasive aspect in healthcare information management is the supply and procurement of healthcare products as described by [2]. Besides being present in

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different areas of care, it contains clinical (safety, traceability) as well as operational (billing, operational efficiency) concerns. Several standards exist for parts of this process – typically the procurement aspects are addressed with commercially-minded systems, while the ordering and tracking are embedded in clinical systems. While there are standards and guidance for these clinical and operational aspects separately, there is no clear overall continuous integration. This gap has several reasons – e.g. the great diversity of business models and clinical workflows, the necessary separation of responsibilities, and several technical aspects. As a consequence, there are several questions unaddressed in patient and population safety, and in product tracking and efficient management. Lacking guidance, the systems tend to be implemented in an isolated manner (across countries or across domains within the same institution).

We propose to define and quantify this problem and the solution constraints, and promote a solution in the manner of an IHE profile, which will then follow the established IHE process [3] – validation by users, experts and vendors, engagement with Standards Developing Organizations (SDOs), and definition and implementation of an IHE profile.

1. Methods

To identify relevant information for the creation of potential IHE profiles for e-supply in the healthcare domain, we used various methods.

First, we performed a literature research to identify all available standards able to electronically support commerce, procurement and supply processes in general. Furthermore, we refined this research to identify specific electronic standards of the healthcare domain. The result was a detailed standards inventory.

Based upon this inventory, the second step was to determine the use of the collected standards in the healthcare domain. Therefore we developed structured questionnaires for all relevant stakeholders including hospitals, producers of medical devices, group purchasing organizations, health business solution providers, resident doctors and laboratories. At this point of time 41 German health care market participants have answered this questionnaire. During each of these 41 interviews an average number of 160 questions were asked, regarding for example the use of specific electronic standards for product identification and classification within purchase departments of hospitals. The current average response rate is 77%. All received information is integrated into a database, peer-reviewed and available for all present and future analyses.

In addition to the questionnaire survey, we analyzed the procurement and supply processes at two German hospitals: *Heidelberg University Hospital* and *Community Hospital Heinsberg*. At each hospital we performed interviews with procurement and supply experts, observed and assisted daily work at the hospital pharmacy, purchasing department and various clinical departments, and examined already available documentation on procurement and supply processes. Based upon these information sources we modelled holistic procurement and supply processes for each hospital using Business Process Model and Notation (BPMN) [4] as graphical representation. The designed processes can be subdivided into high-level business processes and technical workflows.

Finally, we performed a system analysis at *Heidelberg University Hospital* to determine all information systems involved in the procurement and supply process. The

resulting system landscape is modelled using the Unified Modeling Language (UML) [5] and provides detailed information on the systems' interfaces and exchanged data structures.

All results from literature research, questionnaire survey, process and system analyses were merged and resulted in the initial IHE integration profile candidates for e-supply described in the following chapter.

2. Results

IHE's aim is to analyze clinical use cases with regard to improved IT support, define generic integration workflows (IHE integration profiles) and specify reusable components (IHE actors) sending and receiving required messages (IHE transactions) based on existing and stable international standards like TCP/IP, W3C messaging and services as well as clinical IT standards like DICOM and HL7. IHE integration profiles are grouped by medical domains and especially the IHE radiology domain has transformed the radiological routine, because users rely on IHE-compliant products – as radiology-related tenders clearly indicate – such that product manufacturers are forced to offer IHE-compliant products.

The great success of the IHE radiology domain guided our work towards supporting the procurement and supply process in hospitals. Based upon an initial analysis of the results provided by the literature research, questionnaire survey, and process and system analysis, nine distinct areas are revealed where the IHE approach may improve and accelerate procurement and supply in hospitals. These areas constitute initial candidates for IHE integration profiles for e-supply and are listed below:

- *Point-of-care order:* Order of stock-keeping or non-stock-keeping products performed by an end user like a physician or nurse
- *Catalog management:* Maintenance and distribution of product master data and supplier information
- *Stock management:* Reorder of stock-keeping products and stock-control
- *Claims and payments:* Management and handling of invoices, creditors, liabilities, demand notes and credit items (in case of product returns)
- *Assets invested:* Identification and tagging of assets for inventory and further tracing
- *Supply chain intelligence:* Methods regarding commercial and technical analyses of the supply chain and the procurement process
- *Logistics and distribution:* Management and optimization of the physical distribution regarding the ordered products
- *Quality and validation:* Total data quality management with regard to the entire procurement and supply process
- *Medical reasoning and lookup:* Clinical/pharmacological knowledge base for inference, e.g. as a support for searching a specific product

Each of these potential IHE integration profiles consists of various IHE actors and corresponding IHE transactions identified by further analyzing the process models of *Heidelberg University Hospital* and *Community Hospital Heinsberg*. In the following, two designed IHE integration profile candidates for e-supply are listed exemplarily. Uppercase indicates IHE actors.

The first possible IHE integration profile is *Point-of-care order*. It describes the creation and internal forwarding of an electronic procurement order by an ORDER PLACER at the point-of-care towards an internal ORDER RESPONDER, like a stock, pharmacy, workshop or internal procurement office. This profile neither describes the order permission, nor the order routing, nor any contract with external parties. An order may contain one or multiple different order items, each describing a product that is specified in a product catalog and verified a-priori by the ITEM CHECKER. Successfully checked items are placed into the order which is forwarded to exactly one ORDER RESPONDER. Different ORDER RESPONDERs may be assigned to handle different types of items. The ORDER RESPONDER is responsible for delivering, making or purchasing of items. An additional ORDER REVIEWER allows for examining a candidate order as a whole and responds with a modified order, which may substitute the ordered items, limit or complete the quantities and may also change the units of measure. Figure 1 depicts this profile's actors and transactions. Each transaction can be identified by a unique key, e.g. SUP-1.

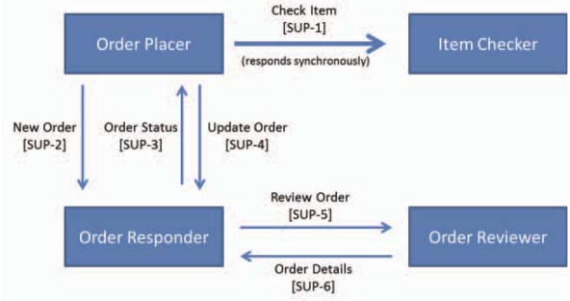


Figure 1. Possible IHE integration profile for *Point-of-care order*

A second possible IHE integration profile is *Stock management*. It describes stock resupply initiated by the actor STOCK. Based upon refill strategies, a refill request is forwarded to the actor RESUPPLY responsible for providing the required items. The actor RESUPPLY is allowed to forward the received refill request to another RESUPPLY actor in a cascaded manner. Thus, the *Stock management* profile can be used to implement various levels of resupply within a hospital and across its boundaries. Figure 2 illustrates this profile.

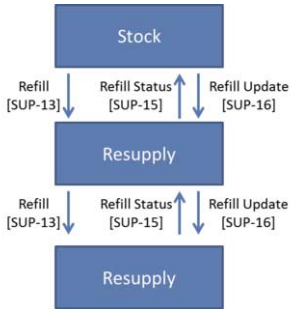


Figure 2. Possible IHE integration profile for *Stock management*

As IHE allows combining various integration profiles and its actors, it becomes possible to set up system architectures facilitating complex process flows. Figure 3 illustrates an exemplary order process based upon the combination of the described IHE integration profile candidates *Point-of-care order* and *Stock management*.

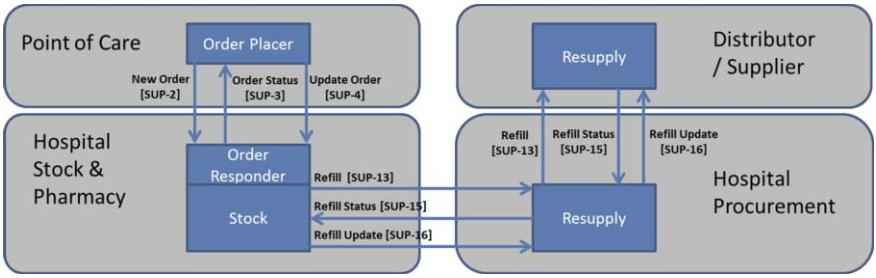


Figure 3. Exemplary order process based upon potential IHE integration profiles

3. Discussion

The potential IHE integration profiles presented in this paper are just an initial step towards a broad and approved set of IHE integration profiles for e-supply. Further effort is needed to refine these profile candidates and to assure its completeness. Especially the IHE transactions between the various IHE actors must be specified in detail, including technical protocols and data structures. Therefore, adequate international standards have to be selected. Important contributions regarding these standards can be extracted from the work of GS1 [6], especially their work for the healthcare domain [7]. Additionally, the potential IHE integration profiles for e-supply have to be aligned with existing IHE integration profiles, like the profiles of IHE pharmacy [8], as these may already define use cases, actors and transactions in some relevant scenarios for ordering and dispensing medicinal products. Finally, an official IHE process regarding e-supply has to be established.

During the performed questionnaire survey – which should be broadened to multiple countries – it became apparent that almost all stakeholders within the healthcare domain await guidance regarding planning and realization of electronically supported procurement and supply processes. Thus, our approach towards IHE integration profiles for e-supply facilitates bridging this gap.

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References

[1] IHE [Internet]. 2013 [cited 2014 Jan 07]. Available from: http://www.ihe.net/
[2] Hübner U, Elmhorst MA, editors. e-Business in Healthcare - From eProcurement to Supply Chain Management. London: Springer; 2008.
[3] IHE Process [Internet]. 2013 [cited 2014 Jan 23]. Available from: http://www.ihe.net/IHE_Process/
[4] BPMN Specification [Internet]. 2014 [cited 2014 Jan 08]. Available from: http://www.bpmn.org/
[5] Unified Modeling Language [Internet]. 2014 [cited 2014 Jan 08]. Available from: http://www.uml.org/
[6] GS1 Standards Knowledge Centre [Internet]. 2014 [cited 2014 Jan 21]. Available from: http://www.gs1.org/gsmp/kc/
[7] Bernasconi C, Hay C, Schneider C. Supply Chain Management im Schweizer Gesundheitswesen - Leitfaden für den Einsatz des GS1 Systems. Bern: GS1 Schweiz; 2013.
[8] IHE Pharmacy [Internet]. 2013 [cited 2014 Jan 13]. Available from: http://www.ihe.net/Pharmacy/

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Separation of Personal Data in a Biobank Information System

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Abstract. Separation of different types of personal data has been introduced as an effective measure to improve data protection in the context of medical research. In particular, research associated with human biomaterials requires not only secure technologies but also trustworthy processing of personal data on a need-to-know basis. Web-based information systems make use of a technological infrastructure that is well suited to distributed data repositories and remote processing systems. This approach was successfully applied to develop an information system supporting acquisition, processing and storage of remnant biomaterial from surgical treatment, as well as its allocation to research projects. In order to enhance data protection, the contents of the originally unified database were divided into identification data and medical data. A web application was created for each part and appropriate functionality to maintain and access corresponding data was developed. It is concluded that a distribution of biobanking data across separate databases can be achieved if workflows and staff roles are redesigned accordingly.

Keywords. Biobanking, Data Protection

Introduction

Routine, quality managed sample and data collection in a clinical context, frequently referred to as "biobanking", can be seen as a prerequisite in advancing translational research [1]. Critical factors, especially for biomarker validation, are not only the molecular quality of the physical sample, but include data annotation and management [2]. Therefore, appropriate IT-support is essential. In cooperation with the Clinic for General, Visceral, Transplantation, Vascular and Thoracic Surgery at Munich University Medical Centre and the Human Tissue & Cell Research (HTCR) Foundation, the Institute for Medical Informatics, Biometry and Epidemiology (IBE) at the University of Munich has developed a web based application for standardized data entry, central data management, sample storage and allocation as well as documentation, including reports, subsequently termed "HTCR Web Application".

The HTCR Foundation was established in 2000 in Regensburg, Germany with the intent to provide a "honest broker model" [3] to foster in-vitro-research with human tissues, with the foundation acting as the donors' trustee across institutions involved in

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sample and data collection as well as research. HTCR asks patients in cooperating clinics for their consent and transfer of ownership of remnant tissues and blood samples to the foundation for use by researchers under the terms of the HTCR-framework of rules and regulations. [3,4]

This special role as an external governance body is particularly important in context of "Biobanking for Research in Surgery" [5] and its project related workflow, where "starting from a clinical or scientific hypothesis, donor identification and selection is the first step in a long chain of generating information towards biobanking."[5, p. 492]. In its support of research based on human specimen, HTCR bears responsibility to its donors for full transparency of sample storage and use in line with data protection considerations. This commitment can only be fulfilled by generating samples with high quality documentation while at the same time making the information available on a strict need-to-know basis with appropriate safeguards.

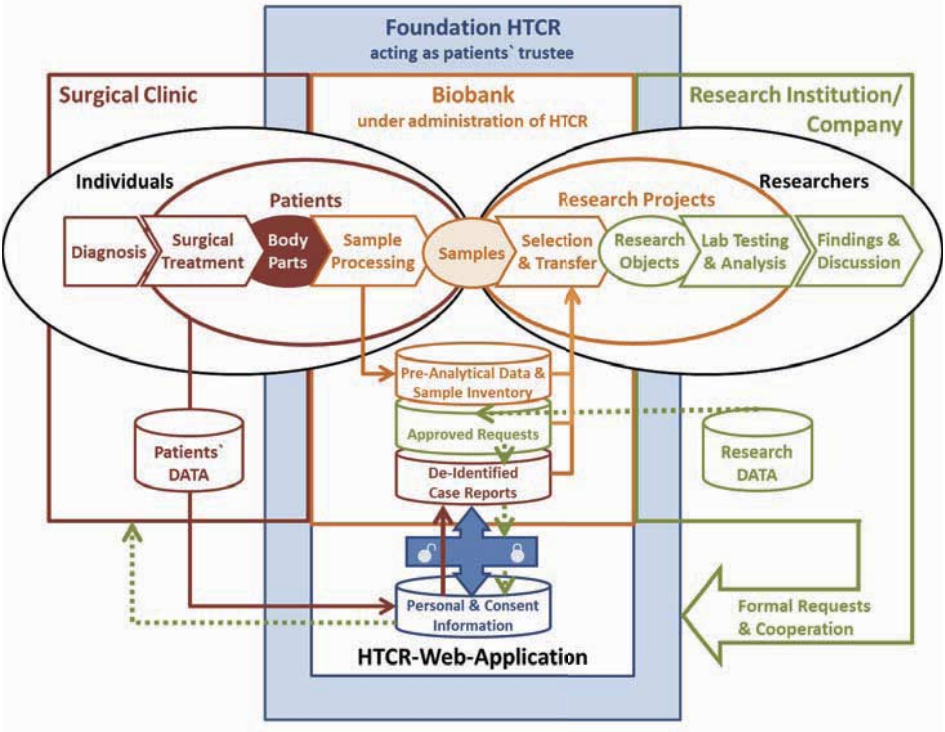


Figure 1. Overview of biobank workflow.

Fig. 1 illustrates the HTCR Web application's role within the general context of the biobanking process it is meant to support. The overall challenge for this process is to transform tissue removed from identified individuals entering the clinical context for surgical treatment into adequately annotated and at the same time anonymized samples to be used in the context of research projects.

In this paper we describe an enhancement of the HTCR Web Application that effectively alters it into a distributed information system, using separate storage for 1)

personal identification data and 2) de-identified medical data as well as sample and project related data in two different, physically separated data bases as a key safeguard.

The experiences gained during this transformation process may serve to improve data protection in other kinds of research data repositories or even provide design hints for a generic implementation of similar distributed web applications.

1. Methods

The HTCR Web Application is implemented using a web forms generator and development kit called "dbform" that has been developed for electronic data capture in clinical research projects at the IBE. The base system has already been used in a number of projects as described previously [6]. In brief, it is based on standard open source components widely used in web applications, including the operating system Linux, the database management system PostgreSQL and the Apache web server. The web forms generator and the associated tools are implemented in object-oriented Perl. The base system is instantiated for each data capture project. The bulk of the data capture characteristics contained in a tabulated data dictionary. This includes role-based access control allowing the definition of arbitrary roles. In addition, presentation and functionality can be changed or extended using HTML/JavaScript templates and a variety of programming interfaces.

Additional functionality to support a hidden linkage of two separate databases, or more precisely, two web-application instances has recently been developed. This feature allows corresponding structures in both databases to be created and maintained in a consistent manner. Interlocking of information is maintained by a common reference key stored in both databases, but not circulated elsewhere. [7]

In the HTCR Web Application this feature is now used to separate donor identification data from associated clinical data and sample data. Implementing this separation in a manner that would improve data protection in turn involved changes in the biobank operational processes. Co-ordination of application development and changes in the biobank standard operations was accomplished through regular meetings with biobank staff and the HTCR data protection officer.

2. Results

The basic requirement to store donor identification data (IDAT) such as name or date of birth separate from information related to the biomaterial sample(s) and the donor's clinical condition (medical data; MDAT) stems from the data protection rationale that access to both should be strictly limited to need-to-know individuals and that a sensitive and long-term data set should not be kept all in one place.

Implementation of the need-to-know principle was found to have a profound impact on biobank operation. As a direct consequence, tasks could no longer be performed ad hoc by any staff member. Instead, specific tasks had to be assigned to specific roles that in turn were assigned to available staff on a rotational schedule. For example, no single user should be able to trace an allocated sample back to the donor identity. Two mutually exclusive core roles were designed so that simultaneous access to these data would be limited as much as possible. Combined with personnel rotation,

substitution and the need to fill certain supporting roles, this reorganisation ultimately resulted in increased minimum staff requirements.

However, for an initial period of about 60 days during donor and sample documentation, simultaneous access to both, IDAT and MDAT databases was found to be necessary, because required information is available, either electronically or in hardcopy, only via the patient's name or case number. Both these identifiers are deserving of protection in the context of biobanking. Therefore, the linkage mechanism, which is fully integrated into the system's role-based access control, needed to be extended by a functionality that allows temporary access to corresponding data in both databases for a limited, possibly renewable time period.

Certain details of the database separation paradigm are also subject to other requirements related to biobank operation or to the research to be conducted with samples. Patients undergoing several surgeries for related or unrelated medical conditions may donate biomaterial on multiple occasions. To carry out research projects in a valid manner, it must be known whether samples are from the same or from different donors. Hence, both databases must support common structures that reflect both, donors and surgeries (in a 1-n relation) albeit with different sets of attributes. Table 1 lists the distribution of some of the attributes and attribute groups among the two databases.

Table 1. Distribution of Data between IDAT and MDAT Databases

Documented Object	Database 1 (IDAT)	Database 2 (MDAT)
DONOR	name, gender, date of birth, case identifier	gender, year of birth
SURGERY	date of consent and consent details, date of surgery, date of revocation	date of surgery, consent status, medical history, diagnosis, surgical procedure, laboratory test results, serology, pathology findings
SAMPLE	(not present)	organ, tissue type (e.g., tumor vs. normal), sample type, aliquots, processing data (e.g., ischemia times), allocation to research projects
RESEARCH PROJECT	(not present)	sample selection criteria (organ, tissue type, sample type,...), project information (aims and methods), recipient of sample & data, etc.

Table 1 also shows that some of the attributes are actually needed in both databases. The donor's gender is a typical example. While it is part of the patient's identification data, it is also needed in most research projects. In other cases, information derived from an identification attribute may be needed to determine a parameter of interest to research projects. While the donor's exact date of birth is normally irrelevant for research projects, it is necessary to determine the donor's age at the time the surgical treatment was performed. This determination can be made with sufficient accuracy using the year of birth. Since the latter is much less precise, it is generally not considered to be an identifying attribute in itself. In order to avoid redundant entry, an automatic update of a configurable set of attributes was implemented.

3. Discussion

Separating identification data and medical of the HTCR Web Application has shown that this type of effort needs to be accompanied by a careful redesign of workflows and roles. Obviously, there are practical limits to such redesigns. For example, there is little benefit to defining a large number of roles in order to "minimise" individual access to critical items of information, if ultimately not enough staff will be available to actually comply with a highly differentiated authorization scheme.

Likewise, the design of generic functionality – tentatively referred to as "database link" – that would facilitate the design and implementation of distributed database systems within the scope suggested by this paper is equally difficult. In particular, no obvious communication standard that is currently available offers itself for this purpose. Nevertheless, some, admittedly elementary conclusions may be drawn for a generic interoperability design:

- The linkage mechanism should distinguish between command data, identification data and medical data.
- For identification and medical data, communication should allow for attribute-value pairs and provide specific cryptographic encryption in addition to security mechanisms associated with the network transport layer. It is also practical to include some form of attribute mapping so that differences in attribute names in both databases can be resolved.
- Necessary link commands include remote object creation, update, search and an interactive session launch focused on a specified remote object. Some of these have already been specified in somewhat more detail in [7]

As a complementary measure, the data protection policy calls for relabeling of samples upon allocation with a randomly generated sample- and project-specific allocation number. This raises the level of anonymization of the allocated samples, thereby controlling the risk of unauthorized identification of donors.

References

[1] Patel A.: Tissue banking for research--bench to bedside and back--myth, reality or fast fading reality at the dawn of a personalised healthcare era. *Cell Tissue Bank*. **12** (2011) ,19-21.

[2] Moore HM, Kelly AB, Jewell SD, McShane LM, Clark DP, Greenspan R, Hayes DF, Hainaut P, Kim P, Mansfield E, Potapova O, Riegman P, Rubinstein Y, Seijo E, Somiari S, Watson P, Weier HU, Zhu C, Vaught J.: Biospecimen reporting for improved study quality (BRISQ). *J Proteome Res.* **10** (2011), 3429-38.

[3] Thasler WE, Schlott T, Kalkuhl A, Plän T, Irrgang B, Jauch KW, Weiss TS: Human tissue for in vitro research as an alternative to animal experiments: a charitable "honest broker" model to fulfil ethical and legal regulations and to protect research participants. *Altern Lab Anim*.. **34** (2006), 387-92.

[4] Thasler WE, Weiss TS, Schillhorn K, Stoll PT, Irrgang B, Jauch KW: Charitable State-Controlled Foundation Human Tissue and Cell Research: Ethic and Legal Aspects in the Supply of Surgically Removed Human Tissue For Research in the Academic and Commercial Sector in Germany. *Cell Tissue Bank*. **4** (2003), 49-56.

[5] Thasler WE, Thasler RM, Schelcher C, Jauch KW: Biobanking for research in surgery: are surgeons in charge for advancing translational research or mere assistants in biomaterial and data preservation? *Langenbecks Arch Surg.* **398** (2013); 487-99.

[6] Müller TH: Central IT-Structures for Integrated Medical Research and Health Care of Viral Hepatitis – Hep-Net. *Stud Health Technol Inform.* **116** (2005), 1016-20.

[7] Müller TH: Key-linked on-line databases for clinical research. *Stud Health Technol Inform.* **180** (2012), 524-8.

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Providing Multilingual Access to Health-Related Content

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Abstract. Finding health-related content is not an easy task. People have to know what to search for, which medical terms to use, and where to find accurate information. This task becomes even harder when people such as immigrants wish to find information in their country of residence and do not speak the national language very well. In this paper, we present a new health information system that allows users to search for health information using natural language queries composed of multiple languages. We present the technical details of the system and outline the results of a preliminary user study to demonstrate the usability of the system.

Keywords. Semantic search, prevention service, multilingual querying, health service

Introduction

Nowadays, more and more people suffer from lifestyle illnesses such as coronary heart disease, obesity or type-2 diabetes, i.e., health conditions that are caused by lack of exercise, poor eating habits and unhealthy lifestyles [7]. Woolf and Atkins [8] argue that many health conditions can be prevented though, for example by educating the people about the consequences of an unhealthy lifestyle. Large education campaigns and seminars have been funded to promote healthier lifestyles, advertising low-fat diets, weight management or physical exercises. With the increasing availability of the Internet, health care providers and governments extended the education campaign to the WWW, offering health information portals with educational texts, videos, graphical illustrations and other type of media. Although health care providers intend to provide health information services to all their clients, immigrants have been identified as vulnerable population [1] that benefit less from existing health care systems since language and cultural barriers prevent them from using existing prevention services. In order to address the issues mentioned above, we introduce a multilingual health prevention service for immigrants that guarantees personalized access to professionally-created health care content. By providing them with available information in the language of their choice, the system helps those people who have language-related difficulties in understanding their physicians. Information is adapted based on users' personal context such as pre-existing medical conditions and their location.

This paper is structured as follows. First, we discuss the use of online health information services. Following that, we introduce the system infrastructure of our system and outline the scientific challenges that it addresses. We then present an initial evaluation of the system. A discussion and conclusion is given in the last section.

Related Work

According to Morahan-Martin [6], up to 4.5% of all Internet searches are about health-related topics, indicating the significance of this topic in our life. An overview of different resources in the Web that can be used for this information gathering task is provided by Johnson et al. [3]. Generally, three types of services can be identified: (a) Professionally maintained health advice and information services where users can check their symptoms in a constantly updated database (e.g., the NHS Direct[1] service maintained by the English National Health Service) or check up on public service announcements (e.g., by the World Health Organization), (b) unsupervised sources such as Wikipedia and (c) discussions of similar cases in online forums, blog posts, or biased advertisements for specific products that can be retrieved by standard Web search engines. From a medical point of view, relying on such sources is not recommended and the consultation of a professional is highly advised. Therefore, the American Medical Library Association recommends to *"trust your physician, not a chat room"* [2]. Morahan-Martin suggests approaching this unconsidered information handling by asking physicians to point their patients to reliable health portals and to work on improving such sites, e.g., by improving search and retrieval techniques. Our works builds on her suggestion.

1. Methods

The next sections describe the main components of the health information system. The presented system builds on semantic technologies to perform the task of multilingual information supply.

1.1. The Health Ontology

In order to provide a knowledge base that can easily be maintained by a computer system, we define a simple health ontology (HO) that defines basic health concepts and their relations. The concepts in the Health Ontology are enriched with multilingual labels, e.g., the concept *obesity* is labelled with the English term "obesity", the Turkish term "Obezite" and the German expression "Fettleibigkeit". Besides, relevant documents are attached to the concept nodes. In a health care scenario, information quality is of crucial importance. False information does not only lead to a loss of trust but also may lead to serious harms. Therefore, information in the HO should be maintained by a group of experts.

[1] http://www.nhsdirect.nhs.uk/

1.2. Multilingual Semantic Search

As explained above, concepts in the health ontology are enriched with multilingual labels. When a user enters a search query, we process the entered text by lowercasing it and pruning unusual characters. The search terms are then used as a query to retrieve matching concept labels contained in the Health Ontology. We use a fuzzy search based on the open-source information retrieval system Lucene[2] to cover slight alterations in term surface forms. Taking the multi-lingual search query "Fettleibigkeit diyetimi nasıl ayarlamalıyım?" (Translation: "How should I arrange my diet in obesity?") as an example, the language-independent concepts General Obesity and Obesity are identified, since they have been labelled using the keyword "Fettleibigkeit". Furthermore, the concept *nutrition* is identified by the label "diyetimi".
Using the retrieved query-relevant ontology concept nodes, we employ a graph-search to find conceptually related information nodes. Different concepts from ontology classes are semantically linked with weighted edges in our ontology. Our algorithm performs a full graph search along these edges. Information nodes found during this traversal are ranked based on the proportion to the edge-weights of the path of the originating concept and anti-proportional to that path's length. Information nodes found via multiple paths receive the sum of the relevance values of all of those paths.

1.3. Supportive User Interface

Figure 1 shows a screenshot of the graphical user interface that allows users to interact with the system. In the remainder of this section, we introduce its key features.

Entering the website, the user can log in to receive context-based search results. On top of the interface, the user can type in a search query. Since the system matches search terms with concepts in the health ontology, the search query can be formulated in different languages. In the screenshot, the user Ali has logged in and typed in the search query used in the example above: *"Fettleibigkeit diyetimi nasıl ayarlamalıyım"* (Translation: *"How should I arrange my diet in obesity?"*) Under the search box, the interface lists the concepts that the system extracted from the search query. In the example screenshot, the following concepts have been detected from the search query: Genel obezite (General obesity), Obezite (obesity), Beslenme (nutrition). Furthermore, the following context has been extracted from Ali's profile that will be considered when ranking search results: home town (Berlin) and pre-existing medical conditions (Diyabet Tip II, Type II Diabetes). Under this visualization, the interface provides a topic box containing professionally edited information for the identified concepts. Under this topic box, the search results are displayed in descending order of relevance.

Each search result offers a button that when clicked shows a view of the paths of the ontology that were traversed to find this search result. The semantic graph allows the user to understand why this search result is relevant to their search query. Additionally, the interface enables users to visually browse through the ontology concepts by expanding concept nodes and traversing semantic edges between concepts, and also finding documents attached to a concept's information nodes.

[2] http://lucene.apache.org/

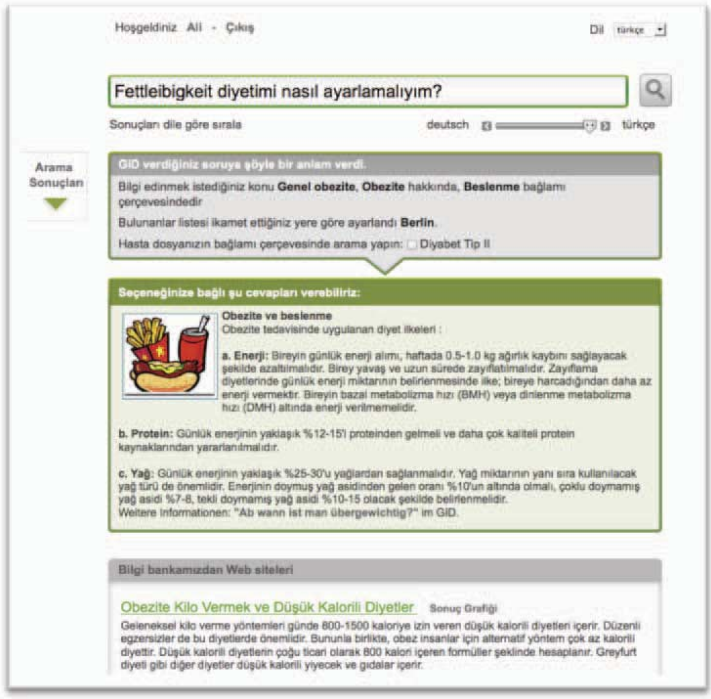


Figure 1. Screenshot of the search interface.

2. Results

Following a demand analysis to assess immigrants' expectations and needs for a personalized preventive health assistant [4], we evaluated the development and implementation of the health assistant. Applying a qualitative research approach, we recruited a small study cohort from a local Turkish community in a mid-sized town in Germany, as well as a German control group. As suggested by Lamnek [5], we invited a homogeneous focus group of six participants with similar socio-economic backgrounds from two different districts of the town to participate in the user evaluation. The participants were asked to interact with the system in a supervised scenario and were further asked to assess the assistant with respect to its technical implementation, relevance of the presented content, usability in daily life and its potential to present health information in a structured manner.

During the user-centric evaluation of the system, the study group was separated into a German-speaking group and a Turkish-speaking group due to limited knowledge of the German language of some participants. Both groups interactively tested the health assistant prototype in a supervised user-scenario. During the test, they were asked several questions concerning the design, usability and cultural sensitivity.

Participants found the search results to be appropriate and clearly presented. Most participants found the adaptation of search results based on the context of a personal user profile useful and found that this feature helped in making an individualized search experience. However, some users were reluctant in providing certain pieces of profile information and wished to know specifically how they would be used.

Performing semantic search was found to be intuitive by a large majority of users in the study. Many users entered full health related questions, as intended, without needing any instructions. The feature to enter mixed-language queries was found to be very useful by all participants, and was considered to be of high importance for everyday use by the group. However, most users needed to be made aware of this functionality, since it was not readily apparent from the interface itself.

3. Conclusion and Discussion

In this paper, we presented a personalized health information system for immigrants. The system provides a search facility on a semantic database to assist people in finding health-oriented documents. The system is mainly designed to assist immigrants with limited knowledge of the national language used in their host country. Therefore, the system allows users to formulate search queries in their mother tongue, the host's language and in a mix of both languages. Search results can be adapted based on the users' preferred language and other personal contexts such as the users' location or pre-existing medical conditions.

The underlying technology of this system is a health ontology. Relevant information is retrieved by exploiting semantic relations between different concepts in this ontology. In order to evaluate the usability of this system, we followed a qualitative analysis scheme. Discussions in a focus group following this evaluation indicate that the system can be employed to assist immigrants to find information in their own and in the host nations' language. This study has been performed within a project with a large national health insurance provider. As future work, a promising approach to evaluate the efficiency of this system on a large scale is to incorporate it into this company's health prevention service.

References

[1] Derose, K., Escarce, J., Lurie, N.: Immigrants and health care: Sources of vulnerability. Health Affairs pp. 1258–1268 (09 2005)
[2] Fox, S., Raine, L.: Vital decisions: How internet users decide what information to trust when they or their loved ones are sick. plus a guide from the medical library association about smart health-search strategies and good websites. (2002)
[3] Johnson, P.T., Chen, J.K., Eng, J., Makary, M.A., Fishman, E.K.: A comparison of world wide web resources for identifying medical information. Academic Radiology 15(9), 1165–1172 (2008)
[4] Klein-Ellinghaus, F., Zeeb, H., Reeske, A.: Bedarf und Erwartungen an einen innovativen, technologiebasierten Gesundheitsassistenten für türkische Migrantinnen und Migranten (GeM-Projekt). Gesundheitswesen 74(A56) (2012)
[5] Lamnek, S.: Qualitative Sozialforschung. Beltz Verlag (2005)
[6] Morahan-Martin, J.M.: How Internet users find, evaluate, and use online health information: a cross-cultural review. Cyberpsyc. and Beh. 7(5), 497–510 (2004)
[7] Pollard, T.M.: Western Diseases: An Evolutionary Perspective. CUP (2009)
[8] Woolf, S., Atkins, D.: The evolving role of prevention in health care. American Journal of Preventive Medicine pp. 13–20 (04 2001)

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Personalized Fall Risk Assessment Tool by using the Data Treasure contained in Mobile Electronic Patient Records

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Abstract. This work presents a novel approach for combining multiple Electronic Patient Records (EPRs) to a self-learning fall risk assessment tool. This tool is used by a new type of home-visiting nurses to track the fall risk of their patients. In order to provide personalized healthcare for elderly people, we combine multiple EPRs using an agent-based architecture, where each patient is represented by an associated agent. The patient agents are enabled to negotiate about possible fall-risk indicators recognized in the specific patient population under care. We use distributed information fusion and opinion aggregation techniques to elaborate new fall-risk indicators and in consequence to adapt the fall risk assessment tool.

Keywords. Electronic patient records, fall risk assessment, personalized healthcare, agent-based, self-learning

Introduction

Over the last decade, there has been an exponential growth in the healthcare costs due to the aging population in many countries. One of the important economic burdens is caused by falls, which are a common cause of injury, and contribute significantly to the costs of injuries in old age. In Germany, the rate of costs due to falls is around 0.8% - 1.5% of the yearly German healthcare costs. These fall-related costs are expected to increase to 3.85 billion Euros a year by 2030 due to the demographic change towards aging population [1]. Besides this economic and social dimension, falls also introduce psychological and medical ramifications for the individuals. The prevention of falls is required to overcome these burdens. Additionally, in Germany, the early detection of risks and the prevention of outset incidents are required by law. For this purpose a magnitude of prevention tools exist aiming to determine the actual risks of a patient to reduce e.g., fall-related injuries. Here, the increasing development of Electronic Patient Record (EPR) systems offers new opportunities as EPRs contain a huge amount of data [2]. This data can be used to analyze the population under care proactively by observing the data set and achieve the goal of "personalized healthcare" [2]. In more detail, personalized healthcare is about the tailoring of the healthcare process to the individual patient. Therefore, it would be beneficial if the tools used in healthcare can

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adapt themselves to the population under care. As a result, leading to personalized healthcare provided not only by professionals but also supported by these semi-automatically adapting tools. This work introduces such a tool in the form of a fall-risk assessment tool [3, 4] developed as part of the agnes[zwei] mobile application software [5]. Presenting this tool, we want to emphasize that existing approaches in different areas of computer science (e.g., agent-based systems, information fusion) can contribute to the challenges associated with personalized healthcare and that such approaches can be used to adapt tools online.

1. Methods

The goal of our study is to implement a personalized fall-risk assessment tool as part of the agnes[zwei] Tablet App, which is a mobile EPR system [5]. This process started with a state-of-the-art analysis to identify the common practice in Germany. Here, we found that there is no standard available yet to develop a fall risk assessment tool for commonly usage and institutions mostly use a fall-risk assessment instruments developed by their own [6]. We proceeded with a literature research to identify fall-risk indicators and their influence through the actual fall risk of a patient. Using the results we were able to develop an initial fall-risk assessment instrument comprising 28 indicators and able to determine the actual fall-risk of a patient based on these indicators in terms of a traffic-light [6]. To adapt the list of indicators through the population under care, we have utilized an agent-based self-learning approach by using opinion aggregation techniques. The basic idea is that each EPR contains knowledge about possible fall-risk indicators of the represented patient and that multiple EPRs can be used to infer fall-risk indicators [3, 4]. In the following, we will provide more details about the methodology followed to reach our goal.

1.1. Meta-analysis of Initial Fall Indicators

We performed a meta-analysis to identify common fall-risk indicators using the keywords “fall”, “risk factors”, “older people” and “community-dwelling” querying the databases PubMed, DIMDI and Google-Scholar. At the beginning, we found more than a hundred confirmed fall-risk indicators. The filter process was done through comparing the statistical relevance and clustering/renaming of similar/synonymous terms. After this process, the literature research concludes with the advice to use 28 as initial indicators within the developed assessment tool. For more details about the meta-analysis, the interested reader is referred to Schenk et al. [6, 7].

The process of excluding risk indicators from assessment tools is common when creating such assessment tools while conducting/analyzing studies. The reason under this exclusion is to find a balance between the statistical relevance of risk indicators examined in studies and the usability of an assessment tool. In consequence, this process prevents to provide personalized healthcare to the population under care.

1.2. Agent-Oriented Software Engineering

On top of the initial meta-analysis study, we have followed the Agent-Oriented Software Engineering paradigm to develop the approach which is a natural approach to model complex distributed software systems [8] as it provides high level

modularization for building such systems. Here the major abstraction layer is that of an agent, which is an autonomous entity situated in an environment and encapsulating its knowledge and capabilities. Given an EPR system like the agnes[zwei] App, each patient (each EPR) can be modeled as an agent encapsulating the data of a specific patient. Furthermore, in agent-based systems, the agents involved typically cooperate with each other to achieve the system goal. We used this mechanism to establish a negotiation process about possible fall-risk indicators between the patient agents.

1.3. Agent-based Simulation

To evaluate the approach, we have developed an agent-based simulation environment using the agent-framework JIAC V [9]. Each patient agent has been equipped with the data model of the agnes[zwei] EPR. Furthermore, we have setup agents simulating the healthcare professional role, responsible to document fall events. Using this simulation environment, we were able to technically evaluate the approach and the applicability of different negotiation techniques in this circumstance. For more details about the technical evaluation, the interested reader is referred to Ahrndt et al. [3, 4].

2. Results

As mentioned above, we have utilized the agent-based approach to model the system based on several EPRs. A conceptual illustration is shown in Figure 1. A single agent represents each patient and multiple patient agents run on a single platform representing a healthcare professional's Tablet. Several professionals meaning that the whole environment consists of several Tablets supply the population under care. Figure 1 also illustrates the negotiation process consisting of four different stages to determine whether adding new fall indicator is necessary or not: The occurrence of a fall, the local information fusion, the global opinion aggregation and the notification stage.

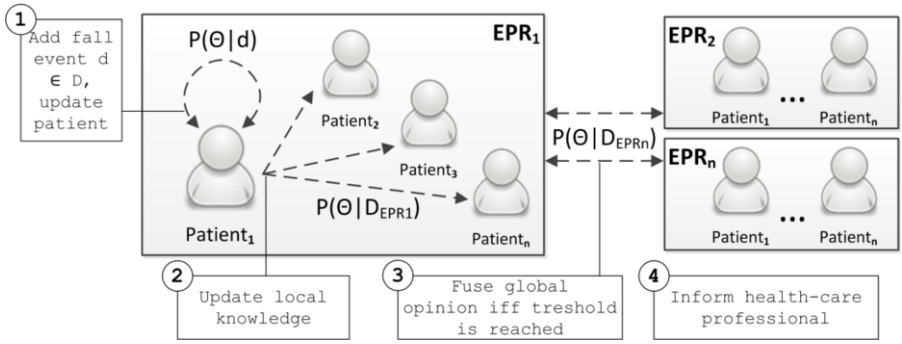


Figure 1. Illustration of the architecture with associated stages to determine the probability of a feature which influence the fall risk of a patient. The agent-based approach is a natural way to model such a system, viewing each patient as encapsulated entity [p. 4, 3].

The process starts when the healthcare professional documents a new fall event using the fall documentation sheet of the software application. Figure 2 shows a part of the assessment tool enabling the healthcare professional to add new fall-event. The affected patient agent then elaborates the evidence of all features observed (all data-points available through the EPR) by analyzing which features has changed its value

since the last observation. The probability of such features is then increased and a new probability distribution of fall indicators is built using Bayesian information fusion [10]. At this point, the affected patient agent publishes its new knowledge to all patient agents on the same Tablet updating their degree of believe about possible fall-risk indicators. As a result of this stage, each patient agent represents some kind of fall-risk expert. This means that each expert can express its opinion about the fall-risk indicators that influence the represented patient by voting for the new fall-risk indicator. Furthermore, the experts are able to express their opinion about the fall-risk indicators found in the population that is treated by a single healthcare professional (each nurse owns its own Tablet).

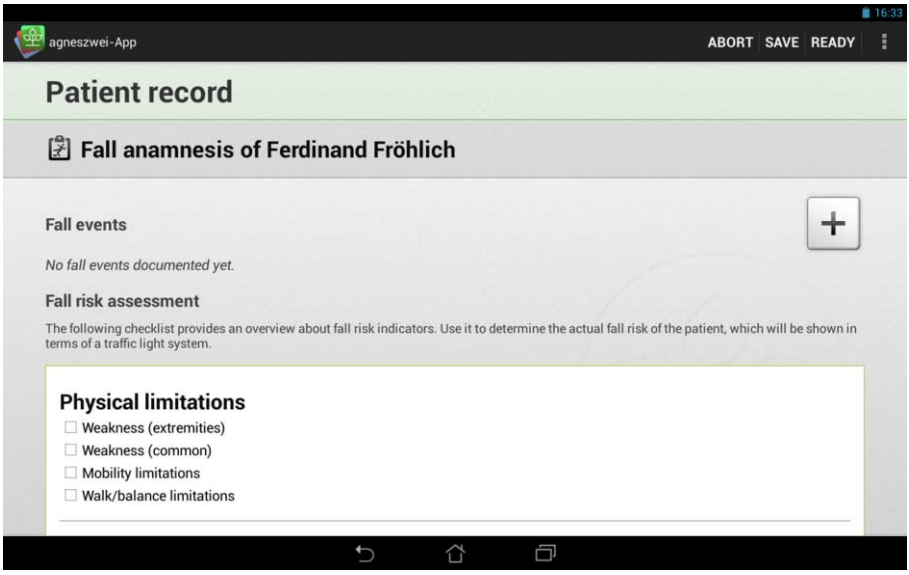


Figure 2. Screenshot of the fall-risk assessment tool as part of the EPR. The upper area contains the possibility to document fall events building a list of all documented incidents. The lower area shows a part of the fall-risk assessment instrument as checklist.

As a next step, the opinion aggregation starts if the probability of one of the features reaches a common threshold, which was empirical established using the agent-based simulation. Then the local believe is shared with all patient agents available through the population under care. To fuse these local expert opinions to a generalized view we have examined different opinion aggregation techniques [4]. After applying and evaluating some theoretically well-researched methods in the real world task, we decided to use the Supra-Bayesian Pooling Method [11] as it outperforms the other methods in time and space complexity.

As a last stage, if one of the features reaches the threshold after building the global opinion about fall-risk indicators, the healthcare professional gets notified. The nurse then has to decide whether this feature is a fall-risk indicator for the population under care or not. The result of this decision is communicated to all available Tablets and if necessary updates the fall-risk assessment tool with the new feature as a new fall-risk indicator that extends the prior checklist.

3. Discussion

Within the scope of this work, we have showed the applicability of our approach on top of the data provided by EPRs to achieve a more personalized healthcare. In order to adapt the assessment tool to the population under care, we have enabled the patients to be a part of the elaboration of arising fall-risk indicators as a novel approach for this specific use case. We have emphasized this using an Agent-Oriented Software Engineering approach to model the system in a distributed way. This approach is promising as it avoids the introduction of centralized entities occupying all data about a population under care. This is a special requirement when developing such applications in Germany considering the strict German privacy laws. This system can also be further improved by applying Natural Language Processing (NLP) techniques on the available free-text fields in EPRs containing a magnitude of data. Additionally, we have used a well-researched method to aggregate opinions about fall-risk indicators in form of probability distributions. We have shown here, that such methods can be applied using light-weight mobile technologies like Tablets, which means that we do not need massive computing power to infer knowledge from EPRs for such use cases in the healthcare domain. We have achieved technical applicability to estimate a fall risk of patients automatically while preventing the additional burden on healthcare professionals' work to find a possible fall-risk indictor. Regarding the evaluation of the fall risk assessment tool in a real healthcare practice from a medical point of view, we need to setup a case study to retrieve enough evidence for observing the fall events. This will be further tested and in future when the agnes^{zwei} app will be deployed as working appliances for the healthcare professionals.

References

[1] H.H. König, Gesundheitsökonomische Aspekte von Stürzen und Frakturen, *1. Nationale Sturzpräventionstagung* (2012), http://www.sturzpraevention2012.de/programm_abstract.php?No=9.
[2] G. Goth, Analyzing medical data, *Communications of the ACM* **55(6)** (2012), 13-15.
[3] S. Ahrndt, J. Fähndrich, S. Albayrak, Preventing elderly from falls: The agent perspective in EPRs, *Advances in Practical Applications of Agent and Multi-Agent Systems* (2013), 1-12.
[4] S. Ahrndt, J. Fähndrich, S. Albayrak, Agents Vote against Falls: The Agent Perspective in EPRs, *Advances on Practical Applications of Agents and Multi-Agent Systems* (2013), 263-266.
[5] S. Ahrndt, A. Rieger, S. Albayrak, Entwicklung einer mobilen elektronischen Patientenakte für die ambulante Versorgung in ländlichen Regionen, *INFORMATIK* **208** (2012), 1167-1181.
[6] A. Schenk, Das Sturzrisiko von zu Hause lebenden älteren Menschen – Entwicklung eines Sturzrisikoeinschätzungsinstruments zur Einbindung in eine elektronische mobile Patientenakte, *Bachelor-Thesis* (2012), Evangelische Hochschule Berlin, 1-62.
[7] A. Schenk, S. Ahrndt, S. Albayrak, Predicting Fall Risks in Electronic Patient Records, *INFORMATIK* **208** (2012), 94-1198.
[8] N.R. Jennings, An Agent-Based Approach For Building Complex Software Systems, *Communications of the ACM, Forthcommings* **44(4)**, 35 – 41
[9] B. Hirsch, T. Konnerth, A. Heßler, Merging Agents and Services – The JIAC agent platform, *Multi-Agent Programming: Languages, Tools and Applications* (2009), 159 – 185
[10] D. Lindley, Theory and practice of bayesian statistics, *The Statistician* **32(1)** (1983), 1-11.
[11] C. Genest, K.K. McConway, M.M. Schervish, Characterization of externally bayesian pooling operators., *The Annals of Statistics* **14(2)** (1986), 487-501.

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Pediatrics Prescriptions with Ontologies and Treatment Suggestions

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Abstract. Diagnosis and treatment for children healthcare are very sensitive activities. The present work presents an ontology based model for a future information system to support these activities. The input data contains children health status, and drug characteristics. During clinical practice a database with what specialists mark as successful treatments is created. This database is gradually growing bigger and is built by physicians based on their good results related to a treatment for a certain health condition. The new ontology system proposed in this paper is supporting the e-prescription process. The relations are managed using the open source application Protégé and for suggesting treatments, using the database with successful treatments, we developed a special module that offers to physicians a selection from which they can chose the best treatment for their current case.

Keywords. Prescriptions, paediatrics, treatments, Protégé, ontologies.

Introduction

One of the most important departments in clinical practice is pediatrics because it treats and monitors children, which are very sensitive patients. The prescription process for children is more complex doses are more critical and reaction to wrong drugs more violent. Medication errors are responsible for significant mortality rates often caused by adverse drug events. Pediatrics prescription errors have a relatively high occurrence and in general are caused by the process of calculation weight-based doses, due to off-label dosing and other common errors [1].

e-Prescription started 1-st January 2012, in Romania. Physicians use specific software to write and send prescriptions to pharmacy.

Prescription has the same format for all types of patients, adults or children. The prescription contains the series and the number of the prescription, identification data of the medical unit, date of the prescription, and identification data of the physician that writes the prescription, patient data: name, ID (CNP), the assurance status, the number of the consultation file, the codification of the diagnostic in Romanian format and information about the prescribed drugs [2]. This type of prescription lacks in important data related to critical healthcare conditions that affect children.

In a study in [3] the authors reviewed a total of 4019 prescriptions in a pediatric care unit. Physicians that wrote the prescriptions were residents in 76.3% of cases and specialists otherwise. The prescriptions contained a total of 151 drugs and 50% were

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related to the 12 most used ones. According to the study, the error rate of the prescriptions was more than one third, 34.2%.

The doctor community concluded that the medical errors for the domain are often. To reduce this rate we introduce a module for information systems in pediatrics that use ontologies to study relations between the characteristics of the children and the drugs and based on previous results to provide suggestions of already successfully performed treatments.

Pediatrics is a field of clinical practice that manages the diseases of the children, from birth up to 18 years old. Pediatrics is not dealing with a disease or an organ or system like cardiology for example, but it deals with the pathology of a very extensive period. Children have some particularities that the physicians need to know to prevent or treat the illnesses as part of the growing process.

Lehman et al. [4] presents the needed information for clinical decision in pediatrics and to maintain the health of the children. These information results from: collection of maternal information and new born information, following and reporting of the immunizations, monitoring and documentation the growth and development of the children, providing corresponding medication according to age, the weight, laboratory test results, protection of information about patients and exact identification of current child.

An important activity in the treatment process is medication given for a certain disease. In this sense the pediatrician needs support with the correct dose of the drugs. Guidelines and pediatrics practice, state that the dose of each drug is given according to weight and age of the child and taking into consideration other characteristics of the child.

The next section presents the subject of ontology and its application in the medical domain followed by the model for pediatric prescription ontology. Section 2 presents the structure of the pediatric prescription module and the suggested treatment tool, followed by conclusions in section 3.

1. Ontologies in Medical Informatics, ontology-model for pediatric prescription

With the help of ontologies we can capture knowledge about any domain in our work. Ontology describes the concepts of a specific domain and the relationship between these concepts. There exist a lot of ontology languages providing facilities to manipulate the developed ontology.

An ontology language very used is Protégé that we also use to develop the pediatric prescription ontology.

It is proper to use ontologies in medicine because it is a domain with a lot of interrelated information. Figure 1 presents a simple ontology with medical terms and relationship between them. With ontologies is simpler to make correlation between certain diseases, patients and treatments.

This approach supports physicians in their decisions in patient management, and treatment for certain diseases, contributing to reducing medical errors, due to a more complex verification and validation.

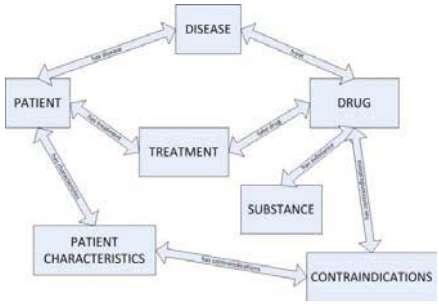


Figure 1. A simple ontology

Providing physicians with a tool that improves their practice and create a more reliable background for diagnosis and treatment is beneficial. This is accomplished supplying an ontology-based module in the process of drug prescription.

For an optimal decision the physician considers information about the child: age, weight, allergies, if the case, current disease, current treatments, and also all the information about the medication to be administrated. When all these information are well correlated and there are no conflicts the prescription is considered good. This means that the suggested medication is not conflicting for the current patient.

The drugs dose administered on children, needs to be according to age and weight, and the ontology module verifies this aspect. It verifies incompatibilities related to allergies to certain substances contained by the drug, and also verifies if there are treatments that may interact with the current one. Figure 2 presents a model of ontology for pediatric prescription process with information and relations developed using Protégé. To generate an improved module we use RxNorm, a nomenclature for clinical drugs produced by the U.S. National Library of Medicine that contains the name of drugs and their main characteristics [5]. The ontology module is used in a software prescription module developed in Visual Studio, previously developed in our group.

Using this model of prescription makes it easier to find all the conflicts and reduce the prescription errors.

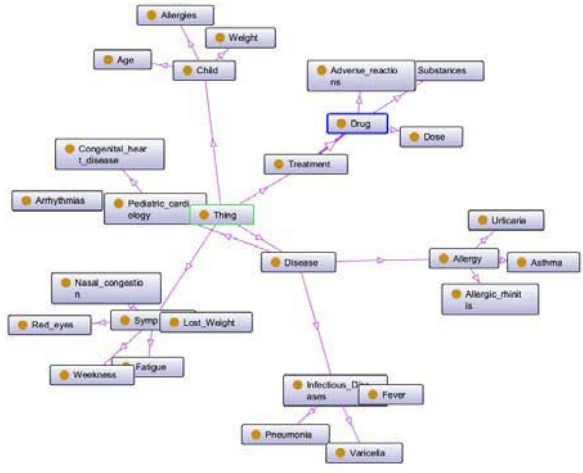


Figure 2. Prescription pediatric ontology

This model we will use next to develop a complex prescription module for pediatrics department.

2. Pediatric prescription and treatment suggestion support

To support better prescription we are using a previously developed module for suggesting treatments according to the disease and child characteristics [6]. When the pediatrician chooses the diagnostic for a case he/she may require from a global database a successful treatment for the child. The module needs the complete information (characteristics) of the child: age, weight, allergies, current treatments, current disease and others important characteristics, and according to this information, and after searching in the successful treatment global database it gets a possible treatment and information about it as rate of treatments of the same disease with this solution, characteristics of the formerly treated child, a.s.o.

The prescription module is extended with the suggestion of treatments module that also supports the physicians in their decision. All the collected treatments are given for to the subscribed physicians who send successful treatments after medical exams that prove that the given treatment treats or ameliorate the illness.

Figure 3 presents the architecture of the entire system. All the data are collected: patient information, consultation information and drugs information from RxNorm nomenclature and the ontology deciding if all interrelated data are correct. In the same time the needed information are sent to the suggested treatments module and is imported as a successful treatment if the case. The resulted prescription can be printed and sent to pharmacy.

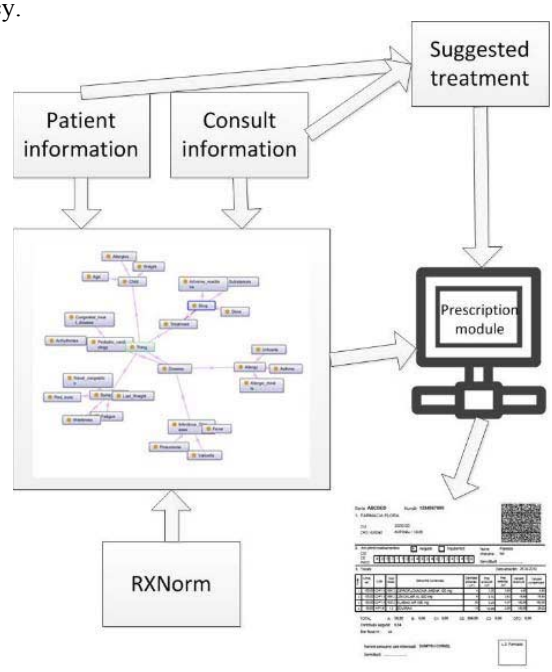


Figure 3. Prescription general architecture

The presented architecture can be used in a medical application for a complex prescription procedure. The module collects all necessary data, make validation of the given information, suggest treatments and make the final prescription for the patient.

3. Conclusion

The paper describes a new support method and an application module for pediatric prescriptions. These modules are connected to previously developed work for a Pediatric information system. In many cases the physicians do not agree the idea of computer assisted programs in medicine because they do not have confidence in the creation process of such systems and with apparently decisions made by computers. The current approach raises the confidence because the application is using real physicians' decisions for suggesting treatments module. The prescription ontology module is performing verifications for inconsistency and alerts useful for the physicians that will not deal with huge amounts of information which may conduct to errors when some data is forgotten or not taken into consideration.

References

[1] G. S. Pacheco, C. Viscusi, D. P. Hays, PHARMD, D. P. Woolridge, The Effects Of Resident Level Of Training On The Rate Of Pediatric Prescription Errors In An Academic Emergency Department, The Journal of Emergency Medicine, Vol. 43, No. 5 (2012), e343–e348.
[2] Electronic prescription, Health Insurance Agency of Romania, www.cnas.ro, accesed in 10.01.2014
[3] A. Martinez-Anton, J. I. Sanchez, L. Casanueva, Impact of an intervention to reduce prescribing errors in a pediatric intensive care unit, Intensive Care Med (2012) 38, 1532–1538
[4] C. U. Lehman, G. R. Kim, and K. B. Johnson, Pediatric Informatics. *Computer Applications in Child Health* ,Springer, 2009
[5] R. Richesson, J. Pathak , W. McLeod, G. Blackmon, K. Vehik, Requirements and Strategy for the Development of a Pediatric Drug Ontology, ICBO, volume 897 of CEUR Workshop Proceedings, CEUR-WS.org, (2012)
[6] O.S. Lupşe, L. Stoicu-Tivadar, C. Golie, Assisted prescription based on successful treatments, E-Health and Bioengineering Conference (EHB), Iaşi, Romania, 2013, 1-4

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G-quest: a Single Platform for Delivering Questionnaires, Educational Material, and Checklists on Mobile Devices

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Abstract. We illustrate G-quest, a platform originally meant to deliver questionnaires on mobile devices that supports the accomplishment of studies involving outpatients. However the constructs made available by the platform proved to be useful also for distributing learning material and checklists, after a paradigm shift in their application was adopted. Thus, in addition to questionnaires, we designed a guide for educating patients affected by a rare disease and conducted a small survey to assess this new application context. Presently we are exploiting G-quest for the provision of medical checklists in critical care.

Keywords. Questionnaires, Mobile Learning, Checklists, Medical Education.

Introduction

The ageing of the population in the developed countries, combined with an often suboptimal lifestyle, are giving rise to an increased prevalence of chronic diseases draining resources at a 5% yearly growth rate, which is higher than that of the average gross national product [1]. In order to better manage that epidemic, the medical practice has seen a transition switching from symptom-based management toward a more comprehensive disease management for chronic outpatients, focusing on their education [2] in order to improve treatment adherence [3-5]. The latest achievements in the Information and Communication Technology are pushing toward the exploitation of mobile devices as a means of improving patient literacy [6] and supporting the clinical practice [7], thus bridging the gap between outpatients and their clinic. Mobile technology seems very promising for widely spreading applications supporting doctors in planning and administering treatments, and patients in adhering to those treatments. Developing similar applications has been always considered a challenging task due to the intensive use of knowledge [8] and its different forms involved [9].

On those bases we developed G-quest, a mobile application able to deliver questionnaires and educational material, that can be used in a variety of different contexts. G-quest was first developed to guarantee a prompt self assessment by outpatients enrolled in home treatment plans. However we soon realized that the power of its features were not limited to the plain acquisition of information from patients but could be used in alternative ways. This encompasses disseminating knowledge,

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improving user literacy or even supporting the medical practice through interactive checklists on medical procedures.

1. Methods

We first designed a flexible model for representing questionnaires in order to capture and shape the dialogue with the users at best. Then we developed an editor that allows to design interactive dialogues whose characteristics fit that model. Finally a mobile application for rendering those dialogues on Android smartphones and tablets has been developed so that they may be administered to end users anywhere and anytime.

As shown in Figure 1, to develop a specific application, the workflow starts with the *design* of a questionnaire which is accomplished through the editor, made available as a regular web application. Users of that editor can be, for example, researchers that must conduct a survey on a target patient population. The editor produces an XML file encapsulating the questionnaire and allowing its *deployment* as a separate module on a server, as shown in the upper part of the figure. G-quest notices the availability of a new module, *downloads* it into its local module repository so that end users (in our case, patients) are able to *select* it among the currently available ones. The answers provided by those patients are locally persisted and finally *synchronized* to a central database in order to undergo any analysis required by the researchers. The synchronization task requires authentication in order to save the results. Depending on the study end users may be assigned personal credentials for giving their answers or use a shared account enforcing anonymity.

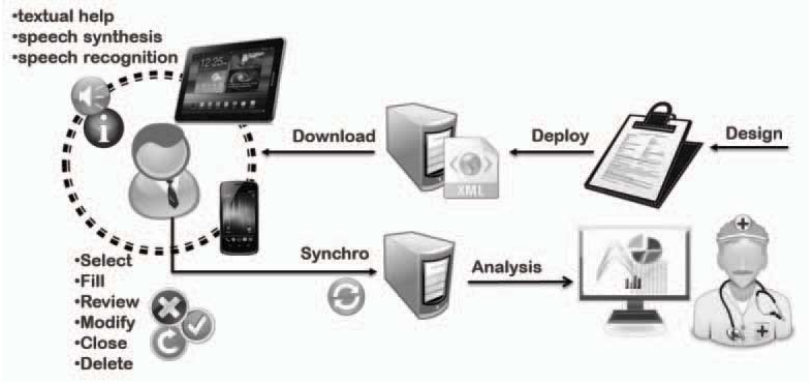


Figure 1. The workflow associated with the design and use of a questionnaire through G-quest.

1.1. The dialogue model

Within the model a *Question* represents an information unit which is regarded and shown as a whole. Its main constructs are the *Question Text* and one or more *Answers*. The former conveys the question primary meaning while answers act as placeholders for *Input elements* but also offer the possibility of displaying accompanying information through *Labels*. In designing the semantics of the input elements we capitalized on the HTML technology allowing types such as *text boxes*, *checkboxes*, *radio buttons* and *choice selections*, but we also support structured types, such as the

yes-no choice, rendered through primitive types. The model allows to specify constraints that help in reducing errors and enforcing consistency over the user input. More precisely, on a local basis we use type checking to avoid introducing a wrong piece of information. Then we implemented a functionality to enforce consistency over all the input fields of the whole question, thus preventing the acquisition of mismatched or misleading information. In order to provide a dynamic adaptation of the questionnaire, which translates into a better user experience, the model also includes rules for navigating across questions. The basic construct for implementing navigation is the *Block*, acting as a container for *Questions*. Facilities are provided for establishing jumps and cycles among questions based on the input previously provided by the user. Help during the process of filling in a questionnaire is available through specific messages which the application renders either in terms of written text or through the text-to-speech library provided by Android. Moreover, also the user may exploit the embedded speech recognition engine to provide his input, which is constrained by the type associated to any input element. This gives rise to improved dialogues with patients, augmenting graphical user interface components with plain speech [10].

2. Results

The first use of G-quest has been for administering the AFEQT questionnaire (http://www.afeqt.org) to home patients affected by atrial fibrillation, in order to collect information about their quality of life. Two screens of that questionnaire are shown in Figure 2A. In Figure 2B we illustrate instead a portion of AmyGuide, an educational application meant to deliver learning material to patients affected by the rare disease amyloidosis. Finally, in Figure 2C we show the interaction with a checklist for the management of hemorrhagic stroke.

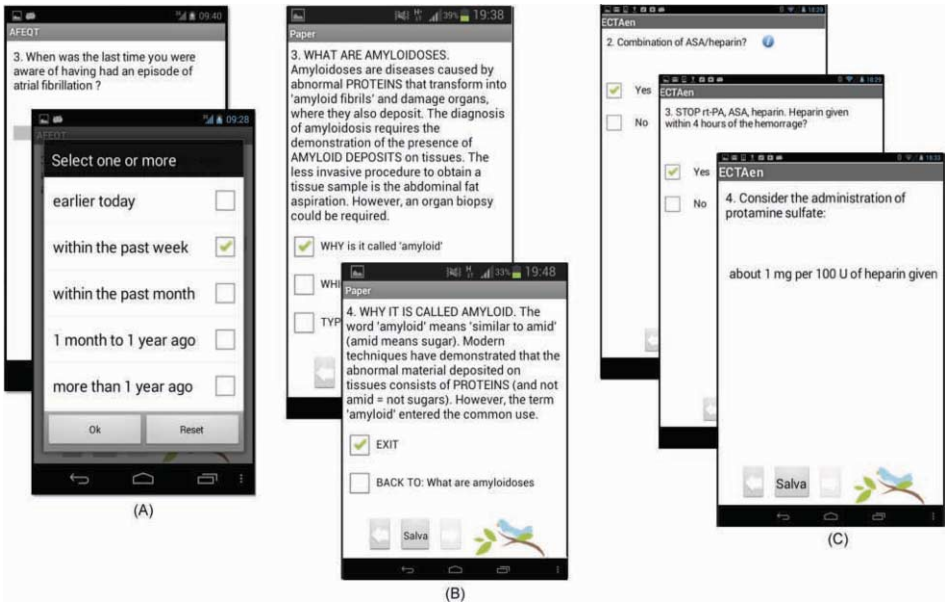


Figure 2. Some screenshots illustrating different applications developed with G-quest.

Albeit those applications are very different in their purpose and particularly in the semantics of the interaction with the users, their implementations were accomplished on the same platform, simply making a different use of the constructs made available by G-quest. More specifically, the questionnaire shown in Figure 2A adheres to the classic paradigm, exploiting the construct *Question Text* (i.e. "When was the last time ...") to pose the actual question, and *Answers* with *Labels* (i.e. "earlier today" and the rest) along with *Input Types* (i.e. the checkboxes) to collect the response. The use of those constructs has been overturned by AmyGuide which virtually reverses the classical notion of a questionnaire. In that case the patient is not asked for information but he is asked instead about which information he wishes to receive by the system. With respect to screen #3 in Figure 2B, the *Answer* with *Label* "WHY is it called amyloid" doesn't represent a true response to be entered by the user. Once clicked, it encapsulates instead a virtual question posed by the user which is then answered by G-quest through the *Question Text* appearing in the following screen #4 in Figure 2B. As a consequence, unlike in the classical questionnaire administration paradigm, the patient plays a leading role rather than a passive one. The same overturned paradigm is adopted by the checklist implementation shown in Figure 2C. In that case the user is not posing any question to the system in order to obtain some knowledge chunk in return. He illustrates instead the actual situation of a patient in order to get the recommendations of a clinical guideline.

3. Discussion

Several studies have already introduced the use of smartphones and tablets as a way of helping the health care staff in remotely supporting patients [11] or completing surveys [12]. Our interest towards the mobile environment was first raised by the need to simplify the delivery of interviewing material and collecting feedback from outpatients. Smartphones and tablets seemed to be the most appropriate technology since they are always at a user's disposal and remain operational even when no network connection is available. Moreover, the delivery of G-quest module instances over the air allows a dynamic update of the dialogues, when needed. This is extremely useful to adapt a questionnaire whenever unforeseen situations to be monitored arise during studies, or when educational material to be delivered must be updated.

With respect to G-quest validation and evaluation, we report on the AmyGuide application experience. The guide was administered in the waiting room of the Italian amyloidosis referral center, in Pavia, to 15 outpatients that were undergoing a follow-up assessment. Since each learning tip is provided in terms of a question, the synchronization capabilities offered by G-quest allowed us to track the users' behaviors by reporting every single click accomplished by them. This has been useful for profiling users and better understanding their needs as well as for improving the guide. A further assessment of G-quest may be accomplished through the combination of both question/answers paradigms. A simple way foresees the integration of a plain questionnaire within a guide module, thus performing a single paradigm shift possibly at the end of a consultation. This has been also pursued within AmyGuide, to which a short questionnaire was added with the aim of further assessing its usefulness just before exiting it. The results were very promising since all the patients expressed a positive opinion about the tool and emphasized their appraisal for information addressing AL amyloidosis.

Another interesting exploitation of G-quest sees the same paradigm shift occur several times while accessing a module. This is what happens, for example, through the administration of checklists which are cognitive aids meant to standardize processes or provide advice to users for an accurate task completion [13]. In that case *Questions* are used according to the classic paradigm for acquiring information about the situation of a patient or the context of a previous action. However they are interleaved with *Questions* adopting the alternative paradigm, that is providing answers and suggesting further actions according to the recommendations of the standardized medical practice. Our present research efforts are addressing this use of G-quest with two different aims. On one side we intend to enhance the support provided by G-quest to the patients already enrolled in studies, integrating the interviewing and reporting functionalities by offering advice about the actions to be adopted in most of the situations they might face during the study. From a different perspective, we are working within the context of a national research project to design a modular library of critical and emergency care procedures. This is particularly useful in geographical regions or rural areas where a trained specialist is not always available in the case of an emergency, and the situation must be handled by paramedic staff or even by volunteers that should promptly undertake a course of action even though they don't master the required knowledge.

References

[1] Evans T and Van Lerberghe W. The World Health Report 2008: primary care now more than ever. The World Health Organization, Geneva, 2008.

[2] Thoonen BPA and van Weel C. Role of Family Physicians in Implementing Asthma Self-Management Programs. *Disease Management and Health Outcomes*, 10(3), 141-146, 2002.

[3] Vermeire E, Hearnshaw H, Van Royen P and Denekens J. Patient adherence to treatment: three decades of research. A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics*, 26(5), 331-342, 2003.

[4] Di Matteo MR. Variations in patients' adherence to medical recommendations: a quantitative review of 50 years of research. *Medical Care*, 42(3), 200-209, 2004.

[5] Gazmararian JA, Kripalani S, Miller MJ, Echt KV, Ren J and Rask K. Factors associated with medication refill adherence in cardiovascular- related diseases: A focus on health literacy. *Journal of General Internal Medicine*, 21(12), 1215-1221, 2006.

[6] Wakefield AB, Carlisle C, Hall AG and Attree MJ. The expectations and experiences of blended learning approaches to patient safety education. *Nurse Education in Practice*, 8, 54–61, 2008.

[7] Davis JS, Garcia GD, Wyckoff MM, Alsafran S, Graygo JM, Withum KF and Schulman CI. Use of mobile learning module improves skills in chest tube insertion. *Journal of Surgical Research*, 177(1),21–26, 2012.

[8] Schreiber A, van Heijst G, Lanzola G and Stefanelli M. Knowledge organisation in medical KBS construction. In: *Proceedings of the Medical Informatics Europe Conference (MIE '93)*, 394-405, 1993.

[9] Lanzola G and Stefanelli M. Inferential knowledge acquisition. *Artificial Intelligence in Medicine*, 5(3), 253-268, 1993.

[10] Azzini I, Falavigna D, Gretter R, Lanzola G and Orlandi M. First steps toward an adaptive spoken dialogue system in medical domain. *Proceeding of EUROSPEECH 2001, 7th European Conference on Speech Communication and Technology, 2nd INTERSPEECH Event, Aalborg, Denmark,* 1327-1330, 2001.

[11] Lanzola G, Capozzi D, D'Annunzio G, Ferrari P, Bellazzi R and Larizza C. Going Mobile with a Multiaccess Service for the Management of Diabetic Patients. *Journal of Diabetes Science and Technology*, 1(5), 730-737, 2007.

[12] Harrington JW, Bai R and Perkins AM. Screening children for autism in an urban clinic using an electronic M-CHAT. *Clinical Pediatrics*, 52(1), 35-41, 2013.

[13] Hales B, Terblanche M, Fowler R and Sibbald W. Development of medical checklists for improved quality of patient care. *International Journal for Quality in Health Care*, 20(1),22-30, 2008.

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A model for Consent-Based Privilege Management in Personal Electronic Health Records

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Abstract. One of the biggest issues in the domain of standardized, regional, cross-institutional, personal, electronic health records is the privilege management. While many health information exchange projects use IHE-based architectures there are still unsolved questions regarding the restricting parameters a patient can use in the electronic consent configuring access control. This work determines these parameters, derives an information model of privilege management, introduces a set representation of the model and shows how to apply them to EHR architectures. The introduced model can serve as framework for health information exchanges using a consent-based privilege management. The set representation can help to understand the complexity of consent representations.

Keywords. PEHR, informed consent, privilege management, access control, IHE

Introduction

One of the biggest issues in the domain of cross-institutional, regional electronic health records (EHR) is the question of access rights management [1-4]. Whereas many health information exchange projects around the world selected the cross-enterprise document sharing profile (XDS.b) from the worldwide initiative Integrating the Healthcare Enterprise (IHE) and some other surrounding profiles to build those EHRs, the question which technology and which concepts to choose in order to implement a proper access rights management being within the law and matching ethical as well as privacy aspects, is still being discussed. From a technological point of view the basic patient privacy consent (BPPC) profile and solutions based on the extensible access control markup language (XACML), an OASIS standard, are in wide spread use [5-8]. Regarding the content and the scope of an informed consent together with the degree of how far it will be used to manage EHR access rights, the situation is more vague.

The health information exchange in the Rhine-Neckar region is based on a personal electronic health record (PEHR). The concept strongly focuses on the involvement of the citizens making tools available to them empowering them to keep their informational self-determination. One tool is the access control and content management component of the patient portal [9]. Using this tool the patient can decide which content will be transferred from the primary systems to the PEHR and who of

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his physicians and caregivers can access it. The architecture of the PEHR is based on IHE profiles and an XACML representation of informed consents. However there are still some open issues concerning the scope, the semantics, and the restricting parameters of the informed consent a patient can use to configure access control.

Thus the objectives of this paper are to

- Determine restricting parameters
- Present a privilege management information model
- Derive a set representation of an electronic consent (eConsent)
- Describe the application in the PEHR

1. Methods

The work presented in this paper is a part of the doctoral thesis of the author. It represents an iteration of the problem-solving design and creation research strategy being used in his thesis.

To determine the restricting parameters the privilege management of the hospital information system of the University Hospital Heidelberg (UHH) has been analysed, the UHH's data privacy officer was interviewed and a literature analysis using MEDLINE was conducted. Afterwards the information model was derived from the parameters and built using entity-relationship-diagrams. Next the model was mapped to our regional setting resulting in the set representation of eConsents. Finally the model and the set representation have been applied to the PEHR architecture.

2. Results

The comprehensive privilege management as well as the content management of the Heidelberg PEHR is controlled by the patient using his electronic consent document as configuration. Integrated health information exchange settings usually use four operations manipulating data in the centralized electronic health record: Create, read, update and delete which are also known as CRUD-operations. In IHE-based setting these operations are executed through message based, standardized transactions, which are used by actors. Actors do represent a role in a software system like a document consumer and are implemented in certain software components. In the case of XDS.b the transactions are

- C: Create/Write: Provide and register document set-b (ITI-41)
- R: Read/Retrieve: Registry stored query (ITI-18) and retrieve document set (ITI-43)
- U: Update: Update document set (ITI-57)
- D: Delete: Delete document set (ITI-62)

2.1. Restricting Parameters

To restrict access to specific content of a PEHR the following question has to be answered: *Who* is allowed to execute *which operation*s on *which information objects* in *what time*?

The who is characterized by a person. A person can have a role, a specialty and it can belong to a professional group and to one or more organizations.

The operations are represented by the CRUD-operations.

The objects represent the content of the record. This can be a single document or a document type. Objects can belong to a specialty, they have an origin like an organization or a subunit and they have an author.

The time restriction can be characterized by a period, a timeframe, an expiring date or a treatment episode (life long, administrative case, medical case).

Finally, a consent document of a patient consists of one or more answers to the question above.

2.2. The privilege management information model

The next step is to derive an information model from the found restricting parameters. Figure 1 displays the entity-relation-ship-diagram of the model including the surrounding of the consent document.

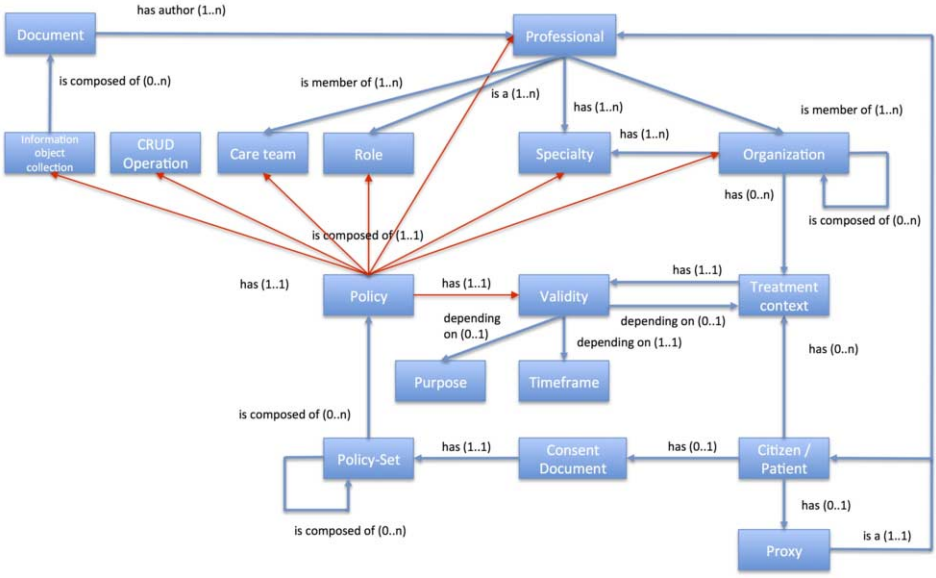


Figure 1. Privilege Management Information Model

Each answer to the question is expressed in one policy and a policy can be grouped inside a policy set, which can be transformed into the XACML syntax representing a consent document. A citizen/patient has got no more than one of them. He has one proxy, which can be another citizen or a professional. A patient has one or more treatment contexts with a validity and one or more organizations. The organization can be composed of other organizations and these can have one or more specialties. A professional has one or more specialties and he can be a member of one or more organizations. He has a role, and he is member of a care team. The red arrows mark the part of the model representing the answers to the question. A policy has a validity, which depends on a timeframe or a purpose (e.g. emergency) and a treatment context.

A policy can be composed of an organization, a specialty, a professional, a role, a care team, a CRUD-operation and an information object collection which is composed of one or more documents, which do have an author who is a professional.

2.3. The set representation of eConsent

For illustration, the information model is mapped to a part of the regional PEHR setting, which is displayed in figure 2. Each policy represents a 3-dimensional set of affected object instances. In the figure the answer to the question is: Each physician with specialty cardiology shall view documents with specialty medication and cardiology. Blue dots are physicians, yellow one's are caregivers, green one's pharmacists. Documents with c are from cardiology with r from radiology and m's do represent medications.

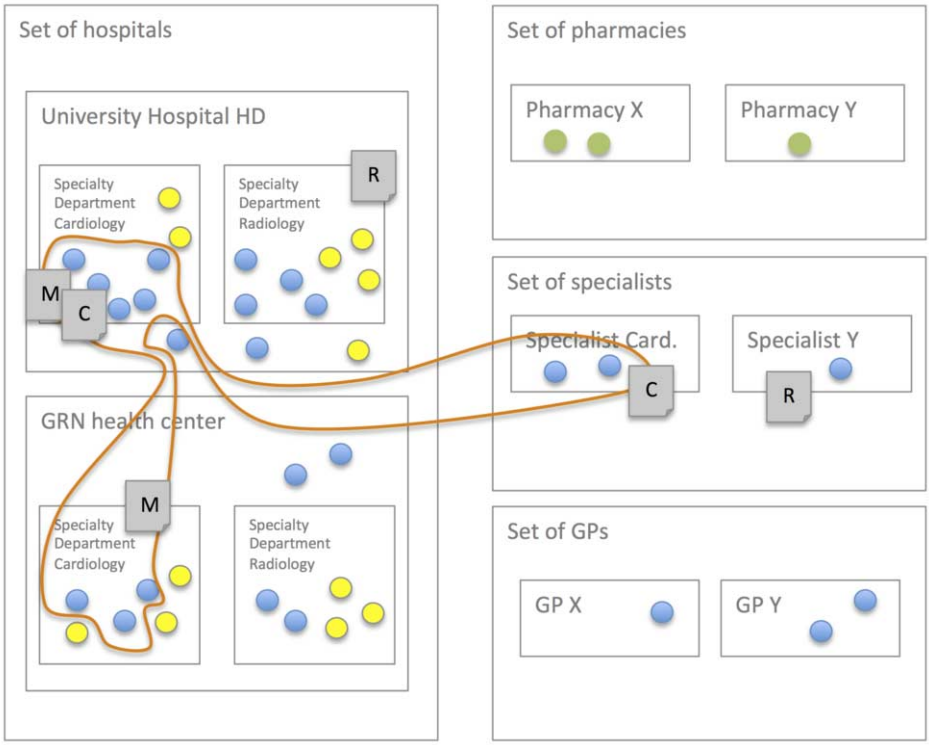


Figure 2. Set representation of eConsent

2.4. Application to the PEHR architecture

To apply the information model to the PEHR architecture it is important to know in which components the restricting parameters are managed and how they are identified and represented. The IHE Health Provider Directory stores information and identifiers of organizations and professionals including specialties and roles. The XDS-Metadata does contain information on the author, the origin, the document type, the specialty and identifiers. The XACML-based consent document has to use the right identifiers and representations of the restricting parameters. Thus the decision making component

(Policy Decision Point) can query the different services for information, compare them with the information inside the consent document and come to a decision if access is granted or not.

3. Discussion

This work describes the derivation of restricting parameters for informed consents and the generation of a comprehensive privilege management information model based on these parameters. The model can be used in any health information exchange project implementing a consent-based privilege management. The comprehensive model can serve as a framework. Not every single parameter has to be implemented. This has to be decided by those responsible. As an example this work described the application to the PEHR architecture of the Rhine-Neckar region.

The introduced set representation of the information model can help to understand the complexity of the consent issue. In the future it might be used in order to graphically configure consent documents.

As a limitation the introduced information model has not been compared to other standardized reference information models like the HL7 RIM yet. This will be one of the next steps in order to derive a standardized representation of the consent document itself as well as the representation of single parameters for example regarding data types.

References

[1] Bergh B, Bach N, Brandner A, Heinze O. *EHR access rights and the role of the patient* in *IFMBE Proceedings World Congress on Medical Physics and Biomedical Engineering*. 2009. Munich, Germany.

[2] Blobel B. *Authorisation and access control for electronic health record systems.* Int J Med Inform, 2004. **73**(3): p. 251-7.

[3] Kluge EH. *Informed consent and the security of the electronic health record (EHR): some policy considerations.* Int J Med Inform, 2004. **73**(3): p. 229-34.

[4] Win KT, Fulcher JA. *Consent mechanisms for electronic health record systems: a simple yet unresolved issue.* J Med Syst, 2007. **31**(2): p. 91-6.

[5] Heinze O, Birkle M, Köster L, Bergh B. *Architecture of a consent management suite and integration into IHE-based Regional Health Information Networks.* BMC medical informatics and decision making, 2011. **11**: p. 58.

[6] Namli T. Dogac A. *Implementation Experiences on IHE XUA and BPPC.* Technical Report Middle East Technical University Ankara, 2006.

[7] Sujansky WV, Faus SA, Stone E, Brennan PF. *A Method to Implement Fine-Grained Access Control for Personal Health Records Through Standard Relational Database Queries.* J Biomed Inform, 2010. **43**(5): p. 46-50.

[8] Idris T, Brandner R, Bergh B, Heinze O. *Eine standardisierte Sicherheitsarchitektur für den einrichtungsübergreifenden Datenaustausch*. in *e-Health2013*. 2012. Solingen: medical future verlag.

[9] Heinze O, Brandner A, Bergh B. *Establishing a personal electronic health record in the Rhine-Neckar region.* Studies in health technology and informatics, 2009. **150**: p. 119.

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HTML5 Microdata as a semantic container for Medical Information Exchange

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Abstract Achieving interoperability between clinical electronic medical records (EMR) systems and cloud computing systems is challenging because of the lack of a universal reference method as a standard for information exchange with a secure connection. Here we describe an information exchange scheme using HTML5 microdata, where the standard semantic container is an HTML document. We embed HL7 messages describing laboratory test results in the microdata. We also annotate items in the clinical research report with the microdata. We mapped the laboratory test result data into the clinical research report using an HL7 selector specified in the microdata. This scheme can provide secure cooperation between the cloud-based service and the EMR system

Keywords. Microdata, Semantic Web, HTML5, HL7

Introduction

We have previously reported an intractable registration system using an ISO/CEN 13606 archetype[1]. However, there remain two principal issues; a scalability of the registration system and an interoperability with the electronic medical record (EMR) system. Clinical research reports contain various data, and prescription histories and laboratory results are helpful to explain the reasoning behind a given diagnosis. It is desirable to retrieve laboratory test results and prescription histories from the EMR system, as this saves the physician from repetitive manual data entry. However, it is not desirable to build a virtual private network (VPN) between our registration system and an in-health network, and it is not straightforward to establish a medical information exchange between EMR systems for all healthcare settings because of the overwhelming cost and complexity of the process – we would need to enable cooperation between 8,565 hospitals and 100,152 doctor's offices in Japan (as of 2012).

Migrating to cloud-computing services has good scalability for the provision of nationwide services; however, currently no universal method exists for exchanging medical information between cloud-based services (which are outside of healthcare premises) and the EMR (which are located inside the healthcare premises). Modifying the existing EMR systems and establishing secure connectivity between the EMR system and cloud computing services requires significant development. Although there have been some studies of server side mashups of open health data in public networks [2], there have been no reports of mashups between the cloud computing services and

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the EMR systems inside healthcare premises. Therefore, we should develop a secure and semantic communication model that can enable cooperation between a cloud computing services and the EMR systems.

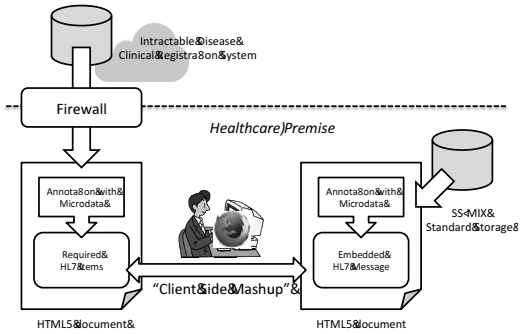


Figure 1. A client-side mashup for message exchange between cross-premises servers.

1. Method

We assume that the scenario in which the user accesses the cloud service and the in-hospital web application server is as shown in Figure 1. The intractable disease clinical registration system is a web application server hosted on the cloud service. We also set up the laboratory reporting system, which is located at the healthcare institution. The server is implemented on Sinatra, a Ruby-based web application framework, as well as Ruby 2.0.

In the laboratory system, we embedded HL7 messages containing laboratory test results into the microdata[3], specifically, in the description part of the table displaying the test results. The original HL7 messages are in raw text format, and so cannot be embedded into an HTML5 document directly. Therefore, we encode the message using a Base64 format. We provide the item type of microdata using "http://umws.tk/HL7Msg" to indicate that the set of microdata holds the Base64-encoded raw HL7 message. The URL "http://umws.tk[2]" is a namespace for this work only, because currently there is no standard framework related to medical information for microdata. The microdata of the HL7 message are inserted into the content attribute of the meta-tag, so that they are not displayed. The source of the HL7 messages is the Standardized Structured Medical record Information eXchange system[4]; standardised storage is proposed as the standard repository of HL7 messages.

We annotate the input element of the HTML document of the clinical research report with the microdata; the item type is "http://umws.tk/HL7Item", and the microdata are bound to the item of the HL7 message. Currently, there is no universal method for uniquely specifying particular HL7 items. We developed custom "data-accessor" attributes and HL7 item selector domain specific language (DSL) to exploit the extensibility of HTML5 to specify which item of the HL7 message should be assigned to the element. For example, "OBX-5@OBX[*]-3.1('WBC')" in the data-accessor attribute indicates that the fifth observation segment (OBX) field of the segment containing the value of the third field is required, and that the first component is 'white blood cell(WBC)'. The fifth field of the OBX segment is the observation

[2] "umws.tk" stands for "Universal Medical Web Service Tool Kit"

value, which in this example is the laboratory WBC count test result. The HL7 item selector DSL parser is implemented using “parslet”, the simple Parsing Expression Grammar (PEG) parser framework for Ruby. When a user drags Document Object Model (DOM) elements in which HL7 messages are embedded (which reside in the laboratory report) and drops them into the research report, the Javascript commands in the research report document send the DOM elements and microdata with the HL7 item selectors on the research report document to the registration system using Ajax via a hypertext transfer protocol secure (HTTPS) connection as shown in Figure 2. The registration system parses the HL7 messages and HL7 item selectors, and makes hash table from the matched entries. The research report updates the input fields with the returned hash table using jQuery.

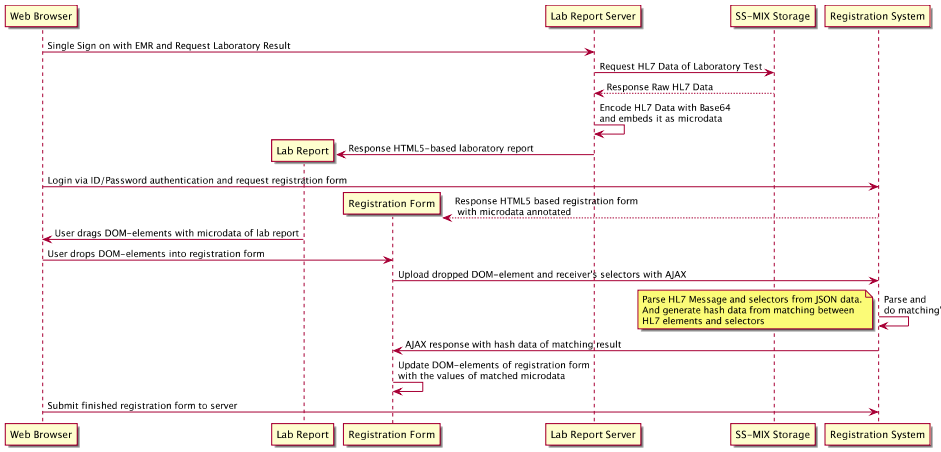


Figure 2. The mashup between the laboratory report and the intractable disease clinical research report

2. Results

The user accesses the registry using a web browser via an HTTPS connection and is authenticated via a one-time password login. The user also logs in to the web application server inside the healthcare premises via a single sign-on using EMR. The laboratory report server shows the laboratory result table, which holds the microdata of the corresponding HL7 message. The user can drag and drop DOM elements from the laboratory report into the research report. When the clinical registration system receives the dropped DOM element via Ajax, it searches for microdata where the item property attribute is “HL7Message”, which is the HL7 message of the laboratory test result. The server also scans the microdata for which the item type attribute is “HL7Item”. The item of the HL7 message is extracted according to the accessor specified in the data-accessor attribute, and the value is stored in the input field.

We verified that the intended laboratory results were correctly mapped to the input fields of the research report according to the HL7 selector, which we annotated on the input fields of the clinical research report, as shown in Figure 3. The user was able to access laboratory results and prescription histories from the EMR system and to transcribe the results to the clinical registration report using the cloud-based service, and without directly linking these systems. During these procedures, only the HL7

messages that the user intended to use were sent to the cloud service via a secure HTTPS connection.

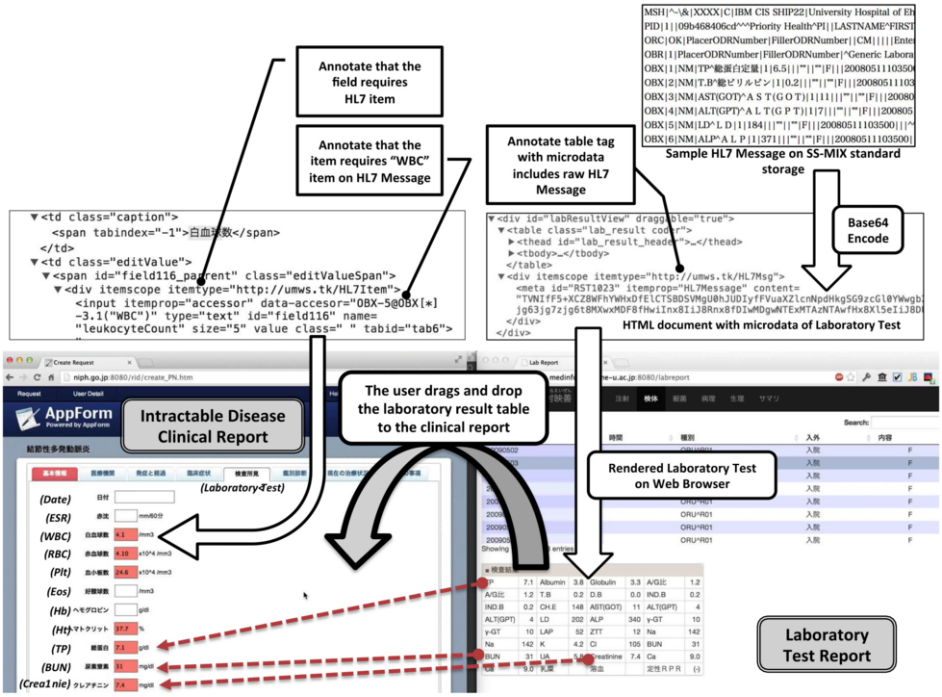


Figure 3. HL7 message embedded in a web page using microdata.

3. Discussion

3.1. Lack of design guidelines for research report microdata in the medical domain

The method described here is a promising scheme because it enables cooperation between a web application server in the healthcare institution and a cloud computing service. However, there remain a number of unsolved problems. The microdata have a description capability similar to the Resource Description Framework (RDF). RDF merely describes the semantic network and does not take into consideration how it will be interpreted (or what will interpret it). In theory, it is possible to embed XML serialised HL7 messages into an HTML document. However, microdata can be bound to any elements in the HTML document and can benefit from the Semantic Web framework because the microdata have the same RDF capability. In other words, the microdata are located closer and tighter to each HTML element of the document so that we have a more fine-grained and standardised annotation method for the GUI elements and events compared to traditional approaches of embedding data into an HTML document. It is desirable to design the web application and microdata so that the concept expressed by the microdata and the contents of the web page (and the user's manipulation thereof) may be consistent. We must also consider how the microdata will be described so that they properly match the intentions of the sender and receiver.

There is no standard for encoding raw HL7 messages into fully parsed microdata so that the web application may take full advantage of the Semantic Web. In the absence of a standard method, we developed a custom accessor for the HL7 message. However, the method is not particularly useful because it lacks a terminology-aware item specification. We should define a more sophisticated accessor method so that it specifies the target item using medical concepts.

3.2. Terminology-mapping service in the cloud

Currently, HL7 messages are composed using healthcare-specific terminology, but without national interoperability. Supplying a data-mapping service using microdata is challenging because of the inconsistencies in the terminology used in HL7 messages. The current terminology-mapping services that support message exchange between medical record systems and departmental systems are not intended for inter-healthcare or inter-cloud mapping. Therefore, we may require a terminology mapping service in the cloud to support inter-healthcare message exchange and interpret microdata.

3.3. Security and inter-domain issues

If there were a VPN established between the cloud computing service and the EMR system, a breach of the cloud service would bring about a breach of EMR system. Therefore, we did not to connect the cloud service and EMR directly to create client side mashup. The client side mashup ensures that minimal data are sent to the cloud service because it is only trigged by the users' drag-and-drop actions.

We implemented a drag-and-drop interface between the server outside the premises and the server in the healthcare institution. We cannot utilise a server-side mashup or a scheme such as JSON with padding (JSONP) because there is no direct connection between the cloud service and the EMR system. Cross-origin resource sharing (CORS) [5] permits the web browser to acquire data from the servers with different URLs. Using this scheme, we add rules for the web application server residing in the healthcare institution to permit interoperation with the cloud computing service.

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References

[1] Eizen Kimura, Shinji Kobayashi, Yasuhiro Kanatani, Ken Ishihara, Tsuneyo Mimori, Ryousuke Takahashi, et al. Developing an Electronic Health Record for Intractable Diseases in Japan. Studies in Health Technology and Informatics. 2011;169:255-9.

[2] Cheung K-H, Yip KY, Townsend JP, Scotch M. HCLS 2.0/3.0: Health care and life sciences data mashup using Web 2.0/3.0. Journal of biomedical informatics. 2008;41(5):694-705.

[3] W3C. HTML Microdata. W3C Working Draft 05 April 2011 http://wwww3org/TR/2011/WD-microdata-20110405/2011.

[4] Kimura M, Nakayasu K, Ohshima Y, Fujita N, Nakashima N, Jozaki H, et al. SS-MIX: A Ministry Project to Promote Standardized Healthcare Information Exchange. Methods of Information in Medicine. 2011;50(2):131.

[5] Van Kesteren A. Cross-origin resource sharing. W3C Working Draft WD-cors-20100727. 2010.

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Adaptive Healthcare Processes for Personalized Emergency Clinical Pathways

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Abstract. Pre-hospital and in-hospital emergency healthcare delivery involves a variety of activities and people that should be coordinated in order effectively to create an emergency care plan. Emergency care provided by emergency healthcare professionals can be improved by personalized emergency clinical pathways that are instances of relevant emergency clinical guidelines based on emergency case needs as well as on ambulance and hospital resource availability, while also enabling better resource use. Business Process Management Systems (BPMSs) in conjunction with semantic technologies can be used to support personalized emergency clinical pathways by incorporating clinical guidelines logic into the emergency healthcare processes at run-time according to emergency care context information (current emergency case and resource information). On these grounds, a framework is proposed that uses ontology to model knowledge on emergency case medical history, on healthcare resource availability, on relevant clinical guidelines and on process logic; this is inferred to result in the most suitable process model for the case, in line with relevant clinical guidelines.

Keywords. Adaptive emergency healthcare processes, ontology, clinical pathways, BPM

Introduction

Recently, personalized clinical pathways (CPs) or care plans have emerged as standardized treatment processes based on clinical guidelines that are instantiated according to patient medical problems for promoting effective healthcare [1,2]. However, as demonstrated by the first international survey of the European Pathway Association (EPA), most countries only use CPs for a few cases (e.g. in the treatment of acute hospital diseases) [3]. In emergency healthcare and especially in pre-hospital care only few cases have been reported of using CPs. Personalized emergency CPs can improve the quality of care provided on site, en route and at the receiving facility (hospital emergency department - ED) by enabling appropriate and timely interventions by emergency care professionals [4-6]. Those can be generated by using patient personal medical history information existing in electronic medical records and emergency case and resource information existing in ambulance and hospital information systems in order to select the execution pathway of standard emergency clinical guidelines. Hence, personalized emergency CPs are actually instances of

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emergency clinical guidelines applied to particular emergency case needs and to care givers' available resources (e.g. ambulance and hospital ED).

Emergency CP implementations require modeling CP logic properly and providing suitable runtime support for variance handling. This can be achieved by integrating emergency clinical guidelines logic into the emergency healthcare processes that are executed from the time of ambulance request till the time of patient exit from the healthcare facility. The resulting process models, however, should be adaptable (as opposed to prescriptive) to changes at run-time imposed by outside events (e.g. emergency case information, ambulance and hospital resource availability) that might suggest different pathways to be followed by care givers (i.e. process participants handling the case) [1,2,7,8]. Hence, the process activities and their coordination for each emergency case might be based on a loosely or partially-specified model which is completed at run-time according to the emergency case and resource information and appropriate clinical guidelines that form emergency care context. Semantic technologies can serve the purpose of modeling emergency care context and Business Process Management Systems (BPMSs) for modeling and executing emergency healthcare processes [1,2,8].

On these grounds, this paper presents a framework that enables the development of personalized emergency clinical pathways based on guidelines by building flexible and adaptive emergency healthcare processes that are aligned to emergency care contextual information. In particular, emergency healthcare process models are loosely-specified using the Business Process Modeling Notation (BPMN) and are made specific at run-time according to the changing context modeled in an enhanced ontology. This ontology incorporates knowledge on emergency case medical history, on healthcare resource availability acquired from a variety of sources (existing information systems), on relevant clinical guidelines and on process logic. Hence, through ontology reasoning, the most suitable process model for the case is dynamically built in line with relevant clinical guidelines and process activities are executed by authorized healthcare professionals. Thus, the general theme of this work lies in the realm of guidance provision to emergency healthcare professionals as to the most appropriate management of emergency cases while improving utilization of healthcare resources available.

The basic motivation for this research stems from our involvement in a recent project concerned with supporting pre-hospital and in-hospital emergency healthcare work processes based on relevant clinical guidelines selected and instantiated according to each emergency case information (e.g. triaging information such as severity of case), while also taking into account ambulance and hospital resource availability information.

1. Methods

1.1. Emergency healthcare process

Figure 1, shows a high level view of a pre-hospital emergency healthcare process model using the BPMN 2.0.The model is divided into three lanes: The first and the second ones represent the group of activities executed by relevant process participant roles (e.g. ambulance dispatching center and vehicle personnel) while the third lane represents an ad-hoc sub-process instantiated at run-time based on relevant clinical

guidelines, emergency case and resource availability information. Upon execution of this sub-process, the "Recommended Action" activity generalization takes on an activity specialization (specialization activity occurrence) at run-time which is executed to send a recommended action to authorized ambulance vehicle personnel.

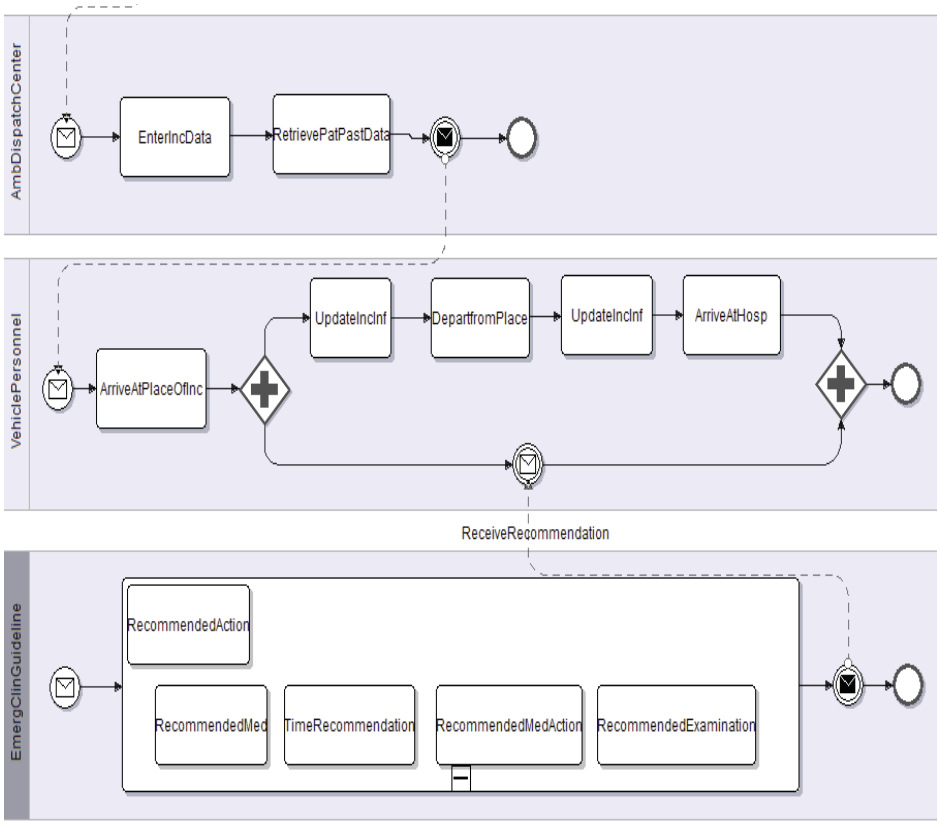


Figure 1. A high-level view of the pre-hospital emergency healthcare process using BPMN 2.0

1.2. Framework Components

The proposed framework consists of the following modules: The knowledge repository module, the service module and the process module.

The knowledge repository module consists of an enhanced ontology and a rule base. The enhanced ontology consists of three components: (a) emergency medical and paramedical knowledge (EMPK) containing the clinical guidelines information, (b) emergency case knowledge (ECK), in turn further divided into current case and medical history information of the patient and (c) emergency resource availability knowledge (ERAK), containing information on ambulance and hospital resource availability. This has been built in Ontology Web Language (OWL) as a hierarchy of classes and sub-classes which are accompanied by a set of ontology properties that are used to capture relationships among class instances. For example the ontology property "isTransfferedBy" is used to associate an emergency case, instance of class "emergency case id" with an ambulance, instance of class "ambulance id".

The rule base consists of two interdependent sets of rules: medical knowledge and process knowledge rules. Medical knowledge rules represent the clinical guidelines knowledge by combining portions of emergency case incident, case medical history and resource availability information to result in a set of strong or weak recommendations that should be adopted or considered for adoption, respectively, and stored into the ontology as facts to be made available upon ontology querying. In addition, medical knowledge rules trigger the execution of process knowledge rules that result in instantiating the ad-hoc sub-process and invoking relevant automated process activities. In particular, process knowledge rules dictate which of the "RecommendedAction" activities of the process model of Figure 1 should be invoked for the case informing authorized ambulance personnel. For example, a medical knowledge rule may require that an emergency case with "chief complaint" *chest pain and/or suspected cardiac arrest* and "evidence" *STEMI* should be "*administered 162 to 325 mg aspirin (chewed)*"; that in turn results in the execution of a corresponding process knowledge rule that results in executing a "RecommendedAction" activity for presenting this strong recommendation to ambulance personnel [9].

The service module consists of a set of web services that actually implement groups of process model activities. These are invoked as triggered by process knowledge rules reasoning. In particular, the services implementing the automated process activities (of the third lane) access the knowledge repository in order to retrieve emergency care context information and/or inferred knowledge information. For example, the web services implementing the "RecommendedAction" activities consults the ontology to retrieve the recommended actions for the current emergency case as inferred by the knowledge of the current emergency case. In addition, the service module includes web services that access existing information systems to retrieve emergency case information from various sources or to update emergency case information.

The process module consists of the process execution engine that instantiates and executes dynamically relevant process model activities based on the outcomes that relevant process knowledge rules arrive at run-time. In addition, the process engine invokes the appropriate services of the service module as required.

2. Results

The proposed framework is intended to be implemented on top of existing ambulance and hospital information systems, interacting with them through web services. Thus, emergency case and medical resource availability information can be accessed from existing systems and a certain view of it is inserted into the ontology of the knowledge repository as a set of facts. Based on this information, relevant ontology rules are triggered to invoke relevant "RecommendedAction" activities of the ad-hoc sub-process that provide guidance to ambulance personnel as to how to best manage specific emergency cases. Then, based on medical evidence, appropriate ontology rules are triggered to invoke other most appropriate "RecommendedAction" activity recommended by a pre-hospital relevant protocol [9].

Currently, work is in progress on developing a full prototype implementation of the proposed framework using the Protege-OWL platform, the Semantic Web Rule Language (SWRL) and the Jess inference engine for knowledge repository

development (i.e. the ontology and the rule base) and the Oracle SOA suite for process model and relevant web services development and execution.

3. Concluding remarks and discussion

Clinical pathways, also known as care pathways, critical pathways, integrated care pathways, or care maps, are among the main tools used to manage quality in healthcare based on standardization of care processes [1,2,3]. The clinical pathways can be supported by healthcare process modeling and execution in conjunction with semantic technologies that can serve for inferring alternative pathways and for suggesting recommended actions to process participants regarding specific cases. In emergency healthcare, clinical pathways are barely embedded in emergency healthcare processes supported by automated systems. However, it is our view that their adoption may substantially improve the quality of emergency care provided, remove poor practices and identify and apply evidence while also better managing the utilization of available emergency care resources [4,5]. This paper proposes a framework for the incorporation of emergency clinical pathways into adaptive emergency healthcare processes through the use of semantic technologies with main outcome expectation being the improvement of the quality of emergency healthcare provided as measured by measures such as the increased life saving rate accompanied by cost containment in terms of resource use. Our intension is to use the proposed framework in conjunction with real world ambulance and hospital information systems in order to evaluate it with regard to performance and suitability for improving emergency care provided through the use of personalized emergency CPs.

References

[1] Yao W., Kumar A. CONFlexFlow: Integrating flexible clinical pathways into clinical decision support systems using context and rules. Decis Support Syst. 2013**;** 55:499-515.
[2] Huang Z., Lu X., Duan H. Using recommendation to support adaptive clinical pathways. J Med Syst**.** 2012**;** 36:1849-1860.
[3] Wanga H., Lia J., Zhanga Y., Suzukib M., Arakib K. Creating personalized clinical pathways by semantic interoperability with electronic health records. Artif Intell Med. 2013; 58:81-89.
[4] Ferri M., Luca A., Rossi P., Lori G., Guasticchi G. Does a pre-hospital emergency pathway improve early diagnosis and referral in suspected stroke patients? – Study protocol of a cluster randomized trial. BMC Health Serv Res. 2005; 5(66).
[5] Poulymenopoulou M., Malamateniou F., Vassilacopoulos G. Emergency healthcare process automation using mobile computing and cloud services. J Med Syst. 2012;36(5):3233-41.
[6] The European Society of Cardiology. Acute myocardial infarction: pre-hospital and in-hospital management. Eur Heart J. 1996;17:43-63.
[7] Neumann C., Schwab P., Wahl A., Lenz R. Alpha-adaptive: Evolutionary workflow metadata in distributed document-oriented process management. Lect Notes Bus Inf Process. 2012;100:225-236.
[8] Reuter C., Dadam P., Rudolph S., Deiters W., Trillsch S. Guarded process spaces (GPS): A navigation system towards creation and dynamic change of healthcare processes from end-user's perspective. Lect Notes Bus Inf Process. 2012;100:237-248**.**
[9] American Heart Association. ACC/AHA guidelines for the management of patient with ST_Elevation myocardial infarction - executive summary. 2004, Available from URL: http://circ.ahajournals.org/content/110/5/588.full.

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A novel EEG-based spelling system using N100 and P300

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Abstract. P300-speller is one of the most popular EEG-based spelling systems proposed by Farwell and Donchin. P300-speller has a 6×6 character matrix and requires at least 12 flashes to input one character. This restricts increasing of the information transfer rate (ITR) by decreasing the number of flashes. In this paper, a novel spelling system is proposed to reduce the number of flashes by sequential stimulation of images. In order to determine the command, the proposed system utilizes two kinds of the event-related brain potentials (ERP), N100 and P300 whereas P300-speller utilizes only P300. Thanks to using both N100 and P300, the proposed system achieves higher accuracy and faster spelling speed than P300-speller. Our experiment by ten subjects showed that ITR of the proposed system is an average of 0.25bit/sec improved compared to P300-speller.

Keywords. EEG; Brain-Computer Interfaces; Visual Evoked Potentials; Event-Related Potentials; P300.

Introduction

Brain-Computer Interface (BCI) is a direct communication pathway to command devices by discriminating brain signals. The major goal of BCI research is to develop systems that make it possible for disabled users to communicate with the other people and control their limbs or the environment [1, 2]. To this end, many aspects of BCI systems have been investigated. Especially BCI systems using Event-Related Potential (ERP) are friendly for disabled users because ERP is reliable and stable for almost all people. In addition, users do not have to train to control the BCI. Electroencephalography (EEG) is often used for BCI since EEG is relatively low-cost, fast, and safe device to observe brain signals such as ERP in different area on the scalp. P300, which is a kind of ERP, is elicited roughly 250ms to 500ms after the target stimulus in the process of the oddball task [3]. In this oddball paradigm, when a user conducts experiment presenting two discriminative stimuli (one is target and another is non-target), P300 is elicited by user's response such as counting the incidences of the target stimuli.

P300-speller proposed by Farwell and Donchin is well-known and the first BCI system using P300 [3]. A 6×6 matrix containing commands such as the letters of alphabets or numerals is displayed on a screen. Each row and column of the matrix is flashed in random order. The user silently counts the number of times that the desired

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command is flashed. The flash containing the desired character evokes P300. The system detects evoked P300, and sends the command.

P300-speller can be extended by enlarging the size of the stimuli matrix to deal with many commands, however, such extension would require more time to present the stimuli and hence the information transfer rate (ITR) may not be improved. Several methods to improve the classification accuracy and ITR of P300-speller or P300-based BCI have been investigated such as signal processing methods [4], classification algorithms [5], and error correcting codes [6]. However, these methods focus more on the signal analysis and less on the reduction of the number of the stimulations. Decreasing the number of stimulations enables us to increase the spelling speed and reduce the user's fatigue.

In this paper, a novel BCI system using N100, which is a kind of visual evoked potential (VEP), in addition to P300, is proposed to reduce the number of the stimulations. In the proposed method, nine kinds of stimulus images including a 2×3 matrix containing four commands are used and only nine flashes per a trial are required (Fig. 1). P300 is used to detect the target stimulus image containing the desired character. N100 is used to detect the target position that the user gazes on. Our experiment by ten subjects shows that N100 and P300 can be detected by the proposed stimulation scheme, and averaged ITR of the proposed method is 0.25bit/sec higher than that of P300-speller.

1. Methods

1.1. P300-speller

P300-speller has a 6×6 matrix containing alphabets and numerals. Each row and column is flashed in random order. The user can type the desired character by counting the number of times it is flashed. The desired character is detected by using P300, which is evoked by the flash of the row and column containing the desired character.

1.2. Proposed method

26 alphabets (A, B, …, Z) and 10 numerals (0,1, …, 9) are used as spelling commands in the proposed system as well as P300-speller. In order to reduce the number of the stimulations, the proposed method detects the desired character by the following two steps: (1) the image containing the desired character is detected by using P300, (2) the position that the user gazes on is detected by using N100. In order to detect the user's gazing position by using N100, we arrange blank positions in the stimulus images. Since N100 is elicited by any visual stimulus without a mental task [7,8], we can detect the position that the user gazes on by comparing N100 responses for the blank and non-blank positions. P300 is elicited by counting the number of times that the desired character is flashed as well as P300-speller.

In our study, nine pattern images are used. Four characters and two blanks are assigned in the 2×3 matrix as shown in Fig. 1. Each position presents six characters and three blanks in a trial. The position on which the desired character is presented, is informed to the user before the experiment.

An example of the detection process of the desired character ‘K’ is shown in Fig.1-(b). The position that the user gazes on is detected by N100, and the image that the user

responds is detected by P300. The desired character is detected by the combination of the target position and the target image.

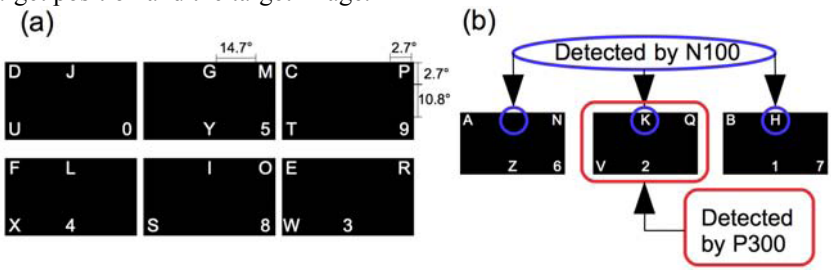


Figure 1. Examples of (a) stimulus images and (b) the method to detect the desired character in the proposed system

1.3. Experimental condition and procedures

Ten healthy subjects (22-24 years old males) participated in our study. They conducted experiments of P300-speller and the proposed system 40 times alternately. P300-speller flashes 24 times (= 12 flashes × two trials), on the other hand, the proposed system flashes 18 times (= nine flashes × two trials) in one session. The subjects were asked to gaze on only one position that the target character is presented and silently count the number of times the target character flashes. The flash has 125ms duration and the inter stimulus interval (ISI) is 62.5ms. The proposed system takes 3.375s to input a character per one session, whereas P300-speller takes 4.5s.

The EEG was recorded using an active EEG (Guger technologies) and a bio-signal amplifier (Digitec) with 0.5Hz analogue high-pass filter and 100Hz analogue low-pass filter. 16 electrodes (FCz, FC2, FC1, Cz, CP1, CP2, Pz, POz, P3, P4, TP8, TP7, C3, C4, C5, and C6 of the extended international 10-20 system) were used [3,8]. AFz was used as the ground and A2 was used as the reference.

1.4. Feature extraction and classification scheme

The second-order Butterworth band pass filter (1-13Hz) is used to filter the EEG and the third-order Butterworth band stop filter (49-51Hz) is used to remove the hum noise. The signal is downsampled from 512Hz to 64Hz. P300 and N100 components are respectively extracted from 125ms to 625ms and from 100ms to 250ms after the stimulus. P300 signals are averaged for each stimulus image in both methods. N100 signals are averaged for each position. For P300, 512-dimensional feature vectors are made by arranging 32 points signal and 16 electrodes. For N100, 160-dimensional feature vectors are made by arranging 10 points signal and 16 electrodes.

The linear SVM is used to classify the signal. The soft margin parameter C is selected to from $\{0.1, 1, 10, 100, 1000\}$.

ITR [bit/sec] is used as the performance index since the length of one session is different. ITR is calculated by

$$B = \frac{1}{T}\left\{\log_2 N + P\log_2 P + (1-P)\log_2\frac{1-P}{N-1}\right\}\ [\text{bit/sec}]\,,$$

where T [sec] is the time of one session, P is the classification accuracy, and N is the number of commands [10].

2. Results

Averaged waveforms over the target and non-target stimuli of electrode Cz are shown in the left of Fig. 2. Averaged waveforms over the attended and unattended stimuli of electrode FCz is shown in the right of Fig. 2.

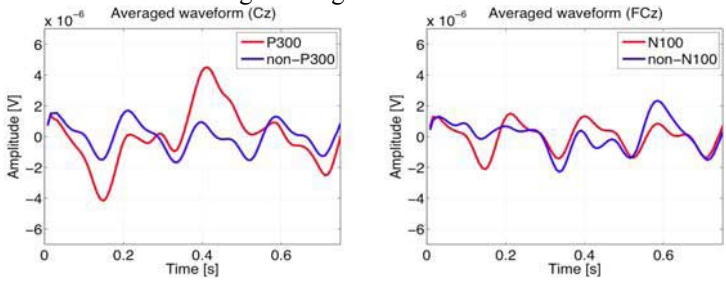


Figure 2. Averaged waveforms of electrode on which the largest amplitude of P300 (N100) is observed.

Table 1 shows the averaged classification accuracies and the standard deviations over ten subjects.

Table 1. Classification accuracy [%] and standard deviation of ERP components (P300,N100).

	P300-speller		Proposed system	
	P300 (row)	P300 (column)	P300	N100
Average	81.3 ± 13.9	80.5 ± 13.2	74.0 ± 18.4	88.5 ± 10.4

Table 2 shows the classification accuracies and ITR. The significance of ITR of the proposed system was confirmed by the F-test at level α=0.05 and the unilateral Welch's t-test at level α=0.05.

Table 2. Classification accuracy and information transfer rate (ITR).

Subject	Classification Accuracy [%]		ITR [bit/sec]	
	P300-speller	Proposed	P300-speller	Proposed
1	75.0 ± 21.7	70.0 ± 14.3	0.713 ± 0.287	0.832 ± 0.267
2	67.5 ± 16.8	60.0 ± 32.4	0.593 ± 0.231	0.728 ± 0.598
3	85.0 ± 13.7	70.0 ± 19.0	0.870 ± 0.255	0.855 ± 0.408
4	70.0 ± 11.2	77.5 ± 18.5	0.619 ± 0.167	1.002 ± 0.389
5	60.0 ± 5.6	62.5 ± 12.5	0.479 ± 0.068	0.691 ± 0.218
6	72.5 ± 10.5	67.5 ± 11.2	0.654 ± 0.156	0.778 ± 0.197
7	70.0 ± 14.3	85.0 ± 10.5	0.624 ± 0.200	1.143 ± 0.256
8	65.0 ± 16.3	57.5 ± 6.8	0.558 ± 0.227	0.598 ± 0.111
9	47.5 ± 10.5	80.0 ± 14.3	0.334 ± 0.118	1.043 ± 0.326
10	65.0 ± 10.5	72.5 ± 10.5	0.549 ± 0.138	0.872 ± 0.208
Average	67.8 ± 15.6	70.3 ± 17.1	0.599 ± 0.222	0.854 ± 0.336

3. Discussion and Conclusion

From the right of Fig. 2, there is a significant difference around 150ms between signals containing N100 and non-N100. The periodic negative peaks (340ms, 530ms, and 720ms) are due to the response of the other stimulations. The difference of N100 around 150ms is caused by utilizing the stimulus images containing the blank positions

in the proposed method. Thus, the proposed method can detect the position that the user gazes on by using N100 component.

From Table 1, the classification accuracy of P300 in the proposed system is an average of 6.9% lower than that in P300-speller. The reasons are as follows: i) the number of the training data for P300 of the proposed system is a half of that in P300-speller since the proposed system evokes P300 only once in a trial, whereas P300-speller evokes twice, that are the row and column; ii) the number of the classes for P300 in the proposed system is larger than that in P300-speller since the proposed system has to classify to nine classes in order to detect the desired image, whereas P300-speller classifies to six classes to detect the desired row and column.

The ITR of the proposed system is an average of 0.25bit/sec higher than that of P300-speller. Moreover, the averaged accuracy of N100 is 7.6% higher than that of P300 in both methods. This is due to the fact that the performance of feature extraction of N100 is better than that of P300 since N100 signal is averaged six times, on the other hand, P300 signal is averaged two times.

We proposed a novel design for a spelling system using P300 and N100 to reduce the number of flashes per trial and increase ITR. The advantages of our system are i) the classification accuracy of N100 is better than that of P300 since the number of averaging for N100 is greater than that for P300; ii) it takes shorter time to input one command since the number of flashes can be reduced to nine flashes; iii) N100 is elicited by the visual stimulation without a mental task, such as counting the number of flashes, hence the user's fatigue can be reduced; iv) each character never flashes in a row whereas at least one character flashes in a row in P300-speller; v) the user has to respond the desired character only once per one trial in the proposed system, whereas in P300-speller the user has to respond it twice, that are the row and column containing the desired character.

In future work, we extend the proposed method to improve ITR by extending the size of matrix. The optimal selection of electrode positions should also be investigated.

References

[1] Pfurtscheller, G., Muller-Putz, G.R., Scherer, R., and Neuper, C., Rehabilitation with brain-computer interface systems, *Computer* **41** (2008), 58-65.

[2] Wolpaw, J.R., Birbaumer, N., McFarland, D.J., Pfurtscheller, G., and Vaughan, T.M., Brain-computer interfaces for communication and control, *Clin. Neurophysiol.* **113** (2002), 767-791.

[3] Farwell, L.A. and Donchin, E., Talking off the top of your head: Toward a mental prosthesis utilizing event-related brain potentials, *Electroenceph. Clin. Neurophysiol.* **70** (1993), 510-523.

[4] Lee, W.L., Tan, T., and Leung, Y.H., An improved P300 extraction using ICA-R for P300-BCI speller, *35th Annual International Conference of the IEEE EMBS* (2013), 7064-7067.

[5] Krusienski, D.J., Sellers, E.W., McFarland, D.J., Vaughan, T.M., and Wolpaw, J.R., Toward enhanced P300 speller performance. *Journal of Neuroscience Methods* **167** (2008), 15-21.

[6] Hill, J., Farquhar, J., Martens, S.M.M., Bießmann, F., and Schölkopf, B., Effects of stimulus type and of error-correcting code design on BCI speller performance. *The Twenty-Second Annual Conference on Neural Information Processing Systems* (2008), 8-11.

[7] Voorhis, S.V. and Hillyad, S.A., Visual evoked potentials and selective attention to points in space, *Perseption and Sychophysics* **22** (1977), 54-62.

[8] Vogel, E.K. and Luck, S.J., The visual N1 component as an index of a discrimination process, *Psychophysiology* **37** (2000), 190-203.

[9] Chang, C. and Lin, C., LIBSVM: A library for support vector machine, *ACM Transactions on Intelligent Systems and Technology (TIST)* **2** (2011), 1-27.

[10] Volosyak, I., SSVEP-based Bremen-BCI interface-boosting information transfer rates, *Journal of Neural Engineering* **8.3** (2011), 036020.

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Supporting talk-based mental health interventions with digital whiteboards

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Abstract. The potential of mental health interventions supported by computers has rarely been explored to date, and the use of technology has hence been limited. There is a need for finding new ways of providing engaging psychotherapy services. We introduce the digital whiteboard system Tele-Board MED (TBM) as a new approach of promoting patient-therapist interaction and joint documentation. Based on observations of cognitive behavioral therapy (CBT) sessions and a text material review we identified possibly useful features. We conducted a qualitative and quantitative feedback study with 34 therapists in the form of a questionnaire based on a video showing the system's fundamental concept and features. This allowed us to evaluate the therapists' attitudes and the ability of a system like TBM to meet user needs. We encountered willingness to use the system primarily driven by practical interest in fulfilling administrative and legal requirements. Skepticism regarding patient file transparency and technology use was also found. The main insight is that reestablishing the nature of CBT sessions towards higher patient engagement can more successfully be pursued if technology provides incentives for therapists, such as features that speed up administrative tasks.

Keywords. Patient-doctor cooperation, psychotherapy, digital whiteboard, electronic patient record, patient empowerment

Introduction

Cognitive behavioral therapy (CBT) is a widely used approach to talk-based mental health care applied for a wide range of problems, including phobias, depression and anxiety disorders. CBT aims to enhance the patient's self-efficacy and uses treatments like coping tactics, relaxation training and social skills training.

The potential of mental health interventions supported by computers has rarely been explored to date, and the use of technology has hence been limited. Coyle et al. [1] give a comprehensive overview of the research field combining mental health care (MHC) and human-computer interaction. They identify domain-specific reasons for skepticism towards technology but also point out that it can play a significant role in helping to address the need of finding new ways of providing accessible, engaging, cost effective MHC services. Most technology used to date in MHC, like electronic contact means, online information sources and electronic questionnaires turned out to improve access, but didn't improve patients' personal engagement in the treatment [1].

We introduce the digital whiteboard system Tele-Board MED (TBM) as a new approach of engaging patient and therapist in cooperation. As an adjunct to the traditional face-to-face therapy it should allow patient and therapist to document

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sessions jointly in a digital format. Figure 1 shows a user scenario with an interactive whiteboard to display and operate the documentation panel via touch gestures, and tablet computers with keyboards as additional input devices.

Traditional whiteboards are common tools in therapy rooms. Digital whiteboards have the potential to broaden the therapeutic space even more by increasing the scope of interactions. One of our highest priorities is to improve – or at least not to damage – the patient-doctor relationship, since a high quality relationship is considered one of the major curative factors in psychotherapy [2].

We are building TBM on the concepts and infrastructure of Tele-Board – a whiteboard software system to digitally support distributed teams in creative, collaborative work [3]. Basic functions include drawing with digital pens, erasing pen strokes, and writing, posting, arranging and clustering sticky notes.



Figure 1. Therapy session with Tele-Board MED, using an interactive whiteboard and tablet computers.

The concept of patient empowerment is discussed extensively both in science [4, 8] and politics. Ajoulat et al. [4] identified two directions in which the process of patient empowerment is brought forward: patient-doctor interaction and the view on the patient alone. In Germany, a law was passed in 2013 which regulates medical documentation anew to promote patient-doctor cooperation at eye level [5]. The law states that doctors are obliged to document the whole process of treatment promptly and comprehensively. Patients have the right to see their record, and to attain an electronic copy.

1. Methods

The research was conducted in three steps. First, we used qualitative, explorative methods to collect data about CBT sessions. Afterwards, insights about common practices were incorporated into system features such as whiteboard panel templates. Finally, a feedback study for the conceptual evaluation of TBM was conducted. Measures involving therapists and patients took place in an ambulant psychotherapeutic clinic and training academy in Germany. The therapy session attendance was done by one research team member who is a psychologist herself and a trainee at the institute just mentioned. Patients at the institute agreed to the possible attendance of trainees at the start of therapy.

1.1. Observation of cognitive behavioral therapy sessions and review of text material

We started by observing the entry phase of over 100 patients, recording which information therapists asked for and wrote down. The sessions were held by three different therapists, each having more than 30 years of therapy experience. Additionally, text material was reviewed, such as anamnesis questionnaires (forms to be filled in by patients as well as guidelines for therapy sessions) and training material. In the German public health service, therapists make a case-based funding application. After up to five probatory sessions assessing therapy need and prospects of therapy success, a case report is sent to the patient's health insurance as financing request.

1.2. Iterative design of an anamnesis template

We designed a template according to the information that is recorded most frequently in anamnesis sessions, and tested it with three experienced therapists. Documentation was done in parallel by the therapists using their standard material and our research team member using a paper prototype of the template. After the sessions, recorded content was compared and missing information led to template revision. After five revision-and-test-cycles no further amendments were suggested by the therapists.

1.3. Feedback study with therapists on the basis of Tele-Board MED explanation video

We conducted a feedback study with 34 behavioral therapists (age: 27 to 61yrs, avg. 35.4, working experience: from less than 1 to more than 10yrs, majority 1-2yrs).

To introduce the aims and functionality of Tele-Board MED (TBM), we generated a 15-minute video [6]. It explains the requirements of the new German patients' rights law with associated documentation needs, and introduces the concept of TBM in terms of setup, interaction, functionality, and hardware. Ideally a big touch screen is used to instantaneously document the therapy session via keywords on sticky notes or in the form of drawings. Additionally, both patient and therapist can use mobile input devices such as tablet computers to write sticky notes (cf. fig. 1). They are sent via a wireless connection to the server and appear instantly on the whiteboard where they can be put in the right place with a swipe of a finger. The template function can help guide the therapy session and allows for documentation from a prepared, yet flexible framework. The Word-export function allows sticky note texts on the whiteboard panel to be exported into a text file. The protocol function generates an overview of opened whiteboard panels during a session. Furthermore there is a picture export function.

A 9-page questionnaire was sent out to therapists per e-mail containing an information text, and the link to the video. In the first part, we asked questions about their attitude towards and use of technology, and about their attitude towards and practices of writing case reports. We then asked questions about the perceived usefulness of TBM after having seen the video.

2. Results

We gained insights in writing case reports, discovered that CBT is highly structured and thus well suited for templates, and we were able to evaluate the concept of TBM.

The anamnesis template shown in fig. 2 addresses the most prominent issues discussed in any first CBT sessions: patient history, emotions, thoughts, family status, plans, energy, therapy experience, concerns, self-endangerment, and medical issues. Since one cannot predict patient-doctor conversations, templates are adaptable and can easily be changed like any other whiteboard panel.



Figure 2. Anamnesis template containing keywords and icons filled with sticky notes regarding the case.

The analysis of text material showed that the case report is a condensed summary of the information worked on in the therapy itself. This often entails redundancy in writing. As the basis for health insurance companies to make pay/no-pay decisions, the case report is an essential document which covers three subjects: a description of the patient's case, an analysis of the problems, and an outline and justification of the treatment. In the feedback study we found that the writing of case reports is regarded as an annoying, time-consuming necessity. At the same time, the questions addressed by case reports are considered highly important and sensible. TBM can support this task with the Word export function whose text output can be used as building blocks to assemble the case report.

More than 2/3 of the therapists need at least 5 hours to write one case report. Therefore the writing is often not done in one sitting – all therapists occasionally or often need one week or longer to get done with one case report. It happens to more than 1/3 of the therapists in every fifth case that they cannot read theirs patients' handwriting. Asking therapists about their pragmatic strategies to cope with the tedious task of writing case reports, we found that more than 2/3 of the therapists often copy passages from existing reports, and more than 1/3 even often copies entire reports.

With the help of TBM therapists would on average save one third of their time for writing case reports. It would also be much easier to provide patients with electronic copies of their own file using TBM as opposed to other strategies they could think of. 88% of therapists stated they could imagine using TBM with their patients. Detailed results of the statistical analysis can be found in [7].

By means of qualitative questions we gained insights about the thoughts, wishes and criticism of therapists. Some expressed fears that a system like TBM might hinder the therapeutic contact and process, due to the mere presence of the device in the room as well to difficulties using the technology. Another user group predominantly was skeptical about the new patients' rights law with its demand for full transparency and

had concerns about data security issues. A third group of users had a thoroughly positive attitude and shared wishes and ideas for new features and templates.

3. Discussion

In order to reach the best possible treatment outcome in CBT, patients need to become actively engaged, patient and therapist need to cooperate productively and the therapist needs to provide an effective treatment. Apart from these curative necessities, there are also administrative or legal requirements on therapists that need to inform technology design for CBT. Considering these goals, which purposes should a digital whiteboard system serve in order to be more advantageous than traditional media? Most importantly, it should support therapists because they decide in the first step whether or not to give technology support a chance. This can be realized by offering features to carry out auxiliary tasks more efficiently. Time can be saved by avoiding handwriting readability issues and by avoiding redundancy in documentation. Current strategies like copying parts of or entire documents from other cases do save time, but may reduce the quality of documentation. Completeness and correctness in documentation are purposes to bear mind – with the highest priority of data security. With a system like TBM, documentation can be turned from a necessity into a curative factor if the patient's access and involvement leads to engagement. The issue of full record transparency is challenging though, especially finding ways of documenting delicate information, such as a therapist's observations that offend the patient when spoken out aloud. Moreover, technology in CBT should be adaptable to the individuality of each case and at the same time take into account the way the treatment is structured. Further research remains on how a system like TBM will impact patients and the actual interaction in a session, and if the joint documentation has the potential we envision.

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References

[1] D. Coyle, G. Doherty, M. Matthews, J. Sharry, Computers in talk-based mental health interventions, *Interacting with Computers* **19** (2007), 545–562.
[2] M.J. Lambert, Bergin and Garfield's Handbook of Psychotherapy and Behavior Change, John Wiley & Sons, New York, 2004.
[3] R. Gumienny, L. Gericke, M. Quasthoff, C. Willems, C. Meinel, Tele-Board: Enabling efficient collaboration in digital design spaces, *Proc. 15th Int. Conf. CSCWD* (2011), 47–54.
[4] I. Aujoulat, W. D'Hoore, A. Deccache, Patient empowerment in theory and practice: polysemy or cacophony?, *Patient Educ Couns* **66** (2006), 13–20.
[5] Gesetz zur Verbesserung der Rechte von Patientinnen und Patienten (2013) Bundesgesetz-blatt Teil I Nr. 9, ausgegeben zu Bonn am 25. Februar 2013 (text of a law, in German).
[6] J.P.A. von Thienen, Tele-Board MED introduction for behavioral therapists – needs and solutions, https://med.tele-board.de, accessed 27 January 2014 (two videos, in German).
[7] J.P.A. von Thienen, A. Perlich, C. Meinel, *Understanding Innovation – Design Thinking Research*, Springer, Berlin Heidelberg New York, in press.
[8] S. Koch, Improving quality of life through eHealth – the patient perspective, *Stud Health Technol Inform* **180** (2012), 25–29.

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ImmunoDB: a web based tool to analyze preclinical data

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Abstract. Often researchers find it difficult to interpret and correlate the results obtained from several experiments thus the development of a system that would allow storage, display and data analysis would be very useful. A web based interface is presented that allows people from a laboratory to submit the collected data and to compare results within different experiments. The interface was designed to be user-friendly and to be a basis of a flexible tool for performing analysis in an intuitive manner.

Keywords. preclinical data, sharing data in multicentre experiments, web based analysis tool.

Introduction

Understanding drug bioactivities is crucial for early-stage drug discovery, toxicology studies and clinical trials [1]. Results from laboratory research become the basis for an investigational new drug and an application seeks permission to use the drug/therapy in clinical trial [2]. Combining or integrating the data sets with similar basic hypotheses can help reduce study bias, increase statistical power and improve overall biological understanding [3]. The data obtained from experiments often result in a large amount of data that must be collected, processed and analyzed.

Generally, the preclinical data is an "unstructured" data, because it comes from multiple sources and is not suitable for efficient manipulation with standard and/or commercial tools, without a strong competence in applied statistics. In fact researchers most of the time collected data in the excel files that allows fast and free analyses, but they do not preserve data structure and relations very useful for a well assessed data analysis. One of the most suitable tools to assist researchers in the management of large sets of preclinical data can be an ad hoc developed web based application [4].

In the present paper, a web application called ImmunoDB is described. It has been created from a collaboration between the Medinfo Laboratory of DIBRIS and the clinical immunology unit at CEBR. ImmunoDB is a user-friendly and flexible tool developed to easily store and manage relational large amount of data in order to prepare them for a correct statistical analysis. As the present version of the application is still at a prototypal stage, the authors preferred to deal with a particular system as the analysis of data obtained from an in vitro study done for assess the immunogenicity of the four telomerase peptides included in the GX301 vaccine. The vaccine GX301 has completed

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a Phase I/II trial in Italy to evaluate safety and immune responses in patients with prostate and renal cancer[5], with very encouraging results.

In the present paper, a web based tool to collect this type of data from different sources and to organize them maintaining the specific experimental features by a structured and normalized database is presented.

1. Methods

1.1. Materials

In this study the blood samples from 21 healthy subjects were used to purify the peripheral blood mononuclear cells (PBMC).

The experimental protocol was conceived in order to analyze in vitro the immunogenicity of the four telomerase peptides present in the vaccine GX301, tested separately or in combination. To this aim, the frequency of responders and the frequency of peptide-specific T cells was also taken into consideration as a measure of the intensity of the T cell response in responders.

These frequency are the preclinical data analyzed with our web-based tool ImmunoDB and were obtained using the following procedures immunological: ELISPOT and Intracellular staining and flow cytometric analysis (IS).

The ELISPOT and IS are functional T-cell assay that employ the antigen-specific induction of cytokines to detect specific T-cells on a single cell level [6].

ELISPOT was chosen because this is the golden standard for measurement of antigen-specific T cell frequency. Moreover, it is commonly applied in the evaluation of T cell responses to tumor antigens in clinical trials administering immunotherapeutic agents. Cytokine intracellular staining by flow cytometry (IS) was selected because this is a widely adopted procedure to analyze antigen-specific T cell responses, which provides the opportunity to separately evaluate CD4+ and CD8+ T cell compartments.

1.2. Methods

The core of the presented application consists of a relational database for the data storage and management. In order to be efficient, a relational database should be carefully designed in order to maintain in its structure the real links that are present in the data that should be maintained. An efficient and easily comprehensible way to model data structure is the E-R diagram. In figure 1, the adopted structure is show.
The core of this structure is the “Esperimenti” table which included all the parameters that characterize each vitro experiment and in the other table variables that classify incoming data as subjects or peptides.

The database was than implemented in SQL Server 2012.

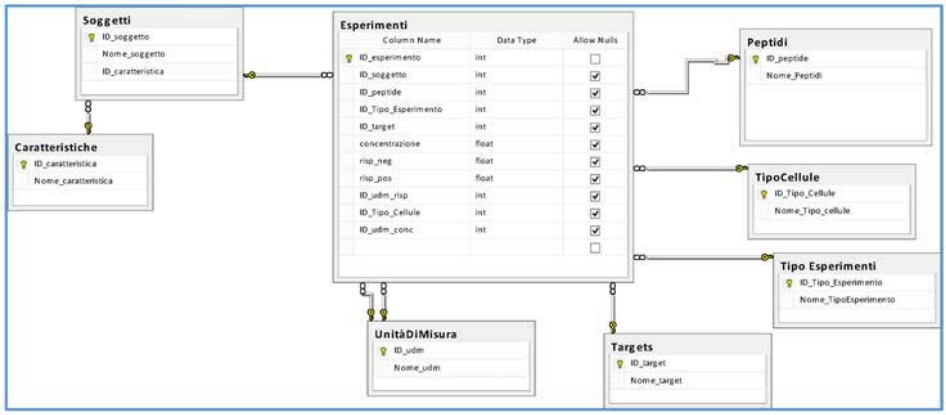


Figure 1. E-R diagram

2. Results

Finally, the Visual Studio 2012 was adopted to implement the web based interface application that is available on the server of the MEDINFO Laboratory of the DIBRIS (http://www.medinfodist.it/ImmunoDB) developed in the ASP.NET 4.0 environment. Several data mining techniques are used for specific operations such as the data extraction or identification of data sources.

Once the authentication and access in ImmunoDB, researchers can store their data (input) by loading the excel file. The presented system has been developed considering that each experiment was performed on different subjects, each subject with different characteristics and different parameters were assessed by different methods. A page has been designed to strictly correlate the features of each experiment with the preformatted file uploaded with the actual measured data.

By this way, each measured data is strictly bounded with its descriptive parameters and these links are permanently recorded in the DB tables. So, these memorized data can be see like in a hypercube in order to give the researchers the possibility to freely analyze data along one of the hypercube dimensions. This structure allows the researchers easily isolate the contribution of one the independent parameter on the measured data (dependent variable). In the following, two specific pages were presented with its performed calculations

Figure 2 shows the web page were the researcher can chose the parameters to be considered and visualize the number of positive responses obtained with the parameters set to the indicated value. In this page the following definition of positive response is applied: “In order to discriminate between responder and non-responder immune responses, the following cut-off values of peptide-specific T cell frequency will be considered as positive: >30% background number of spots for ELISPOT analysis and >0.1% positive cells for intracellular staining and flow cytometry”. A mathematics algorithm is defined to obtain the positive response values.

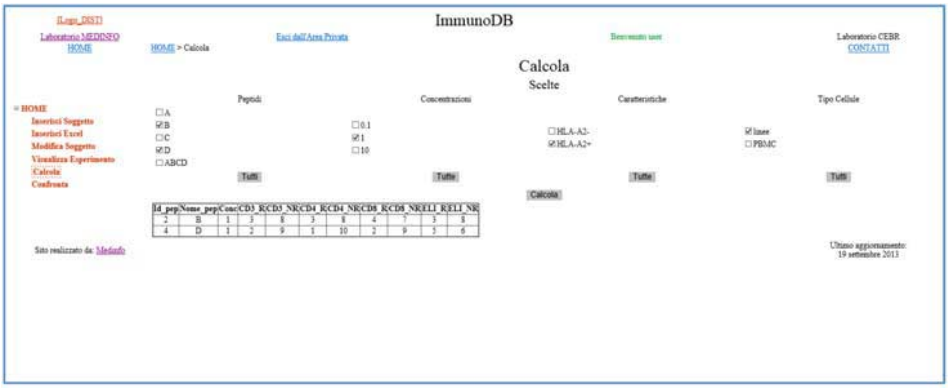


Figure 2. A page were the researcher can check parameters and visualize a table with positive response number

Figure 3 shown the page where the researcher can set the values of some parameters (cells type, concentrations peptide, target type, characteristic type) in order to find the subject responders to single treatments: the four peptides the combine treatment (ABCD) and theoretical sum (A+B+C+D: a subject is positive to it, if it is positive at least to one peptide).

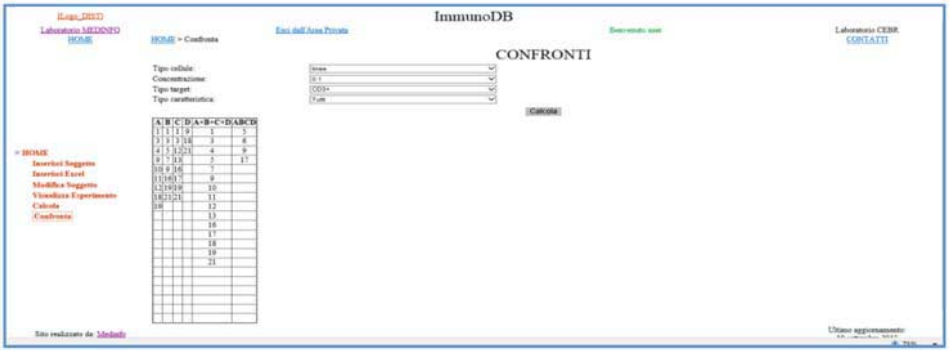


Figure 3. A page with the check list of parameters and a table that shows the responders

The collection of positive responses and responders with their characterized parameters are then exportable with standard format toward commercial statistical tools (like Graph PAD Prism) in order to perform significance analysis.

3. Discussion

The preclinical study has been designed to analyze the immunogenicity of four telomerase peptides (A, B, C, D) included in the GX301 vaccine when used as immune stimulator separately or in association.

Immunogenicity is the ability of a particular substance, such as an antigen or epitope, to provoke an immune response in the body of a human or animal [7] and becoming an important parameter in order to assess the therapies efficacy.

The quantitative determination of immunogenicity by the specific T cells frequencies is useful because are part of this immune response that playing a central role in defense against cancer and viral infection. These preclinical data (frequencies of responses and responders) generally obtained from these type of studies are "unstructured" data, because it comes from multiple sources and is not suitable for efficient manipulation with standard and/or commercial tools, without a strong competence in applied statistics. Researchers collected data in large excel files that not preserve data structure and relations very useful for a well assessed data analysis. ImmunoDB tool is able to assist researchers in the management of large sets of preclinical data has been used independently by researchers. They used the tables calculated by the presented tool to speed up the preparation of manuscripts for publication on immunological journal.

With this tool easy to use, the researcher immediately displays tables containing the number of positive responses and responders that may already be processed into other tools such as Prism or SPSS and thanks to the characterization of each experiment from the structurated information can reduce errors. This web application model has been developed specifically for this preclinical study in which the objective is the evaluation of immunogenicity of the GX301 vaccine, but the structure and organization of data analysis can also be used for studies with other purposes. Finally, this tool requires a limitated budget for the development and management so as to be developed also by small institutions that do not have access to large budgets.

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References

[1] Sun J, Wu Y, Xu H, Zhao Z. DTome: a web-based tool for drug-target interactome construction. BMC Bioinformatics [Internet]. BioMed Central Ltd; 2012 Jan [cited 2014 Apr 28];13 Suppl 9(Suppl 9):S7. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3372450&tool=pmcentrez&rendertype=abstract

[2] Fraccaro P, Dentone C, Fenoglio D, Giacomini M. Multicentre clinical trials' data management: a hybrid solution to exploit the strengths of electronic data capture and electronic health records systems. Inform Health Soc Care [Internet]. Informa UK Ltd. London; 2013 Dec 11 [cited 2014 Apr 28];38(4):313–29. Available from: http://informahealthcare.com/doi/abs/10.3109/17538157.2013.812648#.U16gNtw2408.mendeley

[3] Xia J, Fjell CD, Mayer ML, Pena OM, Wishart DS, Hancock REW. INMEX--a web-based tool for integrative meta-analysis of expression data. Nucleic Acids Res [Internet]. 2013 Jul [cited 2014 Apr 28];41(Web Server issue):W63–70. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3692077&tool=pmcentrez&rendertype=abstract

[4] Giacomini M, Pastorino L, Soumetz FC, Mielczarski JA, Mielczarski E, Rangelow I, et al. Data Modeling for Tools and Technologies for the Analysis and Synthesis of NANOstructures (TASNANO) Project. J Inf Technol Res. IGI Global; 2009;2(3):49–70.

[5] Fenoglio D, Traverso P, Parodi A, Tomasello L, Negrini S, Kalli F, et al. A multi-peptide, dual-adjuvant telomerase vaccine (GX301) is highly immunogenic in patients with prostate and renal cancer. Cancer Immunol Immunother [Internet]. 2013 Jun [cited 2014 Apr 28];62(6):1041–52. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23591981

[6] Letsch A, Scheibenbogen C. Quantification and characterization of specific T-cells by antigen-specific cytokine production using ELISPOT assay or intracellular cytokine staining. Methods. 2003;31:143–9.

[7] Antigenicity IV, Influence FT. chapter 3. :57–75.

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Analysis of the Patients and Physicians Connection Network on an online Health Information Platform

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Abstract. Social network applications have gained popularity in the health domain as they bring health information seekers (patients and alike) and medication advice providers (physicians and other relevant actors) together. By employing a network science perspective, this research is aimed to understand an information network establishing connections among and between information seekers and providers. We found that such a connection network surfaces most of the essential characteristics of a typical complex network. Furthermore, a detailed structural analysis shows some intriguing relations and connection behaviours in the network. Implications of the findings are discussed from the perspectives of medical informatics and social network analysis.

Keywords. Complex networks, social network analysis, health information platforms, health informatics, patient experience, medication advice-seeking

Introduction

The effects of information and communications technologies (ICT) on health information and/or advice-seeking behaviors have been examined at such levels as organizational, group or individual [1]. At the individual level it is essential to understand such effects in terms of establishments of interactions within and between different health groups and actors such as physicians, nurses, patients or alike. Recent reports concerning the adoption of online health applications have shown people and organizations' significant interest in them [2]. Of particular importance among these applications is health information and advice-seeking supporting applications (e.g., WebMD, Healthline) having a direct link to social network sites whereby information support is empowered by human relations or vice versa. This is not surprising especially for the health domain, since peers' opinions for medical practitioners and patients' experience for "like-minded others" are found to be valuable for health-decision making [3]. Thus, one needs to find out if and how human interactions are established due to information and/or advice-seeking behaviors for health issues. Thanks to emerging online health social network platforms (e.g., HealthTap, WebMD, Doktorsitesi), which help in providing relevant data for the analysis of information and social networks.

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This research is aimed to understand an extent to which characteristics are realized for one of the leading online health information websites (www.doktorsitesi.com) in Europe. According to their website, Doktorsitesi has around one million users (patients alike) and 15000 physicians. As shall be explained later on, the website examined provides physicians and patients alike with special features such as private messaging, connections, disclosed questions and answers, and other user-led content related services. In this research we focus on so-called the connection network. An established connection allows a user to send an unlimited number of messages to the user who accepts the connection request. By conducting social network analysis (SNA) we are able to surface intriguing interactions among and between medical practitioners and patients alike. The structures (patterns of interactions) underpinning such interactions turn out to be essential to explain how people learn, form opinions, and affect the others. This research focuses on the structural aspects of a network so that we can identify, if exists, salient features of a typical complex network such as small-world and giant component. As an alternative to conventional methods for analyzing networks in the health domain (that is, survey and observation for data collection and limited unit of analysis [4]), we make use of valuable data generated on a health information platform and employ relevant SNA [5] methods.

1. Methods

We obtained a dataset describing the connection requests of Doktorsitesi members. The set is composed of all records of established connections over the 3-month period from October to December 2012. For each connection, we have all information regarding the transaction that resulted in a connection, where the user identifiers of both parties and the timestamp of the record specify a transaction. Description of the network data and visual analysis of network diagrams are produced with Gephi [6], which is a visualization and exploration platform for SNA. It is open-source and free software.

We model the connection network as a graph of directed edges where patients (abbreviated to Ps) and physicians (abbreviated to Drs) are represented by nodes, and connection requests are represented by directed edges. Table 1 lists the basic statistics of the connection request network as well as the connections solely between Drs and Ps.

Two basic measures, node degrees and network density, provide useful, but limited, insights about the structure of the network. The former focuses on simple counts of in-, out-, maximum connections, and the latter captures how highly connected nodes are by calculating the percentage of all possible connections that are realized. To better examine an extent to which nodes are clustered (that is, clustering coefficient), one can measure number of triplets of nodes where three nodes are connected by two or three edges. Clusters of nodes can create a significant portion of the whole network (called a giant component) or small components [7]. If every node within a component is connected to every other node bi-directionally it is called a strongly connected component (SCC), otherwise it is weakly connected.

Another important characteristic related to the global structure of a network is path length. Path length measures the distance between nodes in terms of number of connections in the network examined. Thus, it simply shows how far apart people (Ps and Drs) are. The small-world effect is present if the average path length between every node is around six [8]. The maximum geodesic distance, called diameter of a network, is the largest distance of all.

2. Results

We present basic characteristics of the connection network for the overall network and two specific connections types (Table 1). To better visualize edges between nodes we provide network models by alternative layouts. Fig 1 utilizes Force Atlas layout algorithm, which produces readable spatial arrangements of nodes.

Table 1. Summary of SNA measures for the connection network

Network	Nodes	Edges	Av Degree	Density	Av Path Length	Av Clustering Coeff
Overall	818	1768	2.161	0.003	3.629	0.022
Drs to Drs	42	52	1.238	0.03	1.587	0.000
Ps to Ps	314	568	1.809	0.006	3.479	0.004

In fig 2 the graph is laid out using a customized layout algorithm (alphabetical ordering of the nodes of the same type on two vertical lines) where the Dr nodes are on the right and Ps are on the left. In this visualization, interactions between the same node types are clearly visible.

The directed network of connections has N = 818 nodes, 572 (70%) of which being Ps and 246 (30%) being Drs, hence the average degree is 2.161, suggesting that a typical member accepts two connection requests and makes two connections requests. Yet, with the help of the degree distribution, we see that this number is misleading, because the majority of actors have less than two requests. To be more specific, 70% of them made fever than two connection requests, and 74% of them accepted fever than two connection requests. These nodes coexist with highly connected nodes, or hubs. The largest two of these hubs have 318 (in 171, out 147) and 235 (in 115, out 120) connections. This is a characteristic seen in many real networks.

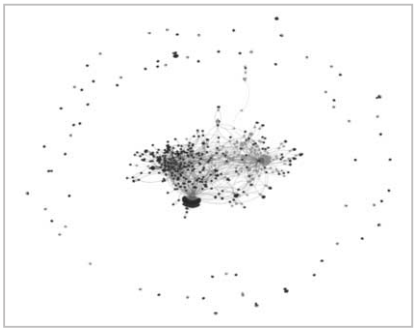


Figure 1. Network by force atlas layout

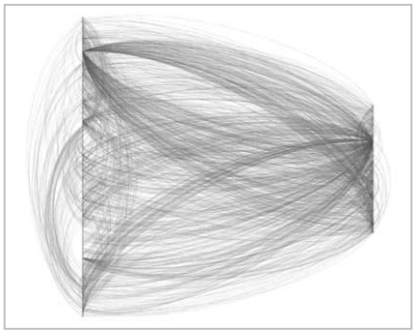


Figure 2. Network by customized layout

The connection network is, to a large extend, weakly connected (fig 1). Overall, there are 73 weakly connected components and 268 SCCs. One of the characteristics of real networks is the emergence of a giant component. In the present work, we observe that the giant connected component comprises 79% of the network. More importantly, 75% of these nodes belong to giant SSC (middle of fig 1). 77% of Ps 84% of Drs are in the giant connected component whereas 53% of Ps and 74% of Dr contribute to the giant SCC. The average path length between all pair of nodes within the SCC is 3.592 and maximal distances vary between graph diameter of 8 and graph radius of 5. A little bit

more exploration reveals that around 55% of the people can reach each other in no more than 8 hops, 40% in no more than 6 hops. It is a *small world* [8].

The density of the whole network is 0.003. It is a sparse network like most of the real networks. The average clustering coefficient is 0.022. Note that clustering is measured by making the network undirected, which is not uncommon in network science [5]. This clustering value is nearly an order of magnitude higher than the clustering of a random graph of the same number of nodes and edges. Connections between Ps and Dr alone are even sparser (fig 2). There is less clustering between Ps and none among Drs (Table 1). On the whole, 66% of the connection requests are reciprocated. 81% of the connection requests between patients and physicians are reciprocated; whereas only 41% of them are reciprocated among patients, and 73% are reciprocated among few physicians.

3. Discussion

The connection network examined exhibits essential properties that characterize most complex networks (e.g. WWW, Power Grid, Movie actors etc.) [9], namely:

i. *Smallworlds*: Despite the large size of the network there exist short paths between any of two platform users (Ps or Dr).
ii. *Clustering:* Small groups form within a network due to various reasons. Within the health context local clusters may be due to, among other things, "like-minded others" sharing common health issues.
iii. *Degree distribution:* The degree distribution of the network examined exhibits a *hub-and-spoke* connection pattern; there exists hubs (nodes with large number of connections) with surrounding spokes. The largest hub is a physician while the next is a patient. One would argue that the reason behind this pattern should be *preferential attachment* [9], which is not atypical for complex networks. However, the key question still remains: what are the underlying reasons for this attachment? One can suspect such other reasons as popularity of the physician for some reasons, misuse of the platform by a spammer, marketing and advertisement.

One of the key implications of the realization of these properties is that the connections on the platform are not by chance but consequences of conscious choices. The results concerning reciprocated connections help us interrogate online behavior of the users examined. Physicians and patients tend to have reciprocated connections with each other. The fact that there are few reciprocated requests among Drs may suggest that they are reluctant to establish connections with their peers. The same holds true for patients as well. We argue that one of the reasons behind few Dr-to-Dr reciprocated requests can be explained by physicians' perception on health information platforms, which is already acknowledged [3] that the majority of the physicians surveyed (68%) in the US concerning attitudes toward online social networks did not agree that it was ethically acceptable to interact with patients on OSN, either for social or patient-care reasons. This suggests that for further research one should take into account physicians' perceptions on OSN with respect to ethics and/or professional use while examining reciprocations among physicians. One can further argue that platform may serve physicians an effective channel to attract patients.

Regarding few patients' reciprocated-connections, one may argue that patients having similar health related issues are not inclined to exchange messages indefinitely. Although Drs and Ps are motivated for different reasons they tend to make reciprocated connections. On the Drs' site the motivation is the opportunity to introduce themselves to

as many patients as they could, on the Ps' site the opportunity to send as many messages as they like to get valuable information. It is also found [3] that the majority of both online and offline health information seekers report reliance upon healthcare professionals as a source of health information.

4. Conclusion

In this research we have shown that network science can contribute considerably to our understanding of an online health information exchange platform. Our attempt to unravel the glue that holds platform users together led us to the conclusion that patients seek information, physicians make use of connections to make patients aware of their expertise.

Further work with a larger data set is needed to deepen our understanding of evolutionary nature of the interactions. Incorporation of time stamps is needed to explore dynamics of the network so as to identify critical changes in the network at a local and global scale. That is, it would be essential to identify key influencers, their roles and information passing behaviors by employing centrality measures such as betweenness, closeness, and brokerage roles.

For comparison purposes and other aspects of the health information platform, one can examine other types of the interactions (questions and answers network, messages network) that may reveal [2]. Another potential research area is the analysis of modularity or formation of communities and cliques to articulate social identity development in online health platforms. Thanks to advances in SNA, the endeavor for better understanding of the structure and dynamics of health actors' interactions will illuminate the future state of health social networks.

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References

[1] Dunn AG, Westbrook JI. Interpreting social network metrics in healthcare organisations: A review and guide to validating small networks. Soc Sci Med. 2011 Apr;72(7):1064-8.
[2] Moss J, Elias B. Information networks in intensive care: A network analysis of information exchange patterns, AMIA Annu Symp Proc. 2010 Nov 13;2010:522–6.
[3] Bosslet GT, Torke AM, Hickman SE, Terry CL, Helft PR. The patient–doctor relationship and online social networks: Results of a national survey. J Gen Intern Med. 2011 Oct;26(10):1168-74.
[4] Chambers D, Wilson P, Thompson C, Harden M. Social network analysis in healthcare settings: A systematic scoping review. PLoS One, 2012 Aug 3; 7(8):e41911.
[5] Leskovec J, Huttenlocher D, Kleinberg J. Signed networks in social media. Proc of the SIGCHI Conf on Hum Factors in Comput Syst, ACM, 2010 Apr; 1361-70.
[6] Bastian M, Heymann S, Jacomy M. Gephi: An open source software for exploring and manipulating networks. Proc of the 3rd Intl AAAI Conf on Weblogs and Social Media, 2009 May, 361-2.
[7] Newman MEJ, D. Watts DJ, Strogatz SH. Random graph models of social networks. Proc of the National Academy of Sciences of the USA, 2002;99(Suppl 1):2566-72.
[8] Milgram S. The small world problem. Psychol Tod. 1967 May;1(1), 61-7.
[9] Albert R, Barabasi A-L. Statistical mechanics of complex networks. Rev Mod Phys. 2002 Jan 30;74(1):47-97.

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Increasing Information Accessibility for Patients in Obstetrics-Gynecology domain

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Abstract. It is important for the patient to have access to personal medical information in order to manage information for increased quality of medical care and life. The paper presents a module added to an Obstetrics-Gynaecology Department information system (OGD IS) supporting patient empowerment. The patient is accessing the system easily using laptops or mobile devices. The application accessed by the patient is web-based, implemented in Visual Studio. NET, using ASP.NET pages and C# language, and the application is published in the Windows Azure cloud. The solution is user friendly using familiar devices and is ubiquitous using the cloud solution. A module for translating medical terms in colloquial ones is integrated in the system. For certain situations the patient will get information related to life style influencing health status as how and what to eat or what type of exercise it is recommended.

Keywords. Patient empowerment, Obstetrics-Gynaecology, information, cloud computing

Introduction

In the last years a new concept became popular in medical information management, patient empowerment. It is related to patient access to medical data and his/her power to manage it in order to gain confidence in the medical act and to reach high quality in medical care.

Patient empowerment is defined as "helping people to discover and use their own innate ability to gain mastery over their disease or status of health" [1], [2]. This includes the necessity of providing education for informed decision – making, setting self – selected behavioral goals, assisting patients to weight costs and benefits of different treatment options and also, providing information about the importance of their role in self – management [1], [2].

The 2011 study evaluating patient satisfaction of healthcare services with duration of 4 month and performed in 17 hospitals in Bucharest, Romania, resulted in a 60% grade of satisfaction. The study investigated the quality of healthcare services; in this moment in Romania the integrated information system, SIUI [3], doesn't allow the access of the patients to medical information. One possibility to raise this rate is to empower the patient to access and manage medical data supporting physicians' activity with valuable input [4] as local solutions for the moment.

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The wok presented in this paper describes a solution for patient empowerment in Obstetrics-Gynecology field. Section 1 describes the system architecture, section 2 shows how the patient manages and has access to information in Obstetrics-Gynecology, and section 3 concludes the paper.

1. System architecture

Figure 1 presents the architecture of the system in which the patient has the opportunity to see his medical data and extra information regarding the medical data.

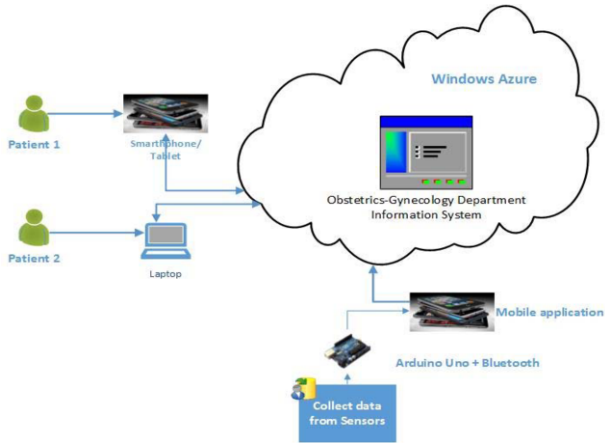


Figure 1. System architecture

The system architecture has two main components: the Obstetrics-Gynecology Department Information System available on the Windows Azure cloud and a home foetal surveillance system. Paper [5] describes previous work using the cloud solution in healthcare information systems.

Based on the architecture the Obstetrics-Gynecology Department Information System (OGD IS) is developed in Visual Studio .NET 2010, using ASP.NET and C# language. Medical staff uses the information system for consultations and for admissions. The information is saved in a database in the cloud, and the application is accessed online. The access is personalized for physicians and nurses. The physician may add in the application patient demographic data, obstetrics/gynecology data, medications, and treatments. The nurses may access only the patient treatment and medication and notify that the patient took the medicine if admitted in the hospital [6]. The mother has full access to her record and can give access to a family member, provided having an account. The security of the information in the cloud is ensured using a cryptographic algorithm, the RSA algorithm. [7] presents a solution to ensure the security in the cloud.

The home fetal surveillance system we propose is a mobile cardiotocograph monitoring the fetal movement and heart rate using sensors, Arduino support and Bluetooth. The home system will send data to a mobile application that sends data

further to the application in the cloud to the OGD IS database to be later accessed by the OGD IS users and also by the patients.

The patient may access her own medical information using a laptop or a mobile device (smart phone or tablet). Mobile devices are a very convenient alternative, being easy to use for persons that are not frequent users of computers, but are users of smart phones and interact using swipe movements in an easy and familiar manner.

The patient may access her information using an application from a mobile device, connecting to the Windows Azure cloud and visualise the needed information about his/her health status reflected in the OGD IS database. The application is developed on Android platform and provides the possibility of showing patient medical information. A module for translating medical terms in colloquial ones is integrated in the system.

2. Modelling the accessibility module for patient management information in Obstetrics-Gynecology field

Paper [8] presents the OGD IS model. The model for patient accessing information is using UML, a standardized general-purpose modelling language used in object-oriented software engineering field [9].

Figure 2 presents a sequence diagram on how the patient can access data using a laptop.

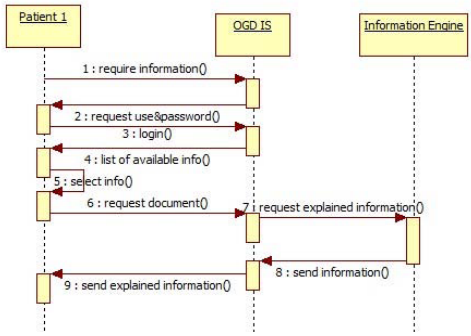


Figure 2. A sequence diagram for patient accessing data using a laptop

Table 1 presents the interactions which occur in the sequence diagram when a patient accesses her medical information from a laptop.

Table 1. Interactions occurring in sequence diagram in Figure 2

Interactions	Description
Interaction 1	Patient 1 request information from OGD IS
Interaction 2	OGD IS request a username and a password for access in the system
Interaction 3	Patient 1 send the credentials
Interaction 4	The OGD IS sends a list with available information which may be selected by the patient
Interaction 5	The patient selects the information of interest
Interaction 6	Patient 1 requests the information the information of interest
Interaction 7	OGD IS requests the explained information
Interaction 8	The explained information is received by the OGD IS
Interaction 9	Patient 1 receives the medical information and the explained information

Figure 3 presents a sequence diagram on how a patient may access her information from a mobile device.

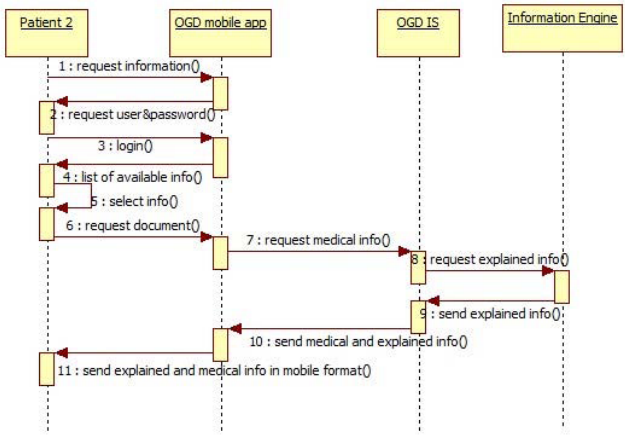


Figure 3. A sequence diagram for patient accessing data using a mobile device

Table 2 presents the interaction which occurs in sequence diagram when a patient access her medical information from a mobile device.

Table 2. Interaction which occurs in sequence diagram in Figure 3

Interactions	Description
Interaction 1	Patient 2 request information from OGD mobile application
Interaction 2	OGD mobile application request a username and a password for accessing the system
Interaction 3	Patient 2 send the credentials
Interaction 4	The OGD mobile application sends a list with available information that may be selected by the patient
Interaction 5	The patient selects the information
Interaction 6	Patient 2 requests the information the information of interest
Interaction 7	The OGD mobile app requests information from the OGD IS database
Interaction 8	OGD IS requests the explained information
Interaction 9	The explained information is received by the OGD IS
Interaction 10	The OGD mobile application receives the medical and the explained information
Interaction 11	Patient 2 receives the medical and the explained information in mobile format

The models are useful because the UML diagrams give a better understanding in the development process and it will be used for further developments of IS in other medical departments such as Paediatrics, Neonatology, and so on. The sequence diagrams present the steps in the development process related to the user (patient in this case) when receiving the requested outcome.

OGD IS offers patient access to their health data, reports and additional medical information. While giving the permission to the patient to her medical information, she may encounter difficulties in understanding the medical terms [1]. To prevent this, the OGD IS will import a component which adapts the medical terms to colloquial language more understandable to the patient. Also, the patient will receive additional information with recommendations or advices for the pregnancy period.

3. Conclusions

Survey results and clinical practice show that it is important to increase the satisfaction of the patient in healthcare services. The paper presents a solution to empower the patient in a specific medical field. For the OGD IS a patient may access information in an easy and familiar way from a laptop or a mobile device.

The OGD IS application and database are uploaded in the Microsoft Azure cloud.

The application is easily accessed by medical staff and patients from anywhere with the only condition to have Internet access. The pregnant woman may have a home fetal surveillance system which is connected to the cloud and she can check her health status and may receive different recommendation, as the OGD IS will calculate the pregnancy week and taking it into account will send specific information. The patient may see the treatment and what she has to do to improve her health. The satisfaction of the patient regarding healthcare services will increase and in time the patient healthcare will be improved and she will be more informed and can contribute to her healthcare condition improvement.

The work presented in this paper concentrated on the entire system modeling and development. The system is qualitatively well received according to several patients' comments. Next step is to prove its utility focusing on defining specific for the field satisfaction rates and to study quantitatively the impact of the provided system. These actions will be done using survey feedback from the patients.

References

[1] V. Topac, V. Stoicu-Tivadar, Patient Empowerment by Increasing the Understanding of Medical Language for Lay Users, *Methods of Information in Medicine*, Volume 52, Issue 5, 2013, pp. 454 - 461

[2] J.G. Frohna, A. Frohna, S. Gahagan and R.M. Anderson, Tips for communicating with patients in managed care, in *Semin. Med. Pract.* 4, 2001, pp. 29-36.

[3] Integrated Information System, SIUS, http://siui.casan.ro/cnas/, Accessed in 08.01.2014

[4] Pilot study regarding the patient satisfaction in care in 2011, http://www.info-sanatate.ro/docs/Studiu_Pilot_Satisfactia_Pacientilor_2011_Info-Sanatate_ASSMB.pdf, Accessed in 10.01.2014

[5] M. Vida, O. Lupşe, L. Stoicu-Tivadar, V. Stoicu-Tivadar, ICT Solution Supporting Continuity of Care in Children Healthcare Services, Proceedings: 6th IEEE International Symposium on Applied Computational Intelligence and Informatics, SACI2011, ISBN: 978-4244-9107-0, Timisoara, România, 635-639

[6] O. Lupşe, M. Vida , L. Stoicu-Tivadar, Cloud computing technology applied in healthcare for developing large scale flexible solutions, *Studies in Health Technology and Informatics*, ISBN 978-1-61499-051-2, Volume 174, 2012

[7] Saravanan N., Mahendiran A., Venkata Subramanian N, Sairam N., An implementation of RSA algorithm in Google Cloud using Cloud SQL, Reasearch Journal of Applied Sciences, Engineering and Technology 4(19): 3574 - 3579, 2012

[8] M. Vida, L. Stoicu-Tivadar, B. Blobel, E. Bernad, Modeling the framework for obstetrics-gynecology department information systems, IHIC Conference, 2012, publicat in European Journal for Biomedical Informatics Vol. 8, Issue 3 "Standard and Solutions for ehealth In-teroperability of the European Journal of Biomedical Informatics", 2012

[9] UML, OMG Unified Modeling Language (OMG UML), Superstructure, Version 2.2, 2009

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Progressive Testing of Health Self-efficacy and Literacy for Personalized Engagement

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Abstract. Patient engagement can be enhanced through continuous monitoring of patient' health knowledge and self-efficacy levels across different co-morbid conditions and key aspects in health improvement and recovery. While self-reported test batteries and computerized instruments have been designed to perform evaluation of patient literacy and self-efficacy, they are not practical to be used in scenarios where concurrent tests are needed to understand the change over time. In this paper we propose an adaptive system that can progressively compose the most pertinent test for each user based on the provisional estimates of a patient's latent trait being measured. This requires modeling not only the latent health literacy and self-efficacy levels of patients and the difficulty and discriminating factors of test items, but also the temporal dependency among concurrent tests. The goal is to account for changes over the course of patient engagement history as the basis for devising personalized patient plans.

Keywords. patient engagement, health literacy, self-efficacy, personalization, computerized adaptive testing, dynamic model.

Introduction

Sustained patient engagement is critical for successful health management, but it is often difficult to determine the engagement level [1]. Two key groups of factors are especially essential to be traced. First, self-efficacy measures evaluate beliefs in ones' abilities and are shown in research to associate with evidence of engagement, especially those related to lifestyle change [6]. Second, health literacy measures evaluate one's knowledge level regarding a condition or group of conditions and have been shown to associate with health outcomes. For example, the health literacy levels of diabetic patients are tied closely to not only diabetes outcomes such as hemoglobin A1C (HbA1c) [2] and co-morbid conditions such as retinopathy [3], but also adherence to medication and treatment [4]. These are all important self-reported measures whose levels indicate whether a patient is likely to continue following the plan [5].

Typically, existing healthcare systems perform patient trait measurements by evaluating patients with a pre-determined set of test batteries during their health education sessions, e.g., using the Mini-Nutrition Assessment form [7] and STENO tool [8] to assess diabetic patients' literacy in medical nutrition therapy. However, as these batteries were originally designed for one-time testing, they are not practical in scenarios where concurrent tests are required to learn the changes in a patient's engagement abilities and intentions over the course of a disease management program.

The concurrent test scenarios have posed challenges to existing test batteries, especially when considering for patients' co-morbid conditions. Patients who suffer

from clinical comorbidities may have different knowledge and understanding of each condition. For each co-morbid condition, care providers often have specific health recommendations regarding key aspects in health improvement and recovery. It is therefore important to learn how to accommodate multiple co-morbid conditions and the various associated key aspects for personalized engagement planning.

In recent years, computerized adaptive testing (CAT), which automatically selects test items by matching them to a patient's level of the trait being measured, has been introduced to long-term care such as physical therapy [9], as well as short-term care such as ambulatory monitoring [10] and headache impact scales [11]. As opposed to the traditional measurements that sum up a patient's scores of the whole test as the estimation of the patient's trait level, CAT systems present only relevant measurements at each checking point. CAT not only helps improve measurement efficiency, but also moderate the ceiling and floor effects the traditional measurements fail to calibrate. However, operational CAT system requires prior knowledge of relative difficulty and discriminability of test items. Yet for co-morbid conditions, it is impractical to assume the existence of manually determined item parameters for subpopulations of every combination of conditions. Moreover, existing CAT techniques are designed for standardized one-time tests and still do not account for the concurrent test scenarios.

In order to provide personalized patient engagement plans, we develop a data-driven approach to overcome the barriers of the development of CAT systems for health literacy and self-efficacy estimation in the concurrent test scenarios. This approach models latent health literacy, self-efficacy levels of patients, difficulty and discriminativeness of items, and temporal dependency among concurrent tests. This is to account for changes over the course of each patient's history and enable the devising of personalized engagement plans.

1. Method

Previous work in CAT commonly adopts Item Response Theory (IRT)-based methods to determine the user's most likely level of the trait given what is known about the items and the users' responses. These methods aim to uncover users' traits that impact the responses to item difficulty and discriminability [12]. Applying them in health outcome research has proven these methods to be efficient in terms of the number of question items needed to present to each patient, and flexible in terms of the accuracy measurement requirement [13]. To develop CAT systems for devising dynamic patient engagement plans, in this paper, we extend the IRT-based methods to incorporate prior test information of a patient so that follow-up tests can be devised in a way relevant to the patient's history.

1.1. Data Collection

Before building models of patient latent traits, test items for different aspects of health improvement and their user responses over all time periods are collected in a test item bank. Some of these test items are collected directly from guideline-based assessment forms. For example the tool of American Association of Diabetes Educators (AADE7™) allows the quantification of a patient's literacy level of healthy eating into scores after assessing his or her answers to validated test items. Other items in some less explored aspects can be developed using open-ended approaches, which identify

common challenges and barriers to the problem. For example, self-efficacy test items for eating habits are developed as a series of statements in the form "How certain you are that you can stick to a healthy diet on a regular basis while watching TV?" with polychotomous response ranging from "Cannot do at all" to "Highly certain can do" [14]. The scores or responses at different scales are then normalized into a scale of 0-100 reading. For a given subpopulation of interest, all normalized scales at checking point t on item i by patient p are then coded in a (I x P) matrix, where $I_t \subset \{1,\ldots I\}$ and $P_t \subset \{1,\ldots P\}$.

The item bank is then calibrated to model how patients with given traits respond to items of a certain difficulty level and to estimate the probability of patients answering an item correctly by chance. Intuitively speaking, the lower the probability is, the more difficult the item is. In the context of self-efficacy, this means the less likely a patient will feel confident about his ability in achieving a goal.

1.2. Adding Dynamicity into Item Response Theory Model

The approach discussed in this paper will enable understanding of how to devise a more relevant follow-up test for a patient, given the changes of a patient's health literacy and self-efficacy levels over the course of a patient's engagement plan. In particular, we extend a standard two-parameter IRT model to trace the changes, which involves incorporating a dynamic component of test items and patient responses for estimating patients' latent trait levels over time. This results in a dynamic patient trait estimation model as shown in (1):

$$z_{t,i,p} = \alpha_i + \beta_i \theta_{t,p} + \varepsilon_{t,i,p} \qquad \varepsilon_{t,i,p} \sim \aleph(0,c), \qquad (1)$$

where $z_{t,i,p}$ represent the normalized measurement of patient p's response to item i at check point t, $\theta_{t,p}$ denote patient p's latent trait levels at check point t, α_i and β_i denote the test item difficulty and discriminability of item i respectively, and $\varepsilon_{t,i,p}$ denote the error term with its variance set to a constant.

Some assumptions are made to enable the calculations of such models. First, the test item parameters α and β are assumed to be drawn from normal distributions. Second, in order to accommodate the clinical insight that a patient's dynamically changing trait levels are not independent of their previous test results, θ is assumed to be drawn from a random walk prior for each patient:

$$\theta_{t,p} = \theta_{t-1,p} + \delta_t \qquad \delta_t \sim \aleph(0, \Delta_{\theta_{t,p}}), \qquad (2)$$

where $\Delta_{\theta_{t,p}}$ denote the evolution variance parameter we include to specify the dependency among test responses obtained at different check points. Each patient p's initial trait level is assumed to be drawn by a random walk at point t_0 .

To infer such a dynamic model from patient history, we summarize the joint posterior density of the model parameters given the measurement data into $p(\alpha,\beta,\theta \mid Z)$, where α and β denote the stacked vectors of test item difficulty α_i and discriminability β_i for all items $i=1,\ldots I$ respectively, θ denote the stacked vector of latent trait θ_i for all patients $p=1,\ldots P$ in all check points, and Z represent the

stacked vector of normalized measurement data. Bayesian inference is subsequently applied to further summarize the joint posterior density into:

$$p(\alpha, \beta, \theta \mid Z) \propto p(Z \mid \alpha, \beta, \theta) p(\alpha, \beta, \theta), \quad (3)$$

where $p(\alpha, \beta, \theta)$ denote the prior beliefs of model parameters (i.e., patient trait, item difficulty and discriminability), and $p(Z \mid \alpha, \beta, \theta)$ denote the sampling density, which can be obtained by summing the normal cumulative function values over all patients' responses to all items in all checking points. Markov Chain Monte Carlo algorithms (MCMC) are applied to sample from the conditional distributions and summarize the results. Then, Bayesian inference of the dynamic model is obtained by timing the prior density with the sampling density.

1.3. Dynamic Estimation of Patient Latent Traits

Having fitted the model, we can then plot the estimated posterior density of the trait levels of each patient across different key aspects of health improvement and use that information to determine what aspect to address during the health education session, and which items to select in this round of testing. The posterior density of the trait levels of different conditions can also be plotted to understand the overall quality of health education and use that information to fine-tune the health education program for further engagement.

2. Discussion

To address the challenges of personalized engagement planning, Figure 1 illustrates a simplified individualized engagement plan for a patient who is exposing to a multitude of co-morbid conditions, including nephropathy, hypertension, congestive heart failure, and diabetes mellitus, but has different literacy levels across three different care dimensions—medication, exercise, and diet. The patient's particular health knowledge level of an existing condition and its treatment aspect is represented as a unique point position in the three-dimensional diagram.

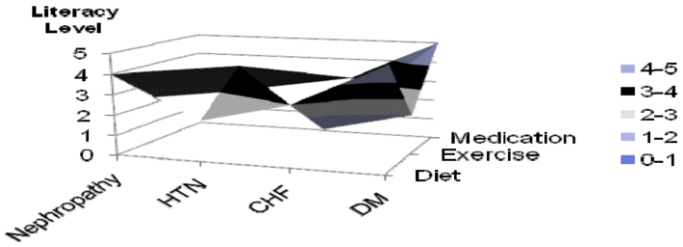


Figure 1. Diagram of Patient literacy Progress across Different Care Aspects and Conditions.

Once the initial assessment is conducted, the three-dimensional diagram illustrates where a patient needs most improvement and which aspects of care he or she has demonstrated profound understanding so he or she can move to the next assessment phase. After health educational intervention, during the next assessment phase, structurally similar but content-wise more challenging questionnaire instruments will

be provided to patients and a new three-dimensional diagram can be produced based on the evaluation of patients' answers. Most importantly, throughout the assessment, patients are actively involved and provide direct feedback to clinicians. Comparison among these diagrams will show care providers additional information on how patients' health knowledge and self-efficacy progress over time, and how educational intervention specifically designed for different care aspects can alter patients' trait levels dynamically.

3. Conclusion

In this paper, we develop a dynamic IRT model to conduct progressive CAT-based testing of patient traits such as literacy and self-efficacy in order to understand changes in the latent traits over the course of a patient engagement plan. The progressive testing method has certain advantages: First, it can assist the gradual increase of test difficulty and discriminability. Second, it is flexible enough to be tuned for the needed measurement accuracy. Last but not least, it can proactively choose the care aspect and condition that suit individual need. Currently, information about patients is not accounted for in the model, and subpopulations of different co-morbidities are pre-selected to calibrate the test item bank. We expect to further improve the method by employing more patient-specific information as parameters in the developed models and systematically accommodating co-morbidities in the system.

References

[1] Coulter A, Parsons S, Askham J, Where are the patients in decision-making about their own care? *WHO European Ministerial Conference on Health Systems* (2008).
[2] Cavanaugh K, Huizinga MM, Wallston KA, et al, Association of numeracy and diabetes control, *Annals of Internal Medicine*, **148**:10(2008), 737–746.
[3] Schillinger D, Grumbach K, Piette J, et al, Association of health literacy with diabetes outcomes, *JAMA* **288:4** (2002), 475–482.
[4] Sudore RL, Mehta KM, Simonsick EM, et al, Limited literacy in older people and disparities in health and healthcare access, *Journal of the American Geriatrics Society* **54:5** (2006), 770–776.
[5] Klasnja P, Consolvo S, Pratt W, How to evaluate technologies for health behavior change in HCI research, *Proceedings of the 2011 annual conference on Human factors in computing systems* (2011).
[6] Andrew A, Borriello G, Fogarty J, Understanding Self-Efficacy and the Design of Personal Informatics Tools, *Proceedings of CHI* (2011).
[7] Vellas B, Villars H, Abellan G, et al, Overview of MNA- Its History and Challenges. *Journal of Nutrition Health and Aging* **10** (2006), 456-465.
[8] Engelund G, *In Balance with Chronic Illness: Tools for Patient Education*, Steno Health Promotion Center (2011).
[9] Hart DL, Wang Y, Cook KF and Mioduski JE, A Computerized Adaptive Test for Patients With Shoulder Impairments Produced Responsive Measures of Function, *Physical Therapy* (2010).
[10] Rose M, Bjorner JB, Fischer F, et al, Computerized adaptive testing -- ready for ambulatory monitoring? *Psychosomatic Medicine* **74:4** (2012), 338-48.
[11] Ware JE, Bjorrner JB, Kosinki M, Practical Implications of Item Response Theory and Computerized Adaptive Testing: A Brief Summary of Ongoing Studies of Widely Used Headache Impact Scales, *Medical Care* **38:9:** supplement 2 (2000), 73–82.
[12] Baker JG, Rounds JB, Zevon MA, A Comparison of Graded Response and Rasch Partial Credit Models with Subjective Well-Being, *Journal of Educational and Behavioral Statistics* **25** (2000), 253-70.
[13] Cook KG, O'Malley KJ, Roddey TS, Dynamic Assessment of Health Outcomes: Time to Let the CAT Out of the Bag? *Health Services Research* **40:5** Part II (2005).
[14] Bandura A, Guide for Constructing Self-Efficacy Scales, *Self-Efficacy Beliefs of Adolescents* Chapter 4 (2006), 307–337.

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The Evolution of Personal Health Records and their Role for Self-Management: A Literature Review

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Abstract. A literature review has been conducted to gain an overview of the evolution of personal health records (PHR) and their role for self-management. This paper presents this evolution overview, based on review of abstracts from relevant publications in addition to full-text review of reviews. A search in the Medline database for 'PHR' and 'self-management' identified 62 unique publications. Of these, 90 % met the inclusion and exclusion criteria. The number of studies per year has increased heavily since the PHR and self-management context originated in the early 1990s. Nine studies described messaging functionality, eleven studies described shared access functionalities, and four described both. However, the general evidence remains sparse to document the value of PHR for self-management. Most PHRs are not based on patients' needs and do not support self-management. To be adopted by the users, and to be useful for self-management, PHRs need to be integrated with physicians' EHR systems and provide shared access both ways in addition to secure e-mail communication and educational modules.

Keywords. Personal health record, PHR, self-management, self-care, patient empowerment, review

Introduction

The aim of self-management is to increase patients' confidence and their ability to manage their symptoms and illness [1]. The core elements are education, learn problem solving and establish skills to overcome barriers, cooperation between patient and provider, and develop action plans and carry them out [1]. Self-management interventions have demonstrated positive effect on patients with chronic conditions [2]. It is well documented in a review of 67 reviews that self-management have both positive effect on patients' knowledge, patients' experience, patients' use of health services, in addition to effects on health behavior and health status [3].

Personal health records (PHRs) are supposed to offer and stimulate patient self-management [4]. In 2006, the American Medical Informatics Association and the Agency for Healthcare Research and Quality sat down in a roundtable to agree on the potential and the barriers of PHRs, and actions on how to move the PHRs closer to the health care mainstream [4]. A PHR system typically offers "a wide variety of features,

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including the ability to view personal health data, exchange secure messages with providers, schedule appointments, renew prescriptions, and enter personal health data; decision support (such as medication interaction alerts or reminders about needed preventive services); the ability to transfer data to or from an electronic health record; and the ability to track and manage health plan benefits and services", p. 15 [5]. In this way, the PHR is a framework for education of both patients and healthcare providers [5, 6]. However, patients own their PHRs and control the access to PHRs [6].

In 2004, a survey involving 2242 USA citizens found that 42 % had used PHRs, but as many as 87 % were paper-based [7]. The PHR systems and models developed today are mainly electronic, standalone systems, tethered or integrated with the provider's electronic health record [4].

Fuji 2012 evaluated 19 standalone PHRs to address how they met identified patient desires [8]. Only five PHRs met more than half of the patient desires. The findings revealed that standalone PHRs more or less functioned as repositories of health information, rather than as a tool to become more knowledgeable and to manage symptom and illness [8]. Detmer 2008 stated that only the integrated model with shared access for patients and providers to both the PHR and the electronic health records (EHRs) achieves the full potential for patients in managing their own health care [4].

The main purpose of this study is, based on review of abstracts and full-text review of reviews, to establish an overview of the evolution of PHRs and their role for self-management, as previously examined in scientific studies. This knowledge will be valuable for establishing state of the art understanding of the field, and for everybody planning to conduct research in the field or develop future PHR systems for self-management.

1. Methods

1.1. Search and assessment strategy

It was considered sufficient to search Medline only, to provide a first overview, as 75% of the articles included in a thorough systematic review within a comparable scope came from Medline [9]. We accessed MEDLINE through the Ovid interface, using no limitations. We based the search on medical subject headings (MeSH) and the Text Words (TW) field to search titles and abstract information. Review publications were used as a template to identify relevant MeSH terms and search words [10, 11]. The search strategies were pilot tested and modified to ensure that they identified relevant publications.

The search was built up around two search strings. The PHR and synonyms search string included: PHR, EPHR, personal health record, personal electronic health record, personally controlled health record, patient shared/held/carried record, patient accessible record, personal medical record, Health Records Personal/. The self-management search string included: self-management, self-care, Self Care/.

The authors reviewed and rated independently all abstracts as "relevant" or "not relevant". The inclusion criteria were publications focusing on PHRs and PHR systems relevant for patient self-management. The exclusion criterion was lack of abstract. If "relevant", the abstracts were rated according to the categories described in the Results section. The results were subsequently merged. In all cases where the reviewers

disagreed in the perceived eligibility of the publication or in categorising it, the two reviewers discussed the abstracts to reach consensus.

1.2. Content analyses of the reviews

All identified reviews were read in full text by the first author, and explored to investigate the evolution of PHRs and their role for self-management using content analysis [12]. Content analysis refers to exploring data through breaking it down into relevant explanations [12], or subheadings, to reply to specific questions [13].

2. Results

2.1. Literature search results

The Medline search in December 2013 identified 85 references, including 23 duplicates. Of the 62 unique references, 56 met the inclusion and exclusion criteria. The two authors agreed 100 % with regard to inclusion and exclusion. Three references did not deal with PHRs, and we excluded three references due to lack of abstract. For categorization of the included references, consensus discussion was necessary for 15 references.

The oldest reference in the search was from 1983 and titled "Personal health records (PHR)" [14]. Unfortunately, the abstract was missing. The oldest included reference was from 1991. Figure 1 illustrates how the number of included papers increased heavily over the past two decades.

As many as 73 % of the 56 included papers were from the United States, while the remaining 15 papers were spread on nine countries. Three of the included papers described paper-based PHRs, the others described electronic PHRs.

The maturity level of the papers was categorized as follows: 14 concept descriptions, 6 system descriptions, 12 pilots, 3 study designs, 11 evaluations of use/ implemented PHRs, 4 RCTs, and 6 reviews.

With regard to level of integration to support the patient in managing their health care [4], 9 studies described patient-provider communication through messaging and 11 of the studies focused on shared access to the PHR, while 4 studies included both functionalities. In three of the 11 studies, providers had access to the PHR. In four studies, the patient had access to the medical record (EHR) or parts of the medical record, like lab results. In three studies, both patient and provider had access to both record types.

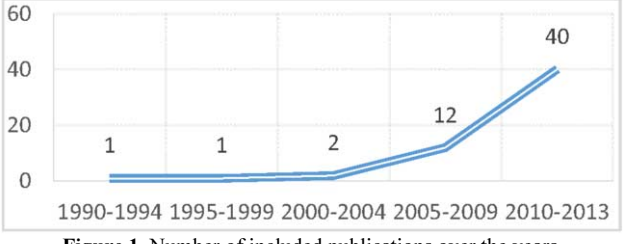


Figure 1. Number of included publications over the years

2.2. Evolution of Personal Health Records and their Role for Self-Management: Content Analyses of the Reviews

Two of the six reviews were excluded after reading the full text. Three of the four included reviews presented studies where the PHR system supported self-management [10, 11, 15]. Studies in Archer et al 2011 referred to positive effects due to patient access to lab-results, patient-provider communication, providers' update through PHR, patient understanding, and communication for prescribing medication [10]. Benhamou found eight studies with positive effects for type 2 diabetic patients, where patients felt safer, felt that non-acute problems were taken care of, and that it was easier to take care of themselves [15]. Tenford et al 2011 found three RCT studies of adults with type 2 diabetes mellitus that could document small improvements in some but not all diabetes care measures [11].

However, the general evidence remains sparse to document the value of PHR for self-management [10, 11, 15]. Most PHRs are not based on patients' needs and therefore do not support self-management [10, 16]. To be adopted by the users, PHRs need to be integrated with physicians' EHR systems and provide shared access both ways in addition to secure e-mail communication [10, 11, 15], and need to include educational modules [11, 15, 16]. In addition, RCTs and other trials of PHR effectiveness and sustainability for patient self-management are needed [10].

3. Discussion and conclusion

Self-management in the context of PHRs is a new and immature field. As many as 40 of 56 publications were published over the last four years (2010-2013), and 62.5 % of them were concept, system, pilot or study design descriptions, while only 37.5 % were evaluation of use, RCTs, or reviews. Nine studies described messaging functionality, eleven described shared access functionalities, and four described both. These functionalities are considered important for user adoption [4, 10, 11, 15], and together with the need for educational modules [11, 15, 16], these functionalities are required to realize self-management.

However, other functionalities also affect the adoption and use of PHR for self-management, and it might be challenging sometimes to explain adoption and non-adoption. The implementation and adoption of My Health Manager from Kaiser Permanente in US was quite successful, while the Health Space solution inspired by the Kaiser model was poorly taken up by the people in England [17]. In 2008, about 2.4 million had registered to use My Health Manager [18]. The solution was perceived useful and of good quality, both parameters being positive and significant predictors of actual usage [18]. The adjusted primary and specialist care office visit rates decreased 25.3 % and 21.5 % respectively, while the number of phone and e-mail contacts, consuming much less time, increased [19]. The adoption in England, however, was low, and the expected benefits were not realized [17]. The risk of being adopted or abandoned seemed to depend on that PHRs "align closely with people's attitudes, self management practices, identified information needs, and the wider care package (including organizational routines and incentive structures for clinicians)", p. 10 [17].

PHR has the potential to be a tool of great value to realize self-management and patient empowerment. However, as the results demonstrate, the field is still immature. General evidence remains sparse, and more studies on health effects and suitability are necessary.

References

[1] Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med.* 2003; **26**(1):1-7.

[2] Wagner EH, Austin BT, Davis C, Hindmarsh M, Schaefer J, Bonomi A. Improving chronic illness care: translating evidence into action. *Health Aff (Millwood)*. 2001; **20**(6):64-78.

[3] Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ*. 2007; **335**(7609):24-7.

[4] Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. *BMC Med Inform Decis Mak.* 2008; **8**:45.

[5] NCVHS. National Committee on Vital and Health Statistics: *Personal Health Records and Personal Health Record Systems: A Report and Recommendations.* U.S. Department of Health and Human Services; 2006 [cited 20140125]. Available from: http://www.ncvhs.hhs.gov/0602nhiirpt.pdf.

[6] Markle Foundation. *Connecting for health, a public-private collaborative*: The Personal Health Working Group final report. 2003. Available from: http://www.providersedge.com/ehdocs/ehr_articles/The_Personal_Health_Working_Group_Final_Report.pdf.

[7] PRNewswire. *Two in Five Adults Keep Personal or Family Health Records and Almost Everybody Thinks This Is a Good Idea*. 2004. Available from: http://www.prnewswire.com/news-releases/two-in-five-adults-keep-personal-or-family-health-records-and-almost-everybody-thinks-this-is-a-good-idea-71581677.html.

[8] Fuji KT, Abbott AA, Galt KA, Drincic A, Kraft M, Kasha T. Standalone personal health records in the United States: meeting patient desires. *Health Technol* 2012; **2**:197-205.

[9] Johansen MA, Henriksen E, Horsch A, Schuster T, Berntsen GK. Electronic symptom reporting between patient and provider for improved health care service quality: a systematic review of randomized controlled trials. Part 1: state of the art. *J Med Internet Res.* 2012; **14**(5):e118.

[10] Archer N, Fevrier-Thomas U, Lokker C, McKibbon KA, Straus SE. Personal health records: a scoping review. *J Am Med Inform Assoc*. 2011; **18**(4):515-22.

[11] Tenforde M, Jain A, Hickner J. The value of personal health records for chronic disease management: what do we know? *Fam Med.* 2011; **43**(5):351-4.

[12] Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ*. 2000; **320**(7227):114-6.

[13] Appelton JV. Analysing qualitative interview data: adressing issues of validity and rehability. *Journal of Advanced Nursing* 1995; **22**:993-7.

[14] Gawthorn EC. Personal health records (PHR). *Australian family physician.* 1983; **12**(6):466-8.

[15] Benhamou PY. Improving diabetes management with electronic health records and patients' health records. *Diabetes & metabolism*. 2011; **37 Suppl 4**:S53-6.

[16] Chomutare T, Fernandez-Luque L, Arsand E, Hartvigsen G. Features of mobile diabetes applications: review of the literature and analysis of current applications compared against evidence-based guidelines. *J Med Internet Res*. 2011; **13**(3):e65.

[17] Greenhalgh T, Hinder S, Stramer K, Bratan T, Russell J. Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. *BMJ*. 2010; **341**:c5814.

[18] Silvestre AL, Sue VM, Allen JY. If you build it, will they come? The Kaiser Permanente model of online health care. *Health Aff (Millwood).* 2009; **28**(2):334-44.

[19] Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: transforming and streamlining modalities of care. *Health Aff (Millwood)*. 2009; **28**(2):323-33.

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Policy-Driven Management of Personal Health Information for Enhancing Interoperability

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Abstract. Based on a system-theoretical approach, aspects of real world systems have been introduced. In this context, the relations between a system's architecture, i.e. its components, their functions and relations, formally represented by domain-specific ontologies considering all domains relevant in the system's use case on the one hand and the system's behaviour ruled by the applied policies on the other hand have been described. A refinement of policies ruling a clinical setting has been exemplified. It could be shown that ubiquitous health systems must be designed and managed following a thoroughly systems-oriented, architecture-centric, ontology-based and policy-driven approach. The feasibility of the approach has been practically demonstrated.

Keywords. Ubiquitous health, system architecture, system behaviour, policy, Generic Component Model

Introduction

Health and social systems around the globe are on the move towards personalized and ubiquitous health, which includes prevention, predictive, proactive care as well as lifestyle and wellbeing. The aforementioned paradigm shift requires a multi-disciplinary, integrative approach, combined with the challenge to manage the resulting complexity and methodological diversity of the resulting eco-system on a trustworthy basis [1]. On the one hand, many different specialties represented by experts using their own terminology based on domain-specific ontologies must be mapped. This requires a formal representation of the domain structure and function as well as underlying natural rules and relationships between the domain elements in consideration. On the other hand, many different and sovereign stakeholders bound to different regulations and representing different interests must cooperate in an efficient, safe and quality-assured way to benefit citizens and patients, health organizations and the society. Also

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those actors' knowledge and skills, impacted by experiences and culture, must be explicitly and formally represented. To meet all those challenges, the ubiquitous health approach has to be as detailed and as general as needed, reducing the complexity on the necessary level for a specific business case/use case, providing any functional flexibility through re-usability of the systems components by appropriate system aggregation and management. Only the formal, abstract, flexible and extendable methodology of system theory meets the aforementioned requirements [2].

1. Methods

A system is a (frequently ordered) composition of interrelated elements. Possible system categories are: System, Element, Structure, and Function [3]. The architecture of a natural system in the sense of a system's structural and functional aspects, i.e., its components, their functions (operations) and possible interrelations including the underlying rules controlling that system and its survival are frequently defined and represented through the ontologies of the domains the system covers. In contrast, humanly designed or managed systems realize intended structures und functions regarding the constituents as well as their interrelations by selecting components as well as constraining their operations and relations administratively and so ruling the behavioral aspect of a system by humans. Sloman has named "rules governing the choices in behavior of a system" a policy [4]. Another policy definition was provided in Bell Labs' Policy Description Language as "collection of general principles specifying the desired behavior of a system" [5]. In ISO 22600, policies have been defined as "set of legal, political, organisational, functional and technical obligations for communication and cooperation" [6]. According to Damianou et al., policies "are often used as a means of implementing flexible and adaptive systems for management of internet services, distributed systems, and security systems" [7]. Boutaba and Aib described policy-based management of systems as being in the "heart of a multitude of management architectures and paradigms including SLA-driven, business-driven, autonomous, adaptive, and self-management". It "separates the rules governing the behavior of a system from its functionality" [8]. "Policies define choices in behavior in terms of the conditions under which predefined operations or actions can be invoked rather than changing the functionality of the actual operations themselves" [7]. In summary, the rules defined for system components and relations according to their ontologies are amended by policies defined according to the business process. It has to be mentioned however that the leeway of humanly administering systems has been continuously widened in the humans' history, also intervening in natural processes.

A meanwhile widely used approach to semi-formally represent systems is the Generic Component Model, as it allows modeling their structure, functions and interrelations, at the same time also enabling the separate representation and management of aspects of that system. Ways to present the GCM formally are given in [9]. In the GCM, the structural and functional aspects of different perspectives on the system are represented by subject-specific GCM domains. The behavioral aspect of that system, i.e., the relations and constraints according to business process, contextual and environmental conditions are summarized in policy domains (see Figure 1a). Following, this approach will be demonstrated for policy-driven design and management [10] of health systems, also such complex ones like ubiquitous health systems.

2. Modeling Policy-Driven Systems

According to good modeling practice and the design principles of the GCM, systems can be decomposed into subsystems, as domains can be refined into subdomains. Ignoring medical subdomains such as clinical care, primary care, or home care, the representation of a clinical care system used by different resources is presented in Figure 1a.

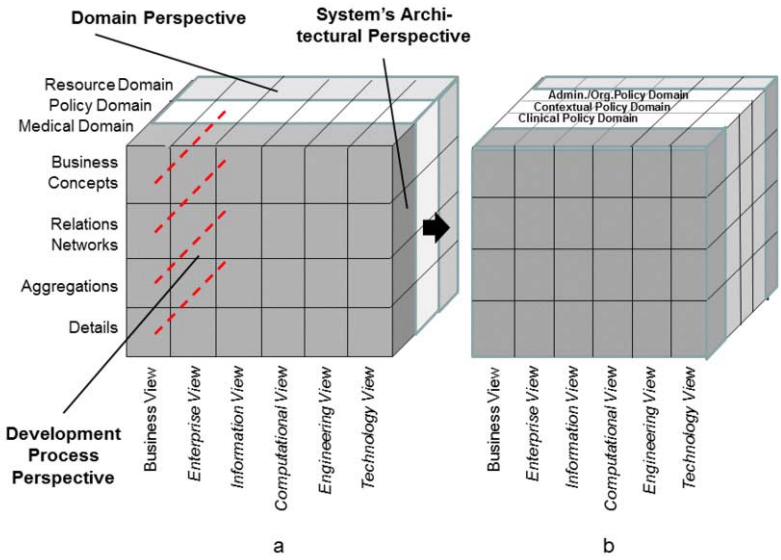


Figure 1. a) GCM representation of a policy-driven system, b) Refinement of the policy domain

Policies can be defined for managing resources, for managing the clinical process (e.g. by Best Practice Clinical Guidelines), but also to rule the relations between resources and targets legally, regulatory and ethically, summarized as context. In Figure 1b, the system presented in Figure 1a has been refined accordingly.

The separately analyzed different system elements (components) aggregated in one domain and represented based on the domain's ontology as well as the different aspects of the system established through the different domains to be considered, must be integrated, by that way realizing the business process. The GCM principles allow only relations at the same level of granularity. Interrelated ontologies are harmonized using their top level ontology. Others are managed as process steps or control the business process. The different aforementioned policies must be harmonized at the corresponding granularity level to define the final behavior of the system. Policy harmonization includes matching, mapping, alignment, and merging [11]. While the first two mechanisms are used at runtime, the others must be performed a priori.

The policy representation works best when using the policy ontology defined in ISO 22600 and deployed in a series of HL7 specifications such as the HL7 Security and Privacy Domain Analysis Model [12], the HL7 Healthcare Classification System [13], the HL7 Security Labeling Services specification [14] or the HL7 Patient Consent spec [15]. Base classes of that policy ontology are BasicPolicy, specialized into AuthorizationPolicy, RefrainPolicy, ObligationPolicy, and DelegationPolicy. For creating policies and for harmonizing policies, a MetaPolicy and a CompositePolicy

have been defined, respectively. When constraining the consideration on implementable ICT solutions instead of covering the entirety of the real world of human cooperation, XCAML, a policy language based on the SOA ontology can be practically deployed [16].

The practicality of the approach has been demonstrated, e.g., at HIMSS 2013, where more than 50 vendors' solutions have provided intelligent policy-based interoperability in real clinical settings [17] using the HL7 Security Labeling Services specification [14]. Those services are based on the HL7 Healthcare Classification System [13], which has defined security labels and related vocabularies for binding them to objects or constraining processes. In detail, following security labels have been specified: Confidentiality, Sensitivity, Integrity, Compartment to characterize security and privacy rules for specific information objects and Handling Caveats for constraining activities, i.e. processes of using information objects. Confidentiality labels are used to classify an information object according to its level of sensitivity, which is based on an analysis of applicable privacy policies and the risk of financial, reputational, or other harm to an individual that could result from unauthorized disclosure. Sensitivity labels categorize the value, importance, and vulnerability of an information object perceived as undesirable to share. Integrity labels convey the completeness, veracity, reliability, trustworthiness, and provenance of an information object. Compartment labels indicate that access and use is restricted to members of a defined community or project. Handling caveat labels convey dissemination controls and information handling caveats such as obligations and refrain policies to which an IT resource custodian or receiver must comply. Confidentiality and Handling Caveats labels are part of the Clinical Policy Domain. Sensitivity and Integrity labels belong to the Contextual Policy Domain, while Compartment labels refer to the Admin/Org Policy Domain. When resolving the selections and constraints regarding the resources, objects and processes according to the defined policies, the architectural schema of Figure 1b has to be reflected.

That way security attributes and coarse-grained privacy policies are used for access control decisions and their enforcement. The labels refer to policies ruling in detail how to perform in the business case for meeting the security and privacy requirements. A detailed description of both HL7 specifications will be published in [18]. One weakness of existing implementations to be overcome is the involvement of citizens/patients regarding appropriate trust models, transparency and understandability of policies, as discussed in more detail in [19].

3. Discussion and Conclusion

Ubiquitous health systems can be best formally and abstractly modelled by the deployment of a system-theoretical approach. Thereby, the different aspects of systems have been highlighted. A system's architecture describes the systems elements (components), their functions and interrelations. The representation of aspects (domains) of real world systems has to be based on the corresponding domain ontologies. Rules for selecting components and functions as well as constraints of the relations according to a business case are called policies. Policies define the intended behavior of systems.

Therefore, flexible, scalable, business-controlled, adaptive, knowledge-based, intelligent ubiquitous health systems must follow a systems-oriented, architecture-centric, ontology-based and policy-driven approach.

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References

[1] Blobel B. Translational Medicine Meets New Technologies for Enabling Personalized Care. Stud Health Technol Inform 2013; 189:8-23.
[2] Blobel B. Architectural approach to eHealth for enabling paradigm changes in health. Methods Inf Med 2010; 49,2:123-134.
[3] Völz H. Information. Berlin: Akademie-Verlag; 1982.
[4] Sloman, MS. Policy Driven Management for Distributed Systems. Journal of Network and Systems Management 1994; 2(4):333-360.
[5] Lobo J, Bhatia R, and Naqvi S. A policy description language. In AAAI '99/IAAI '99: Proceedings of the 16th National Conference on Artificial Intelligence and the 11th Conference on Innovative Applications of Artificial Intelligence, p. 291-298. American Association for Artificial Intelligence: Menlo Park, CA, USA; 1999.
[6] International Organization for Standardization. ISO 22600 Health informatics – Privilege management and access control. Geneva: ISO; 2006.
[7] Damianou NC, Bandara AK, Sloman MS, Lupu EC. A Survey of Policy Specification Approaches. CiteSeerxβ, 2002 – available at www.doc.ic.ac.uk.
[8] Boutaba R and Aib I. Policy-Based Management: A Historical perspective. J Netw Syst Manage 2007; 15;447-480.
[9] Blobel B, Pharow P. Analysis and Evaluation of EHR Approaches. Methods Inf Med 2009; 48,2:162-169.
[10] Blobel B, Nordberg R, Davis JM, Pharow P. Modelling privilege management and access control. Int J Med Inform 2006; 75(8):597-623.
[11] M. Rebstock, J. Fengel, H. Paulheim. Ontologies-Based Business Integration. Berlin: Springer; 2008.
[12] HL7 International Inc. HL7 V3 DAM: Composite Security and Privacy – Release 1. Ann Arbor: HL7 International; May 2014.
[13] HL7 International Inc. HL7 Healthcare Privacy and Security Classification System (HCS) – Release 3. Ann Arbor: HL7 International; May 2013.
[14] HL7 International Inc. HL7 Version 3 Standard: Privacy, Access and Security Services; Security Labeling Service, Release 1. Ann Arbor: HL7 International; January 2014.
[15] Health Level 7 International, Inc., Ann Arbor, USA. www.hl7.org
[16] Blobel B. Ontology driven health information systems architectures enable pHealth for empowered patients. Int J Med Inform 2011; 80(2):e17-e25.
[17] Data Segmentation for Privacy VA/SAMHSA RI/Pilot at HIMSS 2013. http://wiki.siframework.org/Data+Segmentation+for+Privacy+Homepage
[18] Blobel B, Davis MJ, Ruotsalainen P. Policy Management Standards Enabling Trustworthy pHealth. Stud Health Technol Inform 2014; 200 (in print).
[19] Routsalainen P and Blobel B. Trust Information and Privacy Policies – enablers for pHealth and Ubiquitous Health. Stud Health Technol Inform 2014; 200 (in print).

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4. Intelligent Data Analysis

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Development of Temporal Context-based Feature Abstractions for Enabling Monitoring and Managing of Interventions

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Abstract. Disease self-management programs and intervention/care plan monitoring are often unable to systematically leverage patient-generated information, especially those requiring interpretation of the temporal contexts of the measurement. While existing techniques help in capturing and storing the relevant data, their ability to determine appropriate metrics most sensitive to that individual is limited or non-existent. This is attributable to the lack of unifying models for enabling such interpretations and the non-trivial process required to generate meaningful feature abstractions to support individualized prognosis. To address these issues, a data-driven approach designed to identify the right abstractions for key features relevant to personalization and monitoring of care is discussed.

Keywords. Feature abstraction, trend over variance, temporal context, patient-generated information, patient-centered disease management

Introduction

A preponderance of evidence has demonstrated that patient-generated information is effective for disease self-management programs and intervention/care plan monitoring. Examples include increasing awareness to self-monitoring [1,2], promoting behavior changes such as physical activity [1,3] and dietary intake [2], triggering reminders to care plans [4,5], and personalizing communication messages and education materials to increase the likelihood of treatment adherence [6]. Despite the success of these programs in initial goal setting and providing feedback, it is evident that the stored monitoring data have rarely been used to enhance continuous engagement and intervention management.

In fact, many monitored data sources contain temporal contexts crucial to understand patient's engagement and intervention efficacies/design. However, simple first-order moment statistics are often not enough for interpreting these temporal contexts. For example, Diabetic patients with similar mean glycosylated hemoglobin (HbA1c) values may demonstrate similar mean self-monitoring blood glucose (SMBG) readings; however, this does not mean that these patients need or have similar care plans , as they can exhibit markedly different daily or weekly glucose profiles, with

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some that come with highly volatile glucose excursions than the others. Post-hoc analysis of SMBG data has suggested variability and pattern analysis to have direct impacts on the management of chronic conditions [13]. Similar observations emphasize glucose variability of pathophysiological pathways in oxidative stress and severe hypoglycemia, as well as that of long-term glucose variability in microvascular complications in Type 1 and Type 2 diabetes is available in [14]. However, there is currently no easy way for existing programs to account for the signals beyond first-order moment statistics.

Other examples of leveraging temporal context-based indicators of disease progression and treatment include the use of heart rate variability (HRV) features to detect abnormal symptoms of autonomic nervous system that are correlated with lethal arrhythmias [7,8], detection of cardiac events, such as myocardial infarction [9], rapid progression of atherosclerosis [10], and death from heart failure [11]. Similarly, the variability features of B-type natriuretic peptide (BNP) have been used to detect cardiac ischema. The wide adoption of these temporal context-based indicators in practice has been attributed to the ease of use of their standardized feature abstraction process [12]. However, such approaches are typically limited to measurements that are already established in the literature ('knowledge-based').

1. Methods

The motivation of this paper is to create a data-driven approach to enrich the knowledge based approach and to automate the non-trivial process that previously requires artful interpretation of the temporal contexts in patient-generated information to pinpoint key features relevant to the changing presence of outcome-affecting symptoms. In particular, we focus on analyzing the trend over variance.

The five-step data-driven approach, and its learning component that leverages individual historical data to evaluate the sensitivity of the chosen feature abstractions, is show in Figure 1.

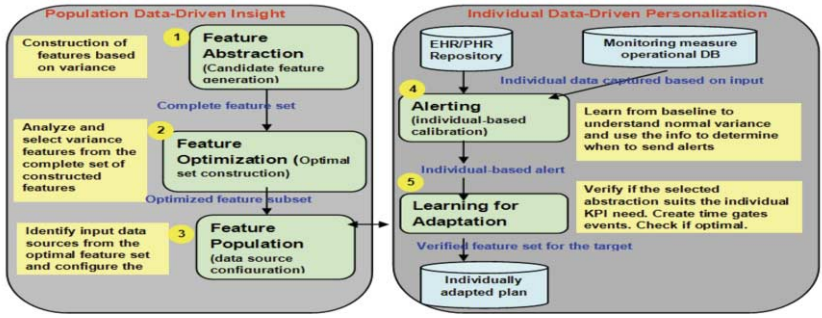


Figure 1. Framework of Temporal Context-based Feature Abstraction.

2. Results

2.1. Feature Abstraction

First, variance trend over time (VAROT) (as shown in Formula (1)) can be abstracted from a sequence of measures indexed by time for a predefined observation window.

$$VAROT = f\left(x, t_s, wl, dt, pt, s\right) \tag{1}$$

Where:
x: a sequence of measures indexed by time
ts: starting point of observation window
wl: length of observation window
dt: incremental period
pt: period type, discrete or rolling period
s: sparsity constraint or minimum requirement for data availability in each period

Example 1: Figure 2a shows a simulated sequence of measures x of 150 days, which is abstracted by a VAROT function with fixed parameters as expressed in (2):

$$VAROT = f\left(x, t_s = 30, wl = 90, dt = 30, pt = \text{ital } discrete, s = 10\right) \tag{2}$$

The sequence is generated by using normal distribution with a constant mean (mu=100) and non-constant variance over time. Note that in real-life scenarios, the starting point of a sequence varies among clinical applications and has to be clearly defined by healthcare professionals. Figure 2b illustrates the estimated variance of this sequence and its trend over time with sample variances for each period called out. The slope of blue line fitted by ordinary least squares (OLS) is the estimated VAROT value. Such feature abstractions help analyze the trend at a coarse-grained scale without having to attend to the details at a granular scale.

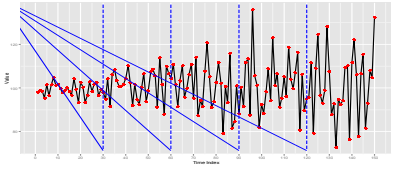


Figure 2a. Simulated sequence for Example 1. The blue lines mark the boundaries of 3 discrete periods (30 days; at least 10 measures) in the observation window (90 days).

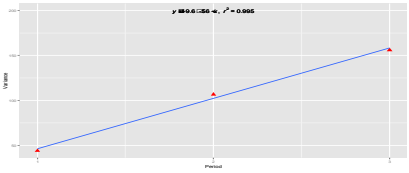


Figure 2b. Estimated variance over time. The red triangles are sample variances in each period.

2.2. Feature Optimization

Obtaining a full sequence of measures does not automatically reveal the sub-period, which is the most relevant to the changing presence of outcome-affecting symptoms. For those outcomes associated with significantly increased or reduced variability in patient's history, VAROT abstracted from a sub-period with steeper slopes (in absolute values) is likely to be more related to patient's outcome. Thus, an optimization

framework is proposed to search for the optimal set of parameters that returns the strongest VAROT signals in patient's time indexed measures.

Example 2: Figure 3a shows a simulated sequence of measures x of 300 days, which is abstracted with a VAROT function (as shown in (3)) with fixed parameters except variable t_s. Figure 3b depicts the variance trend of this sequence. Color coding (from blue to red) indicates the steepness of variance slope (from flat to vertical). In this example, it reaches the steepest gradient on the 111th day.

$$VAROT = f\left(x, t_s, wl = 90, dt = 30, pt = \text{ital}\ discrete, s = 10\right) \tag{3}$$

$$Max_{t_s} f\left(x, t_s, wl = 90, dt = 30, pt = \text{ital}\ discrete, s = 10\right) = 64.78$$

$$where t_s = 111$$

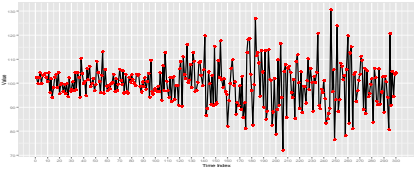


Figure 3a. Simulated sequence for Example 2.

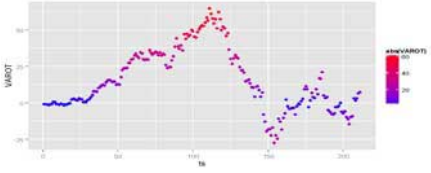


Figure 3b. Estimated variance over time (color coded with steepness).

2.3. Feature Population

The system identifies the input data sources used in the optimal feature subset in order to configure them for feature population and then make them available at the individual level. Design factors include but are not limited to: the number of readings, frequency of readings, time of observations, observation window interval (i.e. daily, weekly, monthly, quarterly), data availability and sensitivity, acceptable levels of fluctuation and sparsity, type of device used, length of the observation window, moving window or discrete window, post/pre meal consideration, and knowledge about response variables.

2.4. Alert Setting

The system collects baseline data at the individual level to understand the normal range of variance and to construct the upper and lower control limits – amenable for viewing via control charts -- and to set up alerts. Such alerts (based on individual calibrations) can be used to define a intervention design space (e.g. adherence programs) and personalize a e plan based on the most predictive VAROT feature for the patient. It could also serve as a basis for evidence generation to understand intervention efficacy.

2.5. Feature learning for adaptation

Given a set of candidate variables for VAROT features, the system facilitates continuous learning to refine an individual's VAROT feature and enable potential patient segmentation to suggest "seed features" for an incoming patient. The system not only verifies if the selected abstraction works for the target user, but also creates time or event-based triggers to search for the optimal subset. It differentiates patients based

on the optimized feature abstraction with strongest VAROT signals, using statistical modeling techniques (e.g., mixed modeling) to segment patients by this optimized set, data availability, and data completeness for outcome prediction.

3. Conclusion

This paper describes a framework of a data-driven approach that enables the capturing of temporal context associated with patient-generated information without the need for defining theoretical models, while also providing the ability to continuously monitor the chosen abstractions and modify them. The use cases of the developed data-driven framework range from clinical diagnosis and prognosis to personalized treatment. For example, personalized care planning based on the most predictive VAROT feature for the patient. This in turn can help design the intervention space and potentially use it as the bases for evidence generation for intervention optimization. It can also serve as a basis for developing adherence programs for patient self-management and for providing feedback on self-efficacy intervention or other coordinated care plans.

References

[1] Prestwich A., Perugini M., Hurling R., Can the effects of implementation intentions on exercise be enhanced using text messages? *Psychol Health* 2009 24(6):677-687.
[2] Burke L.E., Warziski M., Starrett T., Choo J., Music E., Sereika S., Stark S., Sevick M.A., Self-monitoring dietary intake: current and future practices, *Journal of Renal Nutrition* 2005 15(3):281-290.
[3] Michie S., Abraham C., Whittington C., McAteer J., Gupta S., Effective Techniques in Healthy Eating and Physical Activity Interventions: A Meta-Regression, *Health Psychol* 2009 28(6):690-701.
[4] Consolvo S., Klasnja P., McDonald D.W., Landay J.A., Goal-Setting Considerations for Persuasive Technologies that Encourage Physical Activity, Proceedings of the 4th International Conference on Persuasive Technology (Persuasive'09), Claremont, California, 2009.
[5] Hurling R., Catt M., De Boni M., Fairley B.W., Hurst T., Murray P., Richardson A., Sodhi J.S., Using Internet and Mobile Phone Technology to Deliver an Automated Physical Activity Program: Randomized Controlled Trial, *Journal of Medical Internet Research* 2007 9(2).
[6] Thaler R., Sunstein C., Nudge: Improving Decisions About Health, Wealth, and Happiness. Caravan Books, Michigan.
[7] MacFadyen R.J., Intraindividual temporal variance of biomarkers and the definition of individualized prognosis in cardiovascular patients. *Journal of Human Hypertension* 2006 20:383–386.
[8] Hohnloser S.H., Klingenheben T., Zabel M., Li Y.G., Heart rate variability used as an arrhythmia risk stratifier after myocardial infarction, *PACE* 1997 20:2549-2601.
[9] Tsuji H., Larson M.G., Venditti F.J., Impact of reduced heart rate variability on risk for cardiac events: The Framingham Heart Study. *Circulation* 1996 94:2850-2855.
[10] Huikuri H.V., Jokinen V., Syvänne M., et al, Heart rate variability and progression of coronary artery disease, *Arteriosclerosis, Thrombosis, and Vascular Biology* 1999 19:1979-1985.
[11] Nolan J., Batin P.D., Andrews R., Prospective study of heart rate variability and mortality in chronic heart failure: Results of the United Kingdom Heart Failure Evaluation and Assessment of Risk Trial (UK-Heart), *Circulation* 1998 98:1510-1516.
[12] Task Force of the European Society of Cardiology and the North American Society of Pacing and Electrophysiology, Heart rate variability: Standards of measurement, physiological interpretation, and clinical use. *Circulation* 93:1043-1065.
[13] Rodbard D., Optimizing Display, Analysis, Interpretation and Utility of Self-Monitoring of Blood Glucose (SMBG) Data for Management of Patients with Diabetes. *Journal of Diabetes Science and Technology* 2007 1(1):62–71.
[14] Siegelaar S.E., Holleman F., Hoeskstra J., De Vries J.H., Glucose variability: Does it Matter? *Endocrine Review* 2010 31(2):171-182.

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Alignment of High-Throughput Sequencing Data Inside In-Memory Databases

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Abstract. In times of high-throughput DNA sequencing techniques, performance-capable analysis of DNA sequences is of high importance. Computer supported DNA analysis is still an intensive time-consuming task. In this paper we explore the potential of a new In-Memory database technology by using SAP's High Performance Analytic Appliance (HANA). We focus on read alignment as one of the first steps in DNA sequence analysis. In particular, we examined the widely used Burrows-Wheeler Aligner (BWA) and implemented stored procedures in both, HANA and the free database system MySQL, to compare execution time and memory management. To ensure that the results are comparable, MySQL has been running in memory as well, utilizing its integrated memory engine for database table creation. We implemented stored procedures, containing exact and inexact searching of DNA reads within the reference genome GRCh37. Due to technical restrictions in SAP HANA concerning recursion, the inexact matching problem could not be implemented on this platform. Hence, performance analysis between HANA and MySQL was made by comparing the execution time of the exact search procedures. Here, HANA was approximately 27 times faster than MySQL which means, that there is a high potential within the new In-Memory concepts, leading to further developments of DNA analysis procedures in the future.

Keywords. In-Memory-Technology, DNA-Alignment, HANA, high-throughput sequencing, stored procedures

Introduction

Regarding the enormous amount of sequencing data, which is produced every day by next-generation sequencing machines, fast and accurate analysis of DNA sequences in a DNA analysis pipeline is a big challenge [1]. Angiuoli et al. describe an analysis pipeline for microbial genomes, which needs almost ten hours to compute the assembly and annotation steps for a bacterial genome with 89 megabases [2]. Since the human genome with three gigabases is approximately 34 times longer, there is a necessity to develop new methods and innovative technologies for DNA analysis.

With the In-Memory technology, it is feasible not only to store and maintain the sequencing data, but also to compute and analyse them quickly within the database itself. As an In-Memory database, HANA (**H**igh Performance **An**alytic **A**ppliance, SAP AG, Walldorf, Germany) holds all submitted data and created procedures in

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random access memory (RAM), which enables much faster data access compared to a hard disk drive [3]. However, it is unclear if this innovative technology could help to accelerate DNA analysis as well. In this paper, we focused on DNA alignment, considering HANA to solve this first step of a DNA analysis pipeline. Furthermore, we compared if the charge free database solution MySQL, which contains the possibility to create tables in RAM as well, leads to comparable results regarding memory management and execution time.

1. Methods

1.1. Systems information and database configuration

We used the HANA Developer Edition (revision 48) within the instance type *m2.xlarge* from the Amazon Elastic Compute Cloud (EC2), containing 17 gigabyte main memory, two Intel Xeon E5-2665 processors and 420 gigabyte hard disk space. For optimal comparability MySQL server (version 5.0.95) has been installed on this system as well. To avoid conflicts between the HANA and MySQL processes and memory usage, one of both databases has to be shut down while the other one is computing its stored procedures. Since MySQL is not a native In-Memory database a few configurations had to be changed to be able to store the sequence data in RAM and to perform recursive DNA alignment.

1.2. Data acquisition and formats

For DNA analysis tasks, at least one reference genome and one or more sequenced DNA reads are required. The DNA reference sequence GRCh37, which we used for alignment, derives from the NCBI fileserver in FASTA format[2]. FASTA files already include assembled genomic sequences, which can be utilized for further analysis. Against this reference genome we aligned a next generation sequencing data set. These reads are available in the FASTQ file format in which each read is specified in four rows, containing metadata, raw sequence data in a defined length, an optional further description row and quality scores.

1.3. Data transformation and load process

For the fast import of huge amounts of data, HANA and MySQL provide bulkload functionality for accelerated data import. The requirements for the bulkload process are: (i) CSV (character separated value) files, containing the import data and (ii) CTL (control) files to manage the import of the generated CSV files. Data reduction is a crucial step as there is only limited main memory available in our In-Memory systems (section 1.1). Thus, we converted the FASTQ file into FASTA format which is more memory-efficient. To perform the file conversion tasks we used the programming language python.

Within the database systems we created one table for each chromosome in the reference genome. This is of great advantage because HANA in particular provides

[2] ftp://ftp.ncbi.nih.gov/genbank/genomes/Eukaryotes/vertebrates_mammals/Homo_sapiens/GRCh37/Primary_Assembly/assembled_chromosomes/FASTA/

instructions to load and unload tables in and out of memory, which means that we are able to hold only one chromosome at a time in main memory for DNA analysis instead of storing the whole reference genome which further reduces the occupied storage. Table creation and other database administration tasks have been carried out using MySQL Workbench and HANA Studio as client software.

1.4. Implementation of Burrows-Wheeler-Aligner (BWA)

Within the past few years there was a big progress of DNA alignment algorithms, which are utilizing methods out of the field of information retrieval, like the Burrows-Wheeler-Transformation for backward search, to generate aligned sequences [4, 5]. We implemented the widely used alignment algorithm "Burrows-Wheeler-Aligner" (BWA) [6] as stored procedure for our proof of concept. BWA consists of two main steps: (i) Generation of an index out of the reference genome, called Suffix Array (SA) and (ii) carrying out the actual DNA alignment using Burrows-Wheeler-Transformation (BWT). Because indexing the reference genome has to be done only once and for the sake of simplicity, we decided not to implement this step as stored procedure but as an adjusted merge sort algorithm in python and uploaded the resulting SA in an existing In-Memory table within HANA and MySQL. The alignment step has been performed using SQL based stored procedures.

First, the development of the procedures has taken place in MySQL Workbench. The Workbench can be installed on a local computer, which means, that we do not have to run the Amazon instance for development purpose. The next step was deploying the procedures to the MySQL server on the Amazon cloud and porting them into the HANA SQL syntax.

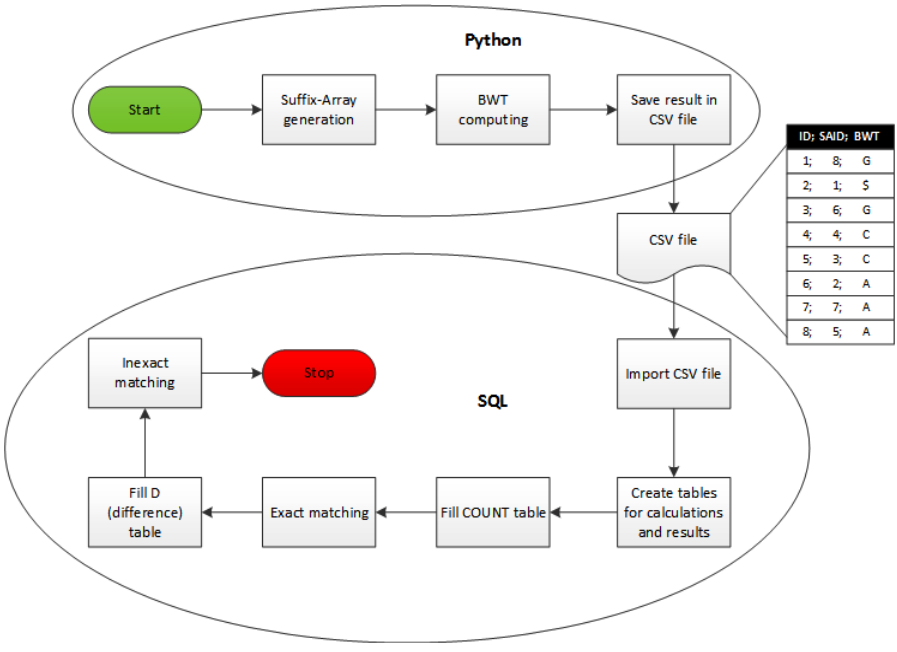


Figure 1. Overall process contains two steps: (i) Generating an index (SA and BWT) of the reference genome with python, (ii) exact and inexact matching of DNA reads as stored procedures.

2. Results

Figure 1 shows the developed process containing genome indexing and matching procedures whereas "Fill COUNT table" and "Fill D (difference) table" are necessary to support the matching operations. We implemented stored procedures including the exact and inexact matching of DNA reads within the reference genome while the inexact matching procedure could not be implemented in HANA because of technical restrictions concerning recursive procedure calls. This is due to a built-in SQL statement optimizer, which creates an execution plan for the stored procedures. If a cycle is detected (recursive call), the optimizer fails with an error message.

Another problem was the available memory space for storing the DNA sequences in RAM. Since the amount of RAM for the HANA developer edition on the Amazon cloud is limited, HANA itself already occupies more than 76% of the available memory as it holds all system tables and functions in RAM. After importing the reference chromosomes 99.5% of memory is occupied indicating that there is no more space for the delivered DNA reads. Thus, reads were simulated by selecting single rows out of the reference genome for the search procedures. In contrast, MySQL has no predefined functions or tables in RAM. This means that all assigned memory by *max_heap_table_size* is completely usable concerning in memory database tables.

Because of restrictions regarding recursion mentioned above, execution time comparison has been carried out by running the exact search procedures in MySQL and HANA. Here we could show in the first two test runs that HANA was 29.8 respectively 24.6 times faster than MySQL (see Table 1). In the third and fourth test run including 1000 and 5000 reads for exact matching, MySQL could not even finish the matching process and terminated with an execution time error message.

Table 1. Execution time comparison between MySQL and HANA for the exact search procedures. Time has been measured in seconds. The last column shows how many times HANA was faster than MySQL in the respective test run.

Number or reads	MySQL	HANA	Performance gain
10	254	8.5	29.8
100	2000	81	24.6
1000	-	787	-
5000	-	2767	-

3. Discussion

We developed stored procedures inside In-Memory databases for the exact and inexact matching of DNA reads within a reference genome based on BWA and compared the execution time between the exact search procedures implemented in MySQL and HANA. Here, HANA was significantly faster than MySQL. This is probably due to HANA specific internal functions, like data compression algorithms and the possibility to store data in a column-oriented structure in RAM. This seems to be better for analysis than row-oriented storage [7]. However, the native BWA alignment could not be implemented in its recursive form as a stored procedure in HANA so far.

There are other DNA alignment algorithms, like MAQ [8], BFAST [9] or SOAPv2 [10] as well. We decided to use the BWA algorithm due to its balance of accuracy and execution time compared to other alignment algorithms [11]. Zhang et al. describe an

optimized and iterative rather than recursive BWA algorithm [12], which should be examined by further efforts to enable alignment in HANA.

One of the major advantages of using stored procedures is to reduce data transfer between database and application, because of the opportunity to implement and maintain the programming logic inside the database itself. This has been shown by the program dbBLAST [13], which implements the Basic Local Alignment Search Tool (BLAST) – a common algorithm to perform local alignments between experimentally determined DNA or protein sequences and already existing sequences in a database.

Our next research steps will be to extend the alignment to a complete bioinformatics pipeline for genome analysis including various annotation steps. For complete analysis of a whole genome we plan to use a production environment of HANA with memory resources sufficient to handle the corresponding data volume.

References

[1] McPherson JD. Next-generation gap. Nat. Methods 2009; 6(11 Suppl):S2-5.
[2] Angiuoli SV, Matalka M, Gussman A, Galens K, Vangala M, Riley DR et al. CloVR: a virtual machine for automated and portable sequence analysis from the desktop using cloud computing. BMC Bioinformatics 2011; 12:356.
[3] Gunduz Oguducu S, Gaybcri M, Akpimar E, Kutluay H. A study for performance comparison of different in-memory databases. In: 2013 7th International Conference on Application of Information and Communication Technologies (AICT). p. 1–5 .
[4] Ferragina P, Manzini G. Opportunistic data structures with applications. In: 41st Annual Symposium on Foundations of Computer Science; 2000. p. 390–8 .
[5] Li H, Homer N. A survey of sequence alignment algorithms for next-generation sequencing. Brief. Bioinformatics 2010; 11(5):473–83.
[6] Li H, Durbin R. Fast and accurate short read alignment with Burrows-Wheeler transform. Bioinformatics 2009; 25(14):1754–60.
[7] Krueger J, Huebner F, Wust J, Boissier M, Zeier A, Plattner H. Main memory databases for enterprise applications. In: 2011 IEEE 18th International Conference on Industrial Engineering and Engineering Management. p. 547–57 .
[8] Li H, Ruan J, Durbin R. Mapping short DNA sequencing reads and calling variants using mapping quality scores. Genome Res. 2008; 18(11):1851–8.
[9] Homer N, Merriman B, Nelson SF. BFAST: an alignment tool for large scale genome resequencing. PLoS ONE 2009; 4(11):e7767.
[10] Li R, Yu C, Li Y, Lam T, Yiu S, Kristiansen K et al. SOAP2: an improved ultrafast tool for short read alignment. Bioinformatics 2009; 25(15):1966–7.
[11] Lindner R, Friedel CC, Salzberg SL. A Comprehensive Evaluation of Alignment Algorithms in the Context of RNA-Seq. PLoS ONE 2012; 7(12):e52403.
[12] Zhang J, Lin H, Balaji P, Feng W. Optimizing Burrows-Wheeler Transform-Based Sequence Alignment on Multicore Architectures. In: 2013 13th IEEE/ACM International Symposium on Cluster, Cloud and Grid Computing (CCGrid). p. 377–84 .
[13] Röhm U, Diep T. How to BLAST Your Database — A Study of Stored Procedures for BLAST Searches. In: Hutchison D, Kanade T, Kittler J, Kleinberg JM, Mattern F, Mitchell JC et al., editors. Database Systems for Advanced Applications. Berlin, Heidelberg: Springer Berlin Heidelberg; 2006. p. 807–16 (Lecture Notes in Computer Science).

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A Hybrid Particle Swarm and Neural Network Approach for Detection of Prostate Cancer from Benign Hyperplasia of Prostate

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Abstract: In present paper, we propose a Hybrid classifier based particle swarm optimization (PSO) and Neural Network method for supporting the diagnosis of prostate cancer. algorithm combining particle swarm optimization algorithm with back propagation neural network (BPNN) algorithm, also referred to as BPNN–PSO algorithm, is proposed to train the feed forward neural network (FNN). The results show that the proposed BP based PSO algorithm can achieve very high diagnosis accuracy (98%) and it proving its usefulness in support of clinical decision process of prostate cancer.

Keywords: Prostate Cancer**,** Particle Swarm Optimization**,** Neural Network

Introduction

Prostate Cancer (PC) is the most commonly diagnosed non-skin cancer and the second leading cause of cancer deaths in western countries. PC is a disease in which cancer develops in the prostate, a gland in the male reproductive system. In general, prostate cancer is a disease that can be diagnosed with prostate biopsy in accordance with the suspicions that arose as a result of Prostate-Specific Antigen (PSA) test, rectal examination, and trans rectal findings. There is a need for biopsy, a definitive diagnosis besides transrectal ultrasonography, and rectal examination for diagnosis of prostate cancer. Despite the need for biopsy for conclusive diagnosis, patients with low cancer risk may avoid this process, which is not without risks due to possible complications that may arise. This is an invasive procedure with the risk of rectal mucosa being damaged, and its high costs. Therefore, before they agree to biopsy, patients may prefer a different methodology that may yield a more accurate result with less associated risks[1].A prediction method has been developed that determines patients' cancer risk based on their; age, ethnic background, history of cancer in the family, and PSA levels.

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This paper considers the use of hybrid machine learning techniques in order to improve the detection and diagnosis of prostate cancer from benign hyperplasia of prostate [2-6].

1. Method

In recent years, the use of Artificial Neural Networks (ANN), in particular, three layer neural networks, which can be trained to approximate virtually any continuous function is the most usual type of Multilayer Perceptron(MLP). Multilayer Perceptron propagates the information from the input towards the output layer. MLP has an input layer of neurons, a number of hidden layers, and an output layer. In recent years, the use three layers feed forward neural networks, is the most usual type of feed forward NN, which propagates the information from the input towards the output layer[4, 7, 8].

Particle Swarm Optimization algorithm (PSO) is a randomly optimal algorithm based on swarm intelligence. The algorithm can be used to solve optimization problems. One of the first implementations of PSO was that of training Neural Networks and one key advantage of PSO over other optimization algorithms in training neural networks is its comparative simplicity. As described by Eberhart and Kennedy, the PSO algorithm is an adaptive algorithm based on a social psychological metaphor; a population of individuals adapts by returning stochastically toward previously successful regions in the search space, and is influenced by the successes of their topological neighbors. Each particle in the swarm represents a candidate solution to the optimization problem, and if the solution is made up of a set of variables the particle can correspondingly be a vector of variables. In a PSO system each particle is ‘‘flown’’ through the multidimensional search space, adjusting its position in search space according to its own experience and that of neighboring particles. The particle therefore makes use of the best position encountered by itself and that of its neighbors to position itself toward an optimal solution. The main operators of the PSO algorithm are the velocity and the position of the each particle. In each iteration, particles evaluate their positions according to a fitness function[9-11]. Then the velocity and the position of the each particle are updated according to below equation 1;

$$V_i(t+1) = wv_i(t) + c_1 r_1\left(p_{id} - x_i(t)\right) + c_2 r_2(p_{gd} - x_i(t)) \qquad (1)$$

Where i is the current step number, w is the inertia weight. Researchers have shown that for large values of the inertia weight, the global search ability of the algorithm increases. Nevertheless, once the algorithm converges to the optimum solution, it can be considered as a disadvantage to select a large value for the inertia weight. For this reason, the methods, which offer to adjust the inertia weight adaptively, have been proposed. c1 and c2 are the acceleration constants, r_1 and r_2 are two random numbers in the range [0, 1], $x_i(t)$ is the current position of the particle, $p_{id}$is the best one of the solutions this particle has reached, $p_{gd}$is the best one of the solutions all the particles have reached. After calculating the velocity, the new position of each particle can be calculated according to equation 2:

$$x_i(t+1) = x_i(t) + v_i(t+1) \qquad (2)$$

The PSO algorithm performs repeated applications of the update equations above until a specified number of iterations has been exceeded, or until the velocity updates are close to zero[9, 10, 12-15 9-11, 15-18].

In order to design PSO-BPNN hybrid algorithm, data records of the Department of Urology, Imam Khomeini Hospital was obtained. The original database contained 360 records of patients that underwent radical Prostatectomy for prostate cancer between 1 January 2006 and 31 December 2010. The dataset is a two-class problem either positive or negative for cancer and benign hyperplasia of prostate (BPH) diseases respectively. Laboratory data belonging to 181 cancerous patients and other 179 patients were diagnostic to the BPH. Results of the final diagnosis after biopsy indicating whether they had cancer or not were used in the study. The dataset included laboratory and demographic data like PSA, freePSA, ratio (fPSA/tPSA), and age. The descriptive statistics of preoperative parameters are given in Table 1:

Table 1:Pro Disease Database description of attributes

Num	Attribute description	Values of Attribute	Mean	Standard Deviation
1	Age	45-91	69	9.89
2	Total PSA	0.1-100	13	17.15
3	Free PSA	0.07-49.9	2.84	4.74
4	Ratio	0.018-2.9	0.25	0.2

*N=360 observations including 181 malignant and 179 benign.

2. Experiment Result and Discussion

The hybrid algorithm combines the features of BP Neural Network with PSO in order to improve the traditional BP Neural Network. In present research, each particle is randomly initialized to a certain position in the problem space. The number of dimensions in the problem space is equal to the number of components there are to optimize. The training and test strategy based PSO-BP algorithm can be seen in Figure 1. Following figure shows the general block diagram of the proposed system.

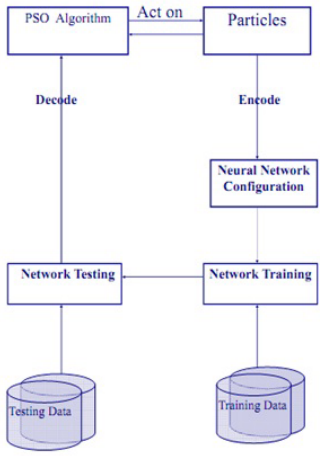


Figure 1. Block diagram of the proposed system.

A particle's individuals are these weights and biases. The number of connections between layers refers to the particle size or search space dimension [9, 15].The basic idea behind medical tests is to calculate the probability of patients being sick based on the patients' test results.

Hybrid algorithm in present study combining the PSO algorithm with back-propagation algorithm, which is to mixed the particle swarm optimization Algorithms strong ability in global search and the back-propagation algorithms strong ability in local search. After implementation BPNN-PSO according to design strategy, Confusion matrix analyses of presented algorithm were conducted to see the success rate of the study that was carried out. The BPNN-PSO that was devised classified 59 of the 60 test data successfully. The confusion matrix obtained through all of the training and test data sets is given in Table 2. When the diagnostic test conducted on all of the data in Table 2 is examined, the following results are reached:

Table 2. Confusion matrix

Classification	CaP	BPH
CaP	31	1
BPH	0	28
Sum of Column	31	29

When the diagnostic test conducted on all of the data in Table 2 is examined, the following results are reached, Sensitivity is the ability to distinguish the patient who diagnosis with prostate cancer from the true cancerous patient. Sensitivity was found to be = 96.87. Specificity is the ability to distinguish the patients with benign hyperplasia of prostate from the true patient. Specificity was found to be = 100. Accuracy is the test's total accurate diagnoses of the prostate cancer and the benign hyperplasia of prostate patient. Accuracy was found to be = 98.33. The proposed system has some advantages of automation. It is rapid, easy to process, non-invasive and cheap for clinical application. Though this system does not diagnose cancer conclusively, but by providing information it helps doctors in deciding whether a biopsy is necessary or not. Such diagnosis method can help physician in making accurate decision about prostate cancer and benign hyperplasia of prostate.

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4. References

[1]. Babaian RJ, Fritsche H, Ayala A, Bhadkamkar V, Johnston DA, Naccarato W, et al. Performance of a neural network in detecting prostate cancer in the prostate-specific antigen reflex range of 2.5 to 4.0 ng/mL. Urology. 2000;56(6):1000-6.

[2]. Djavan B, Remzi M, Zlotta A, Seitz C, Snow P, Marberger M. Novel artificial neural network for early detection of prostate cancer. Journal of Clinical Oncology. 2002;20(4):921-9.

[3]. Stephan C, Cammann H, Semjonow A, Diamandis EP, Wymenga LF, Lein M, et al. Multicenter evaluation of an artificial neural network to increase the prostate cancer detection rate and reduce unnecessary biopsies. Clinical chemistry. 2002;48(8):1279-87.
[4]. Lisboa PJ, Taktak AF. The use of artificial neural networks in decision support in cancer: a systematic review. Neural networks. 2006;19(4):408-15.
[5]. Loch T, Leuschner I, Genberg C, Weichert-Jacobsen K, Küppers F, Yfantis E, et al. Artificial neural network analysis (ANNA) of prostatic transrectal ultrasound. The Prostate. 1999;39(3):198-204.
[6]. Snow PB, Smith DS, Catalona WJ. Artificial neural networks in the diagnosis and prognosis of prostate cancer: a pilot study. The Journal of urology. 1994;152(5 Pt 2):1923-6.
[7]. Zhou Z-H, Jiang Y, Yang Y-B, Chen S-F. Lung cancer cell identification based on artificial neural network ensembles. Artificial Intelligence in Medicine. 2002;24(1):25-36.
[8]. Stephan C, Meyer H-A, Kwiatkowski M, Recker F, Cammann H, Loening SA, et al. A (-5,-7) proPSA based artificial neural network to detect prostate cancer. European urology. 2006;50(5):1014-20.
[9]. Zhang J-R, Zhang J, Lok T-M, Lyu MR. A hybrid particle swarm optimization–back-propagation algorithm for feedforward neural network training. Applied Mathematics and Computation. 2007;185(2):1026-37.
[10]. Kennedy J. Particle swarm optimization. Encyclopedia of Machine Learning: Springer; 2010. p. 760-6.
[11]. Wang Z, Sun X, Zhang D. A PSO-based classification rule mining algorithm. Advanced Intelligent Computing Theories and Applications With Aspects of Artificial Intelligence: Springer; 2007. p. 377-84.
[12]. Shi Y, Eberhart RC, editors. Empirical study of particle swarm optimization. Evolutionary Computation, 1999 CEC 99 Proceedings of the 1999 Congress on; 1999: IEEE.
[13]. Trelea IC. The particle swarm optimization algorithm: convergence analysis and parameter selection. Information processing letters. 2003;85(6):317-25.
[14]. Shi X, Lu Y, Zhou C, Lee H, Lin W, Liang Y, editors. Hybrid evolutionary algorithms based on PSO and GA. Evolutionary Computation, 2003 CEC'03 The 2003 Congress on; 2003: IEEE.
[15]. Da Y, Xiurun G. An improved PSO-based ANN with simulated annealing technique. Neurocomputing. 2005;63:527-33.
[16]. Eberhart R, Kennedy J, editors. A new optimizer using particle swarm theory. Micro Machine and Human Science, 1995 MHS'95, Proceedings of the Sixth International Symposium on; 1995: IEEE.
[17]. Gudise VG, Venayagamoorthy GK, editors. Comparison of particle swarm optimization and backpropagation as training algorithms for neural networks. Swarm Intelligence Symposium, 2003 SIS'03 Proceedings of the 2003 IEEE; 2003: IEEE.
[18]. Yalçın N, Tezel G, Karakuzu C, editors. Epilepsy diagnosis using artificial neural network learned by PSO≠. 9th International Conference on Electronics, Computer and Computation (ICECCO'12), Ankara; 2012.

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Comparison of Enhancement Methods for Mammograms with Performance Measures

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Abstract. Mammograms are generally contaminated by noise which assures the need for image enhancement to aid interpretation. The enhancement of mammograms is a very important problem for easy extraction of suspicious regions known as regions of interest (ROIs). This paper introduces comparison of various hybrid enhancement algorithms based on mathematical morphology, contrast stretching, wavelet transform, anisotropic diffusion filter and contrast limited adaptive histogram equalization (CLAHE). The performances of algorithms have been compared by using three global image enhancement evaluation measures; Enhancement Measure (EME), Absolute Mean Brightness Error (AMBE) and Peak Signal-to-Noise Ratio (PSNR). For this study, we have used MIAS database. Experimental results show that the combination of mathematical morphology, anisotropic diffusion filter and CLAHE methods, yields significantly superior image quality and provides more visibility for the suspicious regions.

Keywords. Mammogram, mathematical morphology, wavelet transform, anisotropic diffusion filter, contrast limited adaptive histogram equalization (CLAHE), contrast enhancement, performance measure

Introduction

In recent years, breast cancer has an important role in number of deaths in woman population and caused more than 30% of cancer incidences in both developing and developed countries [1]. Since mammograms contain low signal to noise ratio (low contrast) and a complicated structured background, there is still a need to enhance imaging. Image enhancement techniques have been widely used in the field of medicine [2-4], where the subjective quality of images is important for human interpretation and diagnosis. Many algorithms for accomplishing enhancement have been developed and applied to medical images such as histogram modification, unsharp masking, median filters, Gaussian filters, and morphological filters [5, 6]. In addition to these, wavelets have been used for the improvement of contrast features and the noise suppression [7].

In this paper, three hybrid enhancement algorithms have been implemented based on mathematical morphology, contrast stretching, wavelet transform, anisotropic diffusion filter and contrast limited adaptive histogram equalization (CLAHE) methods. In addition to these, the algorithms have been evaluated by three global image

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enhancement evaluation measures. The mammograms used in this paper are extracted from the Mammographic Image Analysis Society (MIAS) database which contains 322 digitized mammograms [8].

1. Methods

In this paper, three different algorithms have been implemented for enhancement of mammograms. The developed approaches can be seen in Fig. 1.

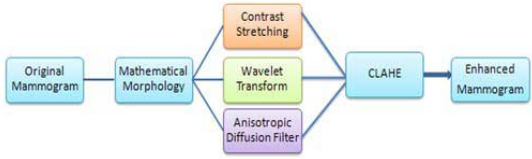


Figure 1. Implemented algorithms for enhancement of mammograms

As seen in Fig. 1, in the first approach; we have used mathematical morphology, contrast stretching and CLAHE which can be called MSC, in the second one; mathematical morphology, wavelet transform and CLAHE which can be called MWC, in the third one; mathematical morphology, anisotropic diffusion filter and CLAHE which can be called MAFC. In summary, at each approach the first method is mathematical morphology and the last method is CLAHE, the second method is changeable.

Mathematical Morphology: Morphological contrast enhancement is based on the notion of morphological top-hats which can be used to remove small noises [9].

Contrast Stretching: Contrast stretching, also called normalization, aims to improve the image through stretching the range of intensity values. This technique aims to adjust the histogram to achieve a higher separation between the foreground and the background gray-level distribution [10].

Wavelet Transform: As wavelets are a mathematical tool they can be used to extract information from many different kinds of data, including - but certainly not limited to - audio signals and images [11]. Information concerning localized high frequency signals such as micro calcifications can be extracted effectively. In this paper, we used biorthogonal wavelets for wavelet transform. Biorthogonal wavelet representation has several advantages compared to orthogonal, critically sampled, wavelet representation. The input image is decomposed at two levels in the paper. The detail coefficients obtained after decomposition are horizontal, vertical, and diagonal coefficients. These detail coefficients are mainly composed of noisy details so they have to be denoised using appropriate threshold value [12]. In the study, soft thresholding has been used.

Anisotropic Diffusion Filter: The main objective of diffusion algorithms in image processing is to remove noise via a partial differential equation (PDE). In the approach introduced by Perona and Malik [13], an anisotropic coefficient is used to "stop" the diffusion over the edges of the image.

Contrast Limited Adaptive Histogram Equalization (CLAHE): Global approaches improve image quality but it may cause washed-out effect by changing the average intensity to middle level. To solve these problems involved in global contrast enhancement techniques, local histogram equalization techniques have been proposed [14, 15]. The Contrast Limited Adaptive Histogram Equalization (CLAHE) limits the slope associated with the gray level assignment scheme to prevent saturation. This process is accomplished by allowing only a maximum number of pixels in each of the bins associated with the local histograms. After "clipping" the histogram, the clipped pixels are equally redistributed over the whole histogram to keep the total histogram count identical [16].

2. Results

2.1. Experimental Results

In this paper, for anisotropic diffusion filtering, we have used edge magnitude parameter *k=30*; for CLAHE, the image is divided into 64x64 blocks and the normalized clip limit has been taken as 0.01. These parameters were obtained as a result of literature searches [13, 16] and experimental results.

The program results of some examples from MIAS database for the three developed algorithms can be seen in Fig.2 and 3.

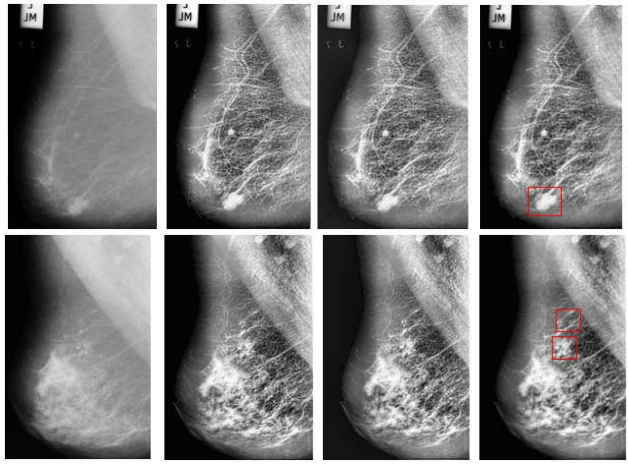


Figure 2. (a) Original mammogram (mdb249), (b) MSC, (c) MWC, (d) MAFC results

The windows show the problem areas such as masses and calcifications *(manual drawn just to show),* which are specified in MIAS database.

2.2. Performance Evaluation

The performances of the developed three algorithms have been evaluated by using three global evaluation measures; Enhancement Measure (EME) [17], Absolute Mean Brightness Error (AMBE) [18] and Peak Signal-to-Noise Ratio (PSNR) [19]. The

quantitative performance measures for 29 numbers of abnormal MIAS mammogram images in terms of both mass and microcalcification for three algorithms are given with graphics.

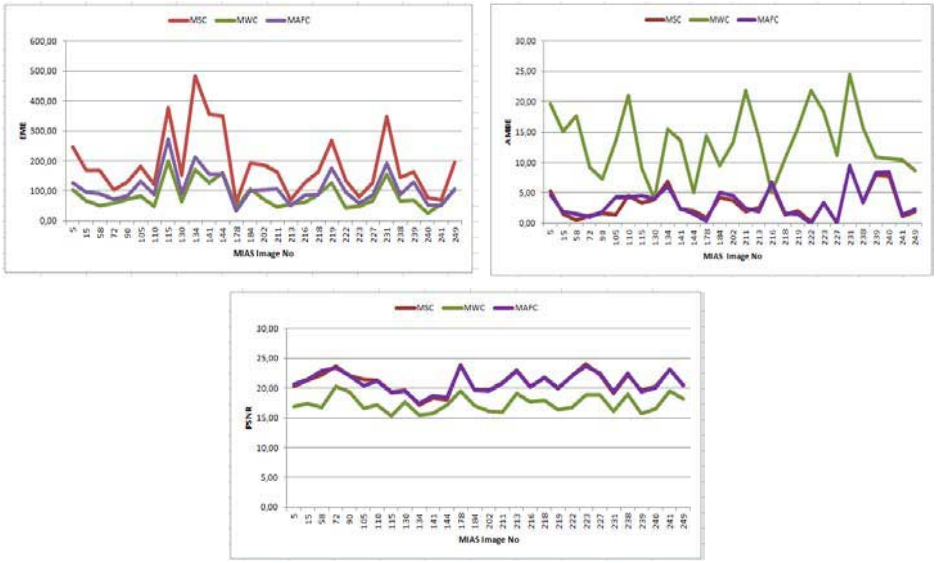


Figure 3. The graphics of EME, AMBE and PSNR measureS for three algorithms

When the value of EME is too high, it indicates over enhancement in the output image and it shows a loss of local information due to washed-out output image [20]. On the other hand, a very low value of EME indicates hidden information is not significantly enhanced. Then it is necessary to have an optimum value of EME. As the same, a median value of AMBE implies better brightness preservation which is usually used to measure the distortion in the processed image when compare to the original [21]. A higher PSNR would normally indicate that the reconstruction is of higher quality [19].

According to these, as seen in both table and graphics of three measures, we can say that the results of MWC and MAFC algorithms are close and better than the MSC. This means, wavelet transforms and anisotropic filter methods are effective than the contrast stretching. Furthermore, the results of the MAFC are slightly better compare to the MWC. Therefore, we can propose the MAFC algorithm for the enhancement of mammograms.

3. Discussion

Experimental results and performance measures show that the wavelet transform and anisotropic filter methods give the most successful results according to the contrast stretching method. Furthermore, when we observe the results, we can say that anisotropic filter is slightly better than wavelet transform. As a result, we proposed the MAFC algorithm which yields significantly superior image quality and contrast when it is compared to the other well-known algorithms. With this study, the statistical

performance evaluation has been implemented for hybrid enhancement algorithms on MIAS database. In future work, we'll aim to develop a CAD (Computer Aided Diagnosis) system for breast cancer.

4. Acknowledgement

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References

[1] Gorgel P, Sertbas A, Ucan ON. A Wavelet-based mammographic image denoising and enhancement with homomorphic filtering. Springer Science + Business Media LLC; 2009.
[2] Jiang H, Lou B, Liao S. Medical image enhancemnt method based on mode decomposition. Advances in Multimedia Technology. 2012;1(1):21-31.
[3] Yasmin M, Sharif M. Brain image enhancement-a survey. World Applied Sciences Journal. 2012;17(9):1192-1204.
[4] Bhardwaj A, Singh MK.A Novel approach of medical image enhancement based on wavelet transform. Int. J. of Engineering Research and Applications. 2012;2(3):2356-2360.
[5] Thangavel K, Karnan M, Sivakumar R, Mohideen A. Automatic detection of microcalcification in mammograms: a review. ICGSTGVIP Journal. 2009;5(5).
[6] Bankman IN. Handbook of medical imaging. Academic press; 2000.
[7] Bouyahia S, MbainaibeyeJ, Ellouze N. Wavelet based microcalcifications detection in digitized mammograms. ICGST-GVIP Journal, ISSN 1687-398X, 8, V; 2009.
[8] University of Essec, Mamographic Image Analysis Society. MIAS; [updated 2003; cited 2014 March 25]. Available from: http://peipa.essex.ac.uk/ipa/pix/mias/
[9] Mirzaalian H, Ahmadzadeh MR, Sadri S, M. Jafari M. Various applying of wavelet transform in digital mammograms for detecting masses and microcalcifications. MVA2007 IAPR Conference on Machine Vision Applications; 2007.
[10] Cruz CF. Automatic analysis of mammography images: enhancement and segmentation techniques. M.Sc.Thesis, Porto University, Porto; 2011.
[11] Wavelet, Wikipedia. [cited 2014 March 24]. Available from: http://en.wikipedia.org/wiki/Wavelet
[12] Kamur HN, Amutha S, Ramesh DR. Enhancement of mammographic images using morphology and wavelet transform. Int. J. Computer technology and Applications. 2012;3(1):192-198.
[13] Perona P, Malik J. Scale space and edge detection using anisotropic diffusion. IEEE Trans. Pattern Anal. Machine Intell. 1990;12:629-639.
[14] Kim K, Han Y, Hahn H. Contrast enhancement scheme integrating global and local contrast equalization approaches. Third International IEEE Conference on Signal-Image Technologies and Internet-Based System; 2007.
[15] Yoon H, Han Y, Hahn H. Image contrast enhancement based sub-histogram equalization technique without over-equalization noise. International Journal of Computer Science and Engineering. 2009;3(2).
[16] Kurt B, Nabiyev V, Turhan K. Contrast enhancement and breast segmentation of mammograms. 2nd World Conference on ınformation Technology. 2011 Nowember 23-27.
[17] Agaian SS, Panetta K, Grigoryan MA. Transform-Based image enhancement algorithms with performance measure. IEEE Trans. Image Processing. 2001;10(3).
[18] Vetterli M, Kovacevic J. Wavelets and subband coding. NY, NJ: Prentice Hall; 1995.
[19] Al-Najjar YAY, Soong DC. Comparison of image quality assessment: PSNR, HVS, SSIM, UIQI. Int. J. of Scientific&Engineering Research. 2012;3(8):1-5.
[20] Sundaram M, Ramar K, Arumugam N, Prabin G. Histogram modified local contrast enhancement for mammogram images. Applied Soft. Computing. 2011;11:5809-5816.
[21] Chen SD, Ramli AR. Minimummean brightness error bi-histogram equalization in contrast enhancement. IEEE Trans. Consumer Electronics. 2003;49(4):1310-1319.

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Animal Testing using 3D Microwave Tomography System for Breast Cancer Detection

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Abstract. The three dimensional microwave tomography (3D MT) system of the Electronics and Telecommunications Research Institute (ETRI) comprises an antenna array, transmitting receiving module, switch matrix module and a signal processing component. This system also includes a patient interface bed as well as a 3D reconstruction algorithm. Here, we perform a comparative analysis of image reconstruction results using the assembled system and MRI results, which is used to image the breasts of dogs. Microwave imaging reconstruction results (at 1,500MHz) obtained using the ETRI 3D MT system are presented. The system provides computationally reliable diagnosis results from the reconstructed MT Image.

Keywords. Microwave tomography, microwave imaging, breast cancer detection, image reconstruction, preclinical, animal testing

Introduction

Breast cancer diagnostic imaging technologies that rely on methods complementary to electromagnetic radiation have been actively investigated in recent years.

Among breast cancer diagnostic technologies X-ray mammography, which is currently the most common breast imaging technique, is the primary means recommended for breast cancer screening in women. However, the rate of false positives in X-ray mammography is relatively high. Other diagnostic imaging techniques such as, computed tomography (CT) and magnetic resonance imaging (MRI). These imaging techniques provide very precise diagnostic results. However, these techniques have a disadvantage in that the patient is exposed to strong magnetic fields and radiation. Further, in X-ray mammography, the patient experiences temporary pain and discomfort because the breast is squeezed to obtain an image. Furthermore, radiation is also a problem in this technology.

Microwave imaging (MI) is regarded as a promising alternative cancer diagnostics method that is safe, noninvasive, sensitive, and inexpensive [1-2].

Only recently has technological progress in microwave tomography (MT) generated interest, for the use of MT as a candidate technology to further investigate and develop breast cancer diagnostics and other clinical applications. The main trends in the progress of MT are the improvement in the sensitivity and spatial resolution of

imaging, decrease in computation time, and development of a more convenient and effective antenna system [3].

Here, we describe the three-dimensional microwave tomography system of the Electronics and Telecommunications Research Institute (ETRI 3D MT) for detecting breast cancer. The operating frequency band is 500 MHz to 2.9 GHz. The developed MT system, which is a high technology preclinical prototype, is convenient for patient trial and animal (dog) breast measurements. This system has a simple and convenient circular array of 16 transmitting and receiving monopole antennas that can be moved in a vertically by a programmed system controller. The antennas are placed into an imaging bath with matching liquid. The transmitting- receiving (TRx) module has high sensitivity, and the microwave switch matrix module (SWM) has high channel-isolation. The MT system use microwave image reconstruction software that computes accurate numerical solutions for the nonlinear 3D inverse electromagnetic scattering problem[3-4]. In this paper, we describe the animal testing images reconstructed (at 1,500MHz) by using the ETRI 3D MT system and compare the results with the MRI results.

1. MT System for Animal Testing

The ETRI MT system consists of coupling liquid and monopole antennas, as well as a TRx module, SWM, reconstruction algorithm, and bath.

The bath is filled with coupling liquid (propylene glycol 90% and distilled water 10%) and includes a circular array of 16 monopole antennas with an operating frequency of 500 MHz to 2.9 GHz.

The distance between the monopole antennas is 15cm and each monopole consists of a semi-rigid coaxial cable.

The TRx module and SWM have the following parameters: operating frequency band of 500 MHz to 2.9 GHz, minimum detective level, -110 dBm, the SWM isolation, 110 dB, and Tx output power, 10 dBm. The Tx power is 10 dBm for each antenna, which is 23 dB less than the peak Tx power of cellular phones [3]. The Federal Communications Commission (FCC) limits the specific absorption rate (SAR) level of cellular phones to 1.6 W/kg [5]. SAR level of ETRI MT system was measured commercial computer simulation technology (CST) tool and ETRI MT system is highly safe for heating the human body because the SAR level of the system is 1.11×10^{-4} W/kg.

The reconstruction algorithm of the ETRI MT system includes a 3D finite-difference time-domain (FDTD) and modified iterative Gauss-Newton methods. This algorithm uses a modified iterative Gauss-Newton method to solve the inverse problem; the forward solver is a 3D FDTD algorithm that uses a commercial library and two graphic processing unit (GPU) processors for acceleration [4].

The reconstruction algorithm is developed in MATLAB using MEX files for acceleration. It includes a GUI that provides quick and easy access to measured data.

2. Animal Testing

2.1. Outline of Animal Testing

In this section, we introduce some results of animal testing using dogs. Animal testing was performed before clinical trial and MT images were reconstructed on the basis of acquired electromagnetic data.

For animal testing, five multiparous female dogs were used. Dogs 1 and 2 had no existing tumors whereas dog 3 had tumor at the fourth left breast (L4) in the MRI result. Dogs 4 and 5 had suspected tumors in the fifth left breast (L5) and fifth right 5 breast (R5), respectively.

Figure 1 shows the MT image measurement of the dog breast with the ETRI 3D MT system.



Figure 1. Animal testing setup: (a) Dog lying face down for diagnosis of breast cancer, (b) Breast of the dog inserted into the bath.

The animal testing conditions were as follows frequency range varied from 500 MHz to 2.9 GHz (in 200 MHz steps), the number of measurement layers was 0 to 14 (10mm gap), the coupling liquid in the bath was propylene glycol 90% and distilled water 10%. The coupling liquid material in the bath had a permittivity of 14.9 and a conductivity of 1.07 S/m (at 1,500MHz).

2.2. Animal Testing Results

In this study, we excluded dog 1 because its breasts were too small and did not have a tumor. Images were reconstructed at 1,500 MHz for dog2(L3), dog3(L4), dog4(L5) and dog5(R5).

The MRI scans were performed before image reconstruction. The MRI results(T2w images) in the sagittal and coronal planes are shown in Figure 2.

Overall, the mammary gland of a normal dog shows a uniform signal in the T1w and T2w images (Figure 2(a) and (e), respectively).

The mammary gland of a dog with a tumor or suspected tumor differs from that of a normal dog because cystic lesions exist in the breast masses of the former. In addition, the boundary between the muscular coat of the abdominal wall and mammary gland is shown to be irregular.

The results of microwave image reconstruction with the ETRI 3D MT system are shown in Figure 3 The panels on the left are the MI results of 3D view and x-z plane view of permittivity and the panels on the right sections are the results of x-y plane view and permittivity value.

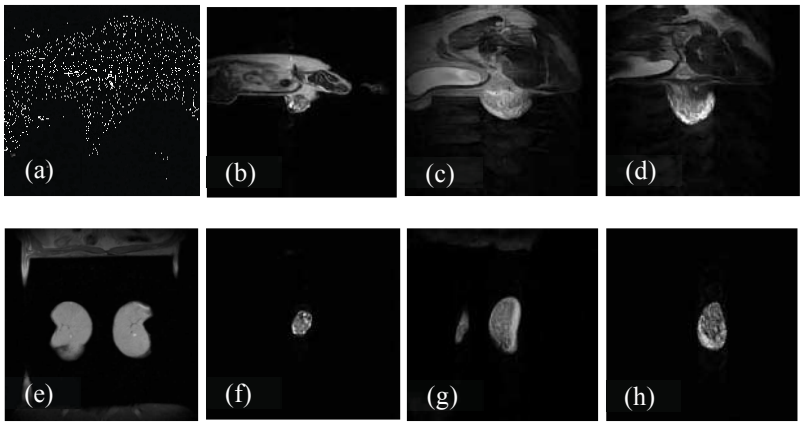
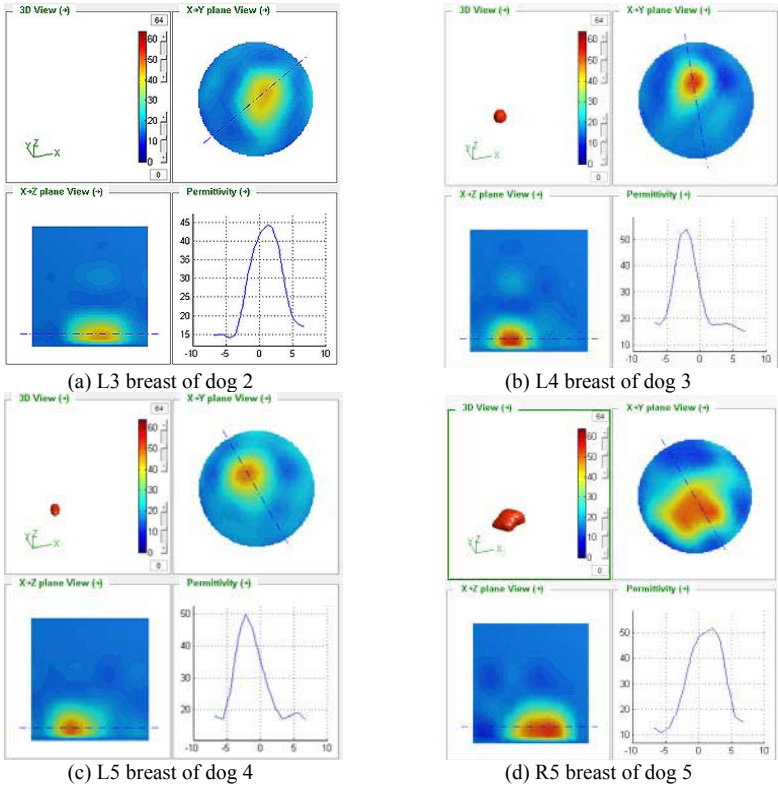


Figure 2. MRI results (T2w images) of sagittal planes : (a), (b), (c), (d) and coronal planes : (e), (f), (g), (h). (a), (e) : L3 breast of dog2, (b), (d) : L4 of breast dog3, (c), (g) : L5 breast of dog4 and (d), (h) : R5 breast of dog5.



(a) L3 breast of dog 2 (b) L4 breast of dog 3

(c) L5 breast of dog 4 (d) R5 breast of dog 5

Figure 3. Reconstructed images of dog breasts at 1,500MHz.

Figure 3(a) shows reconstructed image of a without tumor and permittivity value is about 44, which is 5-6 less then among Dogs. Figure 3(b) shows the successfully reconstructed image of tumor at 1,500MHz.

From the MRI results, dog 4(L5) and dog 5(R5) are suspected to have a tumor, and two dogs are diagnosed with a tumor of the breast (see Figure 3(c) and (d)).

The number of measurement layers is 0 to 14 (10mm gap) although the reconstructed image is 2 layer because of too small breast of the dog.

Piecing together the reconstructed image results at all frequencies (500 MHz to 2.9 GHz in 200 MHz step), the permittivity images are successfully reconstructed below 1,500MHz, however at a higher frequency, tumor shapes are distorted. In contrast, in the conductivity images, tumor shapes are distorted below 1,500MHz although the reconstructed images are at the higher frequency.

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3. Discussion

We assembled the ETRI 3D MT system and performed animal testing in the preclinical phase. We comparatively analyzed MRI and MT images (@1,500MHz) of the breasts of dogs. We are not found that there were tumors in the permittivity images of dog 2. However, dogs 3, 4 and 5 were diagnosed with a breast tumor from the MI results, as from the MRI results. The tumors sizes of the MRI and MT image results were incorrect. Therefore, we will compensate for the errors arising owing to the antennas, TRx module, SWM and 3D FDTD algorithm. In near future, we will also perform human clinical trials by using an advanced ETRI 3D MT system.

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References

1. Xie Y, Guo B, Li J, and Stoica P, "Novel multistatic adaptive microwave imaging methods for early breast cancer detection", EURASIP Journal on applied signal processing volume 2006, Article ID 91961, Pages 1–13, Jan 2008.
2. Hieda I and Nam KC, "2D Image Construction from Low Resolution Response of a New Non-invasive Measurement for Medical Application," *ETRI J.*, vol. 27, no. 4, 2005, pp. 385-393.
3. Son SH et al., "Preclinical Prototype Development of a Microwave Tomography System for Breast Cancer Detection," *ETRI J.,* vol. 32, no. 6, 2010, pp. 901-910.
4. Simonov N et al., "3D Microwave Breast Imaging Based on Multistatic Radar Concept System,"*JKIEES.*, vol. 12, no.1, Mar. 2012, pp. 107-114.
5. Cellular Telephone Specific Absorption Rate. Available: http://www.fcc.gov/cgb/sar.

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ICT Health 2013: Infrastructure and Adoption by Healthcare Providers in Brazil

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Abstract. The potential offered by intensive and strategic adoption of information and communication technologies for obtaining advances in the health sector is worldwide recognized. In order to monitor the implementation of ICT in health policies in Brazil and to establish internationally comparable indicators, a nationwide survey was conducted to identify the current implementation of information and communication technologies in Healthcare facilities and its adoption by providers. Data collection was carried out from February to August 2013 using two structured questionnaires. The results obtained showed that the access to internet is nearly universal in the country but clinical information systems are still in its infancy when it comes to more complex functionalities and linked to clinical decision support. Healthcare professionals indicated that the main barrier to adopt is the lack of availability related to the patient information.

Keywords. Health Technology, information, medical informatics, infrastructure

Introduction

The use of information and communication technologies (ICT) in healthcare is fundamental to assure quality and provision of health services, promoting efficiency and continuity of care. Since 2003, the plan of action of the World Summit on the Information Society-WSIS set forth indicative targets to serve as global reference for improving connectivity and access in the use of ICTs [1]. Among the established goals, it was emphasized the connection of healthcare centers and hospitals to the Internet by 2015 [2]. In Latin America, promoting ICT infrastructure and adoption in several strategic sectors has been monitored by the Action Plan of the Economic Commission for Latin America and the Caribbean (eLAC) Program, which includes the promotion of the use of ICT for the actions of health and social security, considering the incipient development of digital technologies and networks in the health systems in the region [3].

According to the Organization for Economic Cooperation and Development (OECD), the inefficiency of healthcare systems is related to deficits in the transmission of information, which can be improved through the use of technologies. The potential benefits of the application of ICT can increase the quality of treatments and efficiency, reduce operating and administrative costs and open up possibilities for new treatment

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approaches and models [4]. In addition, a key challenge to enhance ICT adoption in healthcare is the consolidation of internationally recognized indicators. The first comprehensive study to collect and analyze information on *e*-Health to ascertain a group of internationally comparable indicators was coordinated by the European Commission. The survey identified 4,400 theme-related indicators in the countries of the European Union, Iceland, Norway, Canada and United States [5].

It is a considerable challenge to define those indicators and to make them consistent and usable to allow benchmarking and recommendations for policies and future investments. Consequently, the absence of substantial and independent research on the topic is a predictable obstacle to the development of *e*-Health in Latin American countries. Considering the international scenario and the Brazilian development in health informatics and technological resources, a national study can contribute to pursuit consistent indicators to measure the impact of the use of information and communication technology for the health of the population.

Thus, the overall objective of this research was to identify the existing infrastructure of information and communication technologies available in healthcare facilities, including the stage of implementation by these facilities and its adoption by health professionals. Based on this context, the research has the following specific objectives: (a) identify ICT infrastructure available at Brazilian healthcare facilities, (b) investigate the use of ICT-based systems to support management, (c) investigate the activities carried out and the professional skills in the use of ICT and, (d) understand motivations and barriers to adopt ICT by healthcare professionals. The current study is the first phase of a three years investigation to underpin political decisions and financial investiments.

1. Methods

This study is a descriptive research with data collection performed from February to August 2013. The sample comprised Executive and ICT Directors (CEO and CIO), physicians and nurses included at the National Record of Healthcare Establishments (CNES), maintained by the Department of Informatics of the Ministry of Health. It was excluded isolated clinics, mobile units and establishments with non-physician and non-nurses. The sample was selected by probability sampling technique considering the country region and the type of establishment (outpatient, diagnosis and therapy services, inpatient up to 50 beds and inpatient with more than 50 beds), including both private and public facilities.

Two questionnaires were used: the first with 43 questions was applied to the CEOs and CIOs investigating the infrastructure and implementation of ICT in the facility. The second, with 37 questions, was applied to the physicians and nurses to understand the adoption of ICT in their daily duties. The questions bring up data and information related to the last 12 months of implementation and adoption of ICT-based systems and services. Both questionnaires were applied via Computer Assisted Telephone Interview – CATI; 8% of healthcare facilities were also selected to apply face-to-face questionnaires. The research project was approved by the Ethical and Research Committee of the Universidade Federal de São Paulo (UNIFESP). An informed consent was read to all participants prior to the application of the questionnaire.

2. Results

The questionnaire was answered by 1,685 executives and ICT directors, 1,484 physicians and 2,696 nurses. At this article we will present some of the major findings. Related to the ICT infrastructure, the results showed that 94% of the healthcare facilities use computers and 91% are connected to the Internet. This scenario is similar to what occurs in the Brazilian enterprises where 97% with 10 or more persons employed have Internet connection [6].

Healthcare facilities with more than 50 inpatient beds and diagnosis and therapy services showed higher proportions of computer usage. On the other hand, deficit in the infrastructure was superior in outpatient facilities responsible for primary care, where 14% did not use any computer-based resources.

Table 1: Use of ICT and data recording according to the type of facility

Percentage (%)		Total	Type of facility			
			Outpatient	Inpatient (up to 50 beds)	Inpatient (more than 50 beds)	Diagnosis and therapy services
Have used computers in the last 12 months		94	86	96	100	98
Have used Internet in the last 12 months		91	80	93	100	97
With an IT department or area		41	24	31	75	35
Method to input information in patients' medical records	Records are totally electronic	25	25	10	14	54
	Records are partially on paper and partially electronic	52	45	54	65	43
	Records are totally on paper	23	30	36	20	3

The presence of health informatics professionals are a relevant indicator to measure the capacity to develop mechanics to face challenges of deploying and implementing ICT and clinical information systems. The results showed that 41% facilities have a dedicated department. The findings also revealed that 52% of the facilities, the patient record is both paper-based and electronic (Table 1).

Administrative data, identification and demographics information are the most available and used components. In addition, 60% of facilities using Internet provide the laboratory test results electronically and 52% refer that all information regarding to the admission, referral and discharge are also electronically available.

Clinical information was less available such as vaccines taken by the patient (21%), allergies (36%), patient's vital signs (26%), notes on the clinical care (42%) and nursing notes (26%). Is still limited the percentage of facilities that have clinical information systems with alerts and reminders about drug interaction (22%), dosage (21%), allergies (22%), drug intervention on laboratory tests (20%) and contraindications (20%). The results indicate that many efforts must be implemented in the area of

decision support systems integrated at the point of care.The results also has shown that, among facilities using Internet in the last 12 months, 22% carried out distance education, 19% performed distance research activities and 25% real-time interaction, such as teleconference.

Related to individual use, 99% of the physicians and nurses are Internet users; 89% of physicians access Internet daily, with increased use among younger people (97% is up to 35 years and 78% is 51 years or more). Among nurses, that ratio is 86% of Internet users, with no significant difference in the age groups. These proportions are particularly high compared to the overall situation of the country: 46% of Brazilian households have access to computer and 40% to the Internet; 49% of Brazilians individuals with 10 years old or more and 93% individuals with higher education degree are Internet users [6].

The availability of the Internet at the healthcare facility encompasses 72% of nurses, 80% of which comes from the private facilities. The proportion of nurses who have access to Internet at the facility is 86% in the Southeast region compared to 62% in the Northeast. The development of skills and abilities is a central element for ICT adoption in healthcare. Related to training opportunities, 23% of the physicians and 25% of nurses reported having participated in health informatics courses, conferences or training program.

The lack of priority of public policies, infrastructure deficits and lack of training programs are described by the executives, physicians and nurses as main obstacles to the deployment and use of clinical information systems and electronic health record; 67% of executive directors considered that the lack of priority of public policy constrain the deployment and use of systems in the establishment. Likewise, 62% considered that the low quality of Internet connection can raises the levels of difficulties; 61% pointed out the equipment obsolescence as the responsible for negative impact on the clinical information system implementation.

The physicians and nurses interviewed also declared that the lack of priority of policies is a barrier that obstructs the deployment (83% of physicians and 72% of nurses) of the information systems. Other aspects emphasized were: the lack of training (75% of the physicians and 71% of nurses), the lack of resources for investment in technology (75% and 74% of physicians and nurses, respectively) and, internal policies (70% of physicians and 66% of nurses).

Regarding the use of system, the findings showed that professionals have an overall positive perception, especially in the improvement of efficiency and quality of care. However, no change was perceived on the reduction of medical errors, on the number of attendances and waiting list and to increase treatment adherence.

3. Discussion

The results presented in the first edition of the ICT in Health Brazil 2013 showed that the main challenges are the expansion of infrastructure, the availability and use of information and communication technologies in healthcare. Despite a comprehensive presence of computer and Internet in the facilities, more efforts must be done related to the infrastructure. A significant gap in the infrastructure (computers and Internet access) is evident on the primary care and outpatient units.

The infrastructure is also an issue to be considered in the establishments in which ICT are already present: physicians and nurses considered that obsolete equipment and

low-speed Internet connection are sensitive to technology adoption barriers. This perception exists even among the professionals working in institutes with more than 50 beds where Internet access is universal.

Infraestrucute is essential. As pointed out by Lovis et al (2011), the fusion of efficient, best clinical practice and patient information at the point of care will directly support improved quality of care and produce cost saving, which has been an important aspect of heath systems discussed by Ministers of Health around the world. However, nothing will be achieved if clinicians cannot enter the data at the point of care [7].

Findings indicated a low availability of more complex functionalities of clinical information systems. Among healthcare professionals, access to ICT and the use of Internet is reduced although available. These findings are consistent with the daily routine in the work environments where the adoption of these technologies is constrained and more dedicated to the administrative functions for billing and supplies.

In summary, it can be inferred that clinical information systems are still in its infancy when it comes to more complex functionalities and linked to clinical decision support. This is evident when the interviewed healthcare professionals stated that the main barrier to adopt and to the everyday use of technologies is the lack of availability to the patient information. Technology adoption is a process, not a product. The results has showed that investments still must be done in the area of ICT and healthcare professionals also must continue to be very active to ensure that all resources will be applied to facilitate their performance and integrate new scientific evidence into practice to the benefit of patients.

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References

[1] World Health Organization. Global Observatory for eHealth Featured Project, 2010. Available on: http://www.who.int/goe/en/. Accessed on 07/01/2013.

[2] World Sumit on the Information Society - WSIS. Plan of Action, Geneva, 2003. Available on http://www.itu.int/wsis/docs/geneva/official/poa.html. Accessed on 07/01/2013.

[3] Comissión Económica para America Latina y Caribe. eLac2015, Plan de Acción sobre la Sociedad de la Información y del Conocimiento de América Latina y el Caribe, 2010, Available on: http://www.cepal.org/socinfo/noticias/documentosdetrabajo/0/41770/2010-819-eLAC-Plan_de_Accion.pdf Accessed on 07/01/2013.

[4] Organization for economic co-operation and Development. Health Policy Studies Improving Health Sector Efficiency: The Role of Information and Communication Technologies. 2010. Available on: http://ec.europa.eu/health/eu_world/docs/oecd_ict_en.pdf

[5] European Comission. eHealth Benchmarking (Phase II). Final Report. European Commission, Empirica. 2010.

[6] Comitê Gestor Internet CGI. Pesquisa sobre o uso das tecnologias de informação e comunicação no Brasil: TIC Domicílios e Empresas 2012. São Paulo: Comitê Gestor da Internet no Brasil, 2013.

[7] Lovis C, Ball M, Boyer C, et al. Hospital and Health Information Systems – current perspectives. IMIA Yearb Med Inform 2011:73-82.

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A novel SVM-ID3 Hybrid Feature Selection Method to Build a Disease Model for Melanoma using Integrated Genotyping and Phenotype Data from dbGaP

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Abstract. The relations between Single Nucleotide Polymorphism (SNP) and complex diseases are likely to be non-linear and require analysis of the high dimensional data. Previous studies in the field mostly focus on genotyping and effects of various phenotypes are not considered. To fill this gap a hybrid feature selection model of support vector machine and decision tree has been designed. The designed method is tested on melanoma. We were able to select phenotypic features such as moles and dysplastic nevi, and SNPs those maps to specific genes such as CAMK1D. The performance results of the proposed hybrid model, on melanoma dataset are 79.07% of sensitivity and 0.81 of area under ROC curve.

Keywords: Genome Wide Association Studies (GWAS), Single Nucleotide Polymorphism (SNP), Data Mining, Support Vector Machines (SVM), Decision Trees, Hybrid Models

Introduction

Genome Wide Association Studies led the discovery of different genetic loci and individual SNPs related with the conditions [1-4] but association of only SNP genotyping profiles are not strong enough for prediction of disease condition. Multiple phenotypic features such as clinical information, environmental factors, and life style habits could consolidate the predictive performance if used together with genotyping information. To our knowledge there isn't any study of melanoma that combines multiple genotypic and multiple phenotypic features, where application of new data mining approaches to handle data with such variety and high dimensionality is required.

In this work we are introducing a hybrid feature selection model of SVM and ID3 for predicting the phenotypic and genotypic features of melanoma.

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1. Methods

The melanoma dataset downloaded from dbGaP consists of 1952 cases and 1055 controls of European ancestry. Each individual in the dataset has 600,000 SNPs and 24 phenotypes, which are either categorical or binary. As the parent of origin was not given with the melanoma data, an alternative coding scheme was generated to treat symmetric alleles.

In order to find statistical power of genotyping associations, Plink analysis was conducted. This revealed a subset of 28,472 associated SNPs. METU-SNP's AHP (Analytical Hierarchical Process) [5] feature was used to prioritize these SNPs based on both the biological and the statistical significance. As a result a final SNP subset of 2783 SNPs was prioritized.

We've found that the most widely used data mining methods to detect genotype-disease relations were ANN [6], SVM [7] and Decision Trees [8]. Hybrid models preferred to increase the classification performance generally rely on optimization of one main method [9].

In our study rather than combining a main method with an advanced optimization, we've combined SVM and ID3. SVM was selected because the decision logic is clear [10] and has less number of parameters to adjust. Most importantly SVM deals with quadratic problem, which has only one solution meaning that the chance to find global optima is more probable. ID3 is selected as a second method because of its strong performance on discrete values, its ability to handle noisy data and missing values, its easy application and easy interpretation with its visual features [11]. Other decision tree methods that construct trees by pruning would hide some decision paths for the disease and also they are more suitable for numerical data.

In order to get optimum performance, each method in the hybrid model was optimized. In SVM part, RBF is chosen for Kernel because of its fast learning speed and flexibility to be used as both linear and sigmoid kernel [12]. A grid search for the optimization of (C,γ) was conducted as recommended [13]. Another grid search was conducted for parameters of ID3 tree.

After the optimization process the SVM is applied as a first step and entire SVM weights are used as weight coefficients for the corresponding attributes in ID3. By this way a weighted information gain ratio was calculated. The overall structure of the Hybrid SVM-Tree [14] model is summarized in Fig. 1.

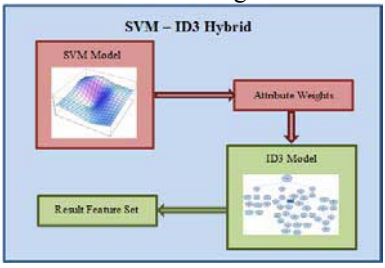


Figure 1. Structure of SVM-ID3 Hybrid Model

2. Results

In order to test the effect of integrating genotyping with phenotypes on classification performance three different datasets were formed. First and the second model was either only genotyping or phenotype based and the third model integrated genotyping and phenotype data. The hybrid SVM-ID3 model is then applied on these three datasets and the results are presented in Table 1 and Figure 2.

Table 1. Performance comparison of different datasets in SVM-ID3 Hybrid Model

Performance Criteria	Only Genotype (OG)	Only Phenotype (OF)	Integrated Set (G+F)
Accuracy	57.12	75.48	80.35
Sensitivity	53.47	68.9	79.07
AUC	0.567	0.799	0.81

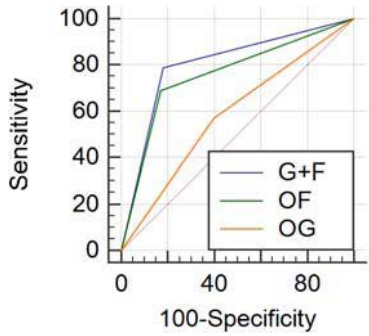


Figure 2. AUC comparisons of different datasets in SVM-ID3 Hybrid Model

Within the phenotypic attributes, the most important finding selected by the hybrid model was moles and dysplastic_nevi. Skin color, eye color, hair color and freckles attributes were at the third level of the structure and family history, having sunburn or being untanned were found at lower levels.

Total of 53 SNPs out of 2783 were identified. We have investigated the SNPs mapping to genes in the SNPnexus database in order to see if they have been associated with melanoma or any other condition before. Results show that a total of 16 unique SNPs match to a gene, which are associated with a condition listed in Genetic Association of Complex Diseases and Disorders (GAD) database.

3. Discussion

Previous studies focus associating complex diseases with genotyping but to our knowledge there is no further work that integrates genotyping with variety of clinical information for phenotypes. In order to fill this gap and to show that the combining of these data can improve the diagnostic performance we have used three separate data sets that consist of only phenotypes, only genotypes and integrated set of genotyping with phenotypes. As presented in Table 1, integrating the phenotype and genotype data increased the decision performance by terms of accuracy, sensitivity and AUC.

The presented ID3-SVM Hybrid Model was able to identify important functional and regulatory SNPs related with melanoma. The annotations of selected SNPs are confirmed by SNPnexus and RegulomeDB. Some prominent SNPs are as follows: rs2246095 is found to affect the regulation of ADCK4 which has an important role in protein kinase and is studied for its relation with melanoma [15], rs2768343 affects CAMK1D which has an important role in Ca2+ cycle and searched for its effects in cancer studies as well as melanoma [16], rs239695 affects binding of RYR2 gene, takes role in calcium channel, is also studied previously for its relation with melanoma [17].

The phenotypes found by our hybrid model were also investigated for their relations in melanoma in previous studies. For example moles, as a phenotype is generally studied by its density, shape and size and risk of melanoma increases with these parameters [18]. Several studies show that subjects with dysplastic nevi have higher risk to develop melanoma [19]. Skin color, eye color, hair color, sunburn, tanned, freckle and family history attributes has been previously studied due to their relations with melanoma [20-22].

In this study, for the first time we are introducing the integration of genotyping data with variety of phenotypes has increased the predictive performance compared to using only genotyping or only phenotypes. We also introduce a hybrid feature selection method of SVM and ID3 that is able to handle integrated dataset of genotyping and phenotypes. As distinct from many previous works both methods are individually used rather than just optimizing the main method. The melanoma data is used as a case study and we have demonstrated that integrating genotype information with multiple phenotypes increases the predictive performance of the disease models.

References

[1] Robert J. Klein, Caroline Zeiss, Emily Y. Chew, Jen-Yue Tsai, Richard S. Sackler, Chad Haynes, Alice K. Henning, John Paul SanGiovanni, Shrikant M. Mane, Susan T. Mayne., et al.. Complement factor H polymorphism in age related macular degeneration. Science 2005; 308(5720):385-389

[2] Lettre G., Cameron D. Palmer, Taylor Young, Kenechi G. Ejebe, Hooman Allayee, Emelia J. Benjamin, Franklyn Bennett, Donald W. Bowden, Aravinda Chakravarti, Al Dreisbac, et al.. Genome wide association study of coronary heart disease and its risk factors in 8,090 African Americans: The NHLBI Care Project. Plos Genetics 2011; 7(2): e1001300

[3] Meredith Yeager, Nick Orr, Richard B Hayes, Kevin B Jacobs, Peter Kraft, Sholom Wacholder, Mark J Minichiello, Paul Fearnhead, Kai Yu, Nilanjan Chatterjee, et al.. Genome wide association study of prostate cancer identifies a second risk locus at 8q24. Nature Genetics 2007; 39:645-649.

[4] Gerstenblith MR, Shi J, Landi MT. Genome wide association studies of pigmentation and skin cancer: a review and meta-analysis. Pigment Cell and Melanoma Research 2010; 23(5):587-606.

[5] Ustünkar G, Aydın Son Y. METU-SNP: an integrated software system for SNP-complex disease association analysis. J Integr Bioinform. 2011 Dec 12;8(1):187. doi: 10.2390/biecoll-jib-2011-187.

[6] Yasuyuki Tomita, Shuta Tomida, Yuko Hasegawa, Yoichi Suzuki, Taro Shirakawa, Takeshi Kobayashi, Hiroyuki Honda. Artificial neural network approach for selection of single nucleotide polymorphisms and construction of predicition model on childhood allergic asthma. BMC Bioinformatics 2004; 5:120.

[7] Li-Yeh Chuang, Kuo-Chuan Wu, Hsueh-Wei Chang, Cheng hong Yang. Support vector machine based prediction of oral cancer using four SNPs in DNA repair genes. Proceedings of the International MultiConference of Engineers and computer Scientists;16 – 18 March 2011; Hong Kong: IMECS; 2011.Vol1.

[8] Fiaschi L., Garibaldi, J.M., Krasnogor N. A frame work for the application of decision trees of the analysis of SNPs data. Proceedings of the IEEE Symposium on Computational Intelligence in Bioinformatics and Computational Biology; 30 March – 2 April 2009; Nashville, TN, USA: IEEE Computational Intelligence in Bioinformatics and Computational Biology; 2009. pp. 106-113.

[9] Turner SD, Dudek SM, Ritchie MD. ATHENA: A knowledge based hybrid back propagation grammatical evolution neural network algorithm for discovering epistasis quantitive trait loci BioData Min. 2010; 3(1):5
[10] Abeel T, Helleputte T, Van de Peer Y, Dupont P, Saeys Y. Robust biomarker identification for cancer diagnosis with ensemle feature selection methods. Bioinformatics 2010; 26(3):392-398.
[11] Jiawei Han and Micheline Kamber. Data Mining: Concepts and Techniques, 2nd ed.. Burlington, Massachusetts, USA. Margon Kauffman Publishers; 2006
[12] Ebrahimi M, Lakizadeh A, Agha-Golzadeh P, Ebrahimie E, Ebrahimi M. Prediction of thermo-stability from amino acid attributes by combination of clustering with attribute weighting: A new vista in engineering enzymes. PLoS One. 2011;6(8):e23146
[13] Frohlich H. , Zell A. Efficient parameter selection for support vector machines in classification and regression via model-based global optimization. Proceedings of the IEEE 2005 International Joint Conference on Neural Networks; 31 July – 4 August 2005; Montreal, QC, Canada: : IEEE Computer Society; 2005. pp. 1431 – 1436.
[14] Yücebaş SC, Son YA. A Prostate Cancer Model Build by a Novel SVM-ID3 Hybrid Feature Selection Method Using Both Genotyping and Phenotype Data from dbGaP. Pone. 2014 March 20. doi: 10.1371/journal.pone.0091404
[15] Nikolaev SI, Rimoldi D, Iseli C, Valsesia A, Robyr D, Gehrig C, Harshman K, Guipponi M, Bukach O, Zoete, et al.. Exome sequencing identifies recurrent somatic MAP2K1 and MAP2K2 mutations in melanoma. Nat Genet. 2011; 44(2):133-139.
[16] Berger MF, Hodis E, Heffernan TP, Deribe YL, Lawrence MS, Protopopov A, Ivanova E, Watson IR, Nickerson E, Ghosh P, et al. Melanoma genome sequencing reveals frequent PREX2 mutations. Nature. 2012 May 9;485(7399):502-506
[17] Dutton-Regester K, Aoude LG, Nancarrow DJ, Stark MS, O'Connor L, Lanagan C, Pupo GM, Tembe V, Carter CD, O'Rourke M. Et al.. Identification of TFG (TRK-fused gene) as a putative metastatic melanoma tumor suppressor gene. Genes Chromosomes Cancer. 2012; 51(5):452-461
[18] Titus-Ernstoff L, Perry AE, Spencer SK, Gibson JJ, Cole BF, Ernstoff MS. Pigmentary characteristics and moles in relation to melanoma risk. Int J Cancer. 2005; 116(1):144-149.
[19] Titus-Ernstoff L, Duray PH, Ernstoff MS, Barnhill RL, Horn PL, Kirkwood JM. Dysplastic Nevi in Association with Multiple Primary Melanoma. Cancer Res. 1988; 48(4):1016-8.
[20] Langholz B, Richardson J, Rappaport E, Waisman J, Cockburn M, Mack T.. Skin characteristics and risk of superficial spreading and nodular melanoma (United States).. Cancer Causes Control. 2000; 11(8):741-50.
[21] Vajdic CM, Kricker A, Giblin M, McKenzie J, Aitken J, Giles GG, Armstrong BK.. Eye color and cutaneous nevi predict risk of ocular melanoma in Australia. Int J Cancer. 2001; 2(6):906-12.
[22] Beral V, Evans S, Shaw H, Milton G.. Cutaneous factors related to the risk of malignant melanoma. Br J Dermatol. 1983 Aug;109(2):165-72.

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Effects of Pathological Respiratory Pattern on Heart Rate Turbulence in Sleep Apnea

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Abstract. Obstructive sleep apnea syndrome (OSAS) is characterized by recurrent episodes of partial or complete upper-airway obstruction during sleep. Although cardiac autonomic impairment is involved in the development of cardiovascular disease in OSAS, the mechanism underlying this derangement is rather unknown. It can be assessed by a recently introduced analysis of the heart rate turbulence (HRT). The aim of the paper is to describe the effects of pathological respiratory pattern on HRT in OSAS. HRT has been assessed by turbulence onset (TO) and turbulence slope (TS) indexes in 20 polysomnographic recordings of severe OSAS patients, and separately calculated during both normal (NR) and obstructive apnea (OA) respiratory pattern. Results showed that, although there is an overall depressed HRT for both indexes, while the TO during OA phases is not significantly different from those of NR epochs, the TS during OA phases is very significantly higher than in NR phases. This novel finding shows a previously unknown paradoxical increase of TS during OA episodes, followed by a marked decrease during subsequent NR phases, where OSAS patient show higher sympathetic tone. Such deeper understanding of the integrated autonomic response in different OSAS pathophysiological conditions could be useful to address an overall cardiorespiratory assessment and treatment in sleep-related breathing disorders

Keywords. Heart rate turbulence, Baroreflex sensitivity, Sleep-Apnea

Introduction

Complex autonomic impairments affecting abnormal heart rate variability modulation are associated to severe breathing disorders in patients with obstructive sleep apnea syndrome (OSAS). Their heart rate is unstable, with abrupt and marked fluctuations in RR intervals [1]. The mechanism underlying the derangement in autonomic control in OSAS is rather unknown. Abnormalities in baroreflex and chemoreflex functions and in their mutual interactions may be implicated. Baroreflex dysfunction is already known to have a significant prognostic value in cardiac patients, and OSAS has been associated to worse prognosis and mortality, mainly due to an increased rate of cardiovascular morbidity, and the observation that the majority of sudden deaths occurred during nighttime [2], and not in the morning, as it is the case for cardiac

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patients. This suggests a great interest in baroreflex sensitivity assessment in OSAS, although few studies addressed such issue.

More recently, heart rate turbulence (HRT) has been shown as an attractive non-invasive way for baroreflex sensitivity assessment [3] and its impairments has been demonstrated as the strongest electrocardiographic risk predictor in cardiac patients [4]. It consists on the analysis of short-term sinus cycle length fluctuations following spontaneous isolated ventricular premature complexes (VPC). The physiologic pattern of HRT is composed of a brief heart rate acceleration followed by a more gradual heart rate deceleration before the rate returns to a pre-ectopic level. Available physiologic investigations confirm that the initial heart rate acceleration is triggered by transient vagal inhibition in response to missed baroreflex afferent input caused by hemodynamically inefficient ventricular contraction. A sympathetically mediated overshoot of arterial pressure is responsible for the subsequent heart rate deceleration through vagal recruitment. HRT seems to be less susceptible to respiration disturbances and cardiac arrhythmias than traditional heart rate variability indexes, so, it may be more suitable for the assessment of cardiac autonomic regulation in OSAS.

Very few papers assessed HRT in OSAS patients and just on the whole polysomnographic recording [5, 6]. This is the first study able to separately assess HRT during normal and apnoeic respiratory periods with the aim to describe the effects of pathological respiratory pattern on HRT in sleep apnea.

1. Methods

1.1. Polysomnographic monitoring

We studied a database of polysomnographic recordings of severe OSAS patients admitted in the Pneumological Rehabilitation Unit Institute of Maugeri Foundation of Telese Terme (BN, Italy). In addition to traditional polysomnographic signals of airflow, snoring, thoracic and abdominal movements, and pulse oximetry, all subjects underwent holter ECG monitoring between 11 p.m. and 6 a.m. All measures were collected by means of Somntè (Compumedics) polysomnographic system. The system automatically classified normal respiratory epochs and apnoeas events automatically detected by respiratory pattern recognition, manually verified by an expert technician, and defined as an airflow amplitude reduction of at least 80% for more than 10 s. Each heartbeat has been labeled as normal, VPC or aberrant according to the ECG Holter analysis and after an investigator's verification.

1.2. HRT Analysis

All data have been imported from Somntè system and post-processed for HRT analysis by a customized Matlab software toolbox developed by the authors [7, 8]. In agreement with standards of measurements [9], HRT was estimated by two numerical descriptors: turbulence onset (TO), reflecting the initial phase of sinus rhythm acceleration, and turbulence slope (TS), describing the late deceleration phase.

TO was calculated as a percentage of the difference between the mean of the first two beat-to beat (RR) intervals following the compensatory pause after a VPC and the last two sinus RR intervals before a VPC. TS was calculated as the maximum positive slope of a regression line assessed over any of 5 consecutive RR intervals within the

first 15 sinus RR intervals after a VPC. Physiological HRT responses correspond to TO<0% and TS>2.5 ms/RR values.

Filtering algorithms were used to identify and delete inappropriate RR intervals and VPC with overly long coupling intervals or overly short compensatory pauses. Filtering algorithms excluded from the HRT calculation RR intervals shorter than 300 ms, longer than 2000 ms, with a difference between two sinus interval greater than 200 ms or with a difference higher than 20% of the reference interval (mean of the 5 last sinus intervals). In addition, HRT calculation has been limited to VPC with a minimum prematurity of 20% and a post-extrasystole interval that is at least 20% longer than the reference interval (mean of last 5 sinus RR intervals).

1.3. Data set and HRT correction

From a wider polysomnographic database of about 200 recordings, we selected a subset of 20 patients (age 57±13 years, 61% males) fulfilling the criteria of showing at least six isolated VPC, each followed by at least 15 sinus RR intervals both falling inside normal respiratory pattern (NR), and during obstructive apnoeic events (OA) such that for each patient HRT onset and slope values could be separately calculated during both conditions (Fig. 1).

Since it has recently been reported that TS is structurally related to the number of VPCs and its estimation method induces a mathematically determined increase inversely related to the square root of the VPC numbers, considering the number of VPCs is higher during NR than in OA epochs, a corrected TS (TSc) has been used as followed and described in [10]:

$$TSc = TS - cTS$$

$$\text{where } cTS = 0.02475 \times 13^{0.9499} \times RMMSD \div \overline{\#VPCs}$$

and where RMMSD is the square root of the mean squared difference of successive normal beat-to-beat differences.

1.4. Statistical analysis

The statistical analysis was performed using GraphPad Prism 5.0 software package (GraphPad Software, San Diego California USA).

Due to the skewed distributions of all variables (D'Agostino & Pearson omnibus normality test $p<0.05$ for all indexes), differences between NR vs OA mean values have been tested by a two-tailed non-parametric Wilcoxon matched pairs test testing the effective pairing between measurements by Spearman non-parametric correlation test.

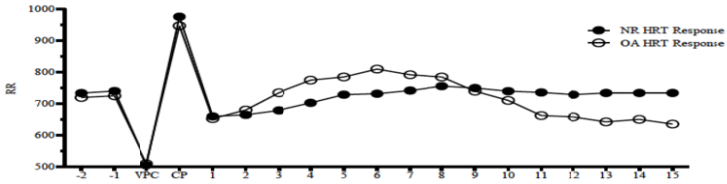


Figure 1. Examples of HRT responses during NR and OA epochs. RR values in ms on Y axis and beat number on X axis. Shorter RR interval corresponding to VPC as third beat of the sequence, followed by a longer RR interval of compensatory pause (CP) as forth beat of the sequence.

Descriptive statistics in Table 1 have been expressed in medians and percentiles.

2. Results and discussion

Results of the analysis are shown in Table 1 and Figure 2, and allow to point out some novel findings. Although an overall depressed HRT response has been observed during NR phases for both indexes, while the HRT onset during OA phases is not significantly different from those of NR epochs, the HRT slope during OA patterns is very significantly higher than in NR phases. Such results are also confirmed after correcting TS for VPC numbers and RMMSD of the RR time series. All indexes exhibited significant to very significant effective pairing for the same patient between HRT measurements in both conditions by Spearman non-parametric correlation.

Table 1. Medians and percentile values of HRT indexes in both NR and OA epochs.

HRT index		NR	OA	Wilcoxon matched pairs test	Spearman correlation test
TO	25% Percentile	- 1,1	- 1,9	0,7726	r = 0.5; p 0.01*
	Median	- 0,1	- 0,5		
	75% Percentile	0,4	1,4		
TS	25% Percentile	1,8	3,0	0,0002***	r = 0.6; p 0.003**
	Median	2,6	5,0		
	75% Percentile	3,3	11,7		
TSc	25% Percentile	0,9	1,1	0,0011**	r = 0.8; p < .0001***
	Median	1,5	2,7		
	75% Percentile	2,8	6,6		

Results may be interpreted considering the primary response to hypoxia as chemoreflex-mediated vagal bradycardia and that repetitive brief inspiration against an obstructed airway, generating significant changes in intra thoracic pressure, causes typical distortions of cardiac chamber geometry namely the Mueller maneuver, that in the initial phase results in marked hypotension and a paradoxical reduction sympathetic activity while toward the end generates a gradually increasing sympathetic activity [11].

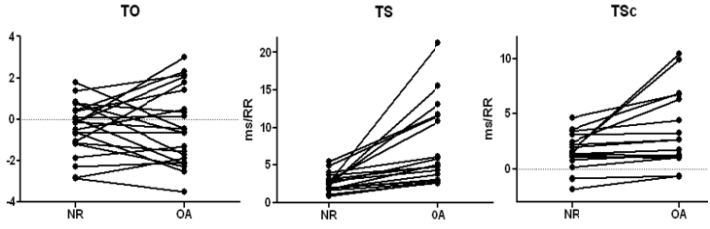


Figure 2. Paired parameters of HRT for each patient in both NR and OA conditions

3. Conclusion

The autonomic effects of OSAS reflect an integrated response to several powerful stimuli. These include hypoxia, hypercapnia, apnea, the Mueller maneuver, and the effect of sleep. Direct and reflex effects of these stimuli are further modulated by other

reflex mechanisms, such as the baroreflex. HRT analysis appeared as a suitable tool for the baroreflex sensitivity assessment in OSAS patients. Although an overall depressed HRT response has been associated to OSAS, its behavior during OA phases showed an unknown paradoxical increase of TS associated with higher unstable heart rate fluctuation, followed by a marked decrease of HRT values during subsequent NR phases, where OSAS patients are generally characterized by higher sympathetic activation's level. Nevertheless the overall HRT response on the whole polysomnographic recording is primary determined by NR epochs, due to the higher VPC numbers falling during these phases. A deeper knowledge of the individual effects of each of the above stimuli helps in understanding the integrated autonomic response to obstructive apneas and variations of responses in different pathophysiological conditions, allowing further studies to investigate diagnostic decision support [12] and in-time HRT prognostic value by means of swarm intelligence-based algorithms [13].

References

[1] Parish JM, Somers VK (2004) Obstructive sleep apnea and cardiovascular disease. Mayo Clin Proc 79:1036–1046
[2] Gami AS, Howard DE, Olson EJ et al. Day-night pattern of sudden death in obstructive sleep apnea. N.
[3] Eng. J. Med 2005, 352(12) : 1206-1214
[4] La Rovere MT, Maestri R, Pinna GD, et al. Clinical and haemodynamic correlates of HRT as a non-invasive index of baroreflex sensitivity in CHF. Clin Sci (Lond). 2011 Sep;121(6):279-84.
[5] Schmidt G, Malik M, Barthel P, et al. Heart-rate turbulence after ventricular premature beats as a predictor of mortality after acute myocardial infarction. Lancet 1999;353:1390–6.
[6] Aytemir K, Deniz A, Yavuz B, et al. Increased myocardial vulnerability and autonomic nervous system imbalance in obstructive sleep apnea syndrome. Respir Med 2007;101:1277– 82.
[7] D'Addio G, Cesarelli M, Romano M, De Felice A. OSAS severity is associated to decreased heart rate turbulence slope. Computing in Cardiology 2013; 40:1007-1010 ISSN 2325-8861
[8] D'Addio G, Cesarelli M, Corbi G, Romano M, Furgi G, Ferrara N, Rengo F. Reproducibility of heart rate turbulence indexes in heart failure patients. Conf Proc IEEE Eng Med Biol Soc. 2010;2010:2573-6.
[9] D'Addio G, Cesarelli M, Romano M, Furgi G, Ferrara N, Rengo F. Pre-ectopic vagal tone affects heart rate turbulence slope in heart failure. Computing in Cardiology 2012; 39:933-936. IEEE Computer Society Press ISSN 0276-6574.
[10] Bauer A, Malik M, Schmidt G, et al. Heart rate turbulence: standards of measurement, physiological interpretation, and clinical use: International Society for Holter and Noninvasive Electrophysiology Consensus", J Am Coll Cardiol. 21;52(17), pp. 1353-65, Oct 2008.
[11] [Hallstrom AP, Stein PK, Schneider R, Hodges M, Schmidt G, Ulm K. Structural relationships between measures based on heart beat intervals: potential for improved risk assessment. IEEE Trans Biomed Eng. 2004 Aug;51(8):1414-20.
[12] Krzysztof N, Fatima H, et al. Influence of Sleep and Sleep Apnea on Autonomic Control of the Cardiovascular System in Sleep Apnea implication in cardiovascular and cerebrovascular disease.
[13] Second edition ISBN 9780849341502 pages 141:162
[14] D'Addio G, De Felice A, Balzano G, Zotti R, Iannotti P, Bifulco P, Cesarelli M. Diagnostic Decision Support of Heart rate Turbulence in Sleep Apnea Syndrome.. Stud Health Technol Inform. 2013;186:150-4.
[15] Arpaia P, Manna C, Montenero, D'Addio G. In-Time Prognosis Based on Swarm Intelligence for Home-Care Monitoring: A Case Study on Pulmonary Disease. IEEE Sensors Journal 2012 March;12(3):692-698.

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Predicting the Disease of Alzheimer With SNP Biomarkers and Clinical Data Using Data Mining Classification Approach: Decision Tree

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Abstract. Single Nucleotide Polymorphisms (SNPs) are the most common genomic variations where only a single nucleotide differs between individuals. Individual SNPs and SNP profiles associated with diseases can be utilized as biological markers. But there is a need to determine the SNP subsets and patients' clinical data which is informative for the diagnosis. Data mining approaches have the highest potential for extracting the knowledge from genomic datasets and selecting the representative SNPs as well as most effective and informative clinical features for the clinical diagnosis of the diseases. In this study, we have applied one of the widely used data mining classification methodology: "decision tree" for associating the SNP biomarkers and significant clinical data with the Alzheimer's disease (AD), which is the most common form of "dementia". Different tree construction parameters have been compared for the optimization, and the most accurate tree for predicting the AD is presented.

Keywords. data mining, single nucleotide polymorphism, integrating genotype and phenotype data, decision tree, alzheimers disease

Introduction

A challenging aspect of the post-genome biology of human is to understand the biological effects of inherited variations in DNA structure between individuals. The most common genetic variations are represented as single DNA building block alterations that they have received much attention recently in terms of the detection of a particular disease [1]. SNPs are single nucleotide alterations found in every 300 to 1000 nucleotides in genomic DNA and cause personal differences in phenotypes as well as underlying reason of a particular disease [2]. SNPs can be used as genomic markers revealing individuals susceptibility to certain disease to produce new approaches for treatment applications and to take prohibitive precaution. SNP association studies are widely done to determine possible relations between genetic variations and diseases.

In the last decades, developments of data mining methods have become a promising approach in bioinformatics in order to solve biological problems [3], [4].

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Drawing conclusions from the high amount of data requires intelligent computational analysis [5]. The main aim of data mining is the classification of the data, and clustering of the data based on the similarities or dissimilarities. It has been recently shown that the data mining applications are extremely useful in order to make decisions over high dimensional data such as whole human genome data that consists of around 3.4 billion nucleotide pairs. Outputs of mining methods in such genetic studies have revealed interesting findings inheritable tendency to contract specific diseases [6].

Alzheimer's disease (AD) is a complex and genetic disorder and the most common cause of dementia. Early onset is the rare form and symptoms start before the age of 65 and caused by mutations in the genes such as APP (amyloid precursor protein), PSEN-1 and PSEN-2 (presenilin genes) [7]. On the other hand late onset is the common form of AD presents a complex genetic inheritance, where the differential diagnosis is critical. Few number of variants in genes have now been identified [7] such as APOE (apolipoprotein E) in chromosome 19, but the genetic factors underlying the late onset Alzheimer's risk are still being investigated.

In this study we have investigated the AD associated genotypes and identified the representative SNP subsets and clinical features through data mining. The performance of the genomic AD model build based on integrated genotyping and clinical data showed its potential as a predictive and diagnostic tool.

1. Methods

1.1. Dataset

The Alzheimer's disease genotyping and phenotyping data is obtained from GENADA [8] study through the dbGAP database. With authorized access, 1718 study participants' individual level data is available through GENADA study. Genotyping and clinical data is collected from eligible individuals who have late onset with mild to moderate level of Alzheimer's disease.

Clinical data included in this study that may be associated to the Alzheimer's disease are cholesterol (mmol/l), hemoglobin (g/l), HBA1C_PCT, HDL cholesterol (mmol/l), LDL cholesterol (mmol/l), triglycerides (mmol/l) and amount of white blood cells. Additional data in medical records are also used such as age onset of first symptoms and body mass index at the moment of the first diagnose [8]. Genotyping data included 410907 SNPs, for all case and controls. SNPs, which have the minor allele frequency greater than 1% is included in the association studies order to reveal the genomic variations associated with AD susceptibility [9]. Interrogating the DNA sequences of people, SNP alleles are included [8].

1.2. Preprocessing

Data preprocessing that usually takes 60% of efforts is the most important step in knowledge extraction process [10]. At first we have eliminated 108 samples whose has missing data in their lab findings. Furthermore, the inconsistent data is corrected. Onset ages of 14 people in the case group were not entered in the dataset; hence missing values in age attribute are filled with the mean age of the cases. All the genotyping data was available, hence there was no need for imputation. After the elimination of the

missing values over clinical findings, 1480 samples were available for the decision model construction.

GENADA study contains different repositories in terms of genotype data, phenotype data, clinical findings and laboratory results. Combining the tables from different sources requires structured query language. We used SQL to transfer all related data tables into one table and to create relationship between keys.

Dimension reduction is beneficial for both computational efficiency and enhancement of model accuracy since biological data contains large amount of variables. First, the p-value associations of 410969 SNP are revealed by PLINK analysis, then SNPs that present statistical significant association with AD are selected. A second selection step for biological relevance of the SNPs is done by METU-SNP's AHP based prioritization algorithm [11]. After prioritization, SNPs with the AHP score above 0.40 are selected for further analysis. There were 958 biologically and statistically significant SNPs identified in total.

1.3. Constructing the Model

Two different decision trees were constructed in order to see how much genotyping data and clinical findings contribute to the prediction of Alzheimer's disease. The first tree is constructed using only representative SNPs found by AHP scoring. The second tree is constructed using both clinical findings and genotyping data. The C4.5 decision tree algorithm with gain ratio which is the best single feature selection criterion is used since it can handle not only categorical but also numeric attributes [12]. For investigation of accuracy of C4.5 prediction model, k-fold cross validation was applied. The process of data classification that models our implementation contains data preprocessing that takes approximately 60% of efforts, data modelling using training data and model validation using test set. The final step is the visualization and knowledge extraction.

Tree construction depends on entropy reduction, but in each division, over-fitting can lead the poor accuracy. In response to this problem, pruning strategy is used. The minimal gain ratio is identified as 0,01 for splitting the dataset for both tree constructions. 11 fold-cross validation is chosen for the error prediction and model accuracy. We also applied C4.5 algorithm to dataset with its 958 independent variables considering the selected genotype data, 8 clinical and 2 demographic features [6] in order to predict whether a person is case or control. Finally, IF_THEN rules are extracted from decision trees and we compared results whether addition of clinical attributes contribute to the prediction of the complex disease or not.

2. Results

Even though combinations of a variety of genetic and other factors are suspected in complex diseases, the genetic factors underlying the Alzheimer's disease are still unknown. In this study we have attempted to construct a decision tree for the differential diagnosis of late onset Alzheimer's disease based on patients' genotyping and clinical data.

The first decision tree which is constructed only with representative SNP biomarkers included 38 significant SNPs, selected among 958 that were associated with the disease. With these 38 SNPs, decision tree generated 26 rules for the

diagnoses of the late onset AD. The genetic variations included in the first decision tree were located on genes such as ABCC4, ANGPT2, ANGPT2, ARHGAP26, ATG5, C9orf3, DBT, DDO, DISC1, ENPP6, FGD4, FMNL2, FOXO3, GABBR2, GSN, KCNN3, KIF26B, LIPH, MAML3, NBN, PDZD8, PLCB1, PTPRM, SEMA3C, SEMA3C, SEMA5A, SLC35A3, SNW1, SYN3, TLL2, TPO, TRHDE, C9orf3, CAMKK2, DOK1, HMGA1, PIKFYVE, STK39. The most significant genetic variations are SNP_A4213932, SNP_A2146889, SNP_A2258450 and SNP_A1849082 when we consider the top levels of the decision tree [6]. When we have integrated the relevant clinical data with SNP data in the second decision tree, the clinical features such as HBA1C_PCT, Body Mass İndex, Hemoglobin, WBC, Trig, Cholesterol and HDL are included. Only 27 SNPs out of 958 are chosen by attribute selection criterion. According to decision tree build by integrating genotyping and clinical data, the most significant genetic and clinical variations were the SNP_A4213932, SNP_A2146889, age and cholesterol (mmol), placed at the first two level of the tree [6]. The performances of classifiers for both decision trees after 11 fold cross validation method are summarized in Table 1.

Table 1. Performances comparison of three model

	Only Genotype		**Only Clinical Findings&Phenotype**		**Genotype and Clinical Findings&Phenotype**	
	Value	Confidence Interval	Value	Confidence Interval	Value	Confidence Interval
Accuracy	56,08% *(std.dev:1,96)*	[54,76%-57,40%]	53,31% *(std.dev:3,65)*	[50,86%-55,76%]	55,07% *(std.dev:2,49)*	[53,40%-56,74%]
Sensitivity (True Positive Rate)	57,53%	-	42,20%	-	61,96%	-
Specificity (True Negative Rate)	54,62%	-	65,54%	-	55,07%	-

3. Discussion

Alzheimer 's disease (AD) is the neuro-degeneration of the brain tissue beyond the effects of normal aging process. Today the only effective diagnostic method for diagnosis of the Alzheimer patients is the confirmation of the lesions in brain tissue during autopsy. AD is a complex and chronic disease and inherited in 80% of the cases. Various genetic changes including the APOE polymorphisms can only explain the 25% of the genetic background of the disease [13], [14]. Studies on large populations of AD cases and controls continue to identify the rest of the genomic variations associated with AD.

Here we have identified 958 biologically and statistically significant SNPs associated with late onset AD, which are later used to construct a decision tree model for the differential diagnosis with the accuracy rate of classification of 56,08%. Even though the performance of the model is not too satisfying and should be improved in further studies, this is a promising demonstration of how genome wide association studies can benefit from data mining approaches for the interpretation of the SNP variations in disease models. In this study [6], not only genotyping data but also clinical information is used. The aim of the clinical information is to show how it

contributes the prediction of disease. Surprisingly, integration of clinical information didn't improve the accuracy rate of the model. Hence, only using genotype data, Alzheimer's disease can be predicted for the new data samples [6]. Considering the difficulties of diagnostic methods, implementation of decision tree using genotypic information of individuals can support distinguishing the Alzheimer's disease patients from dementia [6].

With the guidance of this study, data mining classification methods can be implemented to higher dimensional genome databases in order to extract novel and important patterns.

References

[1] Krishnan VG, Westhead DR. A comparative study of machine-learning methods to predict the effects of single nucleotide polymorphisms on protein function. Bioinformatics [Internet]. 2003 Nov 20 [cited 2014 Jan 29];19(17):2199–209. Available from: http://bioinformatics.oxfordjournals.org/cgi/doi/10.1093/bioinformatics/btg297

[2] Human Genetic Variation [Internet]. National Human Genome Research Institute; 2007 [cited 2012 Sep 11]. Available from: http://www.sciencemag.org/content/318/5858/1842.short

[3] Pirooznia M, Seifuddin F, Judy J, Mahon P. Data mining approaches for genome-wide association of mood disorders. Psychiatr Genet [Internet]. 2012 [cited 2014 Feb 5];22(2):55–61. Available from: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3306768/

[4] Bar-or A, Schuster A, Wolff R, Keren D. Decision Tree Induction in High Dimensional, Hierarchically Distributed Databases. Proceedings of SDM'05 Newport Beach. California; 2005.

[5] Raza K. Application of Data Mining in Bioinformatics. Indian J Comput Sci Eng. 2009;1(2):114–8.

[6] Erdoğan O. Predicting the Disease Alzheimer (AD) With SNP Biomarkers and Clinical Data Based Decision Support System Using Data Mining Classification Approaches [Internet]. METU; 2012. p. 153. Available from: http://etd.lib.metu.edu.tr/upload/12614832/index.pdf

[7] Farlow JL, Foroud T. The genetics of dementia. Semin Neurol [Internet]. 2013 Sep;33(4):417–22. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24425039

[8] Fornazzari L, Gauthier S, St. George-Hyslop P, Wherrett J, Keren R, Feldman H, et al. Multi-Site Collaborative Study for Genotype-Phenotype Associations in Alzheimer's disease [Internet]. 2002 [cited 2014 Feb 5]. p. 1–38. Available from: http://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/GetPdf.cgi?id=phd002049.1

[9] Rapley R, Harbron S, editors. Overview of Microarrays in Genomic Analysis. Molecular Analysis and Genome Discovery. West Sussex, England: John Wiles & Sons, LTD; 2004.

[10] Cabena P, Hadjinian P, Stadler R, Verhees J, Zanasi A. Data Mining: From Concept to Implementation. New Jersey; 1998.

[11] Üskünkar G. An Integrative Approach To Structured SNP Prioritization and Representative SNP Selection For Genome-wide Association Studies:Algorithms and Systems [Internet]. Middle East Technical University; 2008 [cited 2012 Sep 5]. p. 150. Available from: http://etd.lib.metu.edu.tr/upload/12610009/index.pdf

[12] Kohavi R, Quinlan R. Decision Tree Discovery. Citeseer [Internet]. 1999 [cited 2012 Sep 5];3. Available from: http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.4.5353&rep=rep1&type=pdf

[13] Roses a D, Lutz MW, Amrine-Madsen H, Saunders a M, Crenshaw DG, Sundseth SS, et al. A TOMM40 Variable-length Polymorphism Predicts the Age of Late-onset Alzheimer's disease. Pharmacogenomics J [Internet]. Nature Publishing Group; 2010 Oct [cited 2012 Jul 27];10(5):375–84. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2946560&tool=pmcentrez&rendertype=abstract

[14] Bertram L, Lange C, Mullin K, Parkinson M, Hsiao M, Hogan MF, et al. Genome-wide Association Analysis Reveals Putative Alzheimer's Disease Susceptibility Loci in Addition to APOE. Am J Hum Genet [Internet]. 2008 Nov [cited 2012 Jul 13];83(5):623–32. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2668052&tool=pmcentrez&rendertype=abstract

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Correlation Between Symbolic Dynamics Analysis Indexes and Neurohormonal and Functional Parameters in Heart Failure Patients

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Abstract. Heart failure (HF) is a cardiac disease associated with prominent alterations in the autonomic control of the cardiovascular system and high neurohormonal activation levels. Useful assessment tools may be heart rate variability (HRV) analysis and/or the study of norepinephrine (NPE) level. Nevertheless, traditional techniques of HRV analysis have proved not sufficient and the second is an invasive measurement. In this work the correlation between a parameter (kurtosis-K) computed by an emerging nonlinear technique, the symbolic dynamics analysis, and neurohormonal and functional parameters has been investigated. Results obtained show an interesting relationship between K and both ejection fraction and NPE. In particular, higher K values are associated to increasing NPE levels This finding could be useful for highlighting changes in HF patients otherwise detectable only with invasive examinations.

Keywords. Heart failure, HRV, symbolic dynamivs analysis, norepinephrine

Introduction

Cardiovascular diseases are the first cause of morbidity and mortality in western and industrialized countries. Heart failure (HF) is a disabling and deadly condition which usually worsens over time, involving about 10% of the elderly population and accounting for 1-2% of health-care costs [1]. HF is associated with prominent alterations in the autonomic control of the cardiovascular system and high neurohormonal activation levels are known markers of severity and adverse prognosis in these patients [2].

Heart rate variability (HRV) is the result of the interactions between sympathetic and parasympathetic systems, which are considered the principle rapidly reacting systems that control heart rate [3-5]. HRV is hence a well-known and important non-

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invasive technique for assessment of the heart autonomic control and cardiac disease [1, 6]. The HRV has been historically studied by means of time and frequency domain analyses [7]. Traditional linear indexes of HRV provide significant parameters to investigate the cardiac autonomic modulation and have been shown to be associated with neurohormonal activation [8], however partial information is obtained in settings characterized by rapid and no repetitive changes [4]. Therefore, recently, new parameters, derived from non-linear techniques, are arising in order to evaluate the complexity of cardiac regulation system [3, 7], such as Poincaré plots, Shannon entropy, and Symbolic Dynamics Analysis (SDA) [5, 9, 10].

SDA of HRV is an emerging approach to investigate the dynamic aspects of complex systems by means of a limited amount of symbols [11], providing parameters independent of those derived from time and frequency-domains.

Aim of this study is to evaluate the association of quantitative indexes computed by means of SDA with neurohormonal activation levels and functional parameters. The analysis was carried out by analysing beat-to-beat heart intervals series derived from 24-hours Holter recordings in heart failure patients.

1. Methods

1.1. Holter database

For this study, we considered data from the database Montescano, already employed for other studies [9, 12], for which values of neurohormonal parameters were available.

For this study we considered 204 RR series (series of inter-beat intervals), derived from standard 24-hours Holter signals recorded by 90 patients (years 52 ± 9) of which 12 in NYHA 1 class, 52 in NYHA 2 class and 26 in NYHA 3 class (NYHA indicates New York Heart Association).

All patients showed sinus rhythm, stable clinical conditions during the last 2 weeks, absence of pulmonary or neurological disease, or any other disease limiting survival, no recent (within the previous 6 months) myocardial infarction or cardiac surgery.

Before starting the SDA, ventricular premature beats as well as other arrhythmia and artifacts were removed from the RR series obtaining series of only normal beats.

1.2. Symbolic dynamics analysis

The core of the technique is adopted from a previously published method [4, 11] and already employed by the authors, for application both on human subjects and fetuses [13-16]. The methodology consists of four basic steps: signal preprocessing (for example for artifacts removal), symbolic encoding, words generation, words classification and analysis. To make the analysis independent of the mean heart rate, we computed the time series ΔRR, calculating the difference between consecutive RR values. Then, the ΔRR series was transformed into a sequence of symbols chosen from a given alphabet consisting of five symbols: V (vagal activation), D (deceleration of the heart rate), O (absence of significant variability), A (acceleration of the heart rate), S (sympathetic activation) (for each ΔRR value, one symbol is assigned).

The symbol, that had to be associated with a ΔRR sample was chosen comparing theΔ RR value with two set thresholds (a primary threshold – PT=10 ms - and a secondary threshold – ST=50 ms -), according to previous works [15, 17].

Established the encoding rules, for the step of words generation, a sliding window of length L was shifted along the codified ΔRR series with an overlap of L-1 points. The choice of the length L of the words is a crucial point in SDA, so, in a previous work we tested different words length and chosen L=3 [5]. The number of different words which can be obtained is still rather high, so that, in the last step we grouped the words in different classes, by the new dominance's criterion described in table 1.

Obtained all words classes, for each group was computed the distribution of their mean percentages (called pH, pM, pO and pR respectively). Then, according to a previous work [14], we chose as index for their characterization the Kurtosis (K).

Table 1. Dominance criterion employed to group PW.

Description	Meaning	Code
At least 2 symbols "S" or "V" anywhere in the word	high activation	H
At least 2 symbols "A" or "D" anywhere in the word	moderate activation	M
At least 2 symbols "O" anywhere in the word	absence of variability	O
All other cases	random	R

1.3. Neurohormonal and functional parameters

For this study, we considered the following parameters:

left ventricular ejection fraction (EF%), obtained from echocardiography;

maximal oxygen consumption (VO_2max), evaluated by ECG stress test;

plasma norepinephrine (NPE) assay, estimated by a blood sample collected within one week from the Holter recording and assessed by a single-isotope radioenzymatic method.

1.4 Statistical analysis

Regression analyses were carried out for estimating the relationships among kurtosis and neurohormonal and functional parameters.

The associations between Kurtosis, neurohormonal and functional indexes were assessed by Pearson correlation coefficient.

2. Results and discussion

Results of the analysis are shown in Table 2 and in Figure 1. It is possible to observe that NPE showed a strong positive correlation with K, hence higher kurtosis values are associated to increasing norepinephrine levels. Still significant but weaker and negative relationship was found between EF% and K. No relationship correlates VO_2max and K.

Table 2. Results of the statistical analysis. Of course, the number of XY pairs was always 90. *:significant, ***extremely significant, ns: not significant.

	EF% vs K	VO_2max vs K	NPE vs K
Pearson r	-0,2581	-0,1232	0,4007
R square	0,06662	0,01517	0,1606
95% confidence interval	-0,4416 to -0,05385	-0,3221 to 0,08619	0,2111 to 0,5613
P value (two-tailed)	0,0140	0,2475	< 0,0001
Significant? (alpha=0.05)	Yes	No	Yes
P value summary	*	ns	***

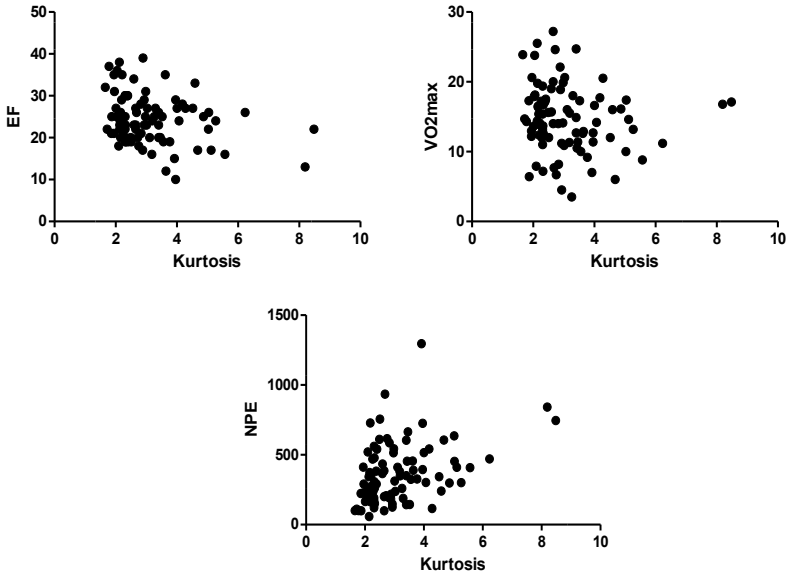


Figure 1. Regression analysis between functional parameters and Kurtosis. 90 pairs of values are shown.

3. Conclusion

HRV reflects the complex interactions of the different control loops of the cardiovascular system and it has strongly affected by cardiac diseases. Hence, its assessment is crucial, for example, to understand the pathophysiology of heart failure. Nevertheless, traditional time and frequency measures are often not sufficient [18]. For this reason, some nonlinear methodologies have been recently proposed to estimate sympathetic and parasympathetic cardiac modulation. Among those, SDA has been introduced to put in evidence non-linear dynamics involved in the autonomic interactions of cardiac control and has already get some success [3, 11, 14, 15].

On the other hand, the measurement of plasma catecholamines levels provides a practical way to assess sympathetic activity and has been widely used although it has the limitation of being a "systemic" instead of organ specific evaluation. The use of more specific measurements, such as cardiac norepinephrine spillover, is very useful but limited to small studies due to the invasiveness and complexity of this technique [19]. Other very important and well-known clinical markers of severity and adverse prognosis in heart failure patients are left ventricular ejection fraction, evaluated by 2D echocardiography, and maximal oxygen consumption under ECG stress [9].

In this paper, the correlation between a parameter (kurtosis) computed by the distributions of words classes obtained by SDA and neurohormonal and functional parameters has been investigated. Results obtained indicate that no one link exists between K and VO_2max, while there is a relationship between K and both EF and NPE. This correlation is stronger for NPE. This finding is very interesting. In fact, it confirms that SDA can be an effective measure for the analysis of HRV, allowing us to highlight changes in HF patients otherwise detectable only with invasive examinations.

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References

[1] A. Bundkirchen, RH Schwinger, Epidemiology and economic burden of chronic heart failure. *Eur Heart J Supplements* 2004;6 (Suppl D): 57-60

[2] JN Cohn, TB Levine, MT Olivari, V. Garberg, D. Lura, GS Francis, et al. Plasma norepinephrine as a guide to prognosis in patients with chronic congestive heart failure. *N Engl J Med* 1984; 311: 819-823

[3] A. Voss, J. Kurths, H. J. Kleiner, A. Witt, N. Wessel, P. Saparin, et al. The application of methods of non-linear dynamics for the improved and predictive recognition of patients threatened by suddencardiac death, *Cardiovascular Research* 31, 419-433 (1996)

[4] S. Guzzetti, E. Borroni, PE. Garbelli, E. Ceriani, P. Della Bella, N. Montano, et al. Symbolic Dynamics of Heart Rate Variability. A Probe to Investigate Cardiac Autonomic Modulation. *Circulation* 2005.

[5] G. D'Addio, M. Romano, R. Maestri, P. Bifulco, M. Cesarelli, Indices of Symbolic Dynamics' Distributions in Cardiac Patients, *CIC* 2013, Zaragoza, Spain, 121-222

[6] G. D'Addio, GD. Pinna, R. Maestri, G. Corbi, N. Ferrara, F. Rengo, Quantitative Poincare Plots Analysis Contains Relevant Information Related to Heart Rate Variability Dynamics of Normal and Pathological Subjects. *Computers in Cardiology*, Vol. 31, 2004, pp. 457-460

[7] Task Force of the European Society of Cardiology and The North American Society of Pacing and Electrophysiology. Heart Rate Variability – Standards of measurement, physiological interpretation, and clinical use. *European Heart Journal* (1996) 17, 354-381

[8] MG Kienzle, DW Ferguson, CL Birkett, GA Myers, WJ Berg, DJ Mariano. Clinical, hemodynamic and sympathetic neural correlates of heart rate variability in congestive heart failure. *Am J Cardiol*; 1992;69(8):761-767

[9] G. D'Addio, M. Cesarelli, R. Maestri, G. Furgi, M.T. La Rovere, N. Ferrara, et al., Neurohormonal and Functional Correlates of Linear and Poincarè plot indexes of Heart Rate Variability in Heart Failure patients, *CIC2012*;39:937-940

[10] G. D'Addio, GD. Pinna, R. Maestri, D. Acanfora, E. Ranaudo, G. Furgi, et al. Changes induced by tilting on Poincarè plots and symbolic dynamics patterns of HRV compared to spectral indexes in post-MI and normal subjects. *CIC*2000; 27:449-452

[11] A. Porta, G. D'Addio, G. Pinna, R. Maestri, T. Gnecchi Ruscone et al., Symbolic analysis of 24h Holter heart period variability series: comparison between normal and heart failure patients, *Comp Cardiology*, 2005, vol. 32, pp. 575-578

[12] G. D' Addio, M. Cesarelli, M. Romano, A. Accardo, G. Corbi, R. Maestri, et al., Correlation between Fractal Behavior of HRV and Neurohormonal and Functional Indexes in Chronic Heart Failure. *Medicon 2010*, May 27-30, Chalkidiki, Greece. IFMBE Proceedings 29, pp. 53–56

[13] M. Cesarelli, M. Romano, P. Bifulco, G. Improta, G. D'Addio. Prognostic Decision Support using Symbolic Dynamics in CTG Monitoring. *Data and Knowledge for Medical Decision Support*. B. Blobel et al. (Eds.) IOS Press, 2013

[14] M. Romano, M. Cesarelli, L. Iuppariello, G. Faiella, P. Bifulco, G. D'Addio, Frequency domain and symbolic dynamics analysis for the study of cardiac pathologies. The 4th IEEE International Conference on E-Health and Bioengineering - *EHB 2013*. Iaşi, Romania, November 21-23, 2013

[15] M. Romano, P. Bifulco, G. Improta, G. Faiella, M. Cesarelli, F. Clemente, et al., Symbolic Dynamics in cardiotocographic monitoring. The 4th IEEE International Conference on E-Health and Bioengineering - *EHB 2013*. Iaşi, Romania, November 21-23, 2013

[16] G. Improta, M. Romano, G. D'Addio, P. Bifulco, M. Cesarelli. FHRV assessment by means of Symbolic Dynamics. Paper n. 299, *GNB2012*, June 26th-29th 2012, Rome, Italy

[17] M. Cesarelli, M. Romano, P. Bifulco, G. Improta, G. D'Addio. An Application of Symbolic Dynamics for FHRV assessment. MIE 2012. Pisa, Italy. 26-29 August 2012. Quality of Life through Quality of Information. J. Mantas et al. (Eds.) IOS Press, 2012. *Journal: Stud Health Technol Inform*. 2012;180:123-7

[18] S. Schulz, FC Adochiei, IR. Edu, R. Schroeder, H. Costin, KJ. Baer et al., Cardiovascular and Cardiorespiratory Coupling Analyses–a Review, *Philosophical Trans. of the Royal Society,* 2013

[19] M. Esler, D. Kaye. Measurement of sympathetic nervous system activity in heart failure: the role of norepinephrine kinetics. *Heart Failure Reviews* 2000;5:17-25

5. Mobile Health

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Mobility Parameters in Health Applications – A Literature Review

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Abstract. Independent mobility is linked to self-determined life and quality of life.[1] Since human mobility follows reproducible pattern [2], it may be useful to assess mobility in health applications. This article represents a literature review which considers the question which parameters represent mobility, how they are assessed (are tracking technologies used?) and their relation to health. There are several mobility parameters which were grouped into quantitative, qualitative and combined parameters. Especially combined parameters seem to be useful in health applications, which should motivate further research.

Keywords. mobility, locomotion, health, parameter, review

Introduction

The preservation of independent mobility as spatial and temporal movement in the environment is essential for a self-determined life and linked to quality of life. [1] This assertion and the assumption that human mobility follows reproducible patterns [2], raises the question if mobility patterns can be used in health applications and if, with a raising availability of location tracking technologies, these technologies already play a role in health applications, which will lead to mHealth. Though, so far, it is not clear which parameters represent mobility in health applications, how they are assessed and if there is a correlation between these parameters and health.

1. Study design

To get an overview of mobility parameters in health applications a literature review has been conducted. An online search request has been done in the databases PubMed and IEEE Xplore in April 2013. First, search queries for both literature-databases have been developed with the following structure:

(mob_1 OR mob_2 OR … mob_n) AND (par_1 OR par_2 OR … par_m) AND ($health_1$ OR $health_2$ OR … $health_k$) AND additional terms,

with mob_i, $i=1…n$: describing mobility,

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par_j, $j=1...m$: describing measuring parameters,
$health_k$, $k=1...l$: describing health.

Search terms were created based on MESH terms [3]. Yet this was not applicable for all terms. The search in PubMed returned 7405 results, in IEEE Xplore 298 results. The results have been cleared for duplicates and limited to articles written in English. All articles have been initially screened by their title by one person following predefined criteria. These criteria include articles describing mobility as movement in the environment, describing mobility parameters, and examining a relation to health. Results have been discussed with another reviewer to consensus. Remaining articles' abstract and full-text have been screened afterwards. 13 articles have been categorized as relevant. Further three more articles have been identified by references.

2. Results

2.1. Mobility parameters

The reviewed articles address several mobility parameters. Only parameters related to spatial movement were taken into account as mobility parameters even though some articles describe other parameters as well (e.g. parameters of functional mobility). Furthermore, to stay focussed on the movement itself rather than on the ability of movement or environmental aspects, sociodemographic aspects like education or income and environmental aspects like lighting and weather conditions or terrain conditions were not considered. Remaining parameters were analysed and clustered into three categories: *quantitative*, *qualitative* and *combined parameters*.

2.1.1. Quantitative parameters

Quantitative parameters are defined as factors, which describe mobility in numerical values. Usually they are represented based on a measuring unit or indicate the frequency of an event.

Reviewed articles discuss the quantitative parameters *action range*, *distance*, *duration*, *pace,* and *frequency*. *Action range* describes how far a person moves outside its house [4]. It is important that one's home is the central point of movement and range of action is measured in relation to it. Another frequently used parameter is *distance* moved [4-9]. In contrast to action range it is measured independently of the extent from one's home as distance per hour [7] or day [7-9], as the maximum distance between two stops [8] or just as an encounter or avoidance of longer distances [5, 6]. Furthermore, *duration* out of house is used to describe mobility [4, 7, 8, 10]. It is measured as percentage of day [7, 8] and as minutes of movement per week or day [8, 10]. Apart from these parameters *pace*, which is discussed in five articles [4-6, 8, 10], and *frequency* of mobility events [8, 11] are other ones.

2.1.2. Qualitative parameters

A parameter is defined as qualitative when it characterizes the movement, without using physical units.

Reviewed articles discuss the qualitative parameters *time of day*, *independence*, and *places*. A mobility event occurs at a specific *time of day*, which is referred to in two of the articles [4, 7]. Another aspect of mobility is the question if a person leaves

the house alone or accompanied by a person and whether the person needs an assistive device [4-6]. Since this aspect characterizes mobility independence, it is represented by the qualitative parameter *independence*. Furthermore, *places* where a person moves to has been taken into account [4-6, 10, 12-14]. Two ways of measuring data about relevant places are described in the articles. Oswald et al. [4] define places relevance by duration of stay. All places where a person stays longer than 5 minutes are marked as relevant nodes. The function of a place is inquired by the person afterwards. All other articles predefine sets of relevant places by their function and document when or how often a person has visited one of these places. Prohaska et al. [10] involve parks, shopping malls, fitness-centers and jogging-trails. Norton et al. [12], Glass et al. [13] and Wang et al. [14] look at social activities. Although the activity itself is focused in these articles, some of the activities are location-based and can be connected to a specific place. To these belong visits to a museum, cinema, exhibition or theater [13, 14] or club and church attendance [12, 13]. Apart from the function, it may be a relevant aspect, how busy or noisy a place is and how (un)familiar it is to a person [5, 6].

2.1.3. Combined parameters

A combined parameter consists of more than one parameter. These parameters can be either quantitative or qualitative. In this review the combined parameter *life-space* has been identified, which is a combination of distance from home, frequency and independence of movement [15-19]. It is represented by a life-space score. This score represents how far and how often a person had moved from his or her home over the four weeks preceding the assessment and if he or she had needed assistance (another person or assistive device). Distance from home is measured in life-space levels which are defined by concentric areas around one's home. Beginning in one's bedroom and getting as far as outside one's town. All included parameters are described in other articles independently, as well [4-6, 8, 11].

2.2. Tools used to gather mobility parameters

In the analyzed articles interviews are mainly used to collect data on mobility [4, 10-19], whereas only Oswald et al. [4] use interviews and diaries in addition to a tracking-technology system. Questionnaires are used in three articles [5, 6, 12]. Tracking-technologies are used in three articles [4, 7, 8]. To validate mobility measurement in two articles direct observation had been used additionally [5, 7].

2.3. Mobility parameters and health

Older persons are the most frequent group of persons considered in reviewed articles [4-7, 9, 10-16, 18, 19]. Most researchers take into account overall health status measured by physical, functional, and cognitive parameters and tests (such as ADL[2], IADL[3], balance tests, SPPB[4], MMSE[5], depression), comorbidities, self-rated health or mobility, and mortality [5, 6, 10, 11, 13, 16, 18, 19]. Other articles focus on Alzheimer disease, dementia, cognitive impairment [4, 7, 9, 12, 14] or age-related eye diseases [15]. Only two articles do not consider older people [8, 17].

[2] Activities of Daily Living, [3] Independent Activities of Daily Living,
[4] Short Physical Performance Battery, [5] Mini Mental State Examination

Most of the articles describe a correlation of at least one of the mobility parameters and health. Two articles are not taken into account here, because the authors didn't look at any mobility parameter separately [4, 5]. For quantitative parameters, on one hand articles measure a positive correlation with better health [6-10]. Here the authors take into account physical or functional health parameters [6, 8, 11] and mortality [11] as well as cognitive parameters [9, 10]. On the other hand, some articles couldn't find a correlation [7, 10] or show even a negative correlation with better health [10]. For qualitative parameters, one article shows a positive relation between independence, character of places (busy, noisy, unfamiliar) and better physical health [6]. Other ones describe a positive correlation of visiting places of social or productive activities with cognitive health [10, 14], or mortality [13], and others again, a negative correlation for a group of unhealthy persons of visiting the church [12] or no correlation of the time of day of out of home events [7] and cognitive health. Articles using life-space as mobility parameter describe in three articles [16, 18, 19] a correlation of life-space with physical performance and functional health. "Better performance in muscle strength and on the SBPP were associated with high life-space, and ADL disability was associated with less life-space"[19]. Further, they report reduced life-spaces for patients with comorbidities, cognitive impairments and high depressive symptoms. This association was less obvious. For specific diseases, life-space score seems to differentiate patients with age-related eye diseases from their healthy controls [15]. For patients with cystic fibrosis (CF), better health seems to be associated with higher life-space scores [17], too. Also, the authors determine that the better the life-space the less the frequency of hospitalization and state that "The Life-Space mobility score is associated with frequency of hospitalization in adults with CF."[17].

3. Discussion

This review presents an overview of mobility parameters. The parameters are commonly assessed by interviews. This suggests that tracking technologies are not common in health applications. But, in line with Oswald et al. [4] who state "Tracking-technologies may support tracking data allow for the detection of individually meaningful mobility patterns" this may be a field of application for tracking technologies. Regarding the relation between mobility parameters and health, it is difficult to make an assertion, since there are just 13 identified articles which describe different kinds of settings and correlations of mobility parameters and health. By that the usefulness of mobility parameters in addition to traditional assessments is not clear. Since articles that use life-space as mobility parameter show most consistent relation between life-space-score and health, it may be helpful to use a combination of parameters in health applications. Baker et al. [18] see life-space even as a possibility to detect disabilities in an early stage. "Life-space restriction may permit identification of persons early in the course of disability development and at a time when such disability can be prevented."[18] This promising assertion should motivate further research to examine the possibilities of mobility parameters in health applications.

Search results are limited by the aspect that all of the discussed aspects (mobility, parameters, health) have diverse meanings dependent on their applications. Despite the attempt to choose terms as specific as possible, the query design may induce noise in the search results, which had to be minimized manually. This was done in the first step

of title screening by just one person. Furthermore it cannot be ruled out that the authors were too selective in the manual review.

References

[1] Altenburg S, Gaffron P, Gertz C. Teilhabe zu ermöglichen bedeutet Mobilität zu ermöglichen. Abteilung Wirtschafts- und Sozialpolitik der Friedrich-Ebert-Stiftung (Editor), Bonner Universitäts-Buchdruckerei, Bonn, 2009.

[2] González MC, Hidalgo CA, Barabási AL. Understanding individual human mobility patterns. *Nature* **453(7196)** (2008), 779–782.

[3] MESH Terms: http://www.ncbi.nlm.nih.gov/mesh/, visited 6th of Febr. 2014

[4] Oswald F, Wahl HW, Voss E, Schilling O, Freytag T, Auslander G, Shoval N, Heinik J, Landau R. The use of tracking technologies for the analysis of outdoor mobility in the face of dementia: first steps into a project and some illustrative findings from Germany, *Journal of Housing For the Elderly* **24(1)** (2010), 55-73.

[5] Shumway-Cook A, Patla A, Stewart AL, Ferrucci L, Ciol MA, Guralnik JM. Assessing environmentally determined mobility disability: self-report versus observed community mobility, *J Am Geriatr Soc* **53** (2005), 700-704.

[6] Shumway-Cook A, Patla A, Stewart A, Ferrucci L, Ciol MA, Guralnik JM. Environmental components of mobility disability in community-living older persons, *J Am Geriatr Soc* **51** (2003), 393-398.

[7] Makimoto K, Lee EA, Kang Y, Yamakawa M, Ashida N, Shin KR. Temporal patterns of movements in institutionalized elderly with dementia during 12 consecutive days of observation in Seoul, Korea, *Am J Alzheimers Dis Other Demen* **23** (2008), 200-206.

[8] Barzilay Y, Shoval N, Liebergall M, Auslander G, Birenboim A, Isaacson M, Alexander RV Kaplan L. Assessing the outcomes of spine surgery using global positioning systems, *Spine* **36(4)** (2013), E263-E267.

[9] Abbott RD, White LR, Ross GW, Webster G, Masaki KH, Curb JD, Petrovitch H. Walking and dementia in physically capable elderly men, *J Am Med Ass* **292(12)** (2004), 1447-1453.

[10] Prohaska TR, Eisenstein AR, Satariano AW, Hunter R, Bayles CM, Kurtovich E, Kealey M, Ivey SL. Walking and the preservation of cognitive function in older populations, *The Gerontologist* **49** (2009), 86-93

[11] Jacobs JM, Cohen A, Hammerman-Rozenberg A, Azoulay D, Maaravi Y, Stessman J. Going outdoors daily predicts long-term functional and health benefits among ambulatory older people, *J Aging Health* **20** (2008), 259-272.

[12] Norton MC, Dew J, Smith H, Fauth E, Piercy KW, Breitner JC, Tschanz J, Wengreen H, Welsh-Bohmer K. Lifestyle behavior pattern is associated with different levels of risk for incident dementia and Alzheimer's disease: the Cache County study *J Am Geriatr Soc* **60** (2012), 405-412.

[13] Glass TA, de Leon CM, Marottoli RA, Berkman LF. Population based study of social and productive activites as predictors of survival among elderly Americans, *BMJ* **319** (1999), 478-83.

[14] Wang H-X, Karp A, Winblad B, Fratiglioni L. Late-life engagement in social and leisure activites is associated with a decreased risk of dementia: A longitudinal study from the Kungsholem Project, *Am J of Epidem* **155(12)** (2002), 1081-1087.

[15] Popescu ML, Boisjoly H, Schmaltz H, Kergoat M-J, Rousseau J, Moghadaszadeh S, Djafari F, Freeman EE. Age-related eye disease and mobility limitations in older adults, *Invest Ophthalmol Vis Sci* **52** (2011), 7168-7174.

[16] Peel C, Baker PS, Roth DL, Brown CJ, Brodner EV, Allman RM. Assessing mobility in older adults: the UAB Study of Aging Life-Space Assessment, *Phys Ther* **85** (2005), 1008-1019.

[17] Gottlieb ER, Smith EC, Wolfenden LL, Allman RM, Tangpricha V. Life-space mobility is associated with frequency of hospitalization in adults with cystic fibrosis, *Clin Respir J* **5(4)** (2011), 245-25.

[18] Baker PS, Bodner EV, Allman RM. Measuring life-space mobility in community-dwelling older adults, *J Am Geriatr Soc* **51** (2003), 1610-1614.

[19] Al Snih S, Peek KM, Sawyer P, Markides KS, Allman RM, Ottenbacher KJ. Life-space mobility in Mexican Americans aged 75 and older, *J Am Geriatr Soc* **60** (2012), 532-537.

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A Usability Study of a Mobile Monitoring System for Congestive Heart Failure Patients

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Abstract. Sensor-based monitoring of congestive heart-failure (CHF) patients living at home can improve quality of care, detect exacerbations of disease at an earlier stage and motivate the patient for better self care. This paper reports on a usability study of the ESUMS system that provides continuous measurements of heart rate, activity, upper body posture and skin temperature via a sensor belt and a smartphone as patient terminal. Five CHF patients were included in the trial, all recently discharged from hospital. The nurses experienced continuous heart rate, activity and posture monitoring as useful and objective tools that helped them in their daily assessment of patient health. They also saw the system as an important educational tool to help patients gain insight into their own condition. Three patients liked that they could have a view of their own physiological and activity data, however the smartphones used in the study turned out to be too complicated for the patients to operate. A smartphone is built to be a multi-purpose device, and this may (conceptually and practically) be incompatible with the patients' demands for ease of use.

Keywords. Telehealth, Home monitoring, Biomedical sensors, Heart failure

Introduction

Vital signs sensor systems and telehealth monitoring will play an important role in new models of care [1][2]. Early discharge from hospital is becoming the rule rather than the exception, emphasizing the need for systems that can enable safe remote medical follow-up of the patient in his/her own home. This puts extreme requirements on usability of the patient system [3]. Patient empowerment", a buzzword of modern healthcare, is only achieved if the patient takes ownership of the tools that are provided for self-care and health follow-up, for instance the sensors for physiological measurements [4]. Exercise and training can improve the course of heart failure and should be an integrated part of care and rehabilitation programs for heart failure patients [5]. Daily measurements can contribute in two ways: i) help the patient understand his/hers condition and establish new ways of conduct, and ii) provide decision support for the clinical personnel in charge of patient follow-up.

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The ESUMS prototype system [6][7] was developed for continuous home monitoring of Congestive Heart Failure (CHF) patients that have recently been discharged from hospital[2]. The two ESUMS patient devices are 1) a wearable sensor belt with form factor similar to an exercise heart rate belt, and 2) a smartphone for viewing and transmitting data to a central server (figure 1). The sensor belt measures heart rate, activity level, upper body posture and skin temperature. Based on measured activity level and heart rate the number of minutes the patient has been in physical activity is calculated. If the user reaches pre-set activity goals for the day, a "motivation heart" appears on the phone (figure 2). The system also allows connection of other sensor devices with a standard interface to the phone; e.g. Nonin finger sensor for blood oxygen saturation measurements. A pc-application retrieves the data from the server and is used by the supervising nurse or doctor for follow-up from a remote site.

This paper reports on a usability study of the ESUMS system. A usability test with a small number of users is a cost-effective way of identifying a system's main positive and negative attributes, which is the purpose of this study [8]. The smartphones used in the study were supplied by the telecom company Verizon Inc. and were of the types Verizon HTC Imagio and Verizon LG Phantom, running Windows Mobile 6.5 operating system. Key questions the study aimed to answer was: How do the patients perceive the ESUMS sensor belt and smartphone with respect to overall usability and ease of use? Do continuous measurements, specifically of heart rate, activity and posture, provide useful decision support for nurses in their follow-up of the patients? Does the system help and motivate the patient to more physical activity?



Figure 1. Patient with ESUMS sensor belt and smartphone



Figure 2. Smartphone screen showing data & "motivation" heart

1. Methods

The study was carried out with 5 CHF patients and their 4 supervising nurses from Spartanburg Regional Health Care System (SRHS) in South Carolina, with approximately 3 weeks of system usage per patient[3]. The ESUMS prototype was hence

[2] The work was funded by the Telemedicine and Advanced Technology Research Center - TATRC (Award number W81XWH-08-2-0187). The sensor belt is being commercialized by the US based company Vitel Net, www.vitelnet.com.

[3] The usability study protocols were approved by Spartanburg Regional Institutional Review Board and the U.S. Army Medical Research and Material Command, Human Research Protection Office.

deployed in a study environment where a set of home care services already was running, thus ensuring validated care for the patients. The patients included in the trial were all female elderly CHF patient recently discharged from hospital and enrolled in a Telehealth program offered by SRHS; had basic skills with smart phones and had no restrictions in movement (not obese). The nurses were all trained nurses with at least 6 months experience with home health services. All received proper training in using the system. Data was collected via questionnaires developed based on the Unified Theory of Acceptance and Use of Technology (UTAUT) [9], and individual interviews of both patients and nurses. Technical errors were logged.

2. Results

The system was used to varying degrees by the patients; on average 120 hours per patient: Patient 1;144 hours, patient 2;116 hours; Patient 3;112 hours, Patient 4; 161 hours. and Patient 5; 67 hours. The subsequent tables, Table 1 and Table 2, provide the patients and nurses overall viewpoints on the system.

Table 1 . Overview of the patients overall perception of the system

Patient	Patient overall perception of system and usefulness	Patient capability in using the system.
1.	Liked using the system, poor health influenced low usage.	No problems in operating the phone after initial start-up problems.
2.	Very positive. Strongly motivated by the "motivation heart"	Learned to use system quickly. Technical problems did not affect motivation.
3.	Enjoyed using the system, low energy level (depression).	Discouraged by technical errors. Patient spouse operated phone for patient.
4.	Suffered from dementia but very positive to using the belt.	Did not learn how to use the phone. Somebody helped her with the system every day.
5.	Found the system more stressful than useful. Did not like it.	Problem with operating the system. Easily discouraged.

Table 2. Overview of the nurses´ perception of the system

Main advantages	Other issues
Continuous heart rate and activity monitoring	Technical problems with the phones
Oxygen saturation measurements	Weight scale sensor and blood pressure sensor must be
Good educational and motivational tool	added to system to align with follow-up procedures for
Wireless and easy to use	CHF patients

The patients seemed generally happy with using the sensor belt and reported few problems in putting it on or taking it off. The general impression from the nurses following up on the patients was that they "*put the belt on and then forgot about it*". The patients´ actual use of the application as a source of information on own health situation was variable. Two patients only turned on the smartphone at the end of the day to transmit data stored on the belt. However, the other three patients did use the phone to view the data. Patient 2 was clearly inspired by it and also by the motivation heart : "*I like that I can see my heart rate. Once I felt my heart beat fast I checked my phone and it was up to a 120.*" The following quote is from the log-book of the head study nurse, regarding the motivation heart:, after a phone call with Patient 2. "*She said: I met my goal! I got my heart! She was very excited and encouraged*." This

patient actually increased her activity as a result of the study. The nurses reported that they saw ESUMS as an excellent tool for educating the patients on their own health, and to help them understand the vital signs that the physiological measurements provided. The head study nurse reflected: "*Motivation is so important with heart failure patients and the ESUMS monitoring gives them incentive and allows them the ability to have some control of meeting their goals."*

Only 2 out of 5 patients however were able to operate the phones with ease. Patient 3 nurse reflected: *"A smartphone is too much to handle for a sick person. There are too many buttons to press"*. Patient 5 clearly stated: *"I don't want to have it! Take it away!"* Technical problems with the phones complicated the matter. The phones "froze" quite frequently, which required phone reset. The battery drained quickly, resulting in unstable operation when on low battery. Another common problem was a Bluetooth pairing instability between smartphone and the blood oxygen saturation sensor.

The nurses all agreed on the usefulness of continuous measurements of patient activity and heart rate, in that it helped them understand the patient better and be more precise in their care. Patient 3 nurse reported: "*It was possible to identify that the patient – who has a bipolar disease- was not moving about. This is often difficult to know with some patients, who just state that they are active."* From the head study nurse daily log*:"From the activity data I can see that patient sits in recliner a lot. Patient explains she prefers to sit because her knees hurt when she walks about."* They also found it very useful to be able to compare the heart rate with activity level to detect deviations. Head study nurse: "*I could see that patient's heart rate drops midday every day. This was consistent with the time the patient took her cardiac medicine every day. The nurse checked this and then reported to the MD".* Regarding the blood oxygen saturation finger sensor, all nurses found this useful. Patient 4 nurse reported: *"The blood oxygen saturation sensor would be an important tool for respiratory patients."* These measurements were however not very actively used in the patient assessment, mainly because it was difficult for the patients to remember to take the measurements.

The nurses were quite in accord with the main advantage and disadvantages of the ESUMS system: "The main advantages of ESUMS are the continuous heart rate and activity monitoring, that it is wireless and easy to use. The disadvantages are the technical problems and that it does not have weight scale and blood pressure sensors integrated, which we also need in our follow-up of CHF patients."

3. Discussion

Telehealth systems in the market today are mainly based on point sensor measurements. The study indicates that continuous heart rate, activity and posture monitoring provided by the ESUMS system are useful and objective tools helping the nurses in their daily assessment of patient's general health condition. The detailed information that the system provided on heart rate, was seen as important to detect and understand deviations and general status. The activity data enabled the nurses to confront patients that would report they were fine when in fact they did not have the strength to get out of bed. However, some sensors must be added to the system for it to be fully useful for follow-up of CHF patients. Weight scales must be included as rapid weight increase is an important indication of fluid retention in the body and hence a weakening heart function. Blood pressure is also an important indicator of disease status. The ESUMS

system architecture allows for future integration of these and other off-the-shelf Bluetooth enabled sensors, and will be part of future work.

Real time physiological measurements provide knowledge that can help the patients understand the triggers for health. Knowledge, in turn, is essential in order to change conduct. The study shows that there is potential in developing personal measurement systems for CHF patients. The concept of providing a view for the patients onto own measurements via the phone screen was liked by both patients and nurses, but the degree in which it was actually used varied with patient energy levels, their general health condition, the stability of the smartphone provided and personal factors: CHF patients are no different than the general population in that some are more triggered by competition and more perceptive than others to technology that can help them reach goals. Even though only one out of the five study patients actually increased her activity during the trial, the nurses were clear on the potential this type of "activity motivation app" has for this and other chronically ill patients groups.

However, the general level of energy for CHF patients is low. Unfamiliar and difficult technical solutions can easily increase stress levels, rather than increasing their motivation for better health and general quality of life. Advantages of using a commercial device like a smartphone include low platform costs and availability of a plethora of healthcare apps. Still, this does not overcome smartphone ease of use issues for seriously ill patients like CHF patients. A smartphone is built to be a multi-purpose device, and this may (conceptually and practically) be incompatible with the patients' demands for ease of use. The issue was further stressed in the study by the fact that smartphones used in the trial turned out to require frequent resetting and recharging, which probably have influenced patient motivation and actual use of the smartphones.

Continuous monitoring systems like ESUMS can be an important tool for helping and motivating the patients to better self-care. As the head study nurse reflected: *"We often go about it the wrong way. We TELL the patients what to do, rather than help them understand their disease. Systems like ESUMS can help us do just that."*

References

[1] Patel S, Park H, Bonato P, Chan L,Rodgers M. A review of wearable sensors and systems with application in rehabilitation. Journal of Neuroengineering and Rehabilitation, vol. 9, 2012.

[2] Pare G, Jaana M, Sicotte C. Systematic review of home telemonitoring for chronic diseases: The evidence base. Journal of the American Medical Informatics Association, vol. 14, no. 3, pp. 269-277, 2007.

[3] Bergmann JHM, McGregor AH. Body-Worn Sensor Design: What Do Patients and Clinicians Want? Annals of Biomedical Engineering, vol. 39, no. 9, pp. 2299-2312, 2011.

[4] Suter P, Suter WN, Johnston D. Theory-Based Telehealth and Patient Empowerment. Population Health Management, vol. 14, 2011.

[5] Fayazi S, Zarea K, Abbasi A, Ahmadi F. Effect of home-based walking on performance and quality of life in patients with heart failure. Scandinavian Journal of Caring Sciences, vol. 27, 2012.

[6] Strisland F, Svagård I, Seeberg TM, Mathisen BM, Vedum J, Austad HO, Liverud AE, Kofod-Petersen A, Bendixen OC. ESUMS: A Mobile System for Continous Home Monitoring of Rehabilitation Patients. EMBC 2013.

[7] Seeberg TM. Development of a wearable multisensor device enabling continuous monitoring of vital signs and activity.. Accepted to be published IEEE-EMBS June 2014..

[8] Turner, CW, Lewis JR, Nielsen J. Determining usability test sample size. In W. Karwowski (ed.), International Encyclopedia of Ergonomics and Human Factors . Boca Raton, FL: CRC Press, 2006.

[9] Venkatesh V, Morris MG, Davis GB, Davis FS. User acceptance of information technology: Toward a unified view. Mis Quarterly, vol. 27, 2003

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Developing an mHealth Framework to Improve Diabetes Self-Management

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Abstract. The need for improved diabetes care outcomes is paramount. Each year, 1.6 million cases are diagnosed with type 2 diabetes and as of 2006; diabetes was the seventh leading cause of death in the United States. Moreover, the financial burden associated with diabetes was estimated to be $174 billion in 2007. Studies show that effective patient-provider communication (PPC) improves diabetes self-care, diabetes outcomes, or both. There has been significant number of studies aimed at improving diabetes care through different telehealth technologies such as patient web portals. However, to the best of our knowledge, there has been limited amount of research done exploring the use of mobile technologies to improve diabetes care.

Keywords. Mobile Health, Diabetes, Self-management, Smartphone.

Introduction

With almost half a billion smart phones shipped globally mobile health (mHealth) smart phone applications are tools accessible to diverse populations to support self-management of chronic diseases and improve patient-provider communication [1]. Previous research has demonstrated value in simplistic mobile phone technology-based interventions, and the superiority of these interventions over traditional internet-based strategies aimed at strengthening patient-provider communication, both in terms of diabetes management outcomes such as decreased HbA(1c) levels, patient satisfaction, and patient adherence to disease management recommendations [2, 3]. Others have tested strategies that combine mobile phone technology with web-based application services, with mixed satisfaction results including patient preferences for mobile tools with versatile features [4-6]. A recent meta-analysis of mobile phone intervention studies demonstrated promising outcomes over 6 months follow-up, including reductions in HbA(1c) among patients with Type 2 diabetes [7]. The limited scope of these interventions includes patient reporting of glucose levels and lifestyle behaviors, educational messaging and SMS text messaging [8, 9].

Our proposed research addresses critical gaps in the science by developing a smart phone application that: (a) securely links and transfers data with the electronic health record thereby avoiding additional clinician/educator burden associated with accessing data on a separate web-based system, (b) delivers a comprehensive set of diabetes self-

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management elements designed to meet the diverse needs and preferences of patients with diabetes, (c) personalizes the behavior tracking, educational messaging, and provider communication elements, (d) automates most elements to reduce clinician/educator burden, and (e) responds to accessibility concerns by being designed for those with low literacy, in English and Spanish. The aim of our research is to deliver an informatics solution that consolidates fragmented efforts in the field.

1. Methods

1.1. Smartphone Application Development

Recognizing that numerous platforms are used on various smartphone devices, our mobile application will be compatible with the Android operating system (android being most commonly used smart phone). The application will include two mutually important components, a user-friendly interface and a well-developed Database Management System (DBMS). A rigorous system development process will take place to deliver the final mobile application: (1) formative data analysis, (2) design, (3) development, and (4) testing. To build a user-centric application, needs and expectations will be collected from end-users via interviews, as described above. Data will be analyzed and recommendations provided to the development team. The second stage is to design the Graphical User Interface (GUI) for the application informed by key informant data. During development (stage 3), the team will utilize a cross-platform runtime environment that will have capacity to run on multiple mobile platforms' devices or desktop applications. The application will provide two-way communication for users, such that users can store and retrieve information; this fast and secure communication requires a well designed and developed database architecture. Approaches such as normalization, optimization, and indexing will be used to reach optimum performance. After the front and back-end of the application have been built, the next stage is to test the application's performance and functionality levels (stage 4). Data will be stored in a separate database management system that can securely link back to the clinic's EHR.

1.2. Application Features

There are three categories of content the application will have: (1) patient health and behavior tracking, (2) patient-provider communication, and (3) education and resources. In addition, there are core features noteworthy to this application (Table 1) that avoid limitations previously described [10]. Our application addresses these needs and will include an insulin calculator that accounts for past behaviors, including recently administered insulin doses and activity. Further, reporting blood glucose levels will not be through open-text fields, which are vulnerable to errors; instead, users will report their glucose levels through interactive pictures with large numbers that are easy to read and include error-checking rule-based systems. Importantly, the educational content available on the application will be adapted from existing national evidence-based diabetes educational resources, including NIH and the American Association of Diabetes Educators; many materials, including written and audio tools, already exist in English and Spanish and address topics including healthy eating, monitoring, and coping. Importantly, the application will be designed with input from individuals with

low literacy so that content and functionality are accessible to them; in addition, the application will operate in English and in Spanish to encourage accessibility to most individuals in the U.S.

Table 1 App. Content & Features

Patient health and behavior tracking	Education and Resources
- insulin calculator	- evidence-based tips - warning signs
- blood glucose levels	- motivational messaging
- dietary patterns	- local events, activities
- physical activity	- emergency resources
	Key Features
Patient-provider communication	- Spanish and English
- automated appointment reminders	- Heavy use of graphics
- pre-appt fasting instructions	- Automated decision aid
- follow-up reminders	- Use of GIS capabilities
- event notifications	- Logs to track data over time
- diabetes educator contact	- Secure data transfer to EHR
	- 3G network and WiFi connectivity

1.3. Health Information Flow

Information flow is the process of ensuring secure data transmission between two or more entities through correct communication mediums. The aim is to link smartphone data with EHR data in order to improve Patient-Provider communication. There are multiple interactions involved in this study, mostly human-computer interaction and mobile-computer interaction. With respect to Human-computer interaction, patients interact with their smartphone applications to send data and review educational information, among data generated by patients is reporting their glucose levels at least once a day. On the other hand, providers login to the EHR system and, view, assess and analyze data reported from patients. As patients and providers interact with their smartphones and computers respectively, shown in Figure 1, there is another layer of communication that needs to happen to facilitate mobile-computer interaction. We utilize Health Level Seven International (HL7), a global authority on standards for interoperability of health information technology, to build common grounds between the two different operating systems. This will facilitate direct communication between smartphones and EHR systems. An informatics server will be the main data repository for this research; its main task is to store and link patient data from smartphone application and EHR. A decision has been made to build the Informatics server in order to avoid accessing and modifying any data in the EHR. Data on the informatics server will be strictly used for research purposes.

1.4. Application Usability

Usability studies are paramount for the success of any new application because they provide initial evaluation before final development processes are completed. The usability lab will include 30 patients and diabetes educators representing varied demographics. During the usability session (approximately one hour), patients will (a) receive a comprehensive walk through of the application functionalities and (b) use the application and provide feedback on design, interface, as well as suggestions for additional functionalities. A usability lab interview questionnaire will assess levels of satisfaction, awareness of application functionalities, areas of strength and weaknesses,

and rate specific screens on the application such as the use of graphics versus text on the homepage. Participants will receive $75 as a token of appreciation for providing feedback on the application features and processes.

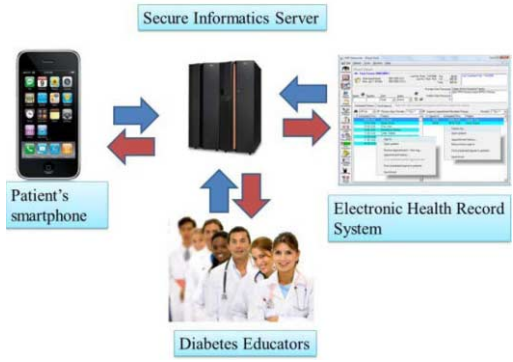


Figure 1. Health Information Exchange Model.

2. Results

Our preliminary work in mHealth continues along with our early studies in underserved populations [11, 12]. Through analyzing the strengths and weaknesses of existing methods of mHealth solutions, we have proposed our innovative method for examining Diabetes care with an emphasis on linking smartphone applications to EHR data, which holds promise in revealing the complexity of Patient-Provider communication. More efforts are needed in understanding Human-Computer interaction and will be contingent on what will be learned in the proposed study as described above. This research will utilize Android smartphones and application development and testing environment will be based on Android infrastructure. Data security will be reached through protecting the databases stored on the Informatics server destructive forces and the unwanted actions of unauthorized users. Data encryption and masking will be exercised at the user end through the Graphical User Interface (GUI) and at the backend by encrypting sensitive and private patient data..

3. Discussion

Mobile applications that aim at improving Diabetes self-management are widely accessible through application stores. These fragmented efforts focus on collected and representing data to individuals to help individuals monitor and assess their progress and performance over a period of time. The missing component is linking data with electronic personal health records at the primary care clinics.

Diabetic patients may experience unexpected hypoglycemic or hyperglycemic situations, where they require immediate assistance. The application will utilize Geographic Information Systems (GIS) to locate the patient and based on the location provide contact information to the closest clinics, emergency rooms, and hospitals for

immediate assistance. Patients can simply click on the telephone number and the application will call that entity using the designated cell phone carrier.

Future direction of our research targets at increasing the breadth of this application to include underserved populations and non-English speaking communities by translating the application into other languages such as Spanish. Eventually, we will like to roll out this application to other chronic diseases such as Cancer, heart diseases. One limitation of the study is the lack of resources to test the applications on more than one EHR.

This research brings innovation to five areas of diabetes health informatics: (1) linking to the EHR, (2) automating clinical guideline risk calculations of mHealth data, (3) delivering evidence-based educational modules, (4) using Geographic Information Systems (GIS) to link patients with emergency resources, and (5) giving providers output options. This study aims to improve PPC by increasing glucose level reporting and by decreasing non-adherence levels and hence, improve diabetes care outcomes.

References

[1] MobiThinking. 2011 handset and smartphone sales statistics worldwide: the big picture. 2012; Available from: http://mobithinking.com/blog/2011-handset-and-smartphone-sales-big-picture.

[2] Larsen ME, Turner J, Farmer A, Neil A, Tarassenko L. Telemedicine-supported insulin optimisation in primary care. Journal of Telemedicine and Telecare. 2010;16(8):433-40.

[3] Cho J-H, Lee H-C, Lim D-J, Kwon H-S, Yoon K-H. Mobile communication using a mobile phone with a glucometer for glucose control in Type 2 patients with diabetes: as effective as an Internet-based glucose monitoring system. Journal of Telemedicine and Telecare. 2009;15(2):77-82.

[4] Lyles CR, Harris LT, Le T, Flowers J, Tufano J, Britt D, et al. Qualitative evaluation of a mobile phone and web-based collaborative care intervention for patients with type 2 diabetes. Diabetes technology & therapeutics. 2011;13(5):563-9. Epub 2011/03/17.

[5] Istepanian RS, Zitouni K, Harry D, Moutosammy N, Sungoor A, Tang B, et al. Evaluation of a mobile phone telemonitoring system for glycaemic control in patients with diabetes. Journal of Telemedicine and Telecare. 2009;15(3):125-8.

[6] Harris LT, Tufano J, Le T, Rees C, Lewis GA, Evert AB, et al. Designing mobile support for glycemic control in patients with diabetes. Journal of Biomedical Informatics. 2010;43(5, Supplement):S37-S40.

[7] Liang X, Wang Q, Yang X, Cao J, Chen J, Mo X, et al. Effect of mobile phone intervention for diabetes on glycaemic control: a meta-analysis. Diabetic Medicine. 2011;28(4):455-63.

[8] Mohan P, Marin D, Sultan S, Deen A, editors. MediNet: Personalizing the self-care process for patients with diabetes and cardiovascular disease using mobile telephony. Engineering in Medicine and Biology Society, 2008 EMBS 2008 30th Annual International Conference of the IEEE; 2008 20-25 Aug. 2008.

[9] Hanauer DA, Wentzell K, Laffel N, Laffel LM. Computerized Automated Reminder Diabetes System (CARDS): e-mail and SMS cell phone text messaging reminders to support diabetes management. Diabetes technology & therapeutics. 2009;11(2):99-106. Epub 2009/10/24.

[10] Demidowich AP, Lu K, Tamler R, Bloomgarden Z. An evaluation of diabetes self-management applications for Android smartphones. Journal of Telemedicine and Telecare. 2012;18(4):235-8.

[11] [11] Khairat S, Garcia C. Introducing a Wireless Mobile Technology to Improve Diabetes Care Outcomes among Specific Minority Groups. Medicine 20; Boston, MA. 2012.

[12] Garcia C, Hermann D, Bartels A, Matamoros P, Dick-Olson L, Guerra de Patino J. Development of Project Wings Home Visits, a Mental Health Intervention for Latino Families Using Community-Based Participatory Research. Health Promotion Practice. 2012;13(6):755-62.

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Integration of Federated Medical Systems for Vendor Neutral Image Access in Teleradiology Applications

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Abstract. This paper proposes a framework designed to interconnect medical imaging facilities and teleradiology service providers on a single access interface. This framework aims to solve the interoperability issues of Picture Archiving and Communication System (PACS), Radiology Information System (RIS) and Hospital Information System (HIS) developed by different vendors and enrich the digital health record delivered to non-local radiologists or physicians with the integrated information from several systems. This is achieved by introducing a "Grid Agent" into the domain of medical software systems, which seamlessly integrates with present systems and forms a network to deliver data between other Grid Agents and the "Grid Manager". Resultant solution decreases the access time of medical images by non-local medical staff and increases the efficiency and durability of the teleradiology service architecture.

Keywords. Grid based teleradiology, information centric network architecture, vendor neutral, federated medical systems.

Introduction

Due to lack of radiologists within the facilities and consultation needs, the business model for radiology practice around the world is formed to include the facility's employing and outsourcing radiology services to non-local radiology groups [1]. PACS and RIS are typically designed to handle local radiology communication and workflow management. However, non-local radiologists that serve several sites need to access medical images with a single interface in order to return medical reports efficiently. In order to accomplish an efficient teleradiology process, previous examinations and health records of patients are also required. This consequently requires the integration of HIS, RIS and PACS independent from the developer vendor. During the evolution of teleradiology studies, non-local access by means of web servers employed in a hospital [2, 3], Hypertext Transfer Protocol (HTTP) to Digital Imaging and Communications in Medicine (DICOM) connectors [4] or Java based web viewer [5] have been proposed. However, these studies usually focus on off-hour access of hospital staff when they are outside the hospital rather than interconnecting hospitals or facilities. Regional PACS [6] solutions provide interconnection of medical archives, but they usually require Virtual Private Network (VPN) structures and single vendor software. Vendor

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dependency causes durability problems in system alteration decisions and high migration costs. Central medical archiving and aged data management solutions [7-9] and PACS based on data grids [10, 11] propose central or co-allocation parallel transfer strategies to improve the non-local access interface and reduce the transfer time for medical images. Integration with heterogeneous resources and systems such as RIS and HIS is also crucial for the quality of the service. This can be achieved by employing agents that support DICOM, Health Level Seven (HL7), HTTP, Cross-Enterprise Document Sharing (XDS) and non-standardized data at regarding sites [12]. In this study, both integration with heterogeneous resources and vendor independent management of federated data are achieved with the proposed framework design. The implemented design employs a Grid Agent that can seamlessly be integrated to the medical facilities at remote sites and a central Grid Manager that can optimize the data flow between sites on a single interface.

1. Methods

Teleradiology data serving and sharing network architecture with an enhanced caching, querying and retrieving mechanism is implemented by seamlessly integrating "Grid Agent" and "Grid Manager" to conventional digital medical systems as illustrated in Figure 1. Grid Agent is deployed on each site and is responsible for rendering medical data and incoming messages or transferring radiology data between PACS, RIS, HIS, Workstations, non-local clients, Grid Manager and other Grid Agents. Grid Manager is responsible for the flow management of images between sites and reporting units or distribution of reports generated by radiologists. It communicates with Grid Agents and performs database, indexing and file operations at the center. A typical data integration and communication scenario example covering most of the interactions is as follows:

- A non-local family doctor requests an MR inspection using the web interface.
- Grid Manager delivers the imaging request as an Extensible Markup Language (XML) message to the Grid Agent at the corresponding medical center.
- The Grid Agent informs the HIS and delivers the Modality Work List request to RIS.
- When the incoming patient is registered in HIS, Grid Agent is informed which gets the index of Grid Agents that have patient's data regarding previous examinations from the Grid Manager.
- Grid Agent pre-fetches the patient's previous medical information and synchronizes PACS and HIS so that the radiologists can access the history of the patient no matter at which hospital, with which vendor's software the data is acquired.
- The radiologist investigating the radiology examination makes a consultation request from a remote radiology group.
- Grid Agent at the reporting unit of the radiology group receives the updated request list from the Grid Manager and fetches the patient's data including previous examination with the Grid Agent Index and synchronizes the data to PACS in the unit.
- The radiologist at the reporting unit retrieves medical images to be reported from several medical centers on a single interface and generates corresponding reports in RIS or using the web interface.

- The report is first delivered to the Grid Manager , then to the Grid Agent at the regarding medical center and finally to HIS.

1.1. The Grid Agent

Grid Agent communicates with PACS, RIS, HIS and workstations using DICOM and HL7 protocols. The communication between Grid Agents and Grid Manager is accomplished using encrypted XML messages using HTTP and Real Time Messaging Protocol (RTMP) protocols. Grid Agent software is developed to run on an open source media server *Red5* which also includes an embedded *Tomcat* servlet container for JEE Web Applications and supports streaming and shared object communication over RTMP. DICOM and HL7 messages are handled by asynchronous java threads using *dcm4che* and *HAPI* java libraries.

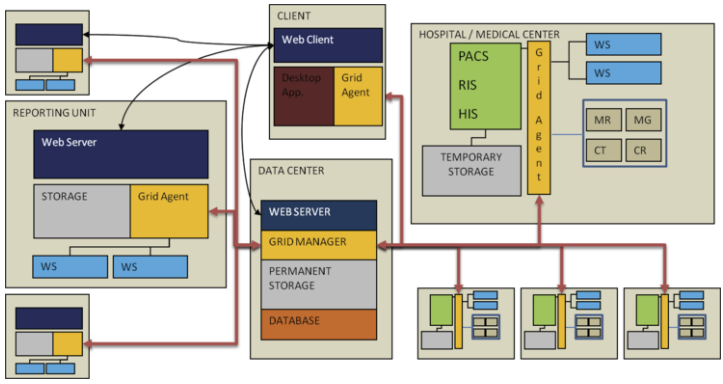


Figure 1. Framework architecture

1.2. The Grid Manager

Grid Manager has the Grid Index which includes the patient examination map cached by Grid Agents. The index is in shared object form so that a change in the index is pushed to all agents with the help of RTMP protocol. The caching mechanism at the agents provides the redundancy of the medical data so that the data archive is distributed and web server maintenance costs are prevented.

Grid Manager is developed to run on *Red5* and is specialized to send and receive encrypted XML and SOAP messages or DICOM files utilizing DICOM, HTTP or RTMP protocols.

1.3. Data Center Architecture

The central server is composed of the Application, Database and File Operation Layers. Grid Manager forms a bridge between these layers as illustrated in Figure 2. The Database layer is implemented with open source *Postgresql* software with 3 virtual servers running in failover. The database instances are implemented in shards to deliver large scale loads. Application layer is implemented with *Red5* media server and 3 virtual servers connected to a load balancer. File Operation layer is implemented with Tomcat Servlet Container with 3 virtual machines connected to a load balancer.

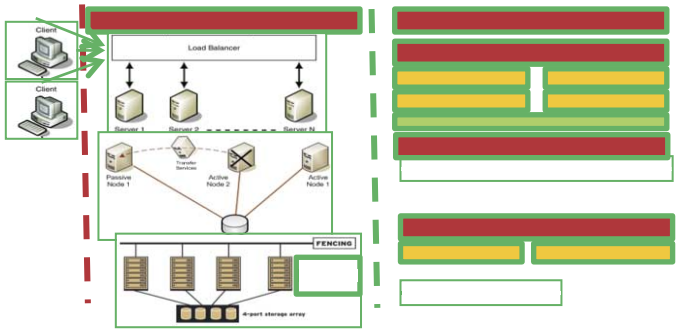


Figure 2. Central Server Hardware and Software Architecture

1.4. Clients

Clients can query and retrieve medical images in parallel from multiple Grid Agents where medical content is cached during the pre-fetching and synchronization processes. For web clients, java based open-source DICOM viewer software, *ImageJ*, is customized to stream image instances in parallel chunks. The DICOM Viewer screen of the web client can be seen in Figure 3. A query that is directed to the grid agent in a hospital by workstations is also directed to other grid proxies. Consequently, the query is performed at every hospital and central web server. Grid Manager provides the Grid Agent and consequently workstations with the result list and the images or data can be retrieved by the help of Grid Manager. Parallel downloading and efficient query algorithms in the Grid Manager enhances the bandwidth usage and time delay.

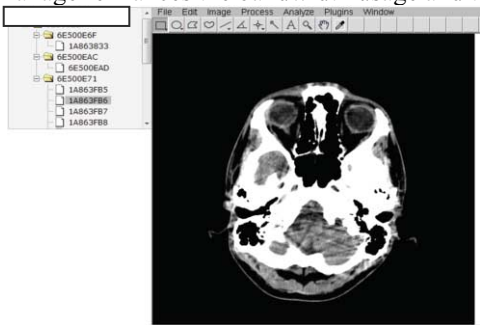


Figure 3. Web based DICOM Viewer

2. Results and Discussion

The framework implementation is tested by simulating medical facilities and information systems using open source dcm4che2 DICOM Toolkit. Three medical facilities, three reporting units are each represented by a virtual machine on different networks. A set of 100 sample radiology inspections for 10 different patients are generated by the facilities. It is observed that the Grid Agent synchronizes the previous inspections of a patient at the site with the arrival of a new examination. Therefore, there are at least two copies of an inspection preventing single point of failure and eliminating the cost of central disaster recovery solutions. The synchronization also

takes place at the reporting unit with the incoming reporting request. The clients can access the images belonging to different sites on a single interface on the web or using their presently installed DICOM viewer software.

The proposed architecture increases the efficiency of reporting, image query and retrieval processes for teleradiology applications and provides a process centric network structure with an enhanced caching, querying and retrieving mechanism. The Grid Agent and Grid Manager solutions provide integration of several standard compliant medical systems regardless of the developer or manufacturer vendor and accomplished medical data redundancy without the maintenance cost of a single central web solution.

It is planned to test the implemented architecture with a real-world scenario including medical sites with different vendor facilities and reporting groups with non-local radiologists and to evaluate the results in terms of user experience and data access time. The data flow algorithm is aimed to be enhanced in order to increase report quality and turnaround time by delivering medical images that require subspeciality or urgency to the best matching radiologist.

References

[1] Branstetter BF. Basics of imaging informatics: part 2. *Radiology.* 2007;**244**:78–84.
[2] Zhanga J, Suna J, Stahl JN. PACS and Web-based image distribution and display. *Comput Med Imag Grap.* 2003;**27**:197–206.
[3] Münch H, Engelmann U, Schroeter A, Meinzer HP., Web-based distribution of radiological images from PACS to EPR. *Int Congr Ser.* 2003;**1256** :873–879.
[4] Reponen J, Niinimäki J, Leinonen T, Korpelainen J, Oikarinen J, Vierimaa E. Linking a web based electronic patient record with a DICOM PACS. *Int Congr Ser.* 2001;**1230**:801–804.
[5] BernardingJ, Thiel A, Grzesik A. A Java-based DICOM server with integration of clinical findings and DICOM-conform data encryption. *Int J Med Inform.* 2001;**64**:429–438.
[6] Sutton LN, PACS and diagnostic imaging service delivery – A UK perpective. Eur J Radiol. 2011;**78**:243-249
[7] Cao P, Hashiba M, Akazawa K, Yamakawa T, Matsuto T. An integrated medical image database and retrieval system using a web application server. *Int J Med Inform.* 2003;**71**:51-55.
[8] Cheung NT, Lam A, Chan W, Kong JH. Integrating images into the electronic patient record of the hospital authority of Hong Kong. *Comput Med Imag Grap.* 2005;**29**: 137–142.
[9] Onbay TU, Kantarcı A. Design and implementation of a distributed teleradiaography system: DIPACS. *Comput Meth Prog Bio.* 2011;**104**:235–242.
[10] Yang CT, Chen CH, Yang MF. Implementation of a medical image file accessing system in co-allocation data grids. *Future Gener Comp Sy.* 2010;**26**:1127-1140.
[11] Yang CT, Yang MF, Cheng LH, Chiang WC. Enhancement of anticipative recursively adjusting mechanism for redundant file transfer in data grids. *J Netw Comput Appl.* 2009;**32**:834-845.
[12] Benjamin M, Aradi Y, Shreiber R. From shared data to sharing workflow: Merging PACS and teleradiology. *Eur J Radiol.* 2010;**73**:3-9.

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Analysis of Social Networks among Physicians Employed at a Medical School

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Abstract. Social network analysis is a well-known method for discovering the social complexities of relationships. In this paper, we present the results of its application in a healthcare environment, i.e. a state university hospital. The sociometric method was adopted to collect social network data. The analysis was performed using Pajek. The medical practice/academic and technological networks among physicians of a state university hospital were explored. Monomorphic and polymorphic opinion leaders (OLs) within the networks were identified using the in-degree measure. Cohesiveness were investigated based on network density and average degree. In addition, it was checked if the mentor system may present impact on the formation of social networks among physicians.

Keywords. social networks, opinion leaders, physicians, technology.

Introduction

Numerous studies in social science have shown that in every community, there is a group of people to whom others look to help them to form opinions regarding various issues and matters [1]. In some studies, they were called "opinion leaders"(OLs), in others "influentials" In their much cited book called Personal Influence [2], Katz and Lazarsfeld defined opinion leadership as

"…leadership at its simplest: it is casually exercised, sometimes unwitting and unbeknown, within the smallest groupings of friends, family members, and neighbors. It is not leadership on the high level of Churchill, nor of a local politico; it is the almost invisible, certainly inconspicuous form of leadership at the person-to-person level of ordinary, intimate, informal, everyday contact."

Opinion leadership theory is often identified with the diffusion of innovations theory. These two theories provide a clarification of how information, new ideas and practices spread within and between communities [3]. According to diffusion of innovations, OLs are adaptation filters of communities. Identifying OLs within a community has serious advantages when it comes to change. It is reported that they can remove the barriers to and promote behaviour change and thereby, increase the rate of the diffusion of innovations [4]. In healthcare settings, opinion leaders may help overcome issues regarding diffusion of innovations, such as information systems. Acceptance of information and communications systems (ICT) in healthcare settings is a serious problem. Many barriers and reasons were reported [5]. Together with

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technological change management, a diffusion strategy based upon OLs may help organizations overcome physician resistance. Designing and conducting such an intervention with OLs-based strategy requires identifying OLs and communication networks.

The objective of this study is to identify monomorphic and polymorphic technology and medical practice OLs together with social networks among members of a specific profession, namely physicians, at a state university hospital, and to explore the impact of academic mechanism (i.e. the mentor system) on the formation of social networks for the development of a technological change management strategy.

1. Methods

Recently, many studies reported data collection methods for the purposes of identifying OLs and social networks [4, 6]. A systematic review study, which describes identifying a method for a particular setting as a methodological work, addressed five basic data collection methods [4] .

1.1. Social Network Data Collection Method (SNDCM)

The adopted SNDCM in this study was identified based on a guideline provided in a systematic review study [6]. The study proposes a comparison model for available methods that depends upon research conditions, nature of the setting, availability of some resources, existence of some limitations and characteristics of available methods. Through the model and its guideline's simple approach, the best suited method can be easily uncovered for any study. For our study, the guideline yielded sociometric method to be the most appropriate. Besides, since no formative study that provides information about the characteristics or structure of the social system was available for our setting, a method with a high reliability and validity was favourable. Sociometric method was reported to have high reliability as well as validity [8].

1.2. The Setting and Sample

Regardless of the academic title and the amount of time spent working at the state university hospital, all employed physicians were eligible to participate in the study. There were a total of 757 physicians employed at three divisions; i.e. basic science division, medical science division, surgery science division; with 39 different departments. The departments and their units are situated at five building blocks located within a 300m radius circle. We obtained up to date lists of physicians working at each department for the purposes of participation follow-up.

1.3. Data Collection Instrument and Procedure

In accordance with sociometric method, we prepared a questionnaire to collect social network data. We underwent a series of steps to optimize and adapt the questions to the nature and characteristics of the medical profession and the setting. The first adaptation effort was about the format of the questionnaire. We preferred using "free recall" type of questionnaires rather than roster/recognition type of questionnaires since recognition

type of questionnaire was not favorable due to population size and the organizational structure with 39 departments. There are conflicting opinions in the literature regarding which type of questionnaire provides more complete data. In the second adaptation effort, since the medical profession by nature owns a formally defined cooperation; i.e. consultation, we needed to make sure that questions were able to imply and address "informal" relations among physicians. For this purpose, we made use of clear and basic expressions addressing informal relations while excluding formal relations. Due to the purposeful advice nature of the questions, we assume that our survey implies a directionality of influence, where necessary.

In the questionnaire, each participant was asked to name those colleagues to/from whom s/he would ask his/her opinion/seek advice or guidance/go for advice regarding (i) technological or computer-related issues/matters, and (ii) medical practice/professional issues/matters. For each name they provide, the participants were also asked to specify the department of the colleague and associate a communication frequency. The responses to the frequency stem "How frequent do you seek advice or guidance from this colleague?" were on a 4 point scale; i.e. daily or almost daily, once or twice a week, once or twice a month and a few times a year. Participants were informed that they might provide as many names as they wanted. We visited and asked physicians for their participation at their offices. Several visits were scheduled for each department. During every visit, each physician was briefed shortly regarding the study one-to-one. Following the briefing, each physician was asked for participation.

1.4. Measures and Tools for the Analyses

Social network analysis was conducted in three dimensions; (i) whole network analysis, (ii) individal measures/analysis and (iii) statistical analysis. The individual measure and identification method adopted for the purposes of identification of influential physicians are called "in-degree centrality" and Cattel's method, respectively. The measure was proposed by Freeman [9]. Given a set of directed communication relations among individuals in an organization, the in-degree for a particular individual indicates the number of individuals who say that they are connected to her/him. Individuals with great number of peer nominations are considered to have high influence. The adopted OL identification method, Given a plot or histogram of in-degrees, one could attempt to identify a point of inflection and set a cut-point in-degree, and thereby, label those individuals whose scores lie above the inflection point as influential[10]. The social network analyses on the collected network data were performed using a social network analysis software called Pajek [11]. Statistical analyses were performed using SPSS, Ca. USA.

2. Results

A total of 394 physicians accepted to participate out of 757 (a response rate of 52%). 151 of respondents are females (38.3%), and 243 of respondents are males (61.7%). Figure 1 shows distributions of in-degrees in the technological and medical practice networks.

Considering Cattel's point of inflection rule, we have identified 5 and 4 as point of inflections on in-degree charts and therefore we set 6 and 5 as minimum in-degrees for being an influential in medical practice and technology networks, respectively.

Consequently, the number of OLs in medical practice is 66, whereas the number of OLs in technology network is 39, out of which 31 are medical doctors. Out of 31 physician OLs of the technology network, 16 were also OLs in medical practice. We found a weak association among being an OL in technology network and being an OL in medical practice network (φ=0.3, $p<0.05$).

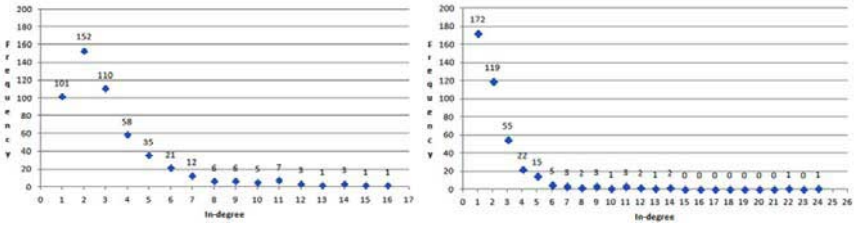


Figure 1. In-degree distributions in the medical practice and technology networks, respectively.

In order to have an idea about the cohesion on both networks, the density of ties for both networks are calculated and shown in Table 1. With respect to the density, it is obvious that medical practice network has a stronger cohesion than technology network does. However, due to different network sizes, a better measure to compare networks based on cohesion, even when they have different network sizes, is average degree. Table 1 also presents average degree for both networks. The results reflect that physicians act more cohesive in their profession than they do in technology.

Table 1. Density and average degree of networks (directed).

Network	Density	Average Input Degree	Average All Degree
Medical Practice	0.0044	2.2625	4.5249
Technology	0.0035	1.4246	2.8452

In order to investigate the impact of mentor system on the formation of social networks, the networks were partitioned based on mentor system (i.e. residents and mentors/faculties (i.e. asst. prof., assoc. prof. and prof.)). Tables 2 shows the number of ties based on this partitioning in medical practice and technology networks.

Table 2. Ties based on mentor system (reads from row to column).

	Medical Practice		Technology	
	Resident	**Faculty**	**Resident**	**Faculty**
Resident	294 (42%)	406 (58%)	259 (72.6%)	98 (27.4%)
Faculty	4 (0.8%)	477(99.2%)	12 (5%)	224(95%)

Statistically, there is a relationship between being a faculty (mentor) or resident and addressing a peer for matters regarding the medical practice. When it comes to technology, analysis reveal that there is statistical association between being a faculty or resident and addressing a peer for technological matters ($p<0.001$).

Table 3 is the contingency table of relationships based on gender for both networks. Statistical analysis has shown that there is a relationship between being female or male and addressing someone from the same sex for both medical practice and technological matters. The same finding goes for the technology network; i.e. statistically, there is a relationship between being female or male and addressing someone from the same sex for both medical practice and technological matters.

Table 3. Ties based on gender (reads from row to column).

	Medical Practice		Technology	
	Female	**Male**	**Female**	**Male**
Female	196 (41.8%)	273 (58.2%)	60 (26%)	171 (74%)
Male	131 (18.4%)	581(81.6%)	20 (5.7%)	328(94.3%)

3. Discussion

In this study, we have analyzed and compared two social networks, medical practice and technology, among physicians of a university hospital with respect to cohesiveness and uncovered the OLs in both networks. Although there are polymorphic OLs (OLs in both medical practice and technology), there is a weak statistical relationship between being a technology OL and being a medical practice OL. In terms of cohesiveness, physicians have shown stronger cohesiveness in their profession than they have done in technology. An interesting finding was related to the mentor system. In both networks, there is statistical association between being a resident or faculty and going to a peer for advice. For faculties, going to a peer for advice in medical practice is predictable. The same can be stated for the residents within the technology network. However, for faculties, not going to a resident for technology-related advice due to the mentor system might be a barrier for behavior change towards ICT today. In addition, the results show that residents go to their peers for medical practice-related advice as much as they go to the faculties. This finding might point to either a hierarchical structure among residents or some deficiency in the mentor system. Taking these into account, the mentor system might need attention within the university hospital.

Future work includes identifying components in both networks and further cohesiveness analysis based on the components and their comparison.

References

[1] Weimann G., *The Influentials. People who influence people*, State University of New York Press, Albany, 1994.
[2] Katz, E., Lazarsfeld, P.F., *Personal Influence. The part played by the people in the flow of mass communication.*, Free Press, Glencoe, IL, 1955.
[3] Rogers, E. M., *Diffusion of innovations* (5th ed.), Free Press, New York, 2003.
[4] Valente, T.W., Pumpuang, P., Identifying opinion leaders to promote behavior change. *Health Education & Behavior* **34** (6) (2007), 881-896.
[5] Medpac, *Information Technology in Health Care*, Chapter 7, Report to the Congress: New Approaches in Medicare, Washington DC, 2004.
[6] Kim, D., A Guideline to Design and Conduct Opinion Leaders Based Diffusion Strategy for Communicative Health Interventions: Methods of Identifying Opinion Leaders and Communication Networks, *National Communication Association 94th Annual Convention*, San Diego (2008)
[7] Sabo, S., Grcar, M., Fabjan, D., Ljubic P., Lavrac, N.: Exploratory analysis of the ILPnet2 social network, *IS-2007*, Ljubljana, Slovenia, 2008.
[8] Marsden, P.V., Network data and measurement. *Annu Rev Sociol* **16** (1990), 435–63.
[9] Freeman, L.C., Centrality in social networks: conceptual clarification. *Social Networks* **1 (**1979), 215–239.
[10] Cattel R B. The scree test for the number offactors. *Multivariate Behav. Res*. **1 (**1966), 245-76,. University ofillinois, Urbana-Champaign, Ill.
[11] Wouter de Nooy, Andrej Mrvar, Vladimir Batagelj, *Exploratory Social Network Analysis with Pajek,* Cambridge Press, 2005.

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GlassAllergy: A Google Glass-based Solution to Empower Patients with Skin Allergies

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Abstract. A variety of substances contained in cosmetic products can lead to allergic reactions for certain individuals. The names of such substances are predominantly printed onto a product in small-sized expert language. For this reason, consumers often have difficulties to assess whether some of the ingredients might be harmful for them. Consequently, patients are exposed to a risk of buying a cosmetic product that might cause a minor to severe allergic reaction. A Google *Glass*-based software solution for consumers suffering from skin allergies is presented. It enables users to check cosmetic products in a mobile context and empowers patients to make informed buying decisions. In particular, the solution could help to avoid or reduce the risk for allergic reactions.

Keywords. Patient Empowerment, Smart Devices, Google Glass, Allergies

Introduction

Nowadays, a large group of people suffers from allergies. Many substances contained in cosmetic products (e.g., shampoos, body lotions, sun blockers, etc.) can lead to allergic reactions for certain individuals. Such reactions are often associated with a decreased quality of life for those affected.

Though all ingredients are printed on the product itself, it is difficult for many consumers to identify those substances, which might trigger allergic reactions. Additionally, some ingredient names are ambiguous, i.e., the names of active agents are similar to each other. Therefore, the meaning and the consequences are difficult to assess for laymen and could lead to misinterpretation and wrong decisions.

Even if an individual had consulted a dermatologist, had himself/herself tested for allergies and knows which allergens to avoid it can be difficult to apply this knowledge in daily life. This especially applies when he/she has to make a buying decision. Consequently, consumers are exposed to a risk of buying a cosmetic product that might trigger a minor to severe allergic reaction.

In this paper we present a Google *Glass* [1] enabled software solution – termed *GlassAllergy* (GA) – that empowers consumers to make an informed buying decision based on facts that originate from an individual allergic profile. Thus, patients are supported to avoid minor to severe allergic reactions.

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Figure 1: Testing for allergies at a dermatologist. This includes an examination with a standardized set of substances found in cosmetic products.



Figure 2: A typical German allergy card as issued by a dermatologist. In this particular example, its owner has been diagnosed to be allergic to (a) *Parfum*, (b) *Cocoamidopropylbeatine* and (c) *Tert.-Butylhydrochinon.*

1. Material & Methods

1.1. Allergic Reactions

According to the German Association for Allergies and Asthma[2] about 20% of the German population (about 16 million people) shows allergic reactions like itching, swelling or pustules if they are exposed to certain allergens. In particular, chemical agents found in cosmetics can cause minor to severe skin reactions [2]. As depicted in Figure 1, skin allergy tests can be conducted to determine which ingredients cause conflicts for an individual.

Figure 2 shows a typical German allergy card as issued by a dermatologist. It lists all names of chemical agents a patient is diagnosed to be allergic to. The allergy card also contains a short description and information on typical product groups a certain substance is contained in, as frequently found in drugstore products. As advised in the allergy card, a patient shall strictly avoid any contact with the substances listed. The names of such substances are predominantly expressed in expert language.

Yet, substance names are often too complex to memorize for laymen and the allergy card might not always be at hand when shopping for cosmetic products. In addition, ingredient names are typically printed in tiny font size. For this reason, reading the complete list of substances can consume a lot of time. Moreover, some substances have different spellings or are shortened due to limited space on the product itself.

1.2. Consumers Seeking for Advice

Finding relevant information can be a challenging task, which is especially true for health related information. People's needs to search for individual health related information is often referred to as health information seeking [3]. In particular, such activities involve "any non-routine media use or interpersonal conversation about a specific health topic and thus includes behaviors such as viewing a special program about a health-related treatment, using a search engine to find information about a

[2] daab – Deutscher Allergie- und Asthmabund e.V. (www.daab.de)

particular health topic on the Internet, and/or posing specific health-related questions to a friend, family member, or medical practitioner outside the normal flow of conversation" [4].

Given a mobile context, some systems focus on prevention aspects by delivering recommendations via mobile (smart-) phones. Thereby, patients suffering from chronic diseases (e.g., Diabetes mellitus) or people addicted to tobacco receive personalized advice based on their individual (daily) condition [5]. Ghorai et al. presented a case based recommender system that sends advice to smokers willing to quit [6]. Their approach computes recommendations based on a user's behavioral data collected over time.

1.3. Wearable Devices & Google's Glass Development Kit (GDK)

Innovative wearable devices are on the verge of entering the consumer market. A well-known example is Google's *Glass* device. It might be the next evolutionary step in the field of mobile computing, as consumers can still use both of their hands while at the same time receiving calls, sending e-mails or taking pictures.

In addition to the regular *Android* software development kit (SDK) for smartphones, Google released the so-called *Glass* development kit[3] (GDK) in late 2013. It enables developers to access the head mounted display and the built-in camera of the device. Thereby, the implementation of a barcode scanning feature is made possible. With the GDK, developers can also use speech recognition techniques provided by built-in hardware and integrated software components. Thus, voice trigger commands can be defined, which allows users to interact with a wearable device hands free.

2. Results

2.1. Concepts & Architecture

As an initial step, an individual has to create a personal profile at a service provider's website. This profile contains all chemical substances that could cause a user (serious) harm.

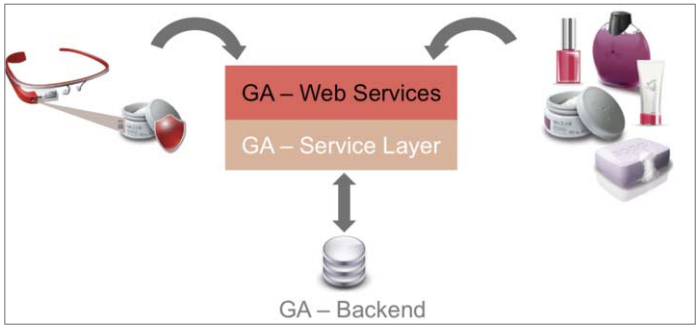


Figure 3: System Architecture of the GA project. Products of different vendors are stored in a database. It contains more than 20,000 chemical agents (i.e., European INCI terms) and about 50 typical drugstore products. Consumers access the GA web services via a secured connection in a mobile context. A Google *Glass* device in combination with a paired smart phone sends REST-based calls to the web service endpoint which computes contraindications of scanned products.

[3] https://developers.google.com/glass/develop/gdk/

The list of agents can be entered and edited by him/herself and should be the outcome of allergy tests conducted by a dermatologist. Such a profile can be altered via a web browser or a smartphone application. As depicted in Figure 3, Google *Glass*' built-in camera is used to scan the EAN-8 or EAN-13 barcode of a product of interest. Thereby, a unique product identifier is obtained while shopping in a drugstore or a supermarket. Thus, a barcode that represents a composition for chemical substances can be used for substance checks against an individual's allergy profile. Subsequently, the identifier is sent to a web service. Such a service computes whether any of the ingredients within the scanned product might be harmful for a customer who originally made the request. As a response to the substance check, a web service implementation sends back a list of conflicting ingredients to the *Glass* device. The result of the check indicates if there are any contraindications related to the product of interest. If so, a visual warning or alert is displayed to the user within the head-mounted display.

In addition, a short explanation can be presented if the user requests detailed information. As a result, consumers are enabled to make an informed buying decision in a mobile context.

2.2. Prototype & Early Findings

As a first prototype, we implemented a *Glass*-enabled mobile application that scans barcodes of cosmetic products. As depicted in Figure 4 (a), we conducted a field test of our solution. We quickly noticed that positioning a product during a scan is essential for a quick and precise recognition of a related barcode.



Figure 4 (a): A drug store visit using a smart glass device. Note well: Only products contained in our database can be checked for.



Figure 4 (b): Different barcode sizes and product shapes can influence the product recognition process. Consumers might need some training to adjust angles and distances.

In a laboratory test setup we experienced minor difficulties with the recognition of some products. As it turned out, ambient light can have negative effects on the scan process and thus on the recognition duration. By contrast, the percentage of products identified correctly was a lot higher in the ambient light in a real-life shopping environment at local drugstores, as depicted in Figure 4 (b). Different product shapes, material and color can also influence the duration of the scan process. Yet, we found that a quick check of a product of interest is possible with our solution.

Establishing a communication channel via a smartphone can be difficult in certain situations, e.g., in buildings with thick walls or in rural areas. As mobile broadband access improves and technology evolves over time, it can be expected that communication via smartphones or wearable devices will become more robust in the next years. During our field tests we experienced no major communication interruptions. For this reason, we consider communication aspects in a mobile context as a secondary issue. In terms of usability and as voice commands can be issued, it is possible to pick up a product and initiate an allergy check in a rather short time. By contrast, a smartphone-based solution would require a consumer to first retrieve the device from a handbag or a jacket. Moreover, it would require him or her to use at least one hand to hold the smartphone.

3. Discussion

A Google *Glass*-based software solution for consumers suffering from skin allergies was presented. It enables users to check cosmetic products in a mobile context and empowers patients to make informed buying decisions. In particular, the solution can help to avoid or reduce the risk for allergic reactions.

As the proposed solution is still at a very early stage, a full evaluation remains an open task. Yet, we tested our solution in a real life scenario during a first field test in various drugstores in Germany. First experiments with colleagues revealed skepticism for being tracked or monitored. In addition, we found that users should be made familiar with the handling of a Google *Glass* like devices up front. In particular, the use of voice commands and touch-enabled temples is a new experience for most users.

As our database of cosmetic products contains only around 50 products, the test with real life products was limited in terms of product diversity. It remains an open task to (semi-)automatically fill a large amount of products into our database. Yet, we are confident to increase that number and are open to find support from the research community. Displaying consumer-friendly translations for chemical agents into the field of vision remains future work. Hence, a huge resource of synonyms, laymen terms and other helpful information could be made available.

References

[1] Google Inc. Google Glass. [Online].; 2014 [cited 2014-1-11]. Available from: http://www.google.com/glass/start.

[2] Deutscher Allergie- und Asthmabund e.V. Kontakt-Allergie: DAAB. [Online].; 2014 [cited 2014-1-27]. Available from: http://www.daab.de/haut/kontakt-allergie/.

[3] Johnson JD, Case DO. Health information seeking: Peter Lang; 2012.

[4] Niederdeppe J, Hornik RC, Kelly BJ, Frosch DL, Romantan A, Stevens RS, et al. Examining the dimensions of cancer-related information seeking and scanning behavior. Health Communication. 2007: p. 153–167.

[5] Chomutare T, Arsand E, Hartvigsen G. Mobile peer support in diabetes. Studies in health technology and informatics. 2011: p. 48-52.

[6] Ghorai K, Saha S, Bakshi A, Mahanti A, Ray P. An mHealth Recommender for Smoking Cessation Using Case Based Reasoning. In Hawaii International Conference on System Sciences (HICSS); 2013; Wailea, HI, USA. p. 2695-2704.

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Examination of Centrality in a Health Social Network

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Abstract. Growing importance of health information platforms are acknowledges in recent studies. Such platforms are subject to discussion about an extent to which social network characteristics are realized. The platform under examination indeed demonstrates social network peculiarities. In this work, we explore the nature of centrality in one of the leading health information networks in Europe. Among other findings, we identify two nodes (representing patient and physician) are as the most important people in the network in terms of structural analysis Egregiously, these nodes are connected with the other types only and exhibit worth noticing connection patterns. These connections have been discussed along with a medication advice seeking behavior.

Keywords. Social Network Analysis, Centrality Analysis, Health Information Platform, Patient Experience

Introduction

Social networks' growing importance in industries such as e-commerce and media, social networks play an increasingly prominent role in health care. While importance of social networks is increasing dramatically, people tend to use health social networks and more Hospitals increasingly are using social networks for promotional purposes and to gauge consumer experiences with their organizations. More than 700 of the U.S.' 5,000 hospitals have a social media and social networking presence to enhance their ability to market services and communicate to stakeholders [1].

In this paper, we aim to analyze an information network of people joining a health platform. We employ a network science perspective to find out an extent to which the platform demonstrates social network characteristics. Our particular research interest is to explore the centrality notion for a social health network. Structural analysis is conducted to identify the most important nodes and their particular connection pattern.

1. Method

1.1. Research Background

Network science has an emerging trans-disciplinary characteristic which provides methods, techniques and tools to understand things and their relations. Online social

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networks have made considerable progress since the launch of Six Degrees.com. After 1997, many other social network platforms were created such as BlackPlanet, LunarStorm, Cyworld, Friendster, LinkedIn and Facebook.

In the health context, one can expect that patients having the same diseases could communicate each other in a social network. Similarly, physicians who have the same area of specializations could consult themselves. In order to call an information network as a social network a well, some characteristics should be examined:

Diameter is the maximum eccentricity of all the vertices [2] meaning the distance between the farthest nodes. Small-world experiment conducted by Stanley Milgram created a model called "Six Degrees of Separation" [3]. If there is a giant component in a non-randomly generated network, that network is worth to examine if it is a social network or not [4].

Centrality in network perspective is the importance of an individual node in that graph, through several algorithms. In this study, we consider Degree, and Betweenness as useful measures to identify important nodes.

Betweenness centrality ranks the nodes according to the how many times a node lies between the path of two nodes [5].

Our case is one of the leading health information platforms in Europe. The platform demonstrates some of the features of Facebook, Twitter, LinkedIn and forums. Some of similar attributes of the platform examined include user connections (patient, physicians) like in Facebook, following other people (like in Twitter), sense of professionalism and having premium accounts (like in LinkedIn) and asking questions (like in Bulletin Boards, Forums).

Patients can receive professional responses from physicians about their sicknesses. Physicians can publish their articles, videos, research and make it commercial like sharing their clinic addresses and making appointments.

There are 3 basic functionalities in the platform that can be considered as an edge. Connection, Questions & Answers, and Messages. The dataset provided consists of connections (physicians as MP and patients as P). We focused on Connection as edge type for the analysis.

1.2. Network Analysis

The provided dataset was in a raw form and analyzed with Gephi, which is an open source social network analysis tool [6].

When the dataset is analyzed, four different connection types are captured in the network: Patient - Patient, Patient - Physician, Physician - Physician, Physician - Patient. In the platform, nodes are modeled as patients and physicians. Since there are no multiple requests from one person to another, the network is considered as un-weighted.

There are 818 nodes with 1768 edges in our network initially and all the edges are directed. There are 246 physicians and 572 patients in the platform. The dataset has a time interval of 3 months (Oct 1, 2012 – Dec 31, 2012).

2. Results

Diameter of the network is 9, meaning it takes 9 nodes at most, to reach from one node to another. Close to the small world effect rule, which is 6.

There is one giant component in our network, covering 646 nodes which correspond to 78.97% of all the nodes. It includes 1611 edges, covering the 91.2% of all the edges. In the giant component, there are 439 patients (68% of the nodes in the giant component), and 207 physicians (32% of the nodes in the giant component).

Table 1. Basics of the Network at a Large Scale

Network at a Large Scale	
# of Nodes	818
# of Edges	1768
Network Diameter	9
Average Degree	2.161
Average Path Length	3.629

As shown in Table 1, the average degree is 2,161 and it means that there are many nodes who have at least 2 degrees (can be in degree or out degree). Lowest degree is 2 and highest degree is 318 (total of in degrees and out degrees) with node numbered as 138.

Node# 138 and node# 230 are ranked much higher than the rest with 0,226 and 0,225 in terms of betweenness centrality shown in Table 2 (normalized between 0 and 1) respectively.

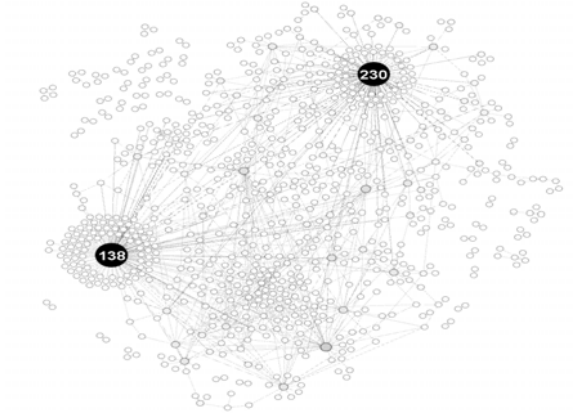


Figure 1. The nodes sized by betweenness centrality

Table 2. The following table shows the most critical nodes in the network in terms of centralities (ranked highest to lowest by betweenness) MP: Physician, P: Patient

Network at a Small Scale					
Node ID	**Roles**	**Betweenness Centrality**	**In-Degree**	**Out-Degree**	**Degree**
138	MP	0.226	147	171	318
230	P	0.225	115	120	235
364	P	0.041	32	42	74
242	P	0.027	15	22	37
267	P	0.026	20	29	49

Focusing on the two nodes with highest betweenness centrality values, their connection graphs are shown in Figure 2 and Figure 3.

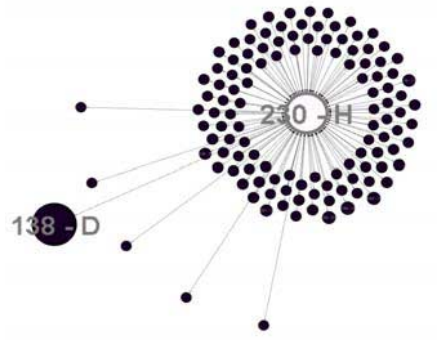


Figure 2. The connection graph of node# 230

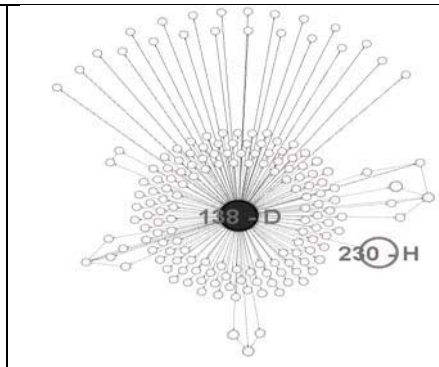


Figure 3. The connection graph of node# 138

3. Discussion

It is more reliable to examine the network for both a large-scale analysis and structural analysis for centrality, which is the importance of individual nodes with respect to network science.

From the point of large scale analysis, one may argue that the network has certain social network characteristics: Having a giant component, diameter value of 9, which is considerably close to Small World Effect and non-zero average clustering coefficient.

Focusing on the giant component; the percentage of patients decreases slightly while the percentage of physicians increase compared to the whole network. Some patients from the network seem to be not connected to the giant component. This could mean that there are more patients who are not actively using the network than physicians. These patients might idle users of the healthcare network.

The lack of validation in published healthcare social network analysis is a difficulty to interpret findings concerning health information platforms [7]. However, some interpretations can still be made about the results gained about the characteristics of the network.

The two nodes, (numbered as 230 and 138) which are a patient and physician respectively, seem to be the most important people in the network in terms of structural analysis. Egregiously, these nodes are connected with the other types only. Node# 230 only connects physicians. For the node# 138, a physician connecting with only his/her patients makes sense, but still this anomaly seems to be worth checking to find the reason behind this. The out-degrees of node# 138 are larger than his/her in-degrees. One can interpret that physicians use this health platform for different purposes such as promoting themselves and marketing. Further investigation, emphasizing on nodes numbered as 230 and 138 could be done.

4. Conclusion

The network meets some of the conditions required to be a social network. Diameter is small and close to what is expected for a social network and has a giant component covering most of the nodes.

From structural analysis, two nodes (Physician, Patient) are found to be the most important people. They have the highest betweenness centrality and degree centrality. The interesting thing is that they are only connected with nodes of the opposite group. One needs to use a larger data set to compare the findings along with time indication. Examining the network for the next 3-6 months period may justify the analysis. Also separation of the network by the groups (physicians and patients) and focusing on them separately can reveal other interesting results.

For the future work, community analysis of the network, node type analysis (brokerage) can be examined. Also with another tool, information exchange in the network (cliques) should be worked on. Dynamic analysis of the network for measuring the ongoing interactions between nodes with respect to the time stamp might be considered in the future works.

5. References

[1] Keckley P, Coughlin S, Gupta S. Privacy and Security in Health Care: Communication. Deloitte Development LLC. 2011.

[2] Mislove A, Marcon M, Gummadi K, Druschel P. and Bhattacharjee B. Measurement and Analysis of Online Social Networks. In: ACM. 2007; p.29-42.

[3] Milgram S. The Small World Problem. Psychology Today 2. 1967; p. 60-67.

[4] Hamill L, Nigel Gilbert L. Simulating Large Social Networks in Agent-Based Models: A Social Circle Model. 2010; p.78-94.

[5] Brandes U. A Faster Algorithm for Betweenness Centrality. Journal of Mathematical Sociology. 2001; p. 163-177.

[6] Bastian M, Heymann S, Jacomy M. Gephi: An Open Source Software for Exploring and Manipulating Networks. 2009.

[7] Dunn AG, Westbrook JI. Interpreting social network metrics in healthcare organisations: A review and guide to validating small networks. Soc Sci Med. 2011 Apr;72(7):1064-8.

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Activity Trackers: A Critical Review

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Abstract. The wearable consumer health devices can be mainly divided into activity trackers, sleep trackers, and stress management devices. These devices are widely advertised to provide positive effects on the user's daily behaviours and overall heath. However, objective evidence supporting these claims appears to be missing. The goal of this study was to review available evidence pertaining to performance of activity trackers. A comprehensive review of available information has been conducted for seven representative devices and the validity of marketing claims was assessed. The device assessment was based on availability of verified output metrics, theoretical frameworks, systematic evaluation, and FDA clearance. The review identified critical absence of supporting evidence of advertised functions and benefits for the majority of the devices. Six out of seven devices did not provide any information on sensor accuracy and output validity at all. Possible underestimation or overestimation of specific health indicators reported to consumers was not clearly disclosed to the public. Furthermore, significant limitations of these devices which can be categorized into user restrictions, user responsibilities and company disclaimers could not be easily found or comprehended by unsophisticated users and may represent a serious health hazard.

Keywords. Consumer health informatics, activity tracker, validity, review

Introduction

One of the key emerging trends in consumer heath informatics found in the resent review [1] was the expansion of mobile health applications [2]. Mobile applications facilitating patient-centered care and supporting self-monitoring using wearable devices are expected to form a new market niche exceeding $30 billion in 2018 [3]. In line with this outlook, growing number of companies consisting of small start-ups and well established manufacturers are hastily entering the wearable fitness app market. In terms of technology, this boom in wearable health apps has been triggered by the widespread availability of inexpensive micro-electro-mechanical systems (MEMS) sensors used, for example, for accelerometers and gyroscopes. Meanwhile, a variety of new brands of wearable devices are being aggressively advertised and sold as effective means to improve users' activity, sleep, and overall health. These devices are aimed at encouraging general population including seniors to make daily efforts to manage their health especially in the domains of activity, sleep and stress. An underlying promise to an unsophisticated consumer is that for a price of a wearable device and online subscription to a health tracking website, the user's health behaviours will be positively affected and overall heath will be improved. However, supportive evidence and systematic evaluation of these claims appears to be missing. The goal of our project was to review availability of objective information on performance of wearable devices

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sold in the market and validity of marketing claims. In this article, as a part of this work, we present our review results related to wearable activity trackers.

1. Methods

Seven wearable activity trackers were selected: BodyMedia FIT, Fitbit Flex, Jawbone UP, Basis band, Polar Loop, Nike+ FuelBand and Scosche RHYTHM. Comprehensive literature and online search was conducted using set of keywords including product name, associated technological terms, and company names in PubMed, FDA's database, and Google Scholar as well as in the vendors' own websites and linked webpages.

2. Results

2.1. Metrics

Seven activity trackers are categorized in two groups: six devices with an accelerometer and one device without an accelerometer (Scosche RHYTHM) which utilizes an optical heart beat detection sensor instead. Six activity trackers with an accelerometer are again divided into four devices (Fitbit Flex, Jawbone UP, Polar Loop and Nike+ FuelBand) embedding an accelerometer solely and two devices (BodyMedia FIT and Basis band) embedding other sensors also as like skin temperature sensor, Galvanic Skin Response (GRS) sensor, electrical/optical heart beat detection sensor and heat flux sensor. In case of Polar Loop, to get more accurate energy estimation, Polar Heart rate sensor can be worn on the chest additionally. The accuracies of sensors adopted in BodyMedia FIT are reported to be high enough (Accelerometer: ±0.08g; Heat Flux: ±10.0W/m^2; GSR: ±9.0nS; Skin Temperature: ±0.8°C). However, any sensor accuracy of the other activity trackers cannot be found. All seven activity trackers provide 'Calories burned' metric and six activity trackers with an accelerometer commonly provide 'Steps taken' metric as well. Accelerometer embedded activity trackers also produce 'Distance traveled', 'Exercise intensity', 'Very active minutes', and/or 'Longest active minutes' metrics. Basis band and Nike+ FuelBand can display additionally 'Perspiration' and 'Temperature' metrics and 'Nike Fuel earned' metric, respectively. In case of Scosche RHYTHM, by deploying a GPS sensor of a smartphone, it provides 'Distance traveled' and 'Speed and pace' metrics. Only a BodyMedia FIT is found to reveal its metric accuracies of 'Total calories burned', 'Total minutes of exercise' and 'Total steps taken'. No other devices report the accuracies of their metrics representing any aspect of physical activity.

2.2. Use of evidence-based methodologies in activity trackers

Since the first micro-electromechanical system (MEMS) accelerometer came into the world [4], a variety of wearable systems embedding a MEMS accelerometer for physical activity monitoring have been studied. Contrary to a pedometer bearing a drawback to estimating activity intensity, an accelerometer was established to be able to pick up acceleration proportional to external force reflecting activity intensity and subsequently energy expenditure (EE). In 1995, Melanson and Freedson reported that,

in a laboratory setting, a linear regression model involving body mass and activity counts measured from a single accelerometer worn on wrist was able to predict actual EE with standard error of estimate of 1.05Kcal·min^{-1} while showing correlation coefficient of 0.85 between actual and estimated EEs [5]. Regarding EE estimation in free-living condition, Bouten et al. [6] reported a correlation coefficient of 0.89 for 13 subjects asked to perform standardized daily physical activity for 36 hours but Hendelman et al. [7] reported correlation coefficients of 0.59~0.62 for 25 subjects asked to complete four bouts of walking at self-selected speeds, to play two holes of golf, and to perform indoor and outdoor household tasks. The latter's relatively low correlation was inferred to be caused by the inability of accelerometers to detect energy consumption related with upper body movement. BodyMedia FIT and Basis band contain more sensors on top of an accelerometer in order to compensate for the limitation of an accelerometer in determining activity intensity. According to the study performed by St-Onge et al., SenseWear Pro Armband, which utilizes the same sensors and the same measuring principle to BodyMedia FIT, showed relatively high correlation coefficient of 0.81 between its estimated EE and measured EE by the doubly labeled water (DLW) method in 45 free-living adults [8]. However, neither BodyMedia FIT nor SenseWear Pro Armband has unveiled any detailed explicit methodology to calculate metrics and it's the same to Basis band. Scosche RHYTHM, which does not rely on an accelerometer, also has not revealed the theoretical background. This device is assumed to be based on the relationship between EE and accumulated or averaged heart rate over a specific period [9-10]. For three different levels of stead-state activities on either a treadmill or a cycle ergometer, the correlation coefficient between measured EE and estimated EE with a regression model involving gender, heart rate, weight and age was found to reach as high as up to 0.857 [11]. However, for sixteen different activities simulating free-living conditions, the EE estimation with minute-by-minute heart rate plus basal metabolic rate was reported to be inaccurate; inter-individual coefficient of variance were 14~18% and estimation error of EE in one individual was predicted to range from -2986 to 2738 kJ/16h [12]. Overall, the majority of activity trackers lacked sufficient information on methodologies they employed and evidence of their efficacy.

2.3. Evaluation works

We also looked into whether each device has any published articles dealing with evaluations performed in scientific and controlled manners. As a result, there were found several published articles for SenseWear Armband and its latter models (Pro and Pro3) [13-18]. The SenseWear Armband or latter model was evaluated mainly by comparing estimated EE with the true value measured by indirect calorimeters or DLW method. The armband was shown to bring out valid and reliable estimation for free-living EE ($r=0.81$; $P<0.01$) [13] and resting EE ($r=0.86$; $P<0.0001$, $r=0.76$; $P<0.004$) [14-15] and, in laboratory exercise conditions, was proved to result in the best estimate of total EE at most speeds compared to CSA (Computer Science Applications Inc., Shalimar, FL), TriTrac-R3D (Professional Products Inc., Madison, WI), RT3 (Stayhealthy Inc., Monrovia, CA) and BioTrainer-Pro (IM Systems, Baltimore, MD) [16]. However, it also was found that SenseWear Pro Armband could significantly underestimate or overestimate total energy expenditure depending on the intensity and type of an exercise [17] and that SenseWear Pro3 Armband could not estimate EE within 16% error of the criterion for nine of the eighteen activities, consisting of six

indoor home-based activities, six miscellaneous activities and six outdoor aerobic activities [18]. One of Fitbit's family models (Ultra and One) and Nike+ FuelBand were found to be evaluated crudely in a few published articles [20-21]. Guo et al. compared Fitbit One, Nike+ FuelBand, iPhone Moves App and pedometers with actual steps taken over 400m distance and measured by a mechanical clicker, they reported that Fitbit One and Nike+ FuelBand showed 1.05±2.26% and 7.79±9.17% of estimation errors, respectively [19]. When Fitbit Ultra and Nike+ FuelBand were applied to people with Stroke and Traumatic Brain Injury, Fitbit Ultra and Nike+ FuelBand resulted in 0.73 (mean difference=-9.7) and 0.20 (mean difference=-66.2) of the intra-class correlation coefficients between actual steps retrieved from video tape and estimated steps, respectively [20]. Jawbone UP was found in a single article whose purpose was to evaluate and compare the accuracy of activity trackers including Nike+ FuelBand, Fitbit Ultra, BodyMedia FitCore and Adidas MiCoach as well as Jawbone UP in terms of steps taken and calories burned [21]. According to the results of the study, the accuracies of all trackers seemed good for steps taken but relatively low for calories burned. The accuracy of trackers, even of BodyMedia FIT, varied widely depending on the exercise modality. In case of Polar Loop and Scosche RHYTHM, there could not find any published scientific article.

2.4. FDA clearance

Only BodyMedia FIT was confirmed to be registered with the U.S. Food and Drug Administration (FDA) as a medical device for isokinetic testing and evaluation.

3. Discussion

First of all, most critical issues found in the devices are questionable or unverified qualities or benefits. Even with seductive claims or testimonies floating over internet, all the companies except BodyMedia do not provide the information on accuracies of sensor(s) and metrics sufficiently or at all. Similarly, only BodyMedia was found to have some published evaluation works supporting the device's reliability. However, even in case of BodyMedia, the disappointing facts are not well-known to general users that it is likely to underestimate total energy expenditure significantly for walking exercise, cycle ergometry and stepping exercise and overestimate total energy expenditure significantly for arm ergometer exercise [17]. It is also apt to result in up to 74% of errors in estimating EE for half of eighteen daily activities [18]. On the other hand, according to a third-party report [21], Nike+ Fuelband, Fitbit Ultra and Jawbone UP showed 0.98, 0.55 and 0.99 of correlations between estimated and actual steps for treadmill walking; 0.99, 0.98 and 0.44 for treadmill running; 0.99, 0.97 and 0.99 for elliptical exercise; 0.34, 0.17 and 0.49 for agility exercise. As a result, the correlations between estimated and measured EEs were limited to 0.24~0.87 for treadmill walking, 0.63~0.72 for treadmill running, 0.08~0.41 for elliptical exercise and 0.47~0.67 for agility exercise. These kinds of information should be disclosed to the public in order to help users understand the technical limitations of the devices before purchasing them. There is another serious issue called the self-imposed limitations which the companies notify through their terms of use, conditions for web services, user manuals, user guide, legal notice or similar but a user hardly recognize. The self-imposed limitations can be categorized into three types; user restriction, user responsibility and company

disclaimer. According to these limitations, 1) some users are not allowed to use some of the devices because of their age or medical and nutritional conditions; 2) users should consult a physician or a qualified medical professional before starting a fitness program or dietary program and could be responsible for all risks involved with the provided services; 3) companies may not be responsible for any risks or any information and services and would not guarantee the device output accuracy, reliability or effectiveness of their services and devices. Inability to access and comprehend these limitations represents a serious health hazard for consumers.

References

[1] M. C. Gibbons et al., Consumer health informatics: results of a systematic evidence review and evidence based recommendations. *Transl. Behav. Med.* **1** (2011), 72-82.
[2] C. Skinner and J. Finkelstein, Review of mobile phone use in preventive medicine and disease management, Proceedings of the IASTED International Conference on Telehealth/Assistive Technologies, 2008, pp.180–189, ACTA Press, Apr. 2008.
[3] J. Finkelstein et al., Enabling patient-centered care through health information technology. *Evid. Rep. Technol. Assess.* (Full Rep). **206** (2012), 1-1531.
[4] L. M. Roylance and J. B. Angell, A batch-fabricated silicon accelerometer, *IEEE. Trans. Electron. Devices* **26** (1979), 1911-1917.
[5] E. L. Melanson and P. S. Freedson, Validity of the Computer Science and Applications, Inc. (CSA) activity monitor, *Med. Sci. Sports Exerc.* **27** (1995), 934-940.
[6] C. V. Bouten et al., A triaxial accelerometer and portable data processing unit for the assessment of daily physical activity, *IEEE Trans. Biomed. Eng.* **44** (1997), 136–147.
[7] P. Freedson et al., Validity of accelerometry for the assessment of moderate intensity physical activity in the field, *Med. Sci. Sports Exerc.* **32** (2000), S442–S449.
[8] M. St-Onge et al., Evaluation of a portable device to measure daily energy expenditure in free-living adults, *Am. J. Clin. Nutr.* **85** (2007), 742-749.
[9] P. Avons et al., Approaches to estimating physical activity in the community: calorimetric validation of actometers and heart rate monitoring, *Eur. J. Clin. Nutr.* **42** (1998), 185-196.
[10] G. B. Spurn, A. M. Prentice, and P. R. Murgatroyd, Energy expenditure from minute-by-minute heart rate recording: comparison with indirect calorimetry, *Am. J. Clin. Nutr.* **48** (1998), 552-559.
[11] L. R. Keytel et al., Prediction of energy expenditure from heart rate monitoring during submaximal exercise, *J. Sports Sci.* **23** (2005), 289-297.
[12] R. Li, P. Deurenberg, and J. G. Hautvast, A critical evaluation of heart rate monitoring to assess energy expenditure in individuals, *Am. J. Clin. Nutr.* **58** (1993), 602-607.
[13] M. St-Onge et al., Evaluation of a portable device to measure daily energy expenditure in free-living adults, *Am. J. Clin. Nutr.* **85** (2007), 742-749.
[14] M. Malavolti et al., A new device for measuring resting energy expenditure (REE) in healthy subjects, *Nutr. Metab. Cardiovasc. Dis.* **17** (2007), 338-343.
[15] M. L. Fruin and J. W. Rankin, Validity of a multi-sensor armband in estimating rest and exercise energy expenditure, *Med. Sci. Sports Exerc.* **36** (2004), 1063-1069.
[16] G. A. King et al., Comparison of activity monitors to estimate energy cost of treadmill exercise, *Med. Sci. Sports Exerc.* **36** (2004), 1244-1251.
[17] J. M. Jakicic et al., Evaluation of the SenseWear Pro Armband to assess energy expenditure during exercise, *Med. Sci. Sports Exerc.* **36** (2004), 897-904.
[18] P. Dudley et al., Validity of a multi-Sensor armband for estimating energy expenditure during eighteen different activities, *J. Obes. Wt. Loss. Ther.* **2** (2012), doi:10.4172/2165-7904.1000146.
[19] F. Guo et al., An evaluation of wearable activity monitoring devices, *21st ACM Int. Conf. Multimedia*, Barcelona, Spain (2013), 31-34.
[20] G. D. Fulk et al., Accuracy of 2 activity monitors in detecting steps in people with stroke and traumatic brain injury, *Phys. Ther.* **94** (2014), 222-9.
[21] C. M. Stackpool, The accuracy of various activity trackers in estimating steps taken and energy expenditure, M. S. Thesis, Univ. Wisconsine, La Crosse, WI, USA, 2013.

6. Natural Language Processing

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Sublanguage Analysis of Medical Weblogs

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Abstract. Analysing medical social media data gains in importance given an increased availability of such data. In this paper, we analyse the language of medical blogs by means of a sublanguage analysis. More specifically, verb usage, semantic categories of used words as well as co-occurrence patterns are determined by means of natural language processing tools. The results show that in this text type, many concepts refer to the semantic categories Living Beings and Chemicals and Drugs. In contrast to clinical documents, the spectrum of verbs in blogs is very broad creating semantic relations of different types. From these language characteristics, we conclude for automatic processing tools for medical blogs that methods for reference resolution and for relation extraction where the relation type does not need to be specified in advance are required.

Keywords. Information extraction, Natural language processing, Healthwebscience

Introduction

The advances in internet and mobile technologies changed the way people access, use and share information. A process of ”revolutionizing healthcare” by improving healthcare and quality of life has begun [1]. Data and experiences on diseases, symptoms and medical treatments are exchanged via instant messaging, blogs, social networking (e.g. Facebook) or video sharing (e.g. YouTube). These tools opened new ways of communicating and enabled for timeless and location-independent information exchange. Patients increasingly rely on the Internet when looking for medical information and advice that extends their ability to share personal experiences and opinions on health concerns [7].

The huge amount of health information available online requires automatic methods for supporting its analysis and interpretation. Among others automatic processing tools that are able to identify relevant pieces of information in medical social media texts are required. Linguistic peculiarities of that particular data need to be considered in the development of appropriate processing tools. Existing language processing tools are especially designed for processing clinical documents and are optimised for that particular sublanguage (i.e., short sentences or even telegraphic style of writing, verbless clauses, use of formal language). It is still an open question, what the differences between the language and word usage in clinical and medical blog are and how existing clinical document analysis tools perform on medical blogs. Clearly, when providing health information or discussing health issues in the Web, the language used is domain-specific, i.e. medical terms and concepts are exploited. Medical social-media data or blogs are written for other purposes than clinical texts and biomedical literature, even though authors can be healthcare professionals, clinical researchers as well as non-professionals. Thus, the term usage and content are expected to be different.

Whereas the linguistic characteristics of clinical and biomedical texts have been analysed comprehensively by other researchers [6] [10] [4], the literary composition of medical social-media data has unfortunately not yet been analysed with the same degree of precision. In this paper, we study the language and content characteristics of medical blogs by means of a sublanguage analysis. We want to find out whether there are characteristic linguistic or semantic patterns in medical blogs that can support or need to be considered in automated processing which is necessary for information retrieval tasks in the medical domain or other applications using medical social media.

1. Methods

1.1. Sublanguage analysis

The sublanguage theory was proposed by Zellig Harris [5]. He claimed that languages of technical domains have a certain structure and regularity which can be specified in computer-processable manner. His theory incorporates domain-specific semantic information and syntactic peculiarities of a domain language. Thus, a sublanguage is in this way a subset of a natural language characterized by the fact that only a subset of the vocabulary and certain grammatical rules are used.

Sublanguage analysis is a technique for discovering units of information and their relationships in narrative text. Semantic categorization of terms, co-occurrence patterns or constraints, usage of terminologies and controlled vocabularies within the sublanguage and other characteristics are assessed within sublanguage analysis [4]. The clinical sublanguage was comprehensively analysed within the context of developing natural language processing tools for clinical documents [12] and compared to the biomedical sublanguage [4], to general English [2] and to newspaper language. One of the most often used mean to analyse the (clinical) sublanguage, is a study of word usage. In this work, we study the sublanguage in medical social media which was so far not considered by existing sublanguage analyses, but can provide useful insights for developing language processing tools for such data. NLP work on social media focused so far mainly on sentiment analysis. Domain-specific usage of terms and language patterns has not yet been analyzed before.

1.2. Study design

We characterise the medical blog sublanguage by studying verb usage, semantic categories of words, and co-occurrence patterns of semantic categories with verbs. For this purpose, language processing tools are applied to the data, namely (1) DragonToolkit [11] for identifying medical concepts in free text and their categories, (2) ReVerb [3] for identifying relations in sentences, (3) openNLP for part of speech tagging and chunking.

As underlying terminology, we are using the Metathesaurus of the Unified Medical Language System (UMLS). Each UMLS concept is assigned to at least one of the 134 semantic types that in turn have been aggregated into a set of 15 semantic groups to reduce complexity. We chose the open information extraction tool ReVerb for extracting relations in form of two arguments connected by a relation type. ReVerb is designed for Web-scale information extraction, where the target relations cannot be specified in advance and speed is important [3]. We selected ReVerb for our study

since it provides correlation patterns without the need of specifying relation types of interest in advance. ReVerb takes as input a sentence tagged with part of speech information and NP chunks and returns relation triples consisting of two arguments and a relation phrase.

A co-occurrence pattern as used in the sublanguage analysis consists of one or two sets of main categories connected by a verb. It is received by first applying ReVerb to a sentence. The arguments extracted by ReVerb are processed by the DragonToolkit to map to UMLS concepts and to get semantic categories of the words in the argument string. An example of a co-occurrence pattern is: *[Procedures + show + Disorders]*. The left argument was mapped to a concept of the semantic category *Procedures* and the left argument to a concept of the semantic category *Disorders*.

The data set underlying our study comprises a random sample of around 12800 texts collected over a period of four years starting in 2009 from RSS feeds provided through the blogs of WebMD (http://www.webmd.com) and EverydayHealth (http://www.everydayhealth.com), from the Medicinenet website (http://www.medicinenet.com), as well as blogs from several sources. WebMD provides health information provided in a blog style by physicians. EverydayHealth.com is a provider of online health information designed for non-health professionals. MedicineNet.com provides authoritative medical information for consumers. The RSS feeds were collected, the URL to the complete text identified and the text extracted from the HTML page. From WebMD 1000 texts were considered; from the other sources 100 texts per source. We chose only physician-written texts to be able to compare with clinical texts that are also written by doctors.

2. Results

In the medical social-media data words that belong to the category *Living Beings* are used often among all studied blog data sets. In addition, words falling into the categories *Disorders, Chemicals and Drugs, Concept and Ideas* are exploited frequently.

The most frequently used co-occurrence patterns determined are:

- Patterns referring to having or developing diseases or symptoms (e.g. [have + Disorders], [develop + Disorders]),
- Patterns on drug consumption (e.g., [take + Chemicals and Drugs], [receiv + Chemicals and Drugs]),
- Patterns representing statements of persons on medical issues (e.g. [Living Beings + say + Concepts and Ideas, Phenomena], [say + Living Beings], and
- Patterns referring to the use of devices for confirming a diagnosis or performing procedures (e.g. [Devices + discov + Disorders, Procedures]).

It can be seen that frequently occurring patterns are referring to having or developing diseases or symptoms and performing actions / medical procedures including drug consumption. Verbs that are used frequently in medical blogs fall into the following categories. (Note that verb forms of *be, have* and *do* were not considered even though they had a high frequency as well.)

- Verbs describing effects of medical procedures, drugs and proteins or genes: affect, regulate, reduce, prevent, improve, help, treat, increase, enhance, enable, benefit, strengthen

- Verbs describing observations: appear
- Verbs referring to education and research: learn, discuss, study, empower, educate
- Verbs describing disease development and transfer: contribute, depend, infect, require, acquire.

Table 1. Linguistic characteristics of medical blogs

Sentence structure	Rather long sentences
Word usage	Adjectives, descriptive and narrative words
Language	Clinical terminology, medical terms are very frequent, Consumer health vocabulary, common language,
Spelling	Abbreviations, misspellings
Semantic categories of words	Living Beings, Disorders, Chemicals and Drugs, Concept and Ideas

3. Discussion

This paper studied the characteristics of medical blogs by means of a sublanguage analysis. Content-wise information on treatments, diseases and drugs are given rather than information on an individual in social media. In contrast to clinical documents, medical blogs can refer to an individual person, but contain seldom measured (clinical) values and in our data set authors often refer to general health statistics or health information. Friedman et al. studied the sublanguage in clinical and biomedical texts [4]. They found out that the clinical sublanguage is characterised by a usage of words belonging to the semantic categories Behaviour, Findings, Medication, Device, Body function, Labtest, Procedure [4]. This is in contrast to our results for medical blogs where concepts referring to *Living Beings, Disorders, Chemicals and Drug* are used most frequently. Also verb usage is different. The biggest differences to language used in clinical documents were found to be the usage of a broad spectrum of verbs in medical blogs, which is in contrast to clinical documents and the reference to terms referring to living beings. This results in challenges for automatic tools that include reference resolution, processing of verbs and detecting relations. The broader spectrum of verbs used in medical blogs results in a need for tools that are able to collect these verbs and analyze their meanings when it comes to automatically analyze social media text. A broad range of verbs is used in medical blogs, which makes it difficult to specify in advance verb patterns or extraction rules that contain verb roots. In contrast a limited set of verbs are used throughout the discharge summaries – a characteristic that is used in natural language processing from those texts. An extended linguistic analysis of medical blogs should therefore concentrate on verb usage, which was studied for medical corpora already [15]. Wang et al. studied operative notes and their content and language by analyzing and categorizing verbs [14]. An alternative approach to study differences between language and content in clinical notes of different types and specialities was suggested by Patterson and Hurdle [13]. They proposed a document clustering approach to study in more detail characteristics of clinical sublanguages. To determine patterns of semantic types, we applied open information extraction, which was so far not considered for sublanguage analysis. We decided to use that approach to be able to extract the relation type. This goes beyond co-occurrence analysis of semantic types and is interesting, since verb meanings would get lost during the

mapping process to UMLS. A limitation of this approach is that only relations with two arguments are extracted by the chosen implementation.

Corpus analysis methods [9] would be an additional option for analyzing medical social media. We chose sublanguage analysis to be able to compare with results from sublanguage analysis from clinical texts.

It is clear that an assessment as described in this paper can only consider a subset of medical social-media data. The data set underlying our study mainly comprised blogs written by health professionals. The content is thus more informational; information on medical treatments is described. Content and language could be different when only patient-written blogs are considered. A generalization of the results to patient-written texts is difficult. A limitation of the study is the mapping to UMLS concepts. The DragonToolkit does not use the latest UMLS version. The tool has already been evaluated on biomedical abstracts collected from MEDLINE and achieved a precision rate of 71.6% and a recall of 75% [11]. However, quality might be different for mapping text of medical social-media to UMLS concepts. Our study focused on identifying linguistic characteristics that might influence the future development of natural language processing tools for medical social-media data. This quality assessment is still an open research questions.

References

[1] L. Aase, G. D., M. Gould, J. Noseworthy, and F. Timimi. Bringing the Social-media Revolution to Health Care. Mayo Clinic Center for Social-media, 2012.

[2] D. A. Campbell and S. B. Johnson. Comparing syntactic complexity in medical and non-medical corpora. Proc AMIA Symp, p.90–94, 2001.

[3] A. Fader, S. Soderland, and O. Etzioni. Identifying relations for open information extraction. In Proceedings of the Conference on Empirical Methods in Natural Language Processing, EMNLP '11, p.1535–1545, Stroudsburg, PA, USA, 2011. Association for Computational Linguistics.

[4] C. Friedman, P. Kra, and A. Rzhetsky. Two biomedical sublanguages: a description based on the theories of zellig harris. Journal of Biomedical Informatics, 35:222–235, 2002.

[5] Z. Harris. A theory of language and information: a mathematical approach. Clarendon Press, Oxford, 1991.

[6] I. Kovic, I. Lulic, and G. Brumini. Examining the Medical Blogosphere: An Online Survey of Medical Bloggers. Journal of Medical Internet Research, 10(3), 2008.

[7] A. Lau, K. Siek, L. Fernandez-Luque, and et al. The role of social media for patients and consumer health. Yearb Med Inform., 6:131–8, 2011.

[8] A. McCray. An upper-level ontology for the biomedical domain. Comp Funct Genom, 4:80–84, 2003.

[9] E. Miscin. Use of Corpus Analysis Tools in Medical Corpus Processing. INFuture2013: "Information Governance", 187-196: 2013 .

[10] S. M. Meystre, G. K. Savova, K. C. Kipper-Schuler, and J. F. Hurdle. Extracting information from textual documents in the electronic health record: A review of recent research. p.128–144, 2008.

[11] X. Zhou, X. Zhang, and X. Hu. Dragon toolkit: Incorporating autolearned semantic knowledge into large-scale text retrieval and mining. In Proceedings of the 19th IEEE International Conference on Tools with Artificial Intelligence (ICTAI), October 29-31, 2007, Patras, Greece, 2007.

[12] N. Sager and N. T. Nhan. The computability of strings, transformations, and sublanguage. In B. E. Nevin and S. M. Johnson, editors, The legacy of Zellig Harris: Language and information into the 21st century, p.79–120. John Benjamins, 2002.

[13] O. Patterson, J.F. Hurdle. Document Clustering of Clinical Narratives: a Systematic Study of Clinical Sublanguages, AMIA Annu Symp Proc., p.1099-1107, 2011.

[14] Y. Wang , S. Pakhomov, N.E. Burkart et al. A study of actions in operative notes. Annu Symp Proc., p.1431-40, 2012.

[15] O. W. Tchami, M-C. L'Homme, N.Grabar. Discovering Semantic Frames for a Contrastive Study of Verbs in Medical Corpora.Terminologie Intelligence Artificielle (TIA) 2013. Villetaneuse, France.

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Computer Based Extraction of Phenoptypic Features of Human Congenital Anomalies from the Digital Literature with Natural Language Processing Techniques

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Abstract. The lack of laboratory tests for the diagnosis of most of the congenital anomalies renders the physical examination of the case crucial for the diagnosis of the anomaly; and the cases in the diagnostic phase are mostly being evaluated in the light of the literature knowledge. In this respect, for accurate diagnosis, ,it is of great importance to provide the decision maker with decision support by presenting the literature knowledge about a particular case. Here, we demonstrated a methodology for automated scanning and determining of the phenotypic features from the case reports related to congenital anomalies in the literature with text and natural language processing methods, and we created a framework of an information source for a potential diagnostic decision support system for congenital anomalies.

Keywords. Human congenital anomalies, information extraction, natural language processing, text processing, clinical decision support

Introduction

With reference to the World Health Organization 2012 data, it is estimated that 3.2 million fetuses and infants are being affected from human congenital anomalies (HCAs) per year and 270.000 newborns die in the first 28 days due to reasons related

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with HCA [1]. Although there are variations among ethnical groups in frequency, HCAs, which affect almost 2-3% of the newborns, are accepted as common and major health issue for all ethnical groups [2-3]. HCAs are mostly challenging and require special expertise, considering the number of the phenotypic features and the rare symptoms in the diagnosis phase. In addition, most HCAs are not diseases that comprise of a particular combination of phenotypic features and that are exactly distinct from other HCAs in terms of the related features [4-6]. This situation renders the use of assistive tools such as clinical decision support systems (CDSSs) almost obligatory for the accurate and exact diagnosis of HCAs.

Natural language processing (NLP) techniques have gained a wide use in obtaining and evaluating the information especially in life sciences due to the excessive increase of information in recent years. Besides, the automatized extraction of clinical information, such as signs, symptoms, medications and/or observations, from scientific documents and free-text formatted medical records using NLP should be considered crucial for the development of the CDSSs [7]. Here we aimed at developing a computational strategy to extract the phenotypic features, which characterize HCAs from the case reports in the literature via text processing and NLP methods. In addition to this, by using the extracted information, we created an initial framework of an information base for a potential CDSS in the diagnosis of HCAs.

1. Methods

The term list, which comprises the C16.131-Congenital Abnormalities subcategory of a branch of the Medical Subject Headings (MeSH) tree structure, is downloaded from the MeSH database for determining HCAs [8]. During the creation of the corpus associated with the HCAs, the free-text literature data served via PubMed database was utilized. Using the query words in the structure of "MeSH term[MeSH Major Topic] AND Case Reports[ptyp]" for each HCA, the abstracts of the case reports pertaining each of the MeSH terms were extracted automatically from the database. Forming the query words and the download procedure were performed with the scripts written in Python programming language.

Natural Language Toolkit modules and the scripts written in Python were utilized in all text processing steps on the corpus [9]. At the first step, the string.lowercase() function was used for standardizing the characters in the corpus. In the following pre-processing step, the sentence segments for each abstract were determined with Punkt algorithm [10]. From these segmented sentences in each abstract, the white spaces were removed via tokenization in the third pre-processing steps. In the fourth step the stopwords with little lexical content such as "a", "an", "the", "at", etc. were removed from the sentence. Thus, preventing possible alignment issues to occur in the following steps, during the searching of pre-defined entities in the texts and mapping these with phrases, was aimed. In the last step, each token were parsed into their roots and affixes and token roots were obtained. The Lancaster stemmer in the nltk module was used for the stemming procedure [11]. By this means, possible issues in mapping a token or a token group with the dictionaries or ontologies due to plural suffixes, past tense suffixes, etc. were solved. The same text processing steps were conducted on the more than 10.000 phenotypic feature terms that comprise the Human Phenotype Ontology (HPO). Later, an inverted index was built up for enabling and facilitating the search of the HPO terms in the case reports. While searching and identification of phenotypic

features, the following rules were applied; each token comprising the HPO term must (i) have the same document ID, (ii) be in the same sentence, and (iii) be ordered sequentially (the difference between the index positions must equal to 1).

For determining whether the terms defined in the case reports were accurately matched with the findings defined in the documents, the randomly selected case reports were manually examined. In addition, the percentage of the features, which could not be determined due to the use of the HPO, even though they were present in the document, was calculated. For this purpose, the features in a randomly selected document were marked and this was compared to the total numbers of features and the number of the HPO terms associated with that document. When the number of the features that could not be determined reached 100, this number was proportioned to the number of the computationally determined HPO terms.

The maximum entropy model for part-of-speech tagging algorithm was used to define the lexical categories of the tokens [12]. By this method, the tokens tagged as verb for each sentence bearing at least one phenotypic feature were identified and their frequencies were calculated. When the total occurrence frequencies of the verb tagged tokens were ordered descendingly, the first 75% of this total value was computationally determined. The tokens in this group were manually examined and it was established whether there were semantic relations between these tokens and the phenotypic features. With this approach, verb labeled tokens frequently used in the expressions for the presence of phenotypic features were identified.

In addition to this, N-gram analysis was performed to find whether the sentences containing HPO terms had common phrase patterns or not, and if there were, what their frequencies were. In the first 5.000 2, 3 and 4-tuple phrase patterns, the verb labeled tokens were searched, which facilitated the direct inference that whether the manually determined phenotypic features were related the HCA in question. Moreover, phrases such as “patient with”, which did not contain any verb token, but provided information about the presence of an abnormality in the patient, were identified. It was manually determined that the aforementioned phrase patterns could positionally precede or follow the findings; and they could be positive or negative semantically. If the phrase pattern had a positive meaning, the negative version of the phrase; or if it had a negative meaning, the positive versions were manually created. Then, a corpus search was conducted using the phrase patterns which facilitated the semantic inferences regarding the computationally determined phenotypic features in the sentences.

2. Results

As a result of the automatic search conducted with the programmatic access and advanced search features through PubMed database using a total of 486 MeSH terms, 115.542 distinct case reports were accessed and 60.306 abstracts belonging to these were downloaded in free-text format. After the text processing procedure steps, 79.544 distinct and unique character sequences comprising all the case reports in the corpus, in other words the token roots, were determined.

After searching the HPO terms, which were put through the text processing procedures, 428.797 phenotypic features were identified on the index table. In order to identify whether the HPO term mapped by the computer is the same with the phenotypic abnormality in the sentence, a total of 336 sentences were analyzed in the sampling process, and it was found that the HPO terms defined in these sentences and

the terms in the ontology list matched with a 97.82% accuracy rate. Moreover, the investigation of the methodology for capturing the phenotypic abnormalities in the case reports showed that the approach used here could catch 89.20% of the features in the document.

With the computer-based approach, 203.907 different sentences including at least one HPO term were found in all the documents comprising the documents. 6.753 distinct tokens were determined with the verb tag. These tokens were used in the corpus for 1.369.478 times; and it was found that the most frequent 125 verbs constituted 75% of the total number tokens with verb tag. After the n-gram analyses conducted for determining the common phrase patterns in the sentences containing at least one HPO term, 5.102.623 bigrams, 4.898.686 trigrams and 4.694.751 four-grams were obtained and the frequencies of these double, triple, and quadruple token groups were determined. In addition to the n-gram analysis, the 125 most frequent verb tagged token were examined and 120 among these were found to have semantic relations with the phenotypic features. The tokens in this group, which did not have any relation with the features, were "performed", "using", "admitted", "did" and "follow".

As a result of the evaluation of the verb tagged tokens together with the double, triple and quadruple token groups obtained with n-gram analyses, the phrases which were present in the case reports and had semantic relations to the phenotypic features were manually tagged. A set of rules, which facilitated the extraction of the phenotypic features from the case reports, was devised using the 190 phrases and generating the antonyms of these phrases, as shown in Table 1. As a result of scanning the rules on the whole corpus 28.853 findings, symptoms and signs were determined from all case reports, which were associated with the 486 HCAs.

Table 1. Some examples of phrase patterns which have semantic relations to the features in the case reports.

Phrase	Polarity	Opposite meaning	Phenotypic feature is observed before/after the phrase
affected with	Positive	not affected with	after
biopsy showed	Positive	biopsy showed no	after
examination showed	Positive	examination showed no	after
found to have	Positive	not found to have	after
not been reported	Negative	previously not been reported, not been reported previously, not been reported before	after/before
was seen	Positive	was not seen	before
were observed in	Positive	were not observed in	after/before
who has	Positive	who has not, who has no	after

3. Discussion

Herein, we described an automated scanning and determining methodology for the phenotypic features related to the HCA, from the case reports in the scientific literature using text processing and NLP methods. In the search procedure performed by using the HPO terms in the sentences, the rate of accurate match between a phenotypic feature determined by the search algorithm and the HPO term is thought highly convincing for such a new designed computational process.

In addition, in the calculations for determining to what extent the features in the case reports could be determined using the HPO term list, we found that approximately nine out of ten of all features in a sentence could be determined with the devised

algorithmic approach. We consider the success rate obtained is within acceptable limits and promising for future works. In the manual analysis for determining the reasons for failing to capture the features in the sentences, we found that the phenotypic features in a document could not be computationally captured due to three main reasons. The first one is that the feature mentioned in the document did not have correspondence in the terms list in the HPO. For instance, the "multiple nodular liver tumors" feature in the document with PubmedID: 2596519, did not have any corresponding entry in the HPO ontology. Second, as in the "inguinal herniae" example, although the term had correspondence in the HPO ontology, "Inguinal hernia" (HP:0000023), the differences in word morphology caused mismatches. The third one is the determination errors due to the abbreviated writing of terms in the documents, such as writing "Mental retardation" (HP:0001249) as retardation.

In this study, a novel approach was implemented, as the rules were constructed using both phrase patterns and the verbs, and these rules were used for semantic inference. Rule-based approach is one of the methods used in semantic inference from natural languages [13]. However, information extraction from case reports, as in this study, is conducted with regard to the rules, and information extraction could not be possible in the existence of structures which violate these rules. We believe that the information extracted with the rules, constructed using both phrase patterns and the verbs, might be a reliable information source for a potential diagnostic decision support system for HCAs. We are currently preparing to practically apply the methodology developed in this work and building a statistical model for defining major phenotypic features that characterize each HCA as wells as creating an easily updatable and completely automated living diagnostic decision support tool which facilitates the decision making processes of potential users.

References

[1] World Health Organization [Internet]. (cited: 2013 November 21) Available from: www.who.int/en/
[2] Rosano A, Botto LD, Botting B, Mastroiacovo P. Infant mortality and congenital anomalies from 1950 to 1994: an international perspective. J Epidemiol Community Health. 2000; 54(9)660–6.
[3] Corsello G, Giuffrè M. Congenital malformations. J Matern Fetal Neonatal Med. 2012; 25 Suppl 1:25-9.
[4] Kumar P, Burton B. Congenital Malformations: Evidence-Based Evaluation and Management. McGraw Hill Professional. 2007; 408.
[5] Rauch A, Hoyer J, Guth S, Zweier C, Kraus C, Becker C, et al. Diagnostic yield of various genetic approaches in patients with unexplained developmental delay or mental retardation. Am J Med Genet A. 2006; 140(19):2063–74.
[6] Srour M, Mazer B, Shevell MI. Analysis of clinical features predicting etiologic yield in the assessment of global developmental delay. Pediatrics. 2006; 118(1):139–45.
[7] Demner-Fushman D, Chapman WW, McDonald CJ. What can natural language processing do for clinical decision support?. J Biomed Inform. 2009; 42(5):760–72.
[8] National Library of Medicine. Medical Subject Headings [Internet]. (cited: 2013 November 23) Available from: www.ncbi.nlm.nih.gov/mesh
[9] Natural Language Toolkit [Internet]. (cited: 2013 November 28) Available from: http://nltk.org/
[10] Kiss T, Strunk J. Unsupervised Multilingual Sentence Boundary Detection. Comput Linguist. 2006; 32:485–525.
[11] The Lancaster Stemming Algorithm. (cited: 2013 November 28) Available from: www.comp.lancs.ac.uk/computing/research/stemming/
[12] Ratnaparkhi A. Maximum entropy model for part-of-speech tagging. In: Proceedings of the Empirical Methods in Natural Language Processing Conference. 1996; Vol 1:133–42.
[13] Mykowiecka A, Marciniak M, Kupsc A. Rule-based information extraction from patients' clinical data. J Biomed Inform. 2009; 42:923–36.

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Exploiting Parallel Corpora to Scale Up Multilingual Biomedical Terminologies

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Abstract. Creating and maintaining biomedical terminologies for multiple natural languages is a resource-expensive task, typically carried out by human domain experts. We here report on efforts to computationally support this process by treating term acquisition as a machine translation-guided classification problem capitalizing on parallel corpora. We report on experiments for French, German, Spanish and Dutch parts of a UMLS-derived terminology for which we generated 18k, 23k, 19k and 12k new terms and synonyms, respectively. Based on expert assessments of a novel German terminology segment about 80% of the newly acquired terms were judged as bio-medically reasonable and terminologically valid.

Keywords. UMLS, multilingual terminology, term acquisition, parallel corpora

Introduction

A large variety of terminological resources for the life sciences have been developed over time, yet mainly for the English language. Many efforts were made by non-English language communities to provide these terminologies in their native languages as well. The premier example for these efforts is the *Unified Medical Language System* (UMLS; http://www.nlm.nih.gov/research/umls/), an umbrella system for various specialized sub-domain terminologies that was originally developed for the English language only. Yet the term gaps encountered for non-English languages are still huge, e.g. the Spanish, German, French and Dutch counterparts lack over two-thirds of the coverage of the English UMLS (see Table 1).

Our approach to help close this gap automatically tries to find translation equivalents for English terms in parallel translation corpora, namely MEDLINE titles (http://mbr.nlm.nih.gov/Download/) and EMEA drug leaflets (http://opus.lingfil.uu.se/EMEA.php). Parallel corpora consist of sets of bilingual documents where the source language documents are translated into target language documents by knowledgeable humans. These translations are considered to be fully meaning-preserving and of high quality. Exploiting parallel corpora for the purposes of term acquisition three types of translation equivalents can automatically be found for the non-English terminologies: *known terms* and *additional synonyms* for concepts already labeled in a terminology, as well as *entirely new terms* for concepts with no prior label in a terminology.

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Identifying new biomedical terms is a tricky task because domain-specific terms not only occur as nominal singletons (e.g. *'appendicitis'*), but also as multi-word expressions (MWE), like *'Alzheimer's disease'* or *'acquired immune-deficiency syndrome'*. Approaches that aim at finding translations for the latter can be classified as either pattern-based [1] or statistically motivated. Pattern-based solutions suffer from the need to supply part of speech patterns, are often hand-crafted and thus become cumbersome to maintain. Statistical approaches circumvent this draw-back by using translation probabilities of the single words of a MWE [2] or of entire phrases [3].

1. Methods

We distinguish three steps in our workflow: corpus set-up, candidate generation and candidate filtering. Both the parallel corpora and the UMLS version we use were taken from the CLEF-ER 2013 challenge (https://sites.google.com/site/mantraeu/clef-er-challenge).

Corpus Set-up. We started by merging the MEDLINE and EMEA parallel corpora, resulting in one corpus per language pair, containing 860k, 388k, 713k and 195k parallel sentences for the German, Spanish, French and Dutch language, respectively. A flat annotation for 'bio-medical entities' was performed based on the UMLS-derived terminology using a LINGPIPE-based gazetteer (http://alias-i.com/lingpipe/). 10% of each of the annotated corpora were set aside and used to train language-specific named entity recognition (NER) systems [4] to find bio-medical entities, in general (no distinction of more fine-grained semantic groups, such as *Disease*, was enforced). Thus, the probabilities provided by the NER systems characterize the bio-medical termhood of a word sequence under scrutiny. The remaining 90% of the corpora were used to train a phrase-based statistical machine translation (SMT) model with the open-source tools GIZA++ [5] and MOSES [6].

Candidate Generation. The so-called phrase table of that SMT model contains bilingual phrase pairs, such as *'indication of tubal cancer' :: 'Hinweis auf ein Tubenkarzinom'* and translation probabilities for each pair. Term candidates for enriching the UMLS were produced by selecting those phrase pairs translating a known English biomedical term into one of the target languages.

Candidate Filtering. We filtered these candidates with a Maximum-Entropy classifier from the WEKA repository (http://www.cs.waikato.ac. nz/~ml/weka/). This classifier was trained using the annotations generated in the corpus set-up step as training material together with the following features: *1)* translational probabilities from the SMT model, *2)* the smoothed ratio between the respective lengths of the term candidate and its translation equivalent, and *3)* the NER system's judgments on each candidate's termhood, computed by running the NER system on all sentences containing the candidate and averaging the probabilities for it being a named entity.

2. Results

The terminology acquisition system found over-all several thousands of entirely new terms and additional synonyms for each of our four lan-guages (see Table 1). Numbers are quite similar for German and French, whereas the much smaller size of the Dutch corpus leads to a higher amount of entirely new terms and the inverse is true for

Spanish due to the comparably higher coverage of the Spanish UMLS. To evaluate the extracted terms we used both an automatic evaluation procedure and human expert assessments, dealing with *already known* terms/synonyms, or *additional synonyms* and *entirely new terms*, respectively.

Table 1. Number of terms and synonyms already contained in the UMLS in contrast with those extracted by our system for four languages (German, French, Spanish, and Dutch). We distinguish three types of extracted items: 'already known terms and synonyms' are already contained as a label for this concept and language (*term re-invention*), 'additional synonyms' supplement terms/synonyms known for this concept and language by new ones (*term enrichment*), 'entirely new terms' comprise really novel terms for a concept in that language previously unlabeled (*term learning*).

Language	English	German	French	Spanish	Dutch
UMLS terms & synonyms	1,822k	120k	137k	644k	116k
Already known terms & synonyms	-	11k	10k	19k	4k
Additional synonyms	-	13k	11k	17k	6k
Entirely new terms	-	10k	7k	2k	6k

In the first setting, we measured the system's ability to *re-invent* UMLS fragments, using 10-fold cross-validation. This was done concept-wise, i.e. a term being a synonym for multiple concepts, or a translation thereof, was examined multiple times depending on its degree of semantic ambiguity. A term was counted as being *correct*, if it was contained in the set of synonyms in the respective language for the relevant UMLS concept. *False negatives* (for recall calculation) were counted by using those concepts as an upper bound for which the (least discriminative) gazetteer system had annotated terms in two aligned sentences. A drawback of this approach is, of course, that additional synonyms and entirely new terms indicative of term enrichment and term learning, respectively, are counted as incorrect since they are not yet contained in the terminology. The automatic analysis was performed for all languages (results are listed in Table 2). A system without any candidate classification, i.e. merely enriching the terminology with all translations contained in the SMT model, is listed as a convenient baseline. Recall is obviously dominated by this baseline, whereas our system consistently outperforms the baseline in F1-score and precision.

Table 2. Evaluation of the *re-invention* performance by considering the UMLS as a gold standard, with F1-score (F), Precision (P) and Recall (R) for all four languages (German, French, Spanish, and Dutch).

	German			French			Spanish			Dutch		
	F	P	R	F	P	R	F	P	R	F	P	R
Baseline	0.14	0.07	**0.98**	0.13	0.07	**0.98**	0.19	0.11	**0.97**	0.11	0.06	**0.95**
Classifier	**0.67**	**0.60**	0.75	**0.62**	**0.60**	0.63	**0.74**	**0.65**	0.87	**0.56**	**0.41**	0.88

In the second setting, terms and synonyms not yet contained in the UMLS were assessed by two experts (bioinformatics graduate students) utilizing online medical dictionaries as an additional source of expertise. Their judgments were collected for a sample of 100 randomly selected German terms. 80% of these items were considered as both being linguistically correct and reasonable from a domain knowledge perspective. A surprisingly big chunk, 49%, is spelled identically as a known English term for the same concept, e.g. the name of the tuna species "*Thunnus thynnus*". This is caused by a large number of entries listed as 'English' in the UMLS, despite being used worldwide to denote the same concept. Furthermore, 8% are linguistically correct translations of an English term, although not yet suited as terminology entries, e.g. the inflected form "*linken Nebenniere*" instead of "*linke Nebenniere*" ('*left adrenal gland*').

Only a small portion (6%) of the errors of our system raises serious concerns as mistranslations, e.g. caused by partial matches during phrasal alignment, such as "*Flussmessung*" ('flow measurement') as a synonym for "*cardiac flow*".

A comparison of these figures to earlier work is hampered by the incompatibility of terminological resources being used and often intrans-parent system design and tuning decisions. Some groups report only precision values based on the number of correct translations produced by their system [1], others communicate F-scores based on the system's ability to re-invent a (small sample) terminology [5]. In these studies, numbers for new and correct translations range between 62% and 81%.

3. Discussion

The performance of our terminology acquisition system can be split into two dimensions–enriching existing terminological structures and finding completely new ones. Given the limitations of the chosen parallel corpora, we encounter acquisition rates of 10.9% (German), 8.0% (French), 5.2% (Dutch) and 2.6% (Spanish) for term enrichment, as well as 8.3% (German), 5.1% (French), 5.2% (Dutch) and 0.3% (Spanish) for term learning. The apparently lower performance for Spanish can be explained by the comparatively high coverage (35.4%) of the Spanish terminology relative to the English master source. Assessments for a German sample reveal that 80% of the acquired terms are bio-medically reasonable and terminologically valid.

For further experiments, it may be worthwhile to include comparable corpora mined from the Web, apply other types of classifiers or consider contextual features (e.g. collocations). The acquired terms will soon be made publicly available to the relevant national and terminological authorities. Manual filtering of our results may be advisable since decisions based on noisy data could be harmful in some applications.

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References

[1] H. Déjean, E. Gaussier, J.M. Renders, et al. Automatic processing of multilingual medical terminology: applications to thesaurus enrichment and cross-language information retrieval. *Artificial Intelligence in Medicine* **33**(2) (2005), 111–124.

[2] Š. Vintar. Bilingual term recognition revisited; the bag-of-equivalents term alignment approach and its evaluation. *Terminology* **16**(2) (2010), 141– 158.

[3] E. Lefever, L. Macken, V. Hoste. Language-independent bilingual terminology extraction from a multilingual parallel corpus. In *EACL 2009 – Proceedings of the 12th Conference of the European Chapter of the Association for Computational Linguistics*, 2009, 496–504.

[4] U. Hahn, E. Buyko, R. Landefeld, M. Mühlhausen, M. Poprat, K. Tomanek, J. Wermter. An overview of JCoRe, the JULIE Lab UIMA component repository. In *Proceedings of the LREC '08 Workshop 'Towards Enhanced Interoperability for Large HLT Systems: UIMA for NLP'*, 2008, 1–7.

[5] F. J. Och, H. Ney. A systematic comparison of various statistical alignment models. *Computational Linguistics* **29**(1), 19–51 (2003)

[6] P. Koehn, H. Hoang, A. Birch, et al. MOSES: open source toolkit for statistical machine translation. In *Proceedings of the Interactive Poster and Demonstration Sessions @ ACL 2007*. 2007, 177–180.

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Link Prediction in a MeSH Co-occurrence Network: Preliminary Results

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Abstract. Literature-based discovery (LBD) refers to automatic discovery of implicit relations from the scientific literature. Co-occurrence associations between biomedical concepts are commonly used in LBD. These co-occurrences can be represented as a network that consists of a set of nodes representing concepts and a set of edges representing their relationships (or links). In this paper we propose and evaluate a methodology for link prediction of implicit connections in a network of co-occurring Medical Subject Headings (MeSH®). The proposed approach is complementary to, and may augment, existing LBD methods. Link prediction was performed using Jaccard and Adamic-Adar similarity measures. The preliminary results showed high prediction performance, with area under the ROC curve of 0.78 and 0.82 for the two similarity measures, respectively.

Keywords. Literature-based discovery, network analysis, link prediction

Introduction

Retrieving and linking different segments of scientific information into understandable and interpretable knowledge is a challenging task. Computer-based text mining technologies complement manual literature management and knowledge discovery from biomedical data sources. Common text mining tasks in biomedicine include information extraction from the literature, document summarization, question answering and literature-based discovery (LBD) [1].

LBD is a methodology for automatically generating hypotheses for scientific research by uncovering hidden, previously unknown relationships from existing knowledge. The LBD methodology was pioneered by Swanson [2], who proposed that dietary fish oils might be used to treat Raynaud's disease because they lower blood viscosity, reduce platelet aggregation and inhibit vascular reactivity. The basic assumption of Swanson's approach is that there exist two scientific domains that do not intersect. A piece of knowledge in one domain may be related to knowledge in the other, but this relationship is unknown. The methodology of LBD relies on the idea of concepts relevant to three literature domains: X, Y, and Z. For example, suppose a researcher has found a relationship between disease X and a gene Y. Further suppose

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that a different researcher has studied the effects of substance Z on gene Y. The use of LBD may suggest an XZ relationship, indicating that substance Z may potentially treat disease X. For a recent review of LBD tools and approaches, see [3].

Analysis of co-occurrence of terms in text is a common method in knowledge representation research. Such analysis in biomedicine, for example, assumes that concepts occurring together in the same MEDLINE title or abstract are in some way biologically related [4]. Since co-occurrence can be considered as a type of relationship between concepts, biomedical knowledge can be viewed as a set of concepts along with the co-occurrence relations between them, and this set can be represented as a graph, consisting of nodes and edges, where the former represent concepts and the latter represent relationships. Such a knowledge network is not static, but dynamic, evolving over time either by adding new nodes or by creating new links between them.

Link prediction is a newly emerging research field at the intersection of network analysis and machine learning. Understanding the mechanisms of link formation in complex networks is a long-standing challenge for network analysis. Link prediction refers to the discovery of future links between nodes that are not directly connected in the current snapshot of a given network [5]. Seen in this way, the link prediction problem is similar to LBD. Several techniques have been proposed to predict new links by estimating the likelihood of link formation between two nodes on the basis of the observed network topology.

In this work we propose a method for predicting and evaluating implicit or previously unknown connections between biomedical concepts. Our approach is complementary to traditional LBD. To evaluate the link prediction techniques for LBD, we investigated performance on networks obtained from Medical Subject Headings (MeSH®) [6] co-occurrence data.

1. Methods

1.1. Basic terminology

A network can be represented as a graph $G(V, E)$ that consists of a set of nodes V representing concepts and a set of edges E representing relationships between the nodes [7]. The number of edges of a node i is denoted by its degree k_i.

The link prediction problem can be formally represented as follows. Suppose we have network $G[t_1, t_2]$ which contains all interactions among nodes that take place in the time interval $[t_1, t_2]$. Further suppose that $[t_3, t_4]$ is a time interval occurring after $[t_1, t_2]$. The task of link prediction is to provide a list of edges that are present in $G[t_3, t_4]$ but absent in $G[t_1, t_2]$. We refer to $G[t_1, t_2]$ as the training network and $G[t_3, t_4]$ as the testing network. We performed the prediction and evaluation on a core subnetwork which consists of nodes having at least $k = 3$ neighbors.

1.2. Data collection

The training and testing networks were constructed from the Unified Medical Language System (UMLS®) [8] co-occurrence table (MRCOC), which includes statistical aggregations of co-occurrences of biomedical concepts in different data sources. Two overall frequencies of MEDLINE co-occurrence are provided: one for recent MEDLINE data (MED) and one for MEDLINE data from a preceding block of

years (MBD). MRCOC provides the frequency of co-occurrence of two concepts in the same indexed articles from MEDLINE (i.e., the number of articles discussing both concepts during a given time period). We selected only those co-occurrence pairs that are MeSH descriptors.

The constructed networks were post-processed to remove all non-useful edges. We applied the Pearson's chi-square (χ^2) test for independence for each co-occurrence pair to obtain a statistic, which indicates whether a particular pair of MeSH descriptors occur together more often than by chance [9].

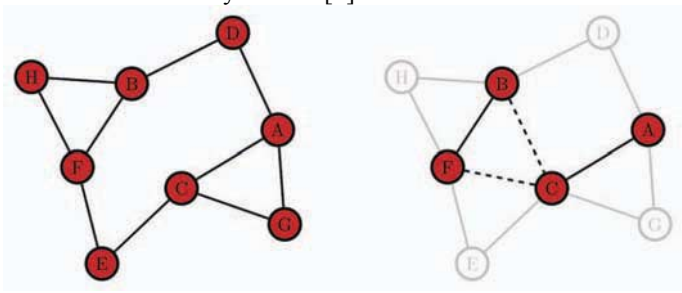


Figure 1. Training (left) and testing (right) networks. New link formation is predicted from the topology of a network obtained from co-occurrences in the training period. We investigate the performance of link prediction techniques by comparing the predicted links with actual new links within the testing period. Prediction and evaluation was performed on a core subnetwork consisting of nodes which have at least $k = 3$ neighbors.

1.3. Experimental setup

The link prediction approach we used follows the procedure first introduced by Liben-Nowell and Kleinberg [10]. We performed link prediction using proximity measures, which are used to find similarity between a pair of nodes. For each node pair (u, v), a link prediction method gives score $s(u, v)$, an estimate of the likelihood of link formation between nodes u and v. From among various proximity measures proposed in the literature we selected Jaccard and Adamic-Adar coefficients [10]. The Jaccard coefficient measures the probability that a neighbor of u or v is a neighbor of both u and v. This coefficient simply divides the number of common neighbors by the number of total neighbors. Adamic-Adar coefficient measures neighborhood overlap between nodes u and v, weighting the overlap of smaller neighborhoods more heavily.

We examined how accurately we can predict which node pairs will connect between times t_3 and t_4 despite not having any co-occurrences before time t_3. The major challenge in prediction evaluation is the huge number of possible node pairs, which can greatly increase computational time. To cope with this issue we use a bootstrap resampling approach, with 100 bootstrap samples [11]. In each bootstrap step we drew a random sample of 1000 nodes and created appropriate training and testing subgraphs. Next, we computed the link prediction score $s(u, v)$ for each node pair (u, v) that is not associated with any interaction before time t_3 by using one of the link prediction techniques introduced in the previous paragraph. We assigned the class label 'positive' to this node pair if the connection occurs in the test network and 'negative' otherwise. Using class labels and computed prediction scores we constructed a ROC (receiver operating characteristic) curve which depicts relative tradeoffs between true positives and false positives. As a measure of prediction performance we used the area under the ROC curve (AUC). The AUC is a widely used performance measure which can be

interpreted as the probability that a randomly selected link is given a higher link prediction score than a randomly selected non-existent link. The final AUC value was averaged over 100 bootstrap samples.

2. Results

Before evaluating the effectiveness of link prediction techniques, we describe the characteristics of the datasets used. The MBD network consists of 24,225 nodes and 4,897,380 edges. We filtered out all non-useful (too general) edges using χ^2 test. After reduction the MBD network contains 3,328,288 edges. The MED network contains 25,570 nodes and 5,615,965 edges. After filtering, the number of edges decreased to 3,810,535. The topological properties of both networks are summarized in Table 1. Both networks are very similar regarding topological properties. The networks exhibit relatively short average path length between all pairs of nodes. On average there are only about two hops from the selected node to any other node. Both networks exhibit the small world property because of small average path length and relatively high clustering.

Table 1. Basic topological characteristics of MeSH networks.

Parameter	MBD network	MED network
Density	0.01	0.01
Mean degree	274.78	298.05
Average path length	2.23	2.20
Clustering coefficient	0.27	0.26
Small-worldness index	21.57	20.70

The classification performance is summarized in Figure 2. Mean AUC for Jaccard coefficient was $AUC = 0.78$ with $SD = 0.02$. Mean AUC for Adamic-Adar coefficient was $AUC = 0.82$ with $SD = 0.01$. Adamic-Adar coefficient exhibited slightly better performance than Jaccard coefficient.

3. Conclusion

In this paper, we applied and evaluated link prediction methods on a network based on co-occurrence patterns between MeSH descriptors. We exploited two methods for the link prediction task, namely Jaccard and Adamic-Adar coefficients and demonstrated that link prediction is plausible with high prediction performance. To the best of our knowledge, this is the first work that investigates unsupervised learning for link prediction in literature-derived networks in the biomedical domain.

There are many possible directions for future work. One is to explore the connection between network attributes and prediction performance. It is well known that nodes which share similar properties tend to create links to each other. For example, persons in a social network who share similar interests are very likely to be friends [12]. In our case we could use attributes such as number of occurrences of particular MeSH descriptor, semantic type from UMLS Semantic Network, etc. We should also systematically analyze the impact of network topology on prediction performance. The process of link creation may be a result of the joint influence of several mechanisms, such as the small world effect and preferential attachment. Finally,

we should examine the role of similarity measure on prediction performance and evaluate statistical differences between them.

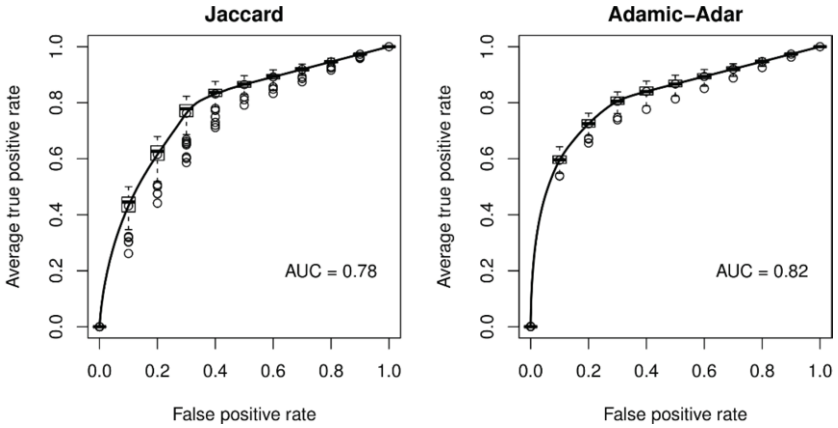


Figure 2. ROC curves.

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References

[1] D. Rebholz-Schuhmann, A. Oellrich, R. Hoehndorf, Text-mining solutions for biomedical research: Enabling integrative biology. *Nature Reviews Genetics* **13** (2012), 829–839.
[2] D.R. Swanson, Fish oil, Raynaud's syndrome, and undiscovered public knowledge, *Perspectives in Biology and Medicine* **30** (1986), 7–18.
[3] D. Hristovski, T. Rindflesch, B. Peterlin, Using literature-based discovery to identify novel therapeutic approaches, *Cardiovascular & Hematological Agents in Medicinal Chemistry* **11** (2013), 14–24.
[4] R. Frijters, M. van Vugt, R. Smeets, R. van Schaik, J. de Vlieg, W. Alkema, Literature mining for the discovery of hidden connections between drugs, genes and diseases, *PLoS Computational Biology* **6** (2010), e1000943.
[5] L. Lü, T. Zhou, Link prediction in complex networks: A survey, *Physica A: Statistical Mechanics and its Applications* **390** (2011), 1150–1170.
[6] Medical Subject Headings [Internet]. 2013 [cited 2014 Jan 19]. Available from: http://www.ncbi.nlm.nih.gov/mesh
[7] M.E.J. Newman, The structure and function of complex networks, *SIAM Review* **45** (2003), 167–256.
[8] Unified Medical Language System (UMLS) [Internet]. 2013 [cited 2014 Jan 19]. Available from: http://www.nlm.nih.gov/research/umls/
[9] C.D. Manning, H. Schuetze, *Foundations of statistical natural language processing*, MIT Press, Cambridge, MA, 1999.
[10] D. Liben-Nowell, J. Kleinberg, The link-prediction problem for social networks, *Journal of the American Society for Information Science and Technology* **58** (2007), 1019–1031.
[11] T. Hastie, R. Tibshirani, J. Friedman, *The elements of statistical learning*, Springer, New York, NY, 2011.
[12] Z. Liu, J.-L. He, K. Kapoor, J. Srivastava, Correlations between community structure and link formation in complex networks, *PLoS One* **8** (2013), e72908.

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Exploring the Application of Deep Learning Techniques on Medical Text Corpora

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Abstract. With the rapidly growing amount of biomedical literature it becomes increasingly difficult to find relevant information quickly and reliably. In this study we applied the word2vec deep learning toolkit to medical corpora to test its potential for improving the accessibility of medical knowledge. We evaluated the efficiency of word2vec in identifying properties of pharmaceuticals based on mid-sized, unstructured medical text corpora without any additional background knowledge. Properties included relationships to diseases ('may treat') or physiological processes ('has physiological effect'). We evaluated the relationships identified by word2vec through comparison with the National Drug File – Reference Terminology (NDF-RT) ontology. The results of our first evaluation were mixed, but helped us identify further avenues for employing deep learning technologies in medical information retrieval, as well as using them to complement curated knowledge captured in ontologies and taxonomies.

Keywords. Deep learning, biomedical literature, evaluation system

Introduction

The large amount of biomedical information in databases such as PubMed [1] is a valuable source for information extraction [2]. Information extraction and, in particular, natural language processing methods are required to annotate and process biomedical literature [3].

The concept of 'deep learning' has recently gained a lot of attention. It refers to unsupervised learning algorithms which automatically discover data without the need of supplying specific domain knowledge [4]. This approach usually has higher performance rates than supervised and informed methods when processing large unstructured corpora. However, the ability of these algorithms has to be evaluated to measure their error rate.

Word2vec[2] implements an efficient deep learning algorithm for computing high-dimensional vector representations of words and their relationships [5], based on unstructured text data. Namely, Word2vec provides two architectures, continuous bag-

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[2] https://code.google.com/p/word2vec/

of-words and skip-gram, for computing continuous distributed vector representation of words from large datasets (up to hundreds of billions of words). Therefore, Word2vec requires training the corpora using one of such architectures and setting some parameters, such as the dimensionality of the vector space or the size of the context window. Word2vec provides two tools to exploit trained corpora: *Distance* and *Analogy*. The *Distance* tool retrieves a vector of words which are closely related to a given word in the corpora. The results also contain the corresponding cosine distances of each word that indicates how close it is related to a given word. The *Analogy* tool, on the other hand, is able to detect linguistic regularities in a vector representation [6], e.g. the analogy tool aims to search for the information related to the relationship *is_capital_of* with an example of such relation in the text, *France* - *Paris*, and a particular city capital, *Berlin*, and resulting in a vector similar to the word *Germany*. Finally, these tools can be used to build more complex natural language processing and machine learning applications.

In this paper, we evaluate the word2vec toolkit on mid-sized medical text corpora. We compared the results of word2vec with knowledge encoded in the National Drug File – Reference Terminology (NDF-RT) ontology[3] to validate its results.

1. Methods

The evaluation was carried out in four steps: (1) gathering and processing openly available medical text corpora; (2) training vector space representations of these corpora with word2vec; (3) test word2vec tools and compare their results against the reference ontology; (4) calculating result statistics.

We created a script for crawling medical data from online repositories using PHPcrawl[4] and API calls. We gathered clinically relevant medical information from PubMed, Merck Manuals[5], Medscape[6] and Wikipedia[7]. We created scripts for stripping non-relevant portions of web pages (such as headers and footers) and HTML markup that would degrade the quality of the corpora. Table 1 gives an overview of the medical corpora created through this process.

Table 1. Corpora used in the experiment. Word counts refer to the final corpora that were derived from source datasets after all processing steps. Vocabulary sizes refer to the number of distinct words found in each corpus.

Corpus	Word count	Vocabulary size
Clinically relevant subset of PubMed, full abstracts	161.428.286	204.096
Conclusion sections from clinically relevant subset of PubMed, *"pubmed_key_assertions"*	17.342.158	47.703
Merck Manuals	12.667.064	49.174
Medscape	25.854.998	63.600
Clinically relevant subset of Wikipedia, *"wikipedia"*	10.945.677	65.875
Combined corpus (including all corpora above), *"combined"*	236.835.672	261.353

These corpora needed to be pre-processed before training since word2vec has no built-in functionalities for term normalisation or dealing with punctuation. We found

[3] http://bioportal.bioontology.org/ontologies/NDFRT
[4] http://astellar.com/php-crawler/
[5] http://www.merckmanuals.com/
[6] www.medscape.com/
[7] http://www.wikipedia.org/

that raw corpora contained an abundance of syntactic variations that had a negative impact on trained corpora and, therefore, the quality of the resulting vector space models. We identified the need of removing all punctuation, transforming the corpora to lower-case, and forming multi-word terms due to the fact that word2vec indexes only single words from the corpora.

Once the gathered corpora were processed to improve their content, we used the training tool of word2vec to generate the corresponding vector model. The corpora were trained using the parameters indicated in the Table 2 to obtain their vector-models.

Table 2. This table provides an example of the parameters used with the word2vec training tool to train the medical corpora. In this example the training tool uses the corpus file "corpora.txt" to generate the vector model into the file "vector-model.bin". It uses the skip-gram architecture with a vector size of 200 and a window of 5. Besides, the vector model was generated hierarchical softmax training algorithm, a threshold of 1e-3 for downsampling the frequent words. The training tool uses 12 threads execution to generate the binary file of the vector model.

Command line execution
word2vec *-train* corpora.txt *-output* vector-model.bin *-cbow* 0 *-size* 200 *-window* 5 *-negative* 0 *-hs* 1 *-sample* 1e-3 *-threads* 12 *-binary* 1

The evaluation of the trained corpora was focused on testing the results of the word2vec distance and analogy tools. The resulting vectors consisted of the 40 most closely related terms in the text for each queried term, determined by cosine distance in the vector space model. A good (i.e., high) cosine distance value meant that two terms were determined to be related by the word2vec algorithm. To compare the resulting vectors we use the manually curated content of the NDF-RT ontology described in Table 3.

Table 3. This table describes the information associated to each relationship of NDF-RT ontology that was collected to do the evaluation of word2vec tool-kit and to form multi-word terms during the processing stage of the pre-trained corpora. Besides, the domain and range of each relationship is described.

NDF-RT relationship	Description
may_treat	Provides the association between drugs and the diseases they may treat.
may_prevent	Provides the list of diseases that a drug may prevent.
has_PE	Relates drugs to their corresponding physiological effects.
has_MoA	The mechanisms of action of each drug.

To perform this evaluation, we developed a system that automatically queried one trained corpus using the analogy and distance tools and matched the resulting vectors with the content of the NDF-RT ontology. Figure 1 shows the software architecture of this evaluation system.

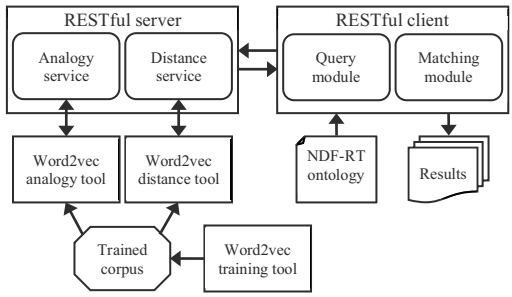


Figure 1. Evaluation system architecture defined to execute word2vec tools and compare their results.

We obtained the following statistics: (i) we checked the number of resulting vectors with at least one correct term from the relationships of NDF-RT; (ii) we computed the distribution of each correct term in the distance vector; and (iii) we

obtained the hit rate of word2vec for a selected subset of terms, for which we determined if they appeared in close proximity in the used corpora.

2. Results

Most of the software we developed for running these evaluations is available open-source on Google Code[8].

We obtained three processed medical corpora and three vector models – "pubmed", "wikipedia" and "combined" – which can be further exploited with word2vec tools. Besides, we developed a system that publishes the functionality of distance and analogy tools using RESTful services, and automatically collect the resulting vectors to evaluate their content with external information sources.

Table 4 provides statistics on the hit rates of correct terms in the vectors retrieved by word2vec tools. The hit rate represents the percentage result lists with at least one correct term that matches the data from the ontology. On the one hand, the best hit rate was yielded using the analogy tool for retrieving "may_treat" information from the "combined" corpus, with a hit rate of 27,37%. On the other hand, the worst hit rate was 0,32% for the result of the "wikipedia" corpus with the distance tool and the "has_PE" relationship.

Table 4. Hit rates obtained by comparing the content of the vectors retrieved by distance or analogy tools, with the information of "may_treat", "may_prevent", "has_PE" and "has_MoA" from NDF-RT ontology.

Corpora	may_treat		may_prevent		has_PE		has_MoA	
	Analogy	*Distance*	*Analogy*	*Distance*	*Analogy*	*Distance*	*Analogy*	*Distance*
combined	27,37%	3,21%	10,59%	6,32%	2,49%	0,67%	6,91%	6,81%
pubmed	15,74%	2,13%	5,09%	4,07%	0,84%	0,37%	1,51%	3,60%
wikipedia	14,9%	1,3%	5,35%	3.34%	2,22%	0,32%	2,69%	3,34%

Figure 2 shows the second statistics about the distribution of positions of correct terms in the result list. In our evaluation the mean position of correct terms in the result list is close to 16, with a standard deviation higher than ten. Besides, the low probability of the last terms in result lists indicates that it is unlikely to find more correct terms in a result list by increasing the length of the result list.

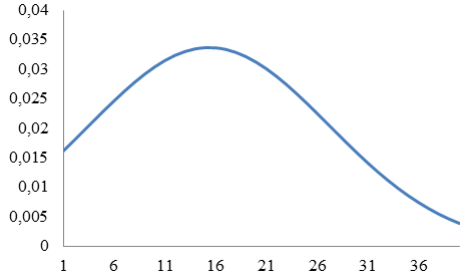


Figure 2. Distribution of the positions of correct words in the vectors as a result of analogy tool with the "combined" corpus and testing "may_treat" relationship.

Table 5 displays the hit rates of 15 drugs when querying "may_treat" information with the analogy tool and the "combined" corpus. We checked how many of the correct terms were in proximity to a particular drug term within a window size of 20 words

[8] https://code.google.com/p/biomedical-text-exploring-tools/

anywhere in the corpus. Then, we calculated how many of those words were found by word2vec tools. We found that the hit rate of the word2vec tool to be approximately 51% and the hit rate in a 20-term window to be approximately 80%.

Table 5. Comparison of the hit rates of 15 drugs using the analogy tool and a simple proximity text search with a 20-term window (for the "combined" corpus and the "may_treat" relationship). A value of 100% means that all of the diseases in a "may_treat" relationship with the drug were recovered.

Drug term	20-term window hit rate	word2vec hit rate
Enoxaparin	40%	33,33%
Fluvastatin	100%	50%
Diazepam	75%	75%
Valporic_acid	66,67%	66,67%
Omeprazole	50%	28,57%
Trientine	100%	50%
Natamycin	100%	7,69%
Valsartan	75%	75%
Prochlorperazine	100%	40%
Formoterol	100%	50%
Imatinib	100%	66,67%
Chloroquine	25%	16,67%
Atorvastatin	100%	75%
Perindopril	75%	75%
Gemfribrozil	100%	66,67%
Mean	80,44%	51,75%

3. Discussion

The obtained statistics showed a low hit rate of word2vec tools. Consequently, the ability of word2vec to retrieve significant words from the restricted corpora we used is not suitable for applications requiring high precision.

Further analyses need to be conducted to test if different parameters of the training tool, such as window size, vector size, or the bag-of-words architecture have a significant impact in the efficiency of the word2vec tools in extracting relevant information.

References

[1] Roberts RJ. PubMed Central: The GenBank of the published literature. *Proc Natl Acad Sci USA.* 2001;16: 381-382.

[2] Kim JD, Ohta T, Tsujii J. Corpus annotation for mining biomedical events from literature. *BMC Bioinformatics*. 2008; 9: 10.

[3] Albright A, Lanfranchi A, Fredriksen A, Styler WF, Warner C, Hwang JD, et al. Towards comprehensive syntactic and semantic annotations of the clinical narrative. *J Am Med Inform Assoc.* 2013; 20: 922-930.

[4] Bengio Y, Courville A, Vincent P. Representation Learning: A Review and New Perspectives. *IEEE Trans*. PAMI, special issue Learning Deep Architectures. 2013 Aug; 8(35): 1798 – 1828.

[5] Mikolov T, Chen K, Corrado G, Dean J. Efficient Estimation of Word Representations in Vector Space. In Proceedings of Workshop at International Conference on Learning Representations; 2013 May 2-4; Scottsdale: Arizona.

[6] Mikolov T, Yih W, Zweig G. Linguistic Regularities in Continuous Space Word Representations. In Proceedings of Conference of the North American Chapter of the Association for Computational Linguistics: Human Language Technologies; 2013 June 9-15; Atlanta: Georgia.

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Improving EHR Semantic Interoperability: Future Vision and Challenges

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Abstract. We propose a semantic-driven architecture to improve EHR semantic interoperability. This architecture is constituted by five layers: structured heterogeneous data (i), as found in (un-)standardised clinical information models, which are consumed by a semantic mapping layer (ii), which links the data items to clinical ontologies via user-friendly content patterns. A semantic mediator (iii) then translates these content patterns into ontology-based annotations, which populate a virtual homogeneous data store (iv), which serves the application layer (v).

Keywords. EHR, semantic interoperability, SNOMED CT, ontology

Introduction

Shared clinical terminologies and ontologies as a means to enable the faithful exchange of the meaning of information had been addressed in the EU SemanticHealth interoperability roadmap [1], but their interplay and their interfaces still constitutes a major desideratum. We here address this issue by proposing a semantic-driven architecture. It is organized in five layers and spans from heterogeneous data repositories to homogeneous and semantically explicit representations. The work is part of SemanticHealthNet (SHN) (http: //www.semantichealthnet.eu/), which has focused, as a use case, on the interoperable representation of heart failure information to support integrated care. The architecture presented here has been partially implemented and validated in this clinical domain. In the following we explain some of the challenges we have faced in each of the layers of this architecture. Some of them are technical and derived from the use of semantic technologies with any data management system. Others are specific to the medical domain and the use of EHR standards and medical terminologies.

1. Vision of an EHR semantic-driven architecture

The architecture is organised as follows:

Structured heterogeneous data (Layer 1): This layer comprises structured clinical data, which may be physically stored within an EHR repository and accessed via an interface conforming to some standard like HL7 CDA, openEHR, EN ISO 13606, or to a proprietary database schema. Advanced EHR representations structure data by clinical models (e.g. archetypes), which provide a set of data elements and value restrictions.

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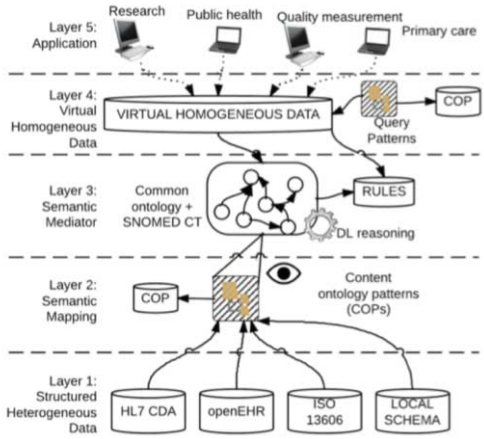


Figure 1. Semantic-driven Architecture

More than one expression [*Data element*: *Value restriction*] can be used for representing the same content [2]: [*Disease*: *Inflammation*] and [*Body location*: *Myocardium*] vs. [*Disease*: *Myocarditis*]. In the first example, the semantic relation between the disease and the body location is *not* provided by the clinical model. Medical data are provided at different levels of detail, depending on the context requirements. E.g. smoking-related information recorded by a GP will be coarser than information recorded in a smoking cessation service. This implies co-existing clinical models, providing different information level detail. Contextual information is essential, e.g. past or family history, etc., as well as the way information has been acquired (e.g. by machine, physician), which will determine its degree of trust. Each data element in a clinical model should provide this information in a standardized way. Data may be coded using terminologies, increasingly grounded on an ontological basis, such as with SNOMED CT. Nevertheless, the selection of a term by a user is usually driven by its – often imprecise – textual description and not by its formal definition. Additionally, some terms blend contextual with clinical information (boundary problem [3]).

Semantic mapping (Layer 2): Semantic content patterns are introduced to bridge between structured data and their semantic representation. They describe recurring information structures and provide a particular view on the underlying model of meaning, tailored to the needs of particular use cases [4], preventing users from a deep knowledge of the underlying ontology formalisms. Patterns can be organized in hierarchies, in which top-level patterns can be specialized following a paradigm similar to object-oriented design, and in which their composition permits to cover larger modelling use cases. Patterns may be encoded as Subject-Predicate-Object (SPO) triples, to which data elements and value restrictions of clinical models are mapped. As a difference with the non-related data elements of clinical models, predicates constitute links between classes as dictated by the pattern such as given by the following examples:

<*InformationItem* 'describes situation' *Inflammation*>,

<*InformationItem* 'describes situation' *Disease*>

<*Disease* 'has location' *Myocardium*>.

Semantic mediator (Layer 3): The core is constituted by a set of ontologies which formalize clinical data meaning: an information entity ontology and a medical domain ontology, constrained by means of canonical categorisations and relations provided by a top-level ontology. We consider SNOMED CT a good candidate as medical domain ontology, due to its high coverage and its grounding in formal-ontology principles [5]. A strict separation between *Information* and the entities represented by this information is fundamental. E.g. *Diagnosis* is a piece of information acquired by some clinician, at some place, at some point in time by following certain method. A *Diagnosis* represents a possibly clinical situation of the patient such as inflammatory disorder. A cause of the *Inflammatory disorder* can be a *Viral infection*. *Severity* information modifies the in-

formation object, as it is inferred by the clinician in the diagnosis process. This separation is essential for a consistent interplay of information models with clinical terminologies. Ontologies lend themselves to be expressed in logic, e.g. description logics (DL) [6], which enables inferencing, with two main goals: (1) detect semantic equivalences across different distributions of content between information models and terminologies; (2) advanced exploitation of clinical information by means of semantic queries. The first goal means that if the same data are represented by using a different combination of data elements and restrictions, by inference it is possible to detect their equivalence: *InflammatoryDisorder* and **hasLocation** some *Myocardium* equivalentTo *Myocarditis*. The second goal refers to the ability to query data at different levels of detail (e.g. patients with inflammatory diseases, with cardiac disorders, etc.).

Virtual homogeneous data (Layer 4): It provides a homogeneous view on clinical data extracted from heterogeneous systems. Data are expressed at different detail levels, but can be accessed homogeneously thanks to the underlying ontology-based annotations. As opposite to traditional databases where complete information is assumed, ontologies assume incomplete information, which affects how data can be queried. Query patterns based on the ontology content patterns used for the semantic mapping should facilitate queries in the same way how content patterns facilitate representations in layer 2.

Application (Layer 5): Here we find clinical systems and services with different information needs. A public health system might be interested in aggregating information results to extract population-level information while a primary care system might be interested in the results of a lab test. A decision support component might need to retrieve one very specific data value. Each use case requires querying data at different detail and precision. Besides, all the data retrieved might not deserve the same trust level and it must be explicitly shown (e.g. seniority of the author, supporting evidence, indication of whether a diagnosis is tentative or confirmed etc.).

2. Architectural Challenges

Structured heterogeneous data (Layer 1): Clinical data rendered according to clinical models or particular database schemas provide vague and mostly implicit contextual information. E.g. “93 kg” assigned to the data element “body weight” leaves open whether the weight is reported by the patient or has been measured in the clinic. Context is often expressed in natural language only or not even documented in database schemas. Therefore, the interoperability degree we can reach is directly dependent on the quality of the source *information* (i.e. data in context). The challenge is to optimize the amount of precisely expressed information quality with a reasonable effort.

The direct annotation of clinical data by ontology-based vocabularies like SNOMED CT may help clarify data meaning at a reasonable workload. However, the role of such resources in the EHR should be clear. Should they limit themselves to represent medical entities like “myocarditis”, or should they claim to provide codes even for complex statements such as “possible myocarditis” which combine a domain term with epistemic information about its specific use by the author of this statement. If the former case is preferred, then information models should represent the epistemic information. In case both variants are valid, interoperability requires additional effort (e.g. the code for “myocarditis” bound to an information model on diagnosis including diagnostic certainty attributes should be found to be equivalent to the code “possible

myocarditis"). This binding has to be guided by the semantic categories of the underlying model of meaning and not primarily by its label, as this can be ambiguous. E.g. "myocarditis" could be interpreted as a disease or a morphology.

Semantic mapping (Layer 2): Here, the main challenge is to use semantic content patterns to package information in order to provide a user friendly handling, which facilitates mapping of data elements and value sets. This requires that patterns provide enough expressivity to represent data and their rendering in a formal and interchangeable way. Patterns encode repetitive modelling issues. They should be compositional, and they should be arranged in hierarchies, from top-level patterns (e.g. process plan) to specific ones (e.g. medication administration pattern). Their composition and specialization will be formalized by means of cardinality and value restrictions. As an example of composition, a comprehensive diagnosis pattern encodes a disease, together with its cause, location, etc. The latter two are provided by the situation (finding) pattern. Tools should also experts in constructing and managing patterns, including mechanisms to check data validity against patterns constraints.

Semantic mediator (Layer 3): The main challenge is the model of meaning (ontology) itself. It must be expressive enough to address the complexity of representing clinical facts, in order to be machine-processable. Besides, it must be independent of particular applications and provide relatively generic content that can be reused by heterogeneous systems. The combination of different domain ontologies requires canonical top-level classes and relationships. Such a top-level ontology should address the boundary problem by enforcing a distinction between information entities and domain entities. The rendering of the model of meaning by using a logic-based language allows performing logical reasoning like inferring myocarditis from the combination of inflammation and myocardium. However the feasibility of the use of semantic technologies is challenged by the computational costs of reasoning [7 and the amount of data [8]. Therefore, scalable solutions of intermediate complexity should be aimed at, which leave the door open to include the upcoming progress in the field. The rendering of the model of meaning using a logic-based or non-logic based formal language and the type of reasoning done, if any, will depend on the technological state of the art and the interoperability requirements. Several renderings of a rich representation might be required, each attending a different purpose, e.g. data validation vs. data query.

Virtual homogeneous data (Layer 4): At this layer data can be accessed homogeneously and have – ideally – their complete meaning (ontological and epistemic) expressed in a formal language, from which logical entailments can be computed. If queries can be supported by a logical reasoner [9], answers might include derived facts. Scalability problems may have to be addressed by query rewriting, optimization of reasoning algorithms, etc. For persisting semantically enriched data, native and non-native triple stores exist [10]. Native triple stores provide their own database implementation and non-native ones rely on particular relational databases. The former ones perform better since their performance has been optimized for that; however the support of reasoners is partly implemented and might be still expensive. Ontologies assume incomplete information (open world semantics): if something has not been explicitly negated it is not considered false as opposed to traditional databases. This has to be considered in the formulation of queries, which constitutes a barrier for most users. The use of query patterns based on principles similar to the content patterns described above could hide that complexity.

Application (Layer 5): Application systems at this level make queries based on the model of meaning, the expressivity of which will determine that queries at different

granularity level lead to answers. Local terminologies will be mapped to the model of meaning. Since application systems might be placed within different medical contexts and be driven by different requirements and use cases, their safe use requires that data can be retrieved within their context. Close-to-user interfaces and the use of query templates facilitate query elaboration and result interpretation.

3. Conclusions

The described layered, semantic-driven architecture is centred on a semantic mediator, constituted by ontologies that formalize the meaning of clinical data. Developed for structured data, it could also be applied to free text once a reliable information extraction system is put in place. Logic-based ontologies allow for computing semantic equivalences across different distributions of content between information models and terminologies, and for advanced exploitation of clinical information by means of semantic query possibilities. Formalisms, not based on logic, can also be considered, depending on the particular purpose (e.g. data validation vs. data query) due to scalability problems. Semantic patterns offer a user-friendlier way to create and modify ontological content, as they hide the complexity of the underlying model of meaning. They should be flexible and expressive enough to formally represent data conveyed by clinical models, but at the same time they should follow strict constraining principles. On top of that, their use by professionals requires tools that support each of the tasks carried out at each layer of the architecture. An important next step is the building of libraries of such patterns, to help design future EHR repositories and message standards.

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References

[1] Stroetmann VM et al. Interoperability for better health and safer healthcare. Deployment and research roadmap for Europe. 2009. ISBN-13 : 978-92-79-11139-6
[2] Campbell KE, Das AK, Musen MA. A logical foundation for representation of clinical data. JAMIA. 1994; 1 (3): 218-232.
[3] Rector A, Qamar R, Marley T. Binding Ontologies & Coding systems to Electronic Health Records and Messages. Applied Ontology. 2009; 4: 51-69.
[4] Blomqvist E, Daga E, Gangemi A, Presutti V. Modelling and using ontology design patterns. [cited 2014 May 9]. Available from: http://www.neon-project.org/web-content/media/book-chapters/Chapter-12.pdf
[5] Schulz S, Jansen L. Formal ontologies in biomedical knowledge representation. Yearbook of Medical Informatics. 2013; 8: 132-146.
[6] Baader F et al. (eds.) The Description Logic Handbook. Theory, Implementation, and Applications (2nd Edition). Cambridge University Press, 2007.
[7] Horrocks I. Reasoning with Expressive Description Logics: Theory and Practice, Lecture Notes in Computer Science. 2002; 2392: 1-15.
[8] Möller R, Neuenstadt C, Özçep ÖL, Wandelt S. Advances in Accessing Big Data with Expressive Ontologies, Lecture Notes in Computer Science. 2013; 8077:118-129.
[9] Kollia I, Glimm B, Horrocks I. SPARQL Query Answering over OWL Ontologies. Proceedings of the 8th Extended Semantic Web Conference. 2011; 382-396.
[10] Comparison of Triple stores. [cited 2014 May 9]
Available from: http://www.bioontology.org/wiki/images/6/6a/Triple_Stores.pdf

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A Framework for Evaluating and Utilizing Medical Terminology Mappings

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Abstract. Use of medical terminologies and mappings across them are considered to be crucial pre-requisites for achieving interoperable eHealth applications. Built upon the outcomes of several research projects, we introduce a framework for evaluating and utilizing terminology mappings that offers a platform for i) performing various mappings strategies, ii) representing terminology mappings together with their provenance information, and iii) enabling terminology reasoning for inferring both new and erroneous mappings. We present the results of the introduced framework from SALUS project where we evaluated the quality of both existing and inferred terminology mappings among standard terminologies.

Keywords. Terminology mapping, semantic interoperability, reasoning, validation

Introduction

Achieving a computable semantic interoperability (CSI) among different healthcare applications is – at its core – deeply dependent on the use of "controlled terminologies" which enable the inter-machine exchange of clear and computationally unambiguous semantics [1]. Aiming towards this goal, clinical experts go through a process of defining "terminology mappings" between "standard" terminologies developed by standards organizations (CDISC, IHTSDO, ICH, etc.), as well as local/legacy terminologies to support a number of specific CSI use cases including (but not limited to): (i) semantic interoperability between clinical care and clinical research systems for pharmacovigilance and patient safety, (ii) clinical decision making, and (iii) clinical data integration and mediation in pharmaceutical R&D.

Recent research projects focusing on CSI—such as SALUS [2], Open PHACTS [3], and EHR4CR [4]—have published their experiences in defining and utilizing multiple mappings between various terminologies [5]. Although, on the surface, it may

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appear to the uninitiated as a simple exercise like "this term in this terminology is the same as that term in that terminology". However, it is often a considerably challenging task [1] due to: (i) availability of up-to-date information to assess the suitability of a given terminology for a particular use case; (ii) difficulty of correctly using complex, rapidly evolving terminologies; (iii) differences in granularity between the source and target terminologies; (iv) lack of semantic mappings in order to completely and unambiguously define computationally equivalent semantics; (v) lack of provenance information, i.e. how, when and for what purposes the mappings were created; and (vi) time and effort required to complete and evaluate mappings. For example, considering SNOMED-CT as hub terminology, both ICD-9-CM and MedDRA codes are mapped to SNOMED-CT codes (see Figure 1). As a result, new mappings are inferred (e.g., "Anaphylactic shock due to serum, not elsewhere classified" (ICD9) ←→ "Anaphylactic transfusion reaction" (MedDRA)). However, via reasoning, problematic or incorrect mappings are also found (see Figure 1: highlighted in red).

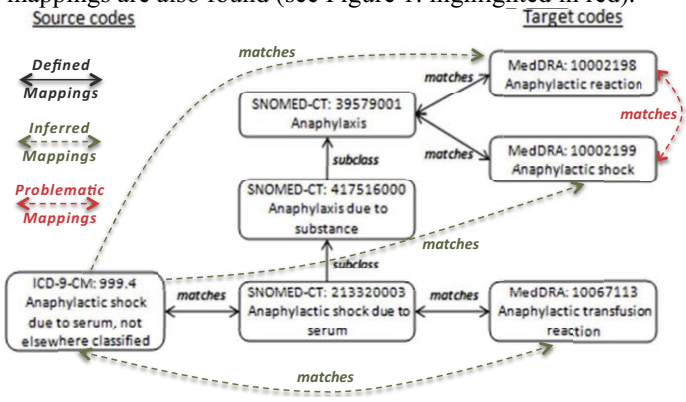


Figure 1. Terminology Mapping: Defined and inferred mappings between ICD-9-CM and MedDRA terms

Another important problem is the inclusion of implicit context in the use of a particular term which can result in certain usage contexts with terms that are semantically equivalent in one usage context but not in another [6]. For example, if a generic code for a TNM grade is used in local templates of anatomic pathology reports for cancer, knowing the context—breast or prostate cancer for example—the local code for pT shall be "bound" to the appropriate cancer specific pT code (e.g. either *LOINC:44663-3 T classification in Breast tumor* or *LOINC:44664-1 T classification in Prostate tumor*). Taking the context information into account, pT3 value for example has a different value in the context of a breast cancer (Tumor >50 mm in greatest dimension) than in the context of prostate cancer (Extraprostatic extension).

1. Terminology Mappings Evaluation and Utilization Framework

In this paper, we present a framework for evaluating and utilizing medical terminology mappings (see Figure 2). This framework features: (i) exploitation of available terminology mapping and alignment strategies [1, 7] for finding similarities between source/reference terminologies; (ii) presenting the resulted mappings to terminology experts for further validation; (iii) representing the supporting arguments and methods used (i.e. provenance) [8] for defining or finding mappings with a focus on the reason for defining the equivalence relation [9]; (iv) exploiting reasoners to perform

terminology reasoning for finding useful inferred mappings and also to validate both asserted and inferred mappings based on formalized validation schemes and policies [10,11]; and (v) offering RESTful Web Services, REST APIs and query endpoints for querying and utilizing available terminology mappings—based on their provenance—for different contexts or usages in mind.

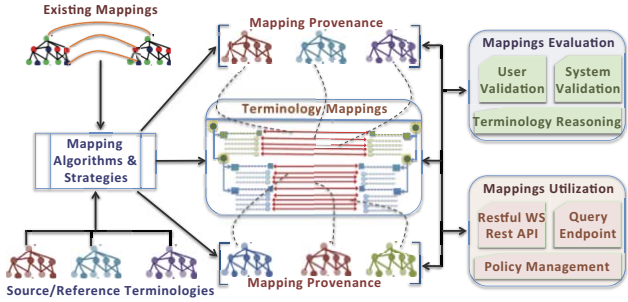


Figure 2. Terminology Mappings Evaluation and Utilization Framework.

1.1. Terminology Mapping Strategies and Mapping Provenance Representations

There have been various efforts in finding and representing mappings between standard medical terminologies [1,7]. BioPortal, a repository of biomedical terminologies /ontologies, with more than 300 ontologies to date, performs a variety of mapping algorithms and strategies [7] include: (i) *Lexical Mappings (LOOM),* represented via `skos:closeMatch` property, generated by performing lexical comparison between preferred labels and alternative labels of terms; (ii) *Xref OBO Mappings,* represented via `skos:relatedMatch` property, processed by using Xref and Dbxref are properties used by ontology developers to refer to an analogous term in another vocabulary; (iii) *CUI Mappings from UMLS,* represented via `skos:closeMatch` property, are extracted by utilizing the same Concept Unique Identifier (CUI) annotation as join point of similar terms from different vocabularies; (iv) *URI-based Mappings,* represented via `skos:exactMatch` property, are generated identity mappings between term concepts in different ontologies that are represented by the same URI.

Existing approaches for exchanging mappings, such as a nanopublication [12] or a VoID linkset [13], focus on capturing and modeling the provenance of the mapping, i.e. what has been mapped, by whom, using what tool. What it does not convey is the context in which the assertion was made, i.e. the operational equivalence that is encoded by the mapping. The Open PHACTS project has extended the linkset approach to include a mapping justification [9]. The linkset header is extended with an additional property that conveys why the mapping holds, e.g. the terms have the same preferred label or that they share an identifier. A key advantage of this approach is that existing reasoning mechanisms, e.g. rules for `skos:exactMatch`, can be applied without change since the links themselves are represented using a standard ontology. In addition, existing mappings can be simply extended with additional metadata then reused; there is no need to regenerate the linking data [14].

1.2. Terminology Reasoning and Mapping Evaluation

Once the existing mappings are formally represented, e.g. using SKOS mapping properties [15], terminology reasoning can be applied to derive new mappings and also

to detect both asserted or inferred problematic mappings [11]. Figure 1 shows the inferred mappings between ICD-9-CM and MedDRA by utilizing the existing ICD-9-CM-to-SNOMEDCT and SNOMEDCT-to-MedDRA mappings. When the mappings are large, a statistically sound sample is extracted, and validations are applied on the sample only [1, 10]. It is also important to point out that the terminology reasoning could also lead to conclusions that the mapping creators do not intend to. It is therefore required to perform automated mapping validation schemes to be applied on the entire mappings to detect and present problematic mappings to experts for further investigations and revisions. When the mapping relations and semantic relations can be considered as transitive, it is possible to infer a relation between two concepts in a same terminology system. If such an inferred relation is not stated in (or cannot be inferred from) a terminology system, then inferring such a relation via mapping relations is considered as "vocabulary hijacking" [11]. For example, Figure 1 shows that a problematic mapping (Anaphylactic reaction (MedDRA) ←→ Anaphylactic shock (MedDRA)) is inferred because both concepts are mapped to the same SNOMED-CT concept (39579001). Mapping validations are thus required to detect such mappings that may lead to unintended inferences.

1.3. Terminology Mapping Querying and Utilization

Once terminology mappings are represented together with provenance information, utilizing them to interoperating applications is another challenge. SALUS Terminology Server addresses this challenge and provides a RESTful interface for querying term mappings [16]. SALUS Terminology Server is built upon a triple-store and inherently supports RDF. Term representations are utilized mainly by using SKOS [15]. REST methods returns query results according to this semantic modeling of the terms.

Table 1. Terminology reasoning and mapping evaluation in SALUS Terminology Server

Mapping	Source	Target	Hierarchy Relations*	Defined Mappings	Inferred Mappings	Problematic Mappings
1	SNOMED-CT	ICD-10	1,839,401	28,056	16,838	104,761
2	MedDRA	SNOMED-CT	1,886,575	10,648	453,615	1,790
3	MedDRA	ICD-10	121,032	-	139,216	3,331
4	SNOMED-CT	ICD-9-CM	1,845,688	16,819	31,862	-
5	MedDRA	ICD-9-CM	174,493	-	270,094	-

2. Results

Table 1 presents the defined, inferred and problematic mappings found in the SALUS Terminology Server [5, 16]. Mappings 1, 2 and 4 were created based on the mappings developed by existing projects. These mappings were represented via `skos:exactMatch`, or `exactOrNarrow` relations. It can be observed that there are many problematic mappings inferred and detected from already defined SNOMED-CT to ICD-10 mappings (see row 1 in Table 1). It is because of wrong assumptions were made in interpreting source mappings stored in Excel sheet to RDF, therefore inappropriate mapping properties were assigned. Based on the already defined mappings and hierarchy structures of related terminologies, new mappings were

inferred. By using SNOMED-CT as a bridge terminology, the MedDRA-to-ICD10 mappings were derived from the mapping 1 and 2, and the MedDRA-to-ICD9CM mappings were derived from mapping 2 and 4.

3. Conclusion

The role of medical terminologies is vital to achieve CSI in clinical informatics. In this paper, we show the challenging nature of mapping utilization among different terminologies. The introduced framework has been built upon existing terminology mappings to (i) infer new mappings for different CSI use cases, (ii) present provenance of the mappings together with the context information—an important problem for term mapping utilization, and (iii) perform mapping validation in order to show that inferred mappings can be erroneous. The framework enables a more collaborative semantic landscape with providers and consumers of terminology mappings. It can also be the basis for additional services, such as usage data and feedback mechanisms for the providers of mappings and of the source and targets terminologies. Making the use, and reuse, of terminology mappings visible could enable new funding and business models in a sustainable semantic landscape across clinical care and clinical research domains.

References

[1] Saitwal H, Qing D, et al. Cross-terminology mapping challenges: A demonstration using medication terminological systems. *Journal of Biomedical Informatics*, **45(6)**:1217 (2012).
[2] Erturkmen, G.B.L., et al. SALUS: Scalable, Standard based Interoperability Framework for Sustainable Proactive Post Market Safety Studies. MIE 2012, Pisa-Italy, 26-29 August 2012.
[3] Williams, A.J. et al. Open PHACTS: semantic interoperability for drug discovery. *Drug discovery today*, 17(21-22), pp.1188–98 (2012).
[4] Ouagne D., et al. The Electronic Healthcare Record for Clinical Research (EHR4CR) information model and terminology. Studies in health tech. and informatics (2012), 534-8.
[5] A Study of Terminology Mapping in SALUS Project. http://www.srdc.com.tr/projects/salus/blog/?p=241, Nov 15, 2013.
[6] Rector A., Qamar R., Marley T. Binding ontologies and coding systems to electronic health records and messages. *Applied Ontology* **4(1)**, (2009), 51-69.
[7] Salvadores, M., Alexander, P. R., et al. BioPortal as a Dataset of Linked Biomedical Ontologies and Terminologies in RDF. Semantic Web Journal, **4(3)** (2013), 277-284.
[8] McGuinness D. L., Silva P. P. Explaining Answers from the Semantic Web: The Inference Web Approach. International Semantic Web Conference, (2003).
[9] Dataset Descriptions for the Open Pharmacological Space. www.openphacts.org/specs/datadesc/, Open PHACTS, Working Draft, 12 September 2013
[10] White S, Paoin W, Brox, G et al. SNOMED CT to ICD-10 Map Phase 1 Content Validation Report. http://www.ihtsdo.org/fileadmin/user_upload/Docs_01/SNOMED_CT/Developmen
[11] t/Content_Validation_Report_20130327.pdf, Last visited on January 2014.
[12] Sun H, De Roo J, Twagirumukiza M, et al. Validation Rules for Assessing and Improving SKOS Mapping Quality. arXiv preprint arXiv:1310.4156, (2013).
[13] Nanopublication Guidelines. http://www.nanopub.org/guidelines/, 15 December 2013.
[14] Describing Linked Datasets with the VoID Vocabulary. http://www.w3.org/TR/void/, W3C Note, 3 March 2011.
[15] Brenninkmeijer, C.Y.A. et al. Computing Identity Co-Reference Across Drug Discovery Datasets. In Semantic Web Applications and Tools for Life Sciences (2013).
[16] SKOS Simple Knowledge Organization System Reference. http://www.w3.org/TR/skos-reference/, W3C Recommendation, 18 August 2009
[17] Depraetere, K., Erturkmen, G.B.L. Deliverable 4.4.2-SALUS Semantic Mediation Framework–R2. http://www.srdc.com.tr/projects/salus/public-deliverables, April 30, 2013.

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Beyond Copy and Paste: Clinician Approaches to Meeting Information Needs During Note Writing

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Abstract. Clinicians need historical information that does not change over time, as well as other information from the notes of others to inform their documentation - to save time, they cut and paste since that is a feature in many conventional EHRs. Copy and paste is a solution to clinicians' needs that has associated downsides including errors. As part of a study of clinicians using an innovative system which gives them complete control over information selection and arrangement, two used the process of note splitting to meet needs that are sometimes solved through cut and paste; four others used text insertion (partial note sections) to address related needs. The purpose of this study is to enhance understanding of the note splitting and text insertion phenomena by describing the processes, the resulting creations, and the associated clinician rationales. Mixed methods included a thinkaloud protocol and analysis of user interface creations and time sequences.

Keywords. User-composable EHR, EHR, EMR, electronic health record, usability

Introduction

Clinicians using an electronic health record (EHR) are faced with the task of communicating the patient condition to self and colleagues, completely, succinctly and accurately and in limited time. One issue is that different pieces of the required information can have different characteristics, e.g. update frequency, ideal level of detail, or optimal place in the user's workflow. This can pose difficulties in forming a coherent usable communication. Clinicians need historical information that does not change over time, as well as other information from the notes of others to inform their note writing - to save time, they cut and paste since that is a feature in many conventional EHRs. However this solution to clinicians' needs can have disadvantages, such as errors induced by false assumption that the copied material is accurate and still relevant[1-3]. As part of a study that gave clinicians the ability to insert text blocks anywhere in the interface, using an innovative widget-based system[4-6], some users (6/12) used the process of note splitting and/or text insertion to meet needs that are sometimes solved through cut and paste. The purpose of this study is to enhance understanding of the note splitting and text insertion phenomena by describing the processes, the resulting creations, and the associated clinician rationales.

We previously described a novel EHR system, MedWISE, in which nonprogrammer clinician users can gather any desired elements such as laboratory test

results, clinical notes, X-ray reports, RSS feeds, or other information on the same screen by drag/drop[4-6]. This includes the ability to incorporate text blocks anywhere in the interface, via the 'stickynote' widget (see Figures 1 and 2). Clinicians can also create and share entire interfaces, which may be patient-specific or reflect specialty or individual preferences. One aim of giving clinician users control to design the EHR is that they may use this freedom to solve existing problems, leveraging their extensive domain and contextual knowledge to create technological solutions better fitting their needs. Here we examine note splitting and block text insertions as examples of such problem-solving. We have reported more complete descriptions of MedWISE and its use[4-6].

1. Methods

Thirteen clinicians (10 residents, 2 attending physicians, and one physician assistant (PA)) were recruited via a focus group announcement and email from the hospitalist and nephrology divisions of NYP. The protocol was approved by the Institutional Review Board of Columbia University. Clinicians gave informed consent before data collection and were each compensated $100 for a two-hour session.

Clinicians were given four real patient cases and asked to assume that they would be taking over care of the patients. They were asked to think aloud as they used MedWISE. To simulate a typical realistic care situation, clinicians were not given instructions regarding use of specific widgets or the order in which to view and organize information. For cases 1 and 2, they were instructed to use MedWISE in any way they wished, in order to familiarize themselves with the patient's condition and state their respective assessments, diagnoses, and plans. For case 3, they were also asked to prepare a screen layout that would be shared with colleagues. For patient case 4, they were told they had ten minutes to view information before summarizing.

Think-aloud protocols [7] from the thirteen users were transcribed and coded according to two coding schemata, which were also applied to the associated screen actions: 1) the schema of Hassebrock and Prietula[8] for diagnostic reasoning: data examination, data exploration, data explanation, hypothesis evaluation, discrepancy processing, meta-reasoning, and summarization; 2) an investigator-derived schema identifying elements pertaining to HCI; some elements were based upon literature pertaining to the intelligent use of space in workplaces[9]. These included behaviors and codes such as spat (spatial arrangement), creat (creation), rati (rationale for the action), split (note splitting), sugg (suggestions), note (note creation), region (assigning regions of the screen for particular purposes), and so on. Data were coded by one investigator (YS) and reviewed by a second (SB) to support the qualitative research criterion of auditability[10].

2. Results and discussion

We surveyed users about their computer skills. All but two users used social networks. One rated himself 'expert' in computer knowledge, seven rated themselves 'above average', and five rated themselves 'average'. Nine used EHRs from other locations, usually from home. Table 1 summarizes subject demographics and their use of EHRs.

Table 1. User demographics and EHR use.

Demographic	Average Time	Range
Service at NYP	2.5 yr	4 mo-6.5yr
Work in field	3.3 yr	4 mo-7 yr
WebCIS use	2.4yr	4 mo-6.5 yr
Eclipsys use	1.9 yr	4 mo-4.5 yr
Other EHR use –5.7	2.7 yr	0-6.5 yr
Hours/week		
WebCIS	26.6 hr	8 hr-80 hr
Eclipsys	25.8 hr	8 hr-80 hr

Users created a variety of interfaces, described in Senathirajah, Kaufman, Bakken, [11]. Six of twelve users (including the PA and one attending) made use of the stickynote, two using it to split notes into multiple sections (in six interfaces total), and four to insert text blocks (e.g., to-do lists, medications and problems) in different parts of the screen for particular purposes (in ten interfaces total). Common note parts were: a) orienting 2-4-line summaries (n=5), b) orienting problems and task lists (n=5), c) active issues/history/medications (n=5), d) problems, medications, plan/tasks (n=2).

Some users sought to address perceived limitations in current conventional systems, and had reflected on a logistical difficulty created by copy-paste, eloquently described by one user: "…for example you're not taking a social history or family history at every single visit but it'll show up in every single note, which … takes up a lot of room and makes the note way longer than it has to be. The problem is that you don't include it, if you want to see it you have to go clicking through note, note, note, and it takes forever. So… have a section of things that aren't necessarily going to be updated every single time, and if something updates it it's fine, but … my most recent progress note will be pretty tight."

This user split the usual clinical note into Background Information and Active Issues sticky notes placed in different columns (Figure 1). He stated that this would allow the less-frequently updated background to be available but separate, allowing a 'clean' active issues section. Another placed a brief 3-line patient summary in the top left-hand corner to orient readers 'as soon as you get to the page', the medication list with other action items, and a health care maintenance list with related labs (Figure 2). Likewise, another placed a problem list and task list in different parts of the screen to structure work processes. Orienting summaries in the upper left corner and to-do lists in the upper right were consistent with a general pattern of left-right progression from orienting information to action items, described in [11]. Another example of user creativity includes the use of the stickynote and column organization as a way to convey a task list. The user stacked lab panels to be monitored in one column with a stickynote saying 'labs to monitor' addressed to subsequent team members caring for the patient. This was faster than writing a list and,made the same widgets serve both display and task list purposes.

Some users gave reflective rationales for their actions. The flexible functionality allowed them to structure information display according to data characteristics and clinician needs, bringing to the surface that which is currently important while leaving other information available. Splitting notes lets the level of detail be suited to the function; thus a 3-line high-level summary served to orient the reader at the beginning of case review while a detailed task list placed at right gave appropriate information toward the session end. Information could be grouped with other EHR elements on the basis of common function. Wrenn et al. suggested modular note formats in which the

most recent note may link to other note sections as a strategy for reducing cut and paste; our users essentially did this[12].

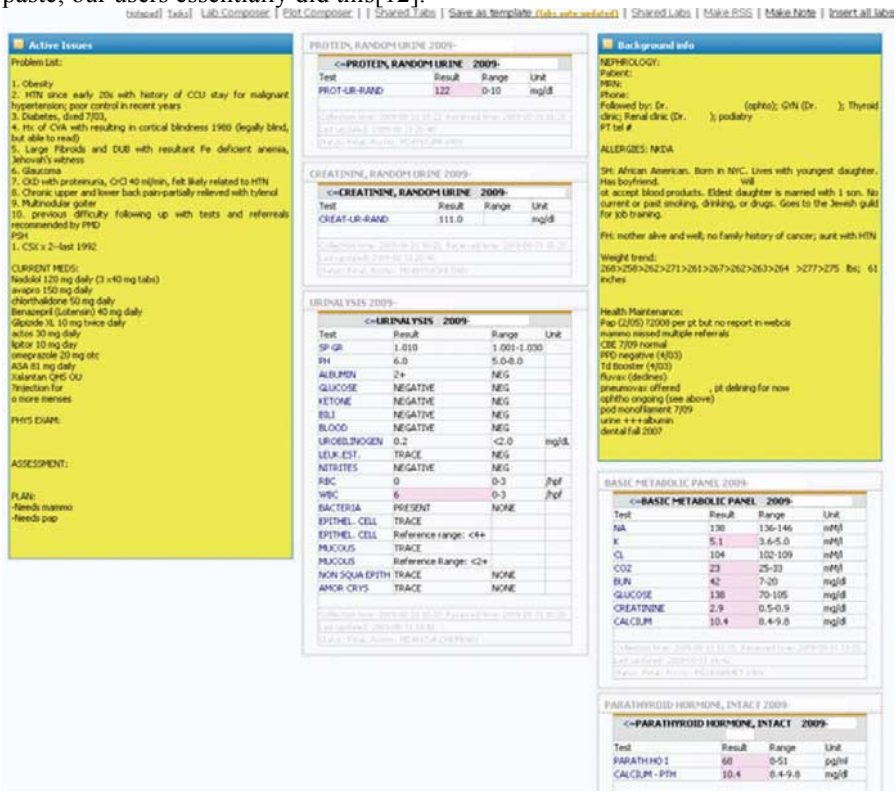


Figure 1. The user split the notes into background information and active issues; the latter is updated frequently while the former is easily available if needed.



Figure 2. The user created a 3-line summary at upper left, the first area viewed, to orient himself, and placed data with healthcare maintenance issues in the middle column, with custom lab panels to monitor and medications in the right column.

Though a simple example, note splitting allowed clinicians to avoid some consequences of note copying, and shows their ability to use new functionality creatively to solve a problem in their daily work.

Limitations of this work include the small number of subjects in the laboratory study and the study at one institution (though with data from two major medical centers) which limits generalizability. The laboratory tasks did not allow for real communication with colleagues. Most clinician subjects were in a training phase (residents). It is also possible that there was a self-selection bias since participation was voluntary. On the other hand, the use of real patient records and realistic tasks were strengths.

3. Conclusion

Clinician users given a flexible user-composable system found a different way to address the problem of efficient and usable note creation in EHR use. Larger studies with a greater range of users and use cases, will help clarify the extent to which this is a desirable approach. The possibility of clinician-directed problem-solving make such design and interaction approaches worthy of further exploration.

References

[1] Siegler EL, Adelman R. Copy and paste: a remediable hazard of electronic health records. Am J Med. 2009;122:495-6.
[2] O'Donnell HC, Kaushal R, Barron Y, Callahan MA, Adelman RD, Siegler EL. Physicians' attitudes towards copy and pasting in electronic note writing. J Gen Intern Med. 2009;24:63-8.
[3] Hammond KW, Helbig ST, Benson CC, Brathwaite-Sketoe BM. Are electronic medical records trustworthy? Observations on copying, pasting and duplication. AMIA Annu Symp Proc. 2003:269-73.
[4] Senathirajah Y, Bakken S. Important ingredients for health adaptive information systems. Stud Health Technol Inform. 2011;169:280-4.
[5] Senathirajah Y, Kaufman D, Bakken S. The Clinician in the Driver's Seat: Part 1 - A Drag/drop User-composable Electronic Health Record Platform. J Biomed Inform. (under review).
[6] Senathirajah Y, Bakken S. Architectural and usability considerations in the development of a Web 2.0-based EHR. Stud Health Technol Inform. 2009;143:315-21.
[7] Kushniruk AW, Patel V. Cognitive evaluation of decision making processes and assessment of information technology in medicine. Int J Med Inform. 51:83-90.
[8] Hassebrock F, Prietula MJ. A Protocol-Based Coding Scheme for the Analysis of Medical Reasoning. Int J Man Mach Stud. 1992;37:613-52.
[9] Kirsh D. The Intelligent Use of Space. Artificial Intelligence. 1995;73:31-68.
[10] Lietz CA, Zayas LE. Evaluating Qualitative Research for Social Work Practitioners. Advances in Social Work. 2010; 11:188-202.
[11] Senathirajah Y, Kaufman D, Bakken S. The Clinician in the Driver's Seat: Part 2 - Intelligent Uses of Space in a User-configurable Electronic Health Record. J Biomed Inform. (under review).
[12] Wrenn JO, Stein DM, Bakken S, Stetson PD. Quantifying clinical narrative redundancy in an electronic health record. J Am Med Inform Assoc. 2010;17:49-53.

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Real-time Monitoring of Clinical Processes using Complex Event Processing and Transition Systems

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Abstract. Dependencies between tasks in clinical processes are often complex and error-prone. Our aim is to describe a new approach for the automatic derivation of clinical events identified via the behaviour of IT systems using Complex Event Processing. Furthermore we map these events on transition systems to monitor crucial clinical processes in real-time for preventing and detecting erroneous situations.

Keywords. Workflow Management, Complex Event Processing, Process Mining, monitoring clinical processes, error-prevention in hospitals

Introduction

Care processes and their tasks within hospitals are complex and can be error-prone, as many people from different organizational units work together hand in hand and rely on each other. Due to the lack of central care plans (clinical pathways), knowledge of a patient's care status, such as past and future treatments, is distributed among several nurses and doctors within a hospital ward. However, medical staff has to be aware of the complex dependencies between tasks, which results in them needing to take care manually that these dependencies are fulfilled within each care process. A surgery for the implementation of a hip joint endoprosthesis, for example, requires multiple steps performed in advance: several diagnostic treatments such as radiologic examinations, taking and examining blood samples or performing patient information by the surgeon and an anaesthesiologist including the signing of a consent form by the patient. Forgotten or neglected patient information can lead to cancellation and postponement of the surgery, will cause financial damages and may as well enhance patient's risk. Other medical errors can harm the patient's health status and even endanger her life [1].

During the last years, specialized IT systems have been used increasingly in supporting tasks within hospitals. Each medical discipline has its own specialized IT system, such as *Clinical Information Systems (CIS)*, *Computerized Physician Order Entry Systems (CPOE)* for drug prescription, *Radiology Information Systems (RIS)*, *Picture Archiving and Communication Systems (PACS)* and many more. Additionally non-medical systems are also being used to support clinical staff e.g. *Materials Management Systems (MMS)* or *Enterprise Resource Planning Systems (ERP)*, only to name a few. According to the widespread use of IT systems throughout hospitals, a

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possible solution for supporting medical staff in keeping track of these complex dependencies between tasks is the usage of *Workflow Management Systems (WfMS)*. In using WfMS care processes are being defined as formal process descriptions, linked to functions and modules of IT systems used within the processes and are then executed in real-time on a workflow engine [2]. However, due to flexibility issues inherent to the complexity of clinical processes the usage of WfMS in the clinical domain remains difficult [3]. In addition only a few hospitals have already defined care processes as clinical pathways. Moreover, a third point is that IT systems have to be open for adaptation and external control by a WfMS; yet, IT systems in the clinical domain are known to be less adaptable as it is required.

However, in order to make the error-reducing benefits of workflow management systems available to the clinical domain, we propose a new approach combining the concept of process mining with methods of *Complex Event Processing (CEP)* and partial process knowledge formalization by the usage of transition systems as finite state automata. In our approach a new infrastructure component called *Transparency Server (TS)* passively observes the behaviour of IT systems and infers domain specific events. These events are then used as triggers within final state automata for formal process knowledge representation. As a result domain users such as nurses and doctors receive transparent real-time information specifically regarding processes performed across different departments e.g. wards or functional areas and will be informed as soon dependencies between tasks are not met.

1. Methods

In the following section the main concept of our approach is described and the underlying methods and formal foundations are explained. As shown in figure 1, our concept is structured in three steps – (1) *message transformation and event recognition*, (2) *Complex Event Processing* and (3) *model knowledge representation*. Each step will now be described in a separate subchapter. In chapter *proof of concept* main facts of experimental usage of the prototypical implementation will be given.

1.1. Message transformation and event recognition

As mentioned in the previous section, nearly all IT systems in hospitals exchange messages containing information like patient data, order data and further [4]. This is necessary to rudimentarily realize domain actions across system borders (e.g. inform all systems about a patient's status). Usually domain standards like HL7 (Health Level 7), DICOM, EDIFACT or proprietary formats are used. Every hospital runs a *communication server* that routes these messages between the IT systems and performs message type transformations, if necessary.

Our approach is built on top of these communication servers as in a ***first step*** copies of all messages exchanged are being sent to our *Event Engine*. The Event Engine parses all incoming messages and derives *Event Objects* according to catalogues that specify message-to-event transformation rules. With our *Event Type Repository* we developed an entire catalogue of relevant event types in hospitals. *Events* specified in this catalogue are meant to have unique semantics throughout different hospitals. Despite these, a mandatory syntactical structure is defined for each event. The underlying data model specifies a typed parameter structure for each event

type (e.g. *case id*, *order id*). Examples of such events are the successful admission of a patient (*New Case Event*) or the placement of a diagnostic order to a functional department (*New Order Event.)* All derived events are put onto an internal *Event Bus* for further processing.

1.2. Complex Event Processing

In a *second sted* we use *Complex Event Processing (CEP)* to derive aggregated events from the event stream on the Event Bus. According to *detection-oriented CEP* we define detection rules inside a Rule Repository utilizing an *Event Pattern Language (EPL)* [5]. In applying different compositional operators on the parameter structure mentioned above, temporal and logical dependencies, as well as parameter transformation rules can be specified to describe complex events. The syntactical structure and semantics of complex events are specified in the Event Type Repository as described previously. After detection, complex events are put onto the Event Bus and can be used recursively for complex event detection. Although the data structure of all events is the same, we distinguish between atomic and complex events by their origin – atomic events are directly derived from messages, complex events are derived using the CEP processor of our Event Engine.

1.3. Model knowledge representation

The main goal of our approach is to map the observed knowledge of our event-based real-time monitoring on a priori knowledge of processes or objects (***third step***). To represent this knowledge and formalize the interaction behaviour of events, we use finite-state machines as transition models. Processes and process fragments as well as objects (e.g. order, rooms, devices) are each described as a *Mealy machine* [6]. The states of the Mealy machine are specified representing interesting aspects of the observed entity such as process states or room states. Every transition defined between two states is assigned to exactly one *Event Matching Pattern*. Event Matching Patterns specify conditions that trigger a transition referring to typed parameters of the event structure. *Example*: As a result it is possible to choose parameters (e.g. *event type code*, *case id* and *order id*) with assigned values. After deployment of the transition model, each event on the Event Bus that contains the specified parameter-value pairs of an Event Matching Pattern, will thus trigger its transition (assuming a Mealy machine instance is currently in the transition's source state and ready to fire).

These entity model representations described by Mealy machines can be used within user interfaces such as cockpit systems to indicate interesting states of the care process. Definition of critical states within these cockpits and attaching alarm systems such as nurse call to the cockpit systems, allow us to inform personnel in real-time at the point of care.

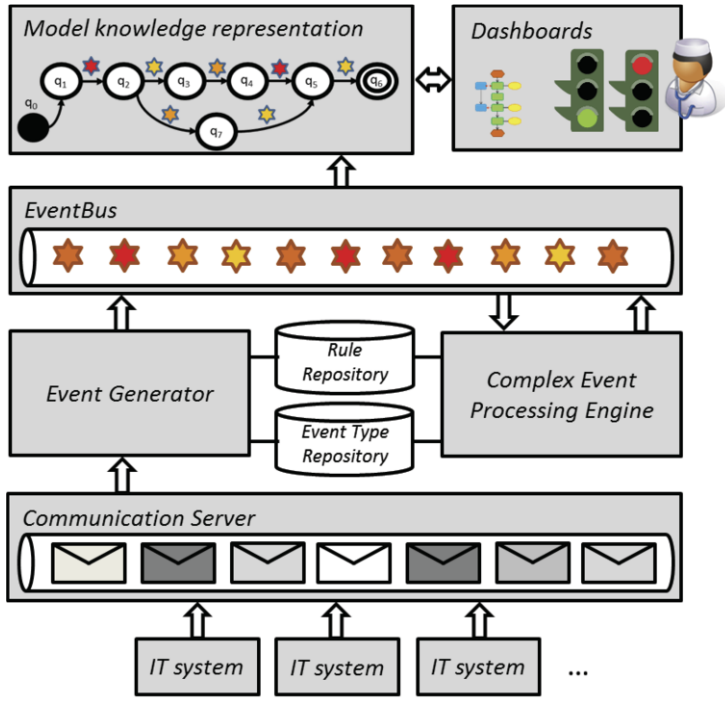


Figure 1. Main components of our approach ('letters' representing messages and 'stars' representing events)

1.4. Proof of concept

As a proof of concept a clinical scenario was chosen to be monitored using our approach. The scenario covers the process of *order placement* and *order release* for a surgery by a hospital ward, including *patient information* by a surgeon and an anaesthesiologist, *performing of the surgery* and internal *accounting*.

A prototype of our approach as shown in figure 1 was implemented in our hospital laboratory and attached to our communication server. The latter was configured to send HL7 messages of five relevant IT systems (CIS, electronic patient information system, CIS OR module, electronic patient record, ERP) to our prototype (event recognition component). We identified 12 relevant events (4 complex, 8 atomic events) and specified rules for event recognition using messages exchanged by the IT systems. As a model we specified a Mealy machine with 11 states (including 2 error states) and 12 transitions, each attached with an Event Matching Pattern. A web application was used to realize a simplified visualization of the Mealy machine (showing current state, error status) on a dashboard system.

2. Results

In our proof of concept we could show that the event-based approach was suitable for real-time monitoring of process fragments in scenarios across department-borders – the targeted application domain of our approach. By interacting with the attached IT systems, messages were sent and led to events triggering the dashboard's process

fragment visualization. Real-time information shown on the dashboard represented newly retrieved information that had not been available before. Due to the lack of a WfMS a global view on processes across departments had not been available before. We monitored two error scenarios (missing patient information and missing order release) and it was shown that our approach can help preventing and detecting errors while informing in real-time about the current process status.

As a pre-configuration it was necessary to analyse all relevant messages exchanged by the involved IT systems and map them to atomic events. This has to be done for each hospital environment and is a rather time-consuming task. We involved medical staff for testing the system in our laboratory and learned that the simplified visualization of the model is suitable for hospital personnel.

3. Discussion

The proof of concept showed, that there are two different methods for defining domain knowledge: one by representing knowledge in the complex event transformation rules, the other within the transition systems' layer. Which one is used, depends on the desired level of transparency and detailedness within the scenario, whether to hide knowledge or make it visual. Another important aspect is the ability for reuse atomic and complex events that are already defined. Due to the time-consuming act of message analysis and rule definition, it would be desirable being able to reuse them in other scenarios and different knowledge representing models. Our definition of complex events keeping the same structure and semantics across hospital borders, make them reusable at a much higher level in contrast to atomic events.

It could be shown that for the majority of hospitals not using WfMS and without continuous and wide-spread definition of processes, our approach can be a reasonable alternative to make the error-preventing and transparency creating properties of WfMS available for this domain. If WfMS will be introduced at a later point, our approach can help both, worklist handlers and workflow engines to get real-time task updates.

Future extensions of our approach are the introduction of an additional layer using linear-time temporal logic (LTL) terms to model constraints and action-rules based on our event objects. This will help hospital staff to be automatically informed if unwanted conditions occur. Another future extension will use output function of Mealy machines for injection of new events back into the Event Bus. This extension will assign the model layer from a passive to an active role, interacting with other transition systems and provide more complex knowledge representing models.

References

[1] Kohn LT, Corrigan JM, Donaldson MS, *To Err Is Human: Building a Safer Health System*, Natl Academy Pr, 2000

[2] van der Aalst WMP, van Hee K, Workflow Management: Models, Methods, and Systems, Mit Press, 2004

[3] Dadam P, Reichert M, Kuhn K, *Clinical Workflows - The Killer Application for Process-oriented Information Systems?*, 4th International Conference on Business Information Systems (1997), 36-59

[4] Kolovou L, *Message communication server for Medical Information Systems' interoperability*, 8th IEEE International Conference on BioInformatics and BioEngineering (2008), 1–6

[5] Luckham DC, Event Processing for Business: Organizing the Real-Time Enterprise, John Wiley, 2012

[6] Roth CH, *Fundamentals of Logic Design*, Thomson-Engineering, 2004 364–367.

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Comparing Narrative versus Numerical Display of Functional Information: Impact on Sense-Making

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Abstract. Contextual information consists of functional, social, and financial information about patients. Physicians routinely have difficulty incorporating contextual information into clinical decision-making despite the emphasis on patient-centered care and functional status. One reason for this difficulty is that such information is not well-represented in the patient medical record. This study assesses the impact of a "story-form" model versus a "medical" model on a practitioner's ability to recall and incorporate contextual information. We assessed this question through the analysis of responses of 30 clinicians to 2 vignettes presenting contextual information in both formats. Overall, there was a statistically significant difference between the narrative and numerical form with those receiving the narrative form for contextual information being more likely to consider it a top issue. Reference to goals in the report of key clinical factors was also significantly higher for the group receiving goal information. Implications for sharing contextual information in EMRs are discussed.

Keywords. Decision-support; writing; computerized documentation

Introduction

Contextual information consists of the functional, social, and financial information about patients.[1,2] Because contextual information is patient specific, it is key to understanding the patient's unique situation and individualizing evidence based care. However, social and functional information is often not communicated across settings and is neglected in clinical decision-making despite the fact that functional information is a powerful predictor of patient outcomes. One reason that it is not integrated well into care is that this information is relatively unavailable or difficult to locate in current EHRs.[3]

Increasing the availability of contextual information, especially functional information, is likely to improve care, enhance decision-making and improve team-work. Smith, et al. showed that enhancing access to the patients' functional information at discharge decreased hospital readmissions.[4] Frick, et al. found that clinicians were better at predicting patients' quality of life and personal goals when they had accurate information about functional status.[5] Clinicians significantly under-estimated post-acute care needs,[6] the degree of frailty in the elderly,[7] and acute

mental status changes.[8] For example, Emergency Room patients' functional status was assessed directly by research personnel and correlated with physicians' decisions to hospitalize or admit to an ICU.[9] Decisions to hospitalize or admit to an ICU were predicted by the physician's perceptions of the patient age and functional status, but not by their real functional status as measured by researchers.

Psychological studies suggest contextual information may be not be organized cognitively the same way as clinical information.[10] Episodic and social information is likely represented in "story-form' and is personal, specific, and linked to a particular time and geography. Clinical information, in contrast, is abstracted, semantic, and de-personalized knowledge and might be best represented numerically.[11,12] Therefore, contextual information, which includes social information, may be best shared through stories or narrative. Yet, much of what constitutes current decision-support eliminates important context-specific information in the effort to minimize information overload. The ironic result is that what appears to be less information is processed more slowly than more information. In other words, narrative information may be better at improving sense-making for functional and contextual patient information than numerical and tabular data.

Sense-making consists of answering the question "what is going on here?" It is high-level automatic information processing that integrates the disparate components of the environment to create an integrated "perception of the situation" and the creation of meaning.[13] Sense-making is highly social because meaning is embedded in our culture and shared context. The clinical narrative provides the best place in the medical record to acquire a true "sense" of the patient. Narratives contain high-level summaries, expected trajectories and overall goals of care.[14]

The purpose of this study is to directly examine the impact of the form of information display on cognitive processes. This work is part of an overall effort to better define the format and structure of a shared information space for contextual information in order to inform the design of a shared information display. A previous study by the authors examined the nature of contextual information and identified seven characteristics of contextual information relevant to its use in a clinical setting.[15] These characteristics represent an initial taxonomy to support future EHR design, Natural Language Processing (NLP) and text searches.

1. Methods

1.1. Design

The design was a 2-way within-subject randomized trial where participants were assigned to one of two presentation sequences for two vignettes. Each vignette had two forms for presenting functional information, a narrative "Story-form" format which included patient goals, versus a numerical/tabulated presentation of functional status. The design was counter-balanced across the participants, with the order of presentation randomly assigned.

Thirty volunteer MD residents, nurse practitioners, and staff physicians from the Salt Lake City VA Medical Center were approached singly and asked to complete the forms.

1.2. Procedures

For each vignette, participants read the material and responded to 2 questions: 1) Identify the top 3 **issues** for the patient, and 2) Identify, the top 3 **factors** used in considering their plan. Open-ended responses were selected in order to minimize response set bias. Study involvement times averaged 10 minutes. The top three issues and top three factors were coded as being either "medical" (e.g. diagnosis, lab, medications) or "contextual" (living arrangements, financial, or patient goals) by the research team (n=5) through a consensus process. The proportions of total items identified within each category were the dependent variables for each participant.

Data Analysis: The proportion metrics for contextual items, medical items and goals were analyzed using a separate within-subjects ANOVA for Identified Issues and for Identified Factors.

2. Results

Overall, there were significant differences between the narrative and numerical form of information presentation with those receiving the vignette containing the narrative form for functional information being more likely to list a contextual topic as a top issue **($F_{1,56}$ = 5.21; p=0.03; M(narrative group) = 69% and M(numerical group)= 31%)**. However, there was no difference between the groups for the top most important factor relevant to decision-making. Reference to goals in the description of factors was significantly higher for the group receiving narrative information (**$F_{1,56}$ = 6.20; p=0.01; M (narrative group) = 74% and M(numerical group)= 26%).**

3. Discussion

The results of this exploratory study indicate that narrative information may be a better method of communicating functional and goal information. The outcome variables were the likelihood of specifying contextual information as a top issue, the ratings of importance for contextual factors in constructing a plan and identification of patient goals. Although these results do not directly deal with the quality of decisions, they do indicate what information was attended to and what was considered important as a function of how it is displayed. Other authors have found that physicians often fail to notice contextual information and these results suggest a possible explanation. Future work could tease out the issues of attention, information processing and patient outcomes.

The evidence that narrative supports higher-level reasoning is substantial in the psychology literature. Narrative answers the sense-making question of “what is going on here with this patient.” It is this sense of the patient and the overall situation that is the foundation of the expert’s naturalistic decision-making. Once the pattern is identified and the situation made clear, then experts move rapidly to identify what needs to be done. Narrative supports the abstract processing which is required to ensure that the “gist” of the situation is attended to and addressed. Knowing the “big picture” is one of the key components of effective decision-making and effective communication. [16]

3.1 Communication

Communication is key to high quality heath-care [17,18] and enhancing collaboration among clinicians should be a goal of contemporary EHR design. Effective collaboration and sharing of contextual information requires creating a shared information space in the medical record. The format and structure of this space is in not well known. There is a need to better elucidate a shared contextual information space for inclusion in EMRs. Coiera has made a compelling argument for the need to maintain communication environments that support clinical narrative that explains and tells complete stories because "stories" are the way that we talk. The clinical text is one place that those kinds of communications occur.[19] Similarly, Berg and Goorman discuss the limitations of the view that information is simply the right data at the right time. Because data is not context independent, it loses meaning when isolated. The clinical narrative provides that context.[20] Finally, Bolan and Tenkasi have noted the importance of our communication systems grounded in narrative in helping the community of work to construct strong shared perspectives and a community of knowing. [21] The clinical narrative is read by all members of the team and is key to creating a community around that patient's case.

3.2 Goals of Care

Patient's goals embody the patient's life-situation. Communication of these goals among clinical team members can make a difference in the delivery of clinical care. A study by Provonost, et. al. in an ICU setting demonstrated that implementing a daily display of patient care goals increased the understanding of goals of care by nurses and residents from 10%-95% (using interview and recall data) and decreased ICU length of stay by 50%.[22] Goals of care are not often documented in EMRs and thus plans towards achieving these goals are also less likely documented.[23] Fox, et al have proposed a model for developing an ontology of goals for this purpose, but the model has not been widely adopted. The current results support these findings by demonstrating that goals are more likely to be included in a care plan if communicated clearly in the patient records. The current results support these findings by demonstrating that goals are more likely to be included in a care plan if communicated clearly in the patient records.

With the recent and widespread Implementation of electronic health records (EHRs) and the emphasis on improving cognitive support, it is important to address issues of display and information presentation based on empirical work. This study indicates that the display of information may make a difference in decision-making. Narrative may be the more effective method to inform clinicians regarding a patient's functional status.

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References

[1] S.J. Weiner, A. Schwartz, F. Weaver, J. Goldberg. R. and S. Yudkowsky, et. al. Contextual errors and failures in individualizing patient care. *Ann of Int Med*, **153** (2010), 69-74.

[2] S.J. Weiner, A. Contextualizing medical decisions to individualize care: Lessons from the qualitative sciences. *J Gen Intern Med*, **19** (2004), 281-5.

[3] K. Wilhelmson, L.E. Rubenowitz, C. Andersson, V. Sundh, and M. Waern. Interviews or medical records, which type of data yields the best information on elderly people's health status? *Aging Clin Exp Res*. **18**, (2006), 25-33. 2006 Feb;18(1):25–33.

[4] B.A. Smith, C.J. Fields, and N. Fernandez. Physical therapists make accurate and appropriate discharge recommendations for patients who are acutely ill. *Phys Ther* **90** (2010 May), 693–703.

[5] S. Frick, D.E. Uehlinger, Z. Zuercher, and R.M. Zenklusen. Medical futility: predicting outcomes of intensive care unit patients by nurses and doctors--a prospective comparative study. *Crit. Care Med*. **31** (2003,Feb), 456–61.

[6] K.H. Bowles, S.J. Ratcliffe, J.H. Holmes, M. Liberatore, R. and Nydick, M.D. Naylor. Post-acute referral decisions made by multidisciplinary experts compared to hospital clinicians and the patients' 12-week outcomes. *Med Care*.**46** (2008 Feb), 158–66.

[7] K.S. Boockvar and D.E. Meier. Palliative care for frail older adults: "there are things I can't do anymore that I wish I could . . . ." *JAMA* 296 (2006 Nov 8), 2245–53.

[8] F.M. Hustey, S.W. Meldon. The prevalence and documentation of impaired mental status in elderly emergency department patients. *Ann Emerg Med*. **39** (2002 Mar), 248–53.

[9] A. Rodríguez-Molinero, M. López-Diéguez, A.I. Tabuenca, J.J. de la Cruz, J.R. Banegas. Functional assessment of older patients in the emergency department: comparison between standard instruments, medical records and physicians' perceptions. *BMC Geriatr* **6** (2006), 13–23.

[10] R.C. Schank and R.P Abelson. Knowledge and Memory: The Real Story. In *Knowledge and Memory: The Real Story*. Wiley & Sons, New York, 1995,1–85.

[11] R.S. Wyer and G.A. Radvansky. The comprehension and validation of social information. *Psychological Review* 106, (1999), 89–118.

[12] R.M. Sorrentino and E.T. Higgins ET. Handbook of motivation and cognition: the interpersonal context. Guilford Press, London, 1996.

[13] C.F. Kurtz and D.J. Snowden. The new dynamics of strategy: Sense-making in a complex and complicated world. *IBM Systems Journal*. 42 (2003), 462–83.

[14] K.E. Weick. *Sense-making in Organizations*. Sage Publications, Inc, New York, 1995.

[15] C.R. Weir, N. Staggers, K. Doing-Harris, R. Dunlea, T. McCormick, R. Barrus. A Taxonomy for Contextual Information in Electronic Health Records. *AMIA International Congress On Nursing Informatic*s. 2012.

[16] A.W. Kruglanski. The quest for the gist: on challenges of going abstract in social and personality psychology. *Pers Soc Psychol Rev*. **8** (2004), 156–63.

[17] To Err is Human: Building A Safer Health System - Institute of Medicine [Internet]. [cited 2012 Mar 12]. Available from: http://www.iom.edu/Reports/1999/To-Err-is-Human-Building-A-Safer-Health-System.aspx.

[18] E. Coiera. Clinical communication: a new informatics paradigm. *Proceedings of the AMIA Annual Fall Symposium*. 1996. p. 17.

[19] E. Coiera. When Conversation Is Better Than Computation. *JAMIA*. **7** (2000), 277–86.

[20] M. Berg, E. Goorman. The contextual nature of medical information. *Int J Med Inform*. **56** (1999 Dec), 51–60.

[21] R.J. Boland and R.V. Tenkasi. Perspective Making and Perspective Taking in Communities of Knowing. *Organization Science*. **6**, (1995 Jul 1), 350–72.

[22] P. Pronovost, S. Berenholtz, T. Dorma, P.A. Lipsett, T. Simmonds, and C. Haraden. Improving communication in the ICU using daily goals. *J Crit Care*. **18** (2003 Jun), 71–5.

[23] S. A. Collins, S. Bakken, D.K. Vawdrey, E. Coiera, and L. M. Currie. Agreement between common goals discussed and documented in the ICU. JAMIA **18** (2010 Nov 27), 45–58.

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7. Patient-Centred Care

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Improving Integrated Care in Chronic Kidney Failure Patients with a Standard-Based Interoperability Framework

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Abstract. This paper introduces the evaluation report after fostering a Standard-based Interoperability Framework (SIF) between the Virgen del Rocío University Hospital (VRUH) Haemodialysis (HD) Unit and 5 outsourced HD centres in order to improve integrated care by automatically sharing patients' Electronic Health Record (EHR) and lab test reports. A pre-post study was conducted during fourteen months. The number of lab test reports of both emergency and routine nature regarding to 379 outpatients was computed before and after the integration of the SIF. Before fostering SIF, 19.38 lab tests per patient were shared between VRUH and HD centres, 5.52 of them were of emergency nature while 13.85 were routine. After integrating SIF, 17.98 lab tests per patient were shared, 3.82 of them were of emergency nature while 14.16 were routine. The inclusion of a SIF in the HD Integrated Care Process has led to an average reduction of 1.39 ($p=0.775$) lab test requests per patient, including a reduction of 1.70 ($p=0.084$) in those of emergency nature, whereas an increase of 0.31 ($p=0.062$) was observed in routine lab tests. Fostering this strategy has led to the reduction in emergency lab test requests, which implies a potential improvement of the integrated care.

Keywords. Comparative Effectiveness Research, Electronic Health Records, Integrated Care, Chronic Kidney Failure, Interoperability Framework, Archetypes.

Introduction

Patients suffering from Chronic Kidney Failure (CKF) are usually involved in haemodialysis (HD) treatment. Being compliant with the Integrated Care Process for HD patients defined by our regional health authorities [1], this process encompasses HD sessions, medical treatments, and follow-up sessions making use of lab tests.

The clinical process for these patients is triggered when they are assessed at the Virgen del Rocío University Hospital (VRUH) Pre-dialysis Unit, where a report is then sent to the VRUH Nephrology Department. Based on this report, nephrologists generate a HD treatment plan. Also, they evaluate whether the patient is stable enough to be transferred to an outsourced HD centre in order to undergo a HD treatment, since

[1] Corresponding Author.

the resources available at the VRUH do not cover the complete CKF patients demand. If the patient isn't stable enough must undergo the HD treatment at the VRUH facilities otherwise. Afterwards, the VRUH Administrative Unit assigns the outsourced HD centre where patients will undergo their HD session, depending on their clinical condition and proximity to the HD outsourced centres. Once they are transferred to an external centre, a follow-up strategy for each patient takes place, leading to the generation of a session report every time the patient undergo a HD session [2].

At this point, also should be taken into account that patients could be transferred again to the hospital whether their health condition become unstable. Furthermore, patients' mobility must be considered in this scenario, taking into account holidays and long-term displacements away from their usual residence. This implies that patients should be transferred from their usual HD centre to another closer to their new location. Each new referral implies reports and lab tests sharing from the original HD centre to the new destination centre. This issue is also managed by the Administrative Unit.

Inherent to this process there is a bidirectional flow of reports and lab tests that need to be shared between the hospital and outsourced HD centres, because nephrologists from both healthcare providers need to keep track of patient response to HD treatment. In addition to these periodical lab tests, CKF patients also require urgent lab test whenever their health status worsens. Therefore, an improved integrated care will result in an optimal control of patient's health status, and this should lead to a reduction of urgent lab test requests. Although there were HIS and EHR systems in VRUH and in some of the HD outsourced centres, the communication between them was paper-based. This kind of communication has several well known drawbacks like privacy and security risks, communication delays, and lack of documentation traceability in general [3]. These issues make paper-based reporting prone to reduce patient's quality of care, since delays in sharing lab test results and clinical information between hospital and outsourced HD centres may burden continuity of care and increase the rate of emergency nature lab test requests, and the lack of traceability may fall for duplicating reports and lab tests and, therefore, increasing costs ineffectively [4]. The aim of this study is to assess the impact of the implementation of a Standard-based Interoperability Framework (SIF) on lab test requests related to patients with CKF undergoing a HD treatment making use of IHE profiles, HL7 standards, and ISO EN 13606 archetypes, integrating it with a Serviced Oriented Architecture (SOA).

1. Methods

1.1. Standard-Based Communication System

In order to overcome the aforementioned drawbacks, an interoperability framework was developed according to current health information standards:

- IHE XDS.b profile [5] for sharing clinical documents between hospital and outsourced HD centres.
- HL7 CDA documents [6] to specify the encoding, structure and semantics of clinical documents.
- HL7 v2.5 messages sent by the Laboratory Information System (LIS) including lab test reports.

- ISO EN 13606 archetypes [7] to define the data model in order to differentiate knowledge from information and take advantage of the reusability capabilities provided by archetypes-driven data models.

In order to create and edit archetypes, and to model transformations between distinct formats of knowledge representation, the LinkEHR-Ed tool was used [8].

According to these standards, three clinical reports were developed: HD session report, treatment report, and referral report. These documents were designed by nephrologists from the VRUH Nephrology Department in order to fully support the Integrated Care Process for HD patients. Lab test reports from LIS were also included in the SIF in order to be compliant with this Integrated Care Process and following nephrologists' indications. All these documents were implemented and integrated under the Andalusian Public Health Regional Service Oriented Architecture (SOA) [9] in order to integrate the SIF with the following regional services: User Data Base, Operator Centralized Access Module, and Centralized Clinical Data [2]. Therefore, demographic data, professional roles, and further clinical information from patients were also integrated in the SIF making use of the already deployed regional services. The correct utilisation of these regional services guarantees the SIF compliance with current information privacy policies.

1.2. Evaluation study

We conducted a prospective, quasi-experimental, pre-post intervention study by means of the evaluation of lab test reports during fourteen months, where control and intervention groups were the same sample of patients.

The inclusion criteria were:

- Patients suffering from CKF undergoing HD.
- Patients being treated at any of the 5 HD outsourced centers included in the study.

The exclusion criteria were:

- Patients without lab test requests in both periods of the study.
- Patients deceased during the study.
- Patients undergone a surgical transplant.

The main outcome was the number and type (routine or emergency) of shared lab test reports between the VRUH and 5 outsourced HD centres regarding to CKF patients being treated in these centres.

Data are presented as average ± standard deviation. In order to test the hypothesis that the number of lab tests requests would drop after fostering a SIF, a non-parametric analysis was performed (Wilcoxon signed-rank test).

2. Results

The SIF has been developed and successfully deployed in the regional SOA infrastructure. In the Figure 1, a schematic description of the SIF and its integration is shown. A deeper explanation of the SIF can be found on [2].

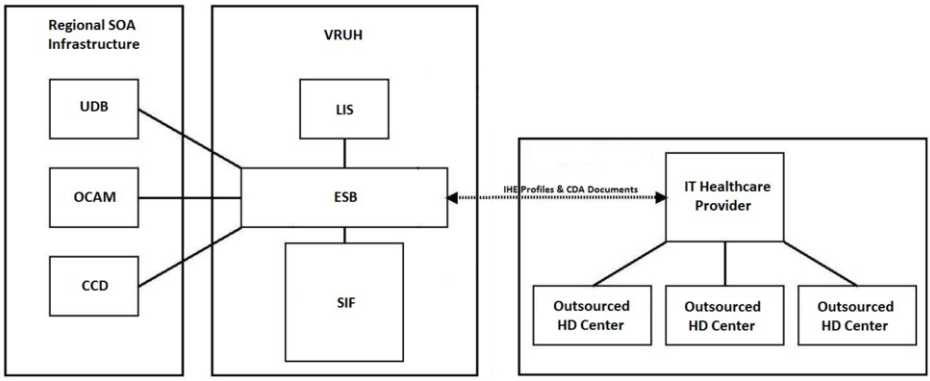


Figure 1. SIF integration with the regional SOA architecture, VRUH systems, and HD outsourced centers.

A total of 488 patients suffering from CKF undergoing HD treatment at outsourced centres were identified. 109 patients were excluded from analysis due to the lack of information of lab test requests in both periods (58), died during the study (3), and renal transplantations (48). Therefore, lab test reports belonging to 379 patients were included in this study, 141 (37 %) women and 238 (63 %) men, with an average age of 66 years.

In table 1, pre-post study results are shown classified by emergency and routine requests per patient. Both periods (before fostering SIF and after fostering SIF) are seven months length each.

Table 1. Lab test reports per patient shared between VRUH and the 5 outsourced HD centers classified by emergency and routine requests.

Study Period	Before fostering SIF	After fostering SIF	P-value
Routine requests/patient	13.85 ± 4.20	14.16 ± 6.10	0.062
Emergency requests/patient	5.52 ± 9.94	3.82 ± 6.79	0.084
Total requests/patient	19.38 ± 11.78	17.98 ± 10.63	0.775

The inclusion of a SIF in the HD Integrated Care Process has led to an average reduction of 1.39 laboratory test requests per patient over a period of seven months. Lab test requests nature analysis yields an average increase of 0.31 in routine lab test requests per patient, whereas emergency lab test requests has been reduced in 1.70 per patient.

3. Discussion

A SIF has been designed and successfully deployed in order to support the HD Integrated Care Process. This SIF has been developed with the ability of replace the previous paper-based communication system. Data models and report communications have been developed according to current health information standards in order to provide a fully interoperable communication system. The SIF have been successfully integrated with the regional SOA infrastructure, including the VRUH Laboratory Information System (LIS), allowing lab test reports being shared automatically as they are released with 5 outsourced HD centers. This integration allows a seamless interoperability with currently deployed regional services.

The deployment of a SIF in this scenario has well-known benefits derived from moving from paper-based health records to EHR such as privacy, data protection, better information management, reduced delays due to reports exchange, improved traceability and, therefore, reduction of duplicities in lab test requests. These benefits have a direct impact on the quality of care perceived by patients.

The SIF evaluation shows that it might impact on patient outcomes. The result shows a no significant reduction in lab tests requests related to patients with CKF and HD treatment in 5 outsourced HD centers, while a reverse trend between routine and emergency testing is appreciated. This reduction may have implications for patient safety since emergency tests are more likely associated with complications in patient health. Furthermore, reduction in the number of emergency tests is associated with an increased efficiency due to planning capabilities in laboratory that would result in reduction of costs.

The authors are aware of the limitations related to this analysis, including the seasonality inherent to the study periods, which may be considered a biasing factor. In this sense, future work will address the extension of the analysis to a period of two years length, one year each, and is envisaged to include the impact on economic outcomes associated with drops in lab tests. If these early results are then endorsed, they will provide a proof strong enough to promote the implementation of SIFs to support Integrated Care Processes in cross-enterprises environments.

Future work will also address the inclusion of treatment, referral, and HD session reports coming from outsourced HD centers in this SIF. This would led to real improvements in patients' integrated care, since their clinical information would be continuously updated at both emplacements (hospital and HD outsourced centers) that will provide a better follow-up of the patients as well as improvements in care delivery in case of urgent interventions.

References

[1] Consejería de Salud, Tratamiento sustitutivo de la insuficiencia renal crónica: diálisis y trasplante renal: proceso asistencial integrado. Consejería de Salud, Sevilla, 2005.

[2] A. Moreno, A. Martínez, F. Núñez, C. Parra. Testing a New CDA Development Strategy in Standardized Infrastructure for Continuity of Care in Chronic Kidney Disease Patients. EJBI. 2012; 8(3): 31–36.

[3] N. Menachemi, T.H. Collum. Benefits and drawbacks of electronic health record systems. Risk Manag Healthc Policy. 2011; 4: 47–55.

[4] J.M. Holroyd-Leduc, D. Lorenzetti, S.E. Straus, L. Sykes, H- Quan. The impact of the electronic medical record on structure, process, and outcomes within primary care: a systematic review of the evidence. J Am Med Inform Assoc. 2011; 18: 732–737.

[5] IT Infrastructure Technical Framework. Volume 3 (ITI TF-3). Cross-Transaction Specifications and Content Specifications. Revision 8.0 – Final Text. [Internet]. Oak Brook: IHE International; 2011 [Cited 2014 Feb 5]. Available from: http://www.ihe.net/Technical_Framework/index.cfm#IT.

[6] R.H. Dolin, L. Alschuler, S. Boyer, C. Beebe, F.M. Behlen, P.V. Biron, et al. HL7 Clinical Document Architecture, Release 2. J Am Med Inform Assoc. 2006; 13: 30–39.

[7] European Committee for Standardization (CEN). ISO/CEN 13606: health Informatics-electronic health record communication. European Committee for Standardization, Brussels, 2010.

[8] J.A. Maldonado, D. Moner, D. Boscá, J.T. Fernández-Breis, C. Angulo, M. Robles. LinkEHR-Ed: a multi-reference model archetype editor based on formal semantics. Int J Med Inform. 2009; 78(8): 559–570.

[9] J.R. Fernández-Engo. Andalusia Health Services: a new SOA and HL7 strategy. HL7 International News. 2012 May. 16–17.

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Screening Radiation Exposure for Quality Assurance

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Abstract. Quality assurance for planned radiation exposure situations (e.g. Digital Radiography, Computed Tomography or Radio Fluoroscopic studies) requires the application of examination-specific scans protocols. These are tailored to patient age or size, body region and clinical indication for ensuring that the dose applied to each patient is as low as reasonably achievable for the clinical purpose of the image acquisition (ALARA principle). The European legal framework – 2013/59/EURATOM – points that health authorities will be more pervasive on inspecting the dosimetry applied to patients. This paper discusses these legal alterations and presents an interoperable distributed system for dose monitoring, which is compliant with legal procedures and the IHE Radiation Exposure Monitoring profile (REM). The system combines the most representative stakeholders affected and directly interested in the patient radiological protection: patients, radiologists, practitioners, health authorities, and ethics committee. The system is capable of gathering, in real-time, dose information applied to the patient and storing it in a regional or national wide dose registry. The paper addresses which information should such systems hold and which should be accessed, from each stakeholder perspective. Furthermore, the system may detect irregular dose patterns, which could indicate dose abuses, and signal those findings to the appropriate stakeholders.

Keywords. Patient Dosimetry, Quality Assurance, Medical Exposure Directive, DICOM, IHE REM.

Introduction

Planned exposure episodes (e.g. Computer Tomography or x-ray) typically apply to the patient low doses of radiation, resulting in no clinically observable tissue consequences (deterministic effects). Nevertheless, the possibility of stochastic effects in organs/tissues still persists, i.e. tissue injury, cancer or stimulate hereditary effects [1] [2]. Furthermore, it is assumed that the probability of a late effect occurrence is proportional to the dose amounts, for instance, for brain tumours [3, 4]. This calls for a specific regulation in radiation protection. European regulations protecting patient from dose abuse date from 1997 [5]. Current legal developments [6] recommend member states to improve the present Quality Assurance reviews in the field. More precisely, Medical Exposure Directive (MED) shifted the speech from member states "should promote" to "shall ensure". For instance, "the member state shall ensure the establishment of regular review and use of Diagnostic Reference Levels (DRLs)" [6].

In theory, radiodiagnostic episodes should always keep the radiation exposure, as low as reasonably achievable, to preserve the required quality of diagnosis – considering the radiotherapeutic and radiodiagnostic purpose, the patient's age, weight,

and body region. Hence, exposures of target mass volumes shall be individually planned, which means individual dose monitoring for ensuring an appropriate dose usage. However, there are numerous information systems installed within the institutions that do not allow dose analysis, and the institutions that continuously monitor it are rare [7]. Furthermore, patient treatments are often not confined to a single facility and, even if the institution holds the dosing record of the patient, the track is lost when the patient enters a distinct facility. In order to ensure that the new MED challenges are respected, health carers must continuously monitor dose centred on the patient, independently where she/he receives care. This associated inter-institutional scenario also touches the lack of interoperability problem in the healthcare domain.

This paper introduces a system that collects dosimetry information from heterogeneous data sources held in various information systems, assuring conformance with MED and with IHE's (Integrating the Healthcare Enterprise) radiation exposure monitoring profile (REM [8]). Furthermore, the paper reflects on the new MED revision – modelling the stakeholder relations accordantly. Finally, it explains how the system supports the dosimetry workflow, ranging from data acquisition, to how dose descriptors are presented to each stakeholder.

1. Stakeholders and dose descriptions relationships

Despite the important guidelines provided by MED and IHE REM, there is still a gap in the exploration of what each stakeholder should access. In order to model the information systems (REM-IS), it is necessary to define stakeholders and their role/profile in a dose registry that aggregates data from multiple centers, as well as the granularity of the data access. **Figure 1** illustrates the interactions between stakeholders within the dosimetry workflow, reflecting the MED and the IHE REM guidelines. The dose descriptors produced by imaging modalities that emit ionic radiation are patient-oriented. However, the dose descriptors are recognized by patient identifiers that are specific to each healthcare institution, which brings additional challenges for harmonizing them into a single cross-organization domain. Furthermore, the dose descriptors are typically vendor-specific and, in some modalities, the only way to access that information is by analysing the pixel data of DICOM (Digital Imaging and Communications in Medicine) objects. Therefore, a normalization layer must be included for importing the dose descriptors into the REM-IS.

The patient is the stakeholder directly affected by the exposure and, consequently, more interested in healthcare quality assurance. The physician that evaluates the patient requests the imaging study and, ideally, should have a notion of the DRL and the associated risk of requesting more studies. Nevertheless, the system must support the physician, e.g. mapping the patient's dose history with the recommended DRL for the study to be requested. The radiologist should know if the planned radiation exposure outbounds the DRL that was performed by X-Ray, i.e. the one that operates the modality and acquires the image. The Service Director is responsible for service quality assurance. Therefore, he/she must be able to access detailed information from each device, room or professional. The ethic commission should be warned about studies that outbound the ranges associating patients, equipment and professionals. Finally, health authorities must follow the quality assurance indicators, centered on the institution.

2. Architecture for a central dose registry

In our proposal, we aimed to combine IHE REM infrastructure components (i.e. IHE actors/transactions) with the requirements overviewed in the previous section. In

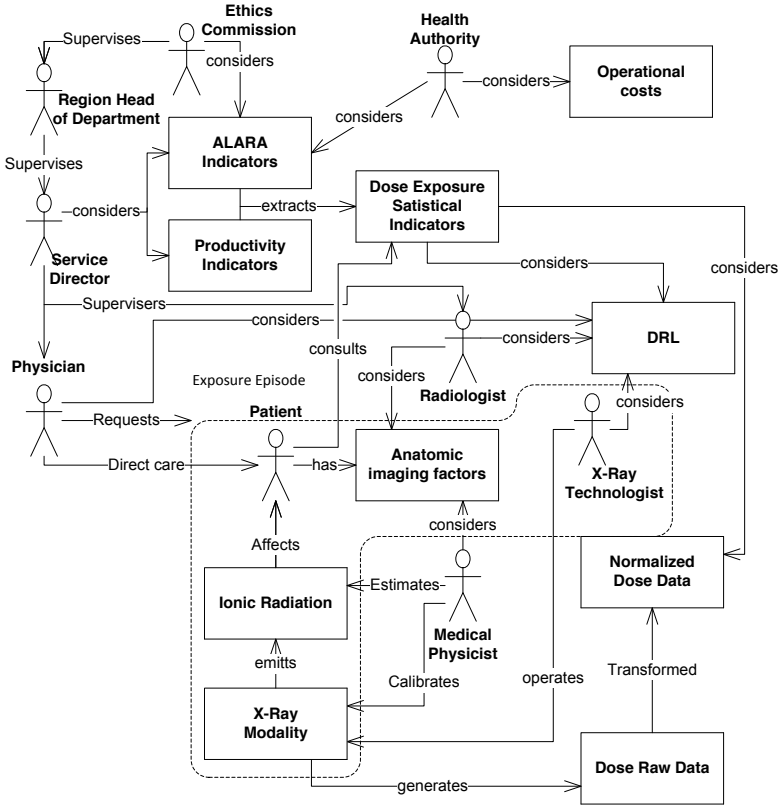


Figure 1 – Diagram of the dosimetry workflow.

the REM profile, the following list of actors are described: Acquisition Modality, Image Manager/Archive, Dose Information Reporter (DIR), Dose Information Consumer and Dose Registry. The workflow between these actors, needed to collect and submit data into a unique dose registry, is depicted in Figure 2. As mentioned before, legacy imaging system does not support interoperability. Therefore, we developed a Dose Reporter importing layer transforming ad-hoc dose metadata into REM dose objects. For instance, different vendors use different scales and different metrics to measure dose radiation exposure. Next, we detail the components of this transformation layer:

- **DICOM Metadata Extractor:** is responsible for accessing DICOM headers and also for supporting an OCR Dose Extractor – extracting dose information from pixel data. OCR can be used for vendors, such as Philips or Siemens.
- **MPPS Dose Gateway:** a service that listens for DICOM MPPS messages and extracts dose descriptors, such as Anatomic Region, Time of Exposure and Dose of exposure. This is the REM's reinforced methodology for collecting dose information.

- **DICOM Sniffer:** captures the DICOM traffic in the network, extracting the headers from the DICOM objects in real time.

In parallel to the importing and transforming processes, the layer continuously submits the collected dose information into the Aggregator Dose Registry (Figure 2). The Aggregator Dose Registry implements the Dose Registry REM actor, which receives all the data from the disperse sources across. The dose information that is submitted into the registry is already homogeneous, due to the transformation process at the importing layer – relieving the registry from the normalization effort.

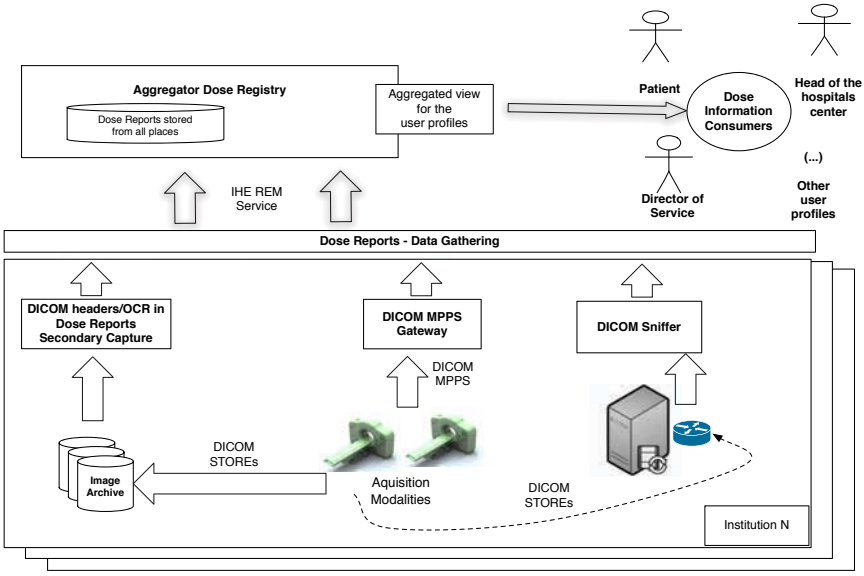


Figure 2: Dose Registry Architecture.

Moreover, the Aggregator is also responsible for providing dose information statistics to stakeholders, according to their profile. The Registry will classify measures by DRL, which may vary depending on the country. Furthermore, the DRL may be tuned for each modality, part of body, condition of the patient, age and sex. Based on these thresholds the Aggregator may trigger alarms and give dose quality feedback to the proper stakeholder. For instance, the dose information may be classified with three qualitative levels for dose indication purposes, such as low exposure, normal exposure or high exposure.

This architecture is inline with former work from our group. In [9] we already gathered dosage data from distinct institutions by parsing DICOM headers. This data was processed to better understand the radiologic procedures in a Portuguese regional hospital [10] . The undergoing work to accomplish the presented model includes the development of the central registry and the Web portal for stakeholders' access.

3. Discussions and conclusion

In Europe, the Medical Exposure Directive (MED) was recently revised, laying down the general principles about radiation protection regarding exposure and reinforcing patient-specific factors as part of their own clinical diagnosis or treatment – not only for diagnosis, but also for active health surveillance and health screening programmes.

Based on these directives, member states tune the Dose Reference Levels charts taking into account the population general characteristics (e.g. weight) and clinical purpose of the planned exposure [11, 12]. An important aspect of the directive is the optimization of DRL approximations based on the continuous dose screening applied to the patient. Across Europe, several initiatives are trying to achieve better compromises between lowering the applied dose and the image acquisition quality. Apart from the definition of the DRL, the MED improved on the responsibilities attribution (i.e. accountability) for the different stakeholders, ensuring that healthcare professionals are informed about the benefits and risks associated with the radiation clinical exposure. Despite the radiologists awareness, new studies reinforcing or indicating risks are constantly appearing [13] and so, information system that assists the decision of professionals, will definitely help improve the quality assurance of these diagnostic services.

In this paper, we described a system' architecture that defines how dose descriptors should be collected, stored and presented to the user, according to the stakeholder needs/responsibilities identified in the revised MED. The system follows the IHE REM guidelines for developing interoperable systems, and, at the same time, it allows easy integration of legacy systems that are not REM compliant, which makes their integration effortless with already in place medical devices. As a conclusion, our architecture combines the knowledge promoted by REM and respects the legal directives promoted by the EU. We believe that the adoption of interoperable dose screening systems is a vital step for effectively assuring the quality of planed radiation exposures.

References

[1] Bartal G, Vano E, Paulo G, Miller DL. Management of Patient and Staff Radiation Dose in Interventional Radiology: Current Concepts. Cardiovascular and interventional radiology. 2013:1-10.
[2] Boice JD, Land CE, Shore RE, Norman JE, Tokunaga M. Risk of breast cancer following low-dose radiation exposure. Radiology. 1979;131(3):589-97.
[3] Finkelstein MM. Is brain cancer an occupational disease of cardiologists? The Canadian journal of cardiology. 1998;14(11):1385-8.
[4] Roguin A, Goldstein J, Bar O. Brain tumours among interventional cardiologists: a cause for alarm. Report of four new cases from two cities and a review of the literature EuroIntervention. 2012;7(9):1081-6.
[5] Euratom, 1997/43: Health protection of individuals against the dangers of ionising radiation in relation to medical exposure, (1997).
[6] Eurotom, 2013/59: Laying down basic safety standards for protection against the dangers arising from exposure to ionising radiation, (2013).
[7] Hu M, Pavlicek W, Liu PT, Zhang M, Langer SG, Wang S, et al. Informatics in Radiology: Efficiency Metrics for Imaging Device Productivity. Radiographics. 2011;31(2):603-16.
[8] IHE. Radiation Exposure Monitoring (REM) Integration Profile. 2008. p. 65.
[9] Luís Bastião Silva MS, Carlos Costa, José Luís Oliveira, editor Dicoogle statistics: analysing efficiency and service quality of digital imaging laboratories. 27th Computer Assisted Radiology and Surgery (CARS 2013); 2013; Heidelberg, Germany.
[10] Santos M, de Francesco S, Silva LAB, Silva A, Costa C, Rocha N, editors. Multi vendor DICOM metadata access a multi site hospital approach using Dicoogle. Information Systems and Technologies (CISTI), 2013 8th Iberian Conference on; 2013: IEEE.
[11] Uffmann M, Schaefer-Prokop C. Digital radiography: the balance between image quality and required radiation dose. European journal of radiology. 2009;72(2):202-8.
[12] Williams MB, Krupinski EA, Strauss KJ, Breeden III WK, Rzeszotarski MS, Applegate K, et al. Digital radiography image quality: image acquisition. Journal of the American College of Radiology. 2007;4(6):371-88.
[13] Einstein AJ, Henzlova MJ, Rajagopalan S. Estimating risk of cancer associated with radiation exposure from 64-slice computed tomography coronary angiography. JAMA: the journal of the American Medical Association. 2007;298(3):317-23.

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TeamTreat – a communication platform for concerted cancer treatment

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Abstract. TeamTreat is an internet platform providing a case record for cancer patients across and inside the primary and secondary health care sector. Due to the slow progress of cross-institutional integration in healthcare IT, we created an alternative low-level approach to this problem and put special emphasis on an easy access for healthcare professionals regardless of the specific IT infrastructure they use. Physicians use the platform to share and collect information to achieve a collaborative treatment of cancer. Furthermore, the data in the case record is searchable for clinical researchers to find suitable patients for inclusion in clinical trials. Reading access for patients is also possible.

Keywords. Neoplasms/therapy, electronic health record, patient selection, clinical trials as topic/methods, patient care team, electronic patient record

Introduction

Cancer treatment of a patient involves many steps of action, different institutions and care settings. Although there is a grown infrastructure in hospitals and as well in most private practices, communication between these institutions is still relying on fax and mail carrier [1]. Electronic documents, in particular x-rays, are mainly exchanged via CD sent by letter mail.

Despite the integration efforts of IHE [2], the German EFA initiative [3] and several private companies to cross this gap, there is no fast breakthrough visible for a direct digital data interchange between German's healthcare providers. There are two main reasons for this: At first it seems that companies offering isolated healthcare information systems lack the commercial interest in integrating with other systems [4]. Secondly, strong privacy issues are always obstacles when collecting data, especially sensitive medical data [5]. In our estimation, a full integration of systems in the near future is unachievable. We had to address this problem by a low-level approach where new partners can join easily without limitations of their infrastructure.

Another challenge in cancer treatment is to include patients in clinical trials since the handling of complex cases often involves research. We want to bring together researchers and physicians from different institutions who are involved in the treatment.

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The collected data should be searchable for research purposes. On this basis suggestions for patient recruitment in clinical trials should be generated automatically.

1. Methods

At first we identified the challenges in communication between collaboration partners in oncological treatment. For this purpose we interviewed physicians involved in clinical-oncological care and research.

As a next step we tried to find an existing appropriate software solution that was ready to use and affordable. Our search focused on electronic patient records in Germany. On basis of the definitions of different patient records [6] we searched for web pages and literature using Google, PubMed and Medpilot.de with topics "electronic patient record", "electronic health record", "elektronische Fallakte" and "elektronische Patientenakte".

2. Results

2.1. Low-level approach

After evaluating the situation, our conclusion was to design a system that imposes as few technical barriers as possible for the health care provider. Our approach to the solution is a password-secured web platform called TeamTreat that can be accessed using a standard browser. It runs on the open source Java EE application server GlassFish and is secured via access control. Transport layer security is guaranteed by using HTTPS-connections. So the basic requirements for participants are a computer with internet connection and a current browser.

Additionally to the conventional file upload, a special "fax upload" is part of TeamTreat. Since most of the users have a fax machine, we offer them to send paper documents as fax messages to temporarily generated numbers, which are used for matching the incoming information to the record. There the documents will be stored in the case record after a manual selection from an inbox and can then be retrieved online. This serves as integration into paper-based systems.

Apart from textual documents, DICOM images are the next most important file type that needs to be shared. In TeamTreat a dedicated applet for DICOM upload [7] provides a convenient way to select and upload files from DICOM-CDs.

In the case record all information for the cancer treatment is collected, which is not only consisting of documents. It contains basic personal information, medication, allergies, diagnoses and the case's history, structured in entries and presented in a form that allows a quick overview over the medical case. The documents may be attached to these record entries. For reasons of interoperability the file formats are limited to PDF and DICOM.

Uploading and downloading files is an immediate and direct improvement to the current practice of sending a physician's letter or a DICOM-CD via letter mail. TeamTreat is designed as a place where comprehensive information for the treatment can be gained quickly. Therefore it can act as basis for an effective concerted treatment of a patient by different specialized institutions in a region.

2.2. Finding eligible patients for inclusion in clinical trials

Data describing age, sex and diagnoses is automatically searchable in TeamTreat. It can be searched by registered principal investigators of clinical trials. The system can then generate suggestions for inclusion of patients in clinical trials to both physicians and researchers. The latter also have the option to take a look inside anonymised records and can browse them manually. But they cannot see the patient's demographics and also no attached documents, since it is not possible to anonymise them automatically with sufficient results: For anonymising a document all identifying information has to be selected and removed from it.

That way an institution that is strong in a particular field of research can find suitable patients for a research-based treatment in hospitals and practices of a whole region and cooperate with them.

2.3. Reading access for the patient

With TeamTreat a patient can access his case record online. This way he can use the platform to get information about his health status and treatment. But the patient can only see an entry in the record if the responsible physician chooses to disclose it explicitly.

2.4. Privacy and access restrictions

The protection of data must be considered both on a technological level, where we rely on standard and state-of-the-art internet technology, and on careful disclosure of data to authorized persons.

All information is stored in one central database and file system on the server. The personal data in the case record will only be stored there as long as it is needed for the specific case. If the record of a patient is not used any longer, the system will automatically close the record and ask all participating physicians if they want to export the data before its deletion. Additionally to this passive closing of the record, it is always possible for the patient to actively induce the erasure of his data.

Only physicians involved in treatment of a patient have access to his case record. An already authorized physician can give the rights for a case record to his colleague and thereby transfer the contained information as if done by sending a report. All access rights granted on the case record are visible to a user that is authorized to view its content.

If the need for accessing the data online has disappeared, e.g. when the cancer is treated successfully and the patient visits only one physician for after-care, the case record can be exported in a structured and human readable form and stored locally. In case of a recurrence of the tumour, which may be years later, the record can be restored by uploading. This way we can minimize the time when the patient's data is available online and also prevent loss of information.

3. Discussion

3.1. Integration

Unlike e.g. the IHE Germany with its "IHE Cookbook" and the therein described models (eEPA, EFA, PEPA) [8,9], it is not our intention to connect health care information systems directly. The integration process is difficult because of many reasons: First of all, different standards have evolved that are not interoperable. For example BDT and LDT[2] specifically target the ambulant sector, whereas hospitals mostly use HL7-Messaging for electronic communication [10]. Besides structural compatibility the exchange of medical data between different systems requires semantic compatibility [11,12]. In contrast to that our primary goal is not a full integration in the systems, but rather a quick introduction in many institutions and practices by letting users participate without having to adjust their systems [12].

3.2. Approaches to the usage of electronic medical records for patient recruitment

Using electronic medical records for research and recruitment of patients for clinical trials has been implemented in several projects [13–15]. These projects focus on identifying patients for recruitment by searching the local hospital information systems. TeamTreat is not competing with these systems. We do not search or connect these already existing pools of patients, but want to explore new possibilities for identifying patients that are treated across several institutions.

3.3. Patient empowerment

Like electronic health record solutions, we provide a reading access to patients because this is a common wish of most patients [10,15]. Patient-centric electronic health records [16] let the patient automatically see all information. By making the choice to share record entries with the patient optional, we let the responsible physician still be in control. This is necessary when physicians want to exchange information between each other which the patient should only get in a personal consultation: A patient shall not get bad news at first from his record or get falsely alarmed by reading speculations over possible diagnoses there.

The EFA approach [3] puts the complete control over the access of the record in the hand of the patient. Because of the usability in daily clinical workflow and the acceptance by the physicians, we allow that the access rights are transferred directly from one physician to another.

4. Outlook

After finishing the implementation process we want to see how TeamTreat performs in routine use and how convenient it is for users. By analysing usage data we plan to

[2] Developed by "Qualitätsring Medizinische Software" (http://www.qms-standards.de) in collaboration with the National Association of Statutory Health Insurance Physicians (NASHIP) in Germany (German: "Kassenärztliche Bundesvereinigung")

evaluate the system. With this knowledge and working IT-solution we want to further explore the possibilities of collaboration in cancer treatment.

References

[1] Schabetsberger T, Ammenwerth E, Andreatta S, Gratl G, Haux R, Lechleitner G, et al. From a paper-based transmission of discharge summaries to electronic communication in health care regions. Int J Med Inf 2006;75:209–15.

[2] Haarbrandt B, Schwartze J, Gusew N, Seidel C, Kleinschmidt T, Haux R. Primary care provider's acceptance of health information exchange utilizing IHE XDS. Stud Health Technol Inform 2013;192:998.

[3] Elektronische FallAkte e. V. [Internet]. Die Elektronische FallAkte; [last visited Apr 2014]. Available from http://www.fallakte.de

[4] Whitten PS, Mair FS, Haycox A, May CR, Williams TL, Hellmich S. Systematic review of cost effectiveness studies of telemedicine interventions. BMJ 2002;324:1434–7.

[5] Warda F. Telemedizin und eHealth in Deutschland. Köln: DIMDI, German Institute of Medical Documentation and Information; 2002.

[6] Arbeitskreis EPA/EFA. Elektronische Akten im Gesundheitswesen Ergebnisse des bundesweiten Arbeitskreises EPA/EFA; Nutzen, Ausprägungen und Datenschutz. Bochum: ZTG Zentrum für Telematik im Gesundheitswesen; 2012.

[7] Neuhaus P, Lablans M, Juhra C, Ataian M, Weber T, Fritzen B, et al. Unterstützung der Rettungskette durch telematische Anwendungen im Traumanetzwerk Nord-West. In: Duesberg F, editor. e-Health 2011. Solingen: medical future verlag; 2010.

[8] IHE Germany [Internet]. IHE DE Cookbook – HL7wiki; [last visited Apr 2014]. Available from http://wiki.hl7.de/index.php/IHE_DE_Cookbook

[9] IHE Germany [Internet]. Aktenbasierte einrichtungsübergreifende Bild- und Befund-Kommunikation; [last visited Apr 2014]. Available from http://www.ihe-d.de/index.php/projekte/ihe-d-cookbook

[10] Lenz R, Beyer M, Meiler C, Jablonski S, Kuhn KA. Informationsintegration in Gesundheitsversorgungsnetzen. Inform Spektrum 2005;28:105–19.

[11] Bates DW, Gawande AA. Improving safety with information technology. N Engl J Med 2003;348:2526–34.

[12] Colomb RM. Impact of semantic heterogeneity on federating databases. Comput J 1997;40:235–44.

[13] Koca M, Husmann G, Jesgarz J, Overath M, Brandts C, Serve H. A special query tool in the hospital information system to recognize patients and to increase patient numbers for clinical trials. Stud Health Technol Inform 2012;180:1180–1.

[14] TMF e. V. KIS-Rek [Internet]. KIS-Daten nutzen zur Patientenrekrutierung für klin Studien [last visited Apr 2014]. Available from: http://www.tmf-ev.de/kisrek

[15] Schreiweis B, Grüber G, Bergh B. First experiences in implementing a software-based support for patient recruitment at Heidelberg university hospital. Stud Health Technol Inform 2012;180:1147–9.

[16] Uckert F, Görz M, Ataian M, Prokosch H-U. Akteonline-an electronic healthcare record as a medium for information and communication. Stud Health Technol Inform 2002;90:293–7.

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Development of a Medical Module For Disaster Information Systems

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Abstract. This study aims to improve a medical module which provides a real-time medical information flow about pre-hospital processes that gives health care in disasters; transferring, storing and processing the records that are in electronic media and over internet as a part of disaster information systems. In this study which is handled within the frame of providing information flow among professionals in a disaster case, to supply the coordination of healthcare team and transferring complete information to specified people at real time, Microsoft Access database and SQL query language were used to inform database applications. System was prepared on Microsoft .Net platform using C# language. Disaster information system-medical module was designed to be used in disaster area, field hospital, nearby hospitals, temporary inhabiting areas like tent city, vehicles that are used for dispatch, and providing information flow between medical officials and data centres. For fast recording of the disaster victim data, accessing to database which was used by health care professionals was provided (or granted) among analysing process steps and creating minimal datasets. Database fields were created in the manner of giving opportunity to enter new data and search old data which is recorded before disaster. Web application which provides access such as data entry to the database and searching towards the designed interfaces according to the login credentials access level. In this study, homepage and users' interfaces which were built on database in consequence of system analyses were provided with www.afmedinfo.com web site to the user access. With this study, a recommendation was made about how to use disaster-based information systems in the field of health. Awareness has been developed about the fact that disaster information system should not be perceived only as an early warning system. Contents and the differences of the health care practices of disaster information systems were revealed. A web application was developed supplying a link between the user and the database to make date entry and data query practices by the help of the developed interfaces.

Keywords. Disaster Information System, Health Information System, Disaster, Medical Informatics

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Introduction

Since the existence of the humanity, natural disasters get out as a part of the life from time to time. A large part of the world's population is at risk of natural disasters. Annual reports are prepared at national and international level about the types, effects, results, political and strategic approaches of disasters and disaster preparedness. Annual reports of International Red Cross and Association of Red Crescent Federation can be given as examples. According to the reports, it has been reported that communities are confronted with dramatic results about biological, physical, social, economic and political aspects independently from the type of the disaster and it's also reported that it has negative repercussions on the countries that have contributions on the disposal of the dramatic results [1,2]. 0-72 hours of the disaster is the most important gold time to save lives. Because of this, it's important to attempt in a quickly, coordinated and effective manner in order to save lives. To correspond the medical needs, in the processes as the dispatch of rescue teams, dispatch operations of the victims according to their triage case and recording the dispatch information, generally voice or paper-based registration systems are used. The size of the physical damage in the affected area as a result of a disaster restricts the usage of the communication technologies and so it's prevented to carry out the processes within the framework of time constraint [3]. With the usage of the information technologies in the processes of data entry and data/information flow required to correspond medical needs, coordination of the processes of victims, logistics, personnel etc. and formalization of process steps have been ensured. Whereby it's expected to play an active role in the process planning about the information that can be obtained among post-disaster data and related disaster risk and crisis management issues. As analyzing the studies about this topic in our country, it can be seen that studies are focused on Geographic Information (GIS)-based systems [4,5]. Whatever purpose of scale does the information system have, it should be capable of data collecting, editing, analyzing and also communication and data evaluation capacity. Responsibility area of each unit that will collect and manage the information should be identified [6].With this study, it's aimed to develop a Medical Module for Disaster Information Systems that performs the medical information flow about the pre-hospital processes of conducting medical services during disasters and also ensures processing, storing and transferring of the records in electronic form.

1. Methods

Software development part of this research study was held at the Department of Medical Informatics in Dokuz Eylül University in İzmir. This study is a complementary software application. In this study which is handled within the frame of providing information flow among health care professionals in a disaster, coordination of health care team and transferring complete information to specified people at real time, Microsoft Access as database and SQL as query language were used. It was developed on Microsoft .Net platform using C# language. Incident information system-medical module was designed to be used in disaster area, field hospital, nearby hospitals, temporary inhabiting areas like tent city, vehicles that are used for dispatch, and providing information flow between medical officials and data centers. For fast recording of the disaster victim data, accessing to database which was used by health

care professionals was provided (or granted) among analyzing process steps and creating minimal datasets. Database fields were created in a manner which gives opportunity to enter new data and search old data which is recorded before disaster.

1.1. System Analysis

A system is a combination of the related components that are brought together in order to accomplish an objective, have predetermined restrictions and have input and output parameters. One of the golden key of competitiveness in the globalized world is the speed of accessing to information. In the health care sector, speed and efficiency of access to information is a vital issue. According to the results of system analysis, general process steps of health services in case of disaster are emerged as seen in Figure 1.

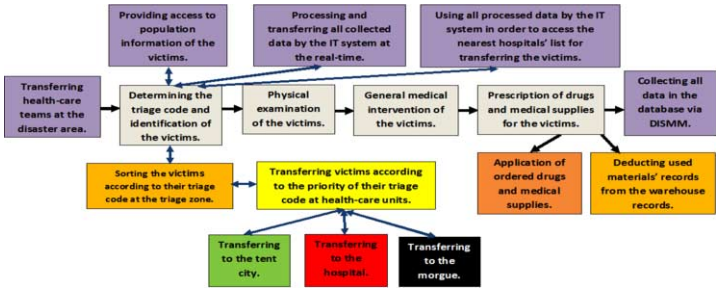


Figure 1. General process steps of health services in case of disaster

1.2. Healthcare Information Flow in case of Disaster

Continuity of information about the victims in case of a disaster must be ensured on the basis of the personal health records' continuity. Continuity of personal health data will be possible when the data produced during execution of health services in the disaster area is correctly directed to where the victim has been transported according to his/her triage case. Data transferred by disaster zone triage teams, field hospital information, ambulances information, tent city information and district hospital information can be collected in disaster data center and also communication of data/information between the units can be provided via internet.

2. Results

Because this study is basically an implementation project, the findings reflect the results of the practice.

2.1. Entity-Relationship Diagram of Disaster Information System-Medical Module (DISMM)

The process beginning at the intervention to the victims by the health personnel until the transportation to the target location was analyzed. Relational database that was modelled as examining the probable entities of this process (victim, health personnel, medical resources, referral vehicles, health institutions, triage code, location

information etc.) was symbolized by entity-relationship diagram. With established relationships between entities, it's guaranteed that data is stored more structured and more efficient.

2.2. Disaster Information System-Medical Module Interface Design

On DISMM's homepage, user must give a valid user name in Latin letters except Turkish characters in order to log in to the system. In password section, numeric and/or character information that is approved by the system administrator including Latin characters except Turkish characters is required from the user. On the left side of the DISMM's homepage, there is the menus' section that is ranked according to user authorization and there is the section including general information and overall queries of the system. In the future in case of an integration with the page of victims' identity information page including credentials and triage code information of victims and central population data supplied by the system of Interior Ministry, General Directorate of Population and Citizenship Affairs, necessary integration field has been created in the database. DISMM's page of health care professionals' credentials is an interface design that allows entering and updating personal information and also creating business charts of health care professionals working in the disaster area. With health care professionals' identification interface and with timeline, it's intended to record the information about professionals' that will serve in the disaster area. Also before disasters, assuming that a system of health care professionals' credentials that all units can use has been available, system is designed in an appropriate structure to be integrated. The reason for this is to service for personnel planning as using the credentials of voluntary health care professionals and also health care professionals that work close to the disaster area and provide their access to the area. Also it's intended to provide storing information about the personnel that takes part in all interventions on the victims. Physical medical examination interface including registration and reporting issues, pages of general interventions, medication order and drug treatment information are given as examples for data entry interfaces of medical practices related with the disaster victims. In designing processes of all interfaces, supports of process steps of paper-based recording practices, literature and expert opinions are taken. Also it's possible to use the system with mobile devices and tablet computers.

3. Discussion

With DISMM, it's intended to improve the speed and service quality in maintaining health care services in unusual cases. Developed web-based system will be a leading practice to collect all health care data under one roof in cases of disaster in our country [7].With this study, used information and communication technology is envisaged to contribute to the coordination of disaster hospital emergency department and pre-hospital emergency medical service team in terms of speed and service quality by transferring "right knowledge" to "right people" at the "right time"[8]. An information system that has whatever scale or purpose, it should be capable of collecting, editing and analyzing data and also communication and evaluation capacity. DISMM records that all units will collect and manage were developed among the literature and expert opinions [6]. In order to ensure the universal standards, system was designed in an integrated manner assuming that data that is likely needed was stored before the

disaster cases and was developed in standard forms ensuring the unity of language. In disaster-based medicine, according to the studies about the usage and efficacy of mobile technology in last ten years, studies can be gathered under five groups of remote monitoring of disaster victims, incident area management, medical image transmission, decision-support applications and field hospital information technology systems. Disaster Information System-Medical Module is developed to be run on stationary computers and mobile devices as smart phones as well; it was tested and observed that it can be run on all these devices [9-11]. Real test of the system in a disaster case couldn't be done. Thus, it's not known what kind of implementation problems may be faced in a real disaster case. The main reason of this condition is that human behaviors cannot be predicted in a usual situation in advance [12]. However, it's the superiority of the proposed system that can be run on mobile devices as minimizing data loss in pre-hospital operations compared to the paper-based processes [9]. In the literature, information system recommendations in unusual situations like disasters are available. With this study, a suggestion has been put forward how to use the disaster information systems in medical fields. Awareness has been developed on the issue that disaster information systems should not be perceived only as an early warning systems. Contents and differences of medical practices in disaster information systems were revealed. By the help of designed interfaces, a web application was developed to support the user to do the data entry and data query functions. In our future project we plan to simulate this application.

References

[1] International Federation of Red Cross and Red Crescent Societies [Internet]. World Disasters Report 2012. Focus on forced migration and displacement; [updated 2012 Jul 4; cited 2012] Available from: http://www.ifrcmedia.org/assets/pages/wdr2012/resources/1216800-WDR-2012-EN-FULL.pdf.

[2] Aydın M, Afet sonrasına yönelik planlama çalışmaları: izmir örneği, TMMOB Izmir Kent Sempozyumu, İzmir, Turkey, 2009 Jan 8-10; p. 105-130.

[3] Jang HC, Lien YN, Tsai TC, Rescue information system for earthquake disasters based on MANET emergency communication platform. IWCMC'09, Leipzig, Germany, 2009; p.623-627.

[4] Gülkan P, Balamir M, Yakut A, Afet yönetiminin stratejik ilkeleri: Türkiye ve dünyadaki politikalara genel bakış, Orta Doğu Teknik Üniversitesi Afet Yönetimi Uygulama ve Araştırma Merkezi, 2003.

[5] Eraslan C, Alkis Z, Emem O, Helvacı C, Batuk F, Gümüsay U, et al, System design of disaster management information system in Turkey as a part of e-government. XXth Congress International Society for Photogrammetry and Remote Sensing, Commission VII, WG II/5, 2004; p.284-289.

[6] McDonnell SM, Perry HN, McLaughlin B, McCurdy B, Parrish RG, Information for Disasters, Information Disasters, and Disastrous Information, Prehospital and Disaster Medicine, 2007, Vol:2, No:4, p. 315-322.

[7] Tang PC, AMIA Advocates national health information system in fight against national health threats, J Am Med Inform Assoc. 2002;9:123–124.

[8] Reddy MC, Paul SA, Abraham J, McNeese M, DeFlitch C, Yen J, Challenges to effective crisis management: Using information and communication technologies to coordinate emergency medical services and emergency department teams, Int. J Med. Informatics, 2009, 78, p. 259–269.

[9] Case T, Morrison C, Vuylsteke A. The clinical application of mobile technology to disaster medicine. Prehospital Disaster Med. 2012;27(5):473-480.

[10] Qiantori A, Sutiono AB, Hariyanto H, Suwa H, Ohta T, An emergency medical communications system by low altitude platform at the early stages of a natural disaster in Indonesia, JMed Syst, 2012, 36:41–52.

[11] Levy G, Blumberg N, Kreiss Y, Ash N, Merin O, Application of information technology within a field hospital deployment following the January 2010 Haiti earthquake disaster, JAm Med Inform Assoc. 2010;17:626e630.

[12] Franc-Law JM, Bullard MJ, Corte FD, Accuracy of computer simulation to predict patient flow during mass-casualty incidents, Prehospital and Disaster Med. 2008, Vol.23, No.4, p.355-60.

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Structuring Medication Related Activities for Information Management

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Abstract. Medication treatment and the related information management are central parts of a patient's health care. As a cross-organizational and cooperative process, medication information management is a complex domain for development activities. We studied medication activities and related information management in a regional project in order to produce a shared broad picture of its processes and to understand the main issues and the needs for improvement. In this paper we provide a summary of the findings in a structured form, based on a six-dimensioned framework for design and analysis of activities and processes.

Keywords. Medication management, work process, eHealth, development project

1. Introduction

Medication treatment is a central part of a patient's health care. Medication management is a highly cooperative process that involves several actors with specific roles from several organizations, and the patient as the object of medication and as an active actor in the process. Furthermore, medication treatment is highly regulated [1].

Medication information management (MIM) is a supportive activity for medication information sharing and communication between the providers, patients and families [1]. The aim of MIM is to collect the information that is related to the patient's medication in correct, trustworthy and organized way. In addition, it aims to keep the information updated and available for those who have the right to access information during the medication treatment process of the patient. Information Technology can reduce errors and thus improve patient safety [2]. However, medication information management is a highly complex area, and should be studied as a whole [2].

In Finland, public and private healthcare services are arranged in primary, secondary and tertiary care. Patient data, including medication data, is mainly in electronic format in different systems such as different Electronic Patient Records (EPR), prescription systems, and pharmacy systems of the organizations. National level shared e-Prescription and e-archive services are in implementation phase to support the sharing of patient data between the actors related to the care of the patient [3].

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Personal Medication Management project was a recent regional research and development project in Northern Savonia region in Finland, conducted in 2012 -2013 [4]. The objective of the project was to construct a shared understanding of the current baseline state of medication information management and the most important needs for improvement. The research group was multidisciplinary, including researchers with expertise on healthcare and ICT. In this paper we present a structured view to the medication related activities by using a six-dimensioned framework [5] designed for activity and process analysis and design. The purpose of the structured approach is to support development, design and modelling activities on various levels that aim at improving medication information management through improved cooperation and new or improved ICT tools.

2. Methods and materials

The research represents qualitative research [6]. We adapted Activity-Driven approach [7] and used thematic interviews (n=15), focus group discussions in a workshop (42 participants divided in four groups), and written feedback form (n=17) as main data gathering methods. SOLEA6D framework [5] was used for structuring the findings. The research process, as a methodological research result, is described in detail in another publication [8].

The informants represented 19 organizations, including primary and specialized public healthcare, pharmacy, home healthcare, patient safety association, information management units of health service providers, and national authorities in medication and healthcare. The roles of the informants included pharmacists, specialised MDs, project managers, association managers, development managers, practical nurses, qualified nurses, homecare managers, software developers, research managers, chief medical officers, and volunteer workers. Most of the informants also had personal or next of kin experience of medication management as a patient. In addition, the national specifications related to ePrescription and EPR medication information management were used as source material.

SOLEA 6D is a novel framework for structured analysis and design of functionalities and behaviours of systems, work activities and processes. It provides analysts and designers with the following six dimensions to be considered: *Context, Overview, Process, Activity, Task* and *Act*. Each dimension acts as a filter, revealing certain aspects of the object of the study: When an object is studied through a certain dimension, a selected set of things can be seen while the other things are hidden.

Prior to focusing on the analysis on any dimension, the scope and target area as well as the goal of development activities must be defined. In this paper, we utilize the dimensions to present our summarized findings related to medication information management and its development points.

3. Results

3.1. Context of medication information management

General *context* of medication management included generic trends, changes in the population structure such as ageing, conditions which concern all actors in medication,

transition towards self-care and organizational structure of health services including public, private and third sector services. In addition to societal trends, technology trends such as mobility and standardization were taken into account. Furthermore, current strategies and changes in financial incentives were considered. Relevant legislation, licensing and policies governing the medication management as well as health information management including privacy and security were also identified in the context dimension. Specific operational environments as target areas for more detailed operational models were also identified for further analysis (see Section 3.4).

3.2. Overview

To provide an *overview* of medication management, we analyzed the elements of MIM and considered the following core elements: Organizational Roles, Personal Roles, Information Entities and Information Tools. Each core element was refined on basic categories as shown in Table 1 (main instance types are provided in brackets). Also actual instances of each element type were identified.

Table 1. Elements in the Overview dimension of medication

Core element	Basic categories of the elements (examples)
Organizational roles	Based on the main responsibilities and activities in relation to medication: decide and implement medication treatment (different hospitals and other healthcare organizations, e.g. occupational health care); Provide drugs (hospital pharmacy, outpatient pharmacy, other drug and alternative treatment stores); Education and research (vocational school, university, National Institute for Health and Wellfare); Patient Support (patient association, information management service); Counsel, guide, develop knowledge, supervise or regulate (authorities, patient safety council)
Personal Roles	Based on the location: roles present at home (client or citizen, relative, home helper, practical nurse, homecare nurse); at healthcare service unit (patient, physician, practical nurse, nurse, inpatient ward pharmacist); at pharmacy (client, relative, pharmacist, qualified chemist)
Information Entities	Based on the content of information: patient information (personal medication and other health and welfare information, services and service relationships, consents, denials and authorizations); drug information (catalogues, directories and databases of substances and products); guidelines and recommendations supporting medication implementation and know-how; other information that manage professional information use (ID management, authentication, professional rights, user rights, medical and security certificates)
Information Tools	Based on the users of information tools: drug provider (pharmacy system, dispensing, SMS messages to clients); healthcare actor (EPR, statistics, special applications, automated drug cabinets); client or patient (self care applications and portals, health information in medication card files, e-services for medication evaluation, counseling and informing tools, supportive tools for medication intake, communication tools); shared (medication information portal, medication databases, national e-Prescription Center and eArchive)

3.3. Process

Elements from the overview are instantiated in various *processes* and concrete operational environments. Figure 1 displays the basic process phases evident in most medication process instantiations. In addition to participants and process phases, descriptions in the process dimension included relationships to organizations and information management activities. Issues for further development were identified

based on the results of the interviews and the workshop. Specific features of inpatient medication process were also considered. As the specifics of process instantiations vary widely between different operational environments, target areas, patient groups and individuals, no detailed process descriptions were specified. Instead, tasks which should be included and combined in different contexts were identified (see Section 3.5).

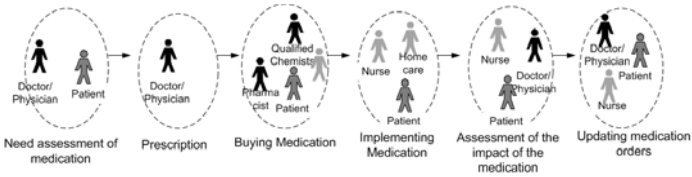


Figure 1. Basic process phases and actors of medication care chain.

3.4. Activity

Specific operational environments as target areas for more detailed operational models and solutions were identified in the context dimension and refined in the *activity* dimension. Needs for detailed solutions for activity systems in each of the following environments in relation to medication management were identified:

- location independent services such as phone or tele-consultation, electronic self services used by phone or over internet, tasks performed using portable or mobile devices regardless of location
- home or other home-like environment for independent or supported living, including home care and facility services
- outpatient services in the proximity of patients such as pharmacies, health kiosks, health centers and municipal clinics
- appointment services, maternal and child clinics, occupational and educational health services, dental services, rehabilitation, mental health and substance abuse services, prevention, health counseling, screening services
- departmental outpatient care, emergency services on basic and advanced levels, specialized outpatient care services and outpatient surgery
- inpatient care
- clinical support services such as laboratory and imaging services
- ambulatory care.

3.5. Task and Act

The analysis in *task* dimension was similar to [9], and will be presented in more detail in other publications. We identified 102 key tasks related to medication information management. The tasks were grouped under the 12 categories based on the main phases of the medication process. The categories and examples of identified tasks include:

1. Searching and retrieving patient's medication information from various sources; e.g. the overall list of his/her medication
2. Examining, assessing and considering patient's health conditions and history; e.g. allergies and risks
3. Evaluating patient's past and current medication and its impact
4. Planning the medication as a part of patient care; incl. e.g. goals, instructions

5. Prescribing or ordering medication incl. renewals and confirmations
6. Documenting patient's medication; incl. updates and new entries
7. Acquiring and dispensing medication; incl. availability information
8. Implementing medication; incl. e.g. dosing, reminders to take drug
9. Making changes to the medication or ending a medication
10. Counseling, advising, consulting, and knowledge retrieving
11. Identifying and authenticating, managing consents and access
12. Developing medication-related knowledge, know-how capabilities, and education; incl. e.g. clinical training, certification, user training.

4. Discussion and conclusion

The main result reported in this paper was the construction of a multi-dimensional structured view of medication processes and activities, focusing on medication information management. Number of development activities were identified and prioritized based on this view. We categorized the identified needs for development in the following interrelated classes: 1) new operational models in different contexts of the activity dimension for the actors related to medication, 2) the tools for medication information management, and 3) the capabilities and skills of the actors related to medication [4]. The SOLEA6D framework was successfully adapted in the analysis. It provided a logical means to structure activities in a complex and multi-faceted research area: MIM in regional settings. Several development points highlighted by the results have been picked up by different actors in further research and development efforts.

Acknowledgements. This work was supported by the EU, European Social Fund through projects "Yksilöllinen lääkehoidon hallinta" and "YLÄVÄT" through the Centre of Economic Development, Transport and the Environment in Northern Savonia.

References

[1] Bassi J, Lau F, Bardal S. Use of information technology in medication reconciliation: a scoping review. The Annals of pharmacotherapy 2010; 44(5): 885-897.
[2] Bates DW, Gawande AA. Improving safety with information technology. N Engl J Med. 2003; 348(25): 2526-2534.
[3] Saranummi N, Ensio A, Laine M, Nykänen P, Itkonen P. National health IT services in Finland, Methods Inf Med. 2007; 46(4):463-469.
[4] Kivekäs E, Luukkonen I, Mykkänen J, Saranto K. Improving the coordination of patients' medication management: A regional Finnish development project. In Proceedings of the 12th International Conference on Nursing Informatics, June 21-25. 2014, Taipei, Taiwan (forthcoming).
[5] Luukkonen I, Mykkänen J, Itälä T, Savolainen S, Tamminen M. Toiminnan ja prosessien mallintaminen – tasot, näkökulmat ja esimerkit. (Modeling Activities and Processes – Levels, Perspectives and Examples; in Finnish); 2012 Univ. of Eastern Finland: Finland. Available from: http://epublications.uef.fi/pub/urn_isbn_978-952-61-0697-7/.
[6] Myers MD. Qualitative Research in Business & Management. 2009; Sage Publications: London.
[7] Luukkonen I, Toivanen M, Mursu A, Saranto K, Korpela M. Researching an Activity-Driven Approach to Information Systems Development. In Miranda IM, Cruz-Cunha MM, and Gonçalves P. (eds.) Handbook of Research on ICTs and Management Systems for Improving Efficiency in Healthcare and Social Care. IGI Global 2013. p. 431 – 450.
[8] Luukkonen I, Mykkänen J, Kivekäs E, Saranto K. Capturing Multiprofessional Perspective for Medication Information Management. MIE2014; 2014 (Forthcoming).
[9] Mykkänen J, Virkanen H, Kortekangas P, Savolainen S, Itälä T. Task Analysis and Interoperable Application Services for Service Event Management. Stud Health Technol Inform. 2011; 169: 295-299.

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Medication Information Management: Capturing Multiprofessional Perspective

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Abstract. Medication information management (MIM) is a crucial activity for good quality of medication, but unfortunately not without problems. In order to improve medication information management the core activity of medication as a cooperative activity is to be studied as a whole, and the multiprofessional viewpoint for the improvement needs must be captured. In this paper we present our approach to gain such shared understanding, based on our regional development project experiences in Northern Savonia, Finland. The central features of the approach include thematic interviews supported by activity-driven models and a workshop with professionally mixed groups. Participants agreed strongly on the usefulness of the approach.

Keywords. needs analysis, participatory, thematic interview, workshop, eHealth

Introduction

Medication management, as well as the related medication information management (MIM), is highly regulated and cooperative process that involves several actors with specific roles from several organizations, and the patient as the object of medication and as an active actor in the process [1]. The problems in communication between the participants of care and medication process, fragmented medication information and non-integrated information systems cause inadvertent loss of information, medication errors, and risks for patient safety [1, 2]. Information and Communication Technology (ICT) can help in reducing errors in health care, also in medication related tasks [2].

In Finland, the ICT is widely used both in public and private health care organizations. Electronic Patient Record (EPR) coverage is 100% [3]. At the regional and national levels, the patient data will be increasingly shared through the national Kanta eArchive amongst the health care organizations, starting from public health organizations and expanding towards private and occupational health care. Recently, public healthcare have started to use the national ePrescription service, and the private sector is obligated to follow. Physicians write prescriptions in electronic form via their EPR system, and the prescriptions are available through the national ePrescription

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center, from where pharmacies can retrieve them. Patients can view their information including ePrescriptions through the national eView web site. Nevertheless, many challenges remain in patient and medication information management.

In order to improve the means for information management– including both tools and practices – that support medication, the multifaceted reality of medication must be considered and studied as a whole [2]. For such investigation, the participation of different actors with their specific knowledge related to their practical work is crucial.

The broad participation is not without problems. For example, challenge of arranging timetables and biased data due to dominant participants are typical problems in participatory methods [4]. Although participatory methods have been broadly researched, tools and practices must always be adjusted to the situational goals. To develop adjustable methods, both the research process and the tools for data gathering and communication must be documented and evaluated [4].

As a part of a long term research on activity-driven and participatory methods, we conducted a short research and development project in Northern Savonia region in Finland (Personal Medication Management, 2012-2013) [5] for producing baseline information about status of MIM practices at the regional level, and what are the most important needs for further development. The primary objective was to explore and clarify the baseline state of medication management as well as its major development points in the region, considered holistically from the different perspectives of the related actors. The secondary research objective was improving and operationalizing the methods for such investigation, to be used in future research and development.

In this paper, we focus on our methodological results. We present the research setting and the methods for data gathering, as well as the given feedback. The key findings concerning medication activities and the revealed problems are presented in a practical open access Finnish project report, and also shortly reported in other conference papers [5, 6]).

1. Methods and Participants

We had a multidisciplinary research group of four researchers with long term research experience on health information systems development, Activity-Driven method development, nursing, and healthcare information management. Two researchers had professional work experience in nursing. Although the backgrounds were different, the researchers had also experience of joint research in several previous projects.

The informants represented 19 organizations both on regional and national levels, including primary and specialized healthcare, pharmacy, home healthcare, patient safety association, information management units of providers, and national authorities in medication and healthcare. The roles of the informants included pharmacists, specialised MDs, project managers, association managers, development managers, practical nurses, qualified nurses, homecare managers, software developers, research managers, chief medical officers, and volunteer workers in the patient association. Most informants had also their own or next of kin patient experience of medication management. In addition, national specifications related to ePrescription and medication entries in national EPR specifications were used as a source material.

In this research, we mainly drew on qualitative research on information systems [7], and particularly, for data gathering we adapted Activity-Driven approach [8]. The research utilized thematic interviews (n=15), focus group discussions in a workshop

(42 participants divided in four groups), and written feedback form (n=17) as main data gathering methods. The interview data was voice recorded and individually analyzed by two of the authors in the first place and then jointly discussed and agreed. Then the main points of the findings were discussed in the workshop by the focus groups and joint sessions. The interviews and the focus group method are presented in more detail in the next section.

2. Results: methodological considerations

The research process and methodological tools were carefully documented during the research. They form a reusable data set for this kind of investigation, and are summarized here. We also provide main points of the feedback from the workshop as it reveals how the participants experienced the workshop and the used methods. The concluded findings concerning the medication management baseline state, needs and recommendations for development were presented in a project report in Finnish and in other research papers [see e.g. 5, 6].

2.1. Thematic interviews supported by diagrams in data gathering

Our aim was to encourage the informants to bring up their professional viewpoint about the medication related issues they have faced in their everyday work. Therefore, a preliminary understanding of the scene of medication as a whole was formulated by the researchers, based on literature and professional experience. We summarized our shared understanding as two diagrams. The diagrams served as facilitator in the interviews, instead of predefined accurate question sheets.

The first diagram was a mind map organizing the elements of medication around four main elements and related sub-elements. The core elements were: Organization, Participant Role, Information Entity, and Information Tool. For each core element, refinements based on functional differences in relation to medication were identified, e.g. organizations where decisions are made and where phases of medication process are performed, organizations that provide medicines, provide education, conduct research, set regulations and guidelines, are related to financing medication care, and develop tools for medication and medication information management. In each interview we asked the interviewed person to complete the missing parts of the picture and tell if there are any problems or challenges in his / her daily work in relation to the elements.

The second diagram portrayed medication care as a chain of activities in its context and in relation to information management (figure 1). The diagram was a simplistic overview of information management and its relations to the phases of the core medication process. In reality, fragmentation of medication care is evident in all elements included in the MIM activity (Activities, Information entities and Cooperation and communication tools). However, by stating such a ‘blank’ picture about the MIM we tried to lead the informants away from any pre-defined generally known problems. This would help ensuring that the problems the informants mentioned here were the topmost problems in their minds and concerning their particular daily work.

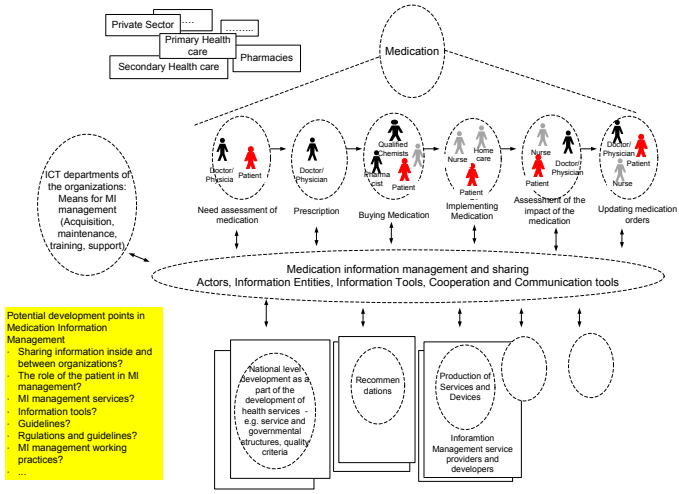


Figure 1. Medication care chain, information management and surrounding organizations

The use of figures was a successful method as a facilitator of discussion. Each interview took 40-60 minutes. All participants shared the goal of high quality and safe medication process. The professionals and the client also faced different types of problems, despite the fact that some of the problems and development needs were broad and concerned all participants. We also identified several good practices that were documented. The results of the interview were used as an input to the workshop.

2.2. Multi-professional workshop in data elaboration and validation

Multi-professional workshop was arranged after the first analysis of the interviews in order to validate and elaborate the data further. We used pre-defined focus groups in the workshop. After all participants (n=42) had registered, we decided to have four groups and carefully considered the composition of each group. We mixed different types of professionals into each group in order to let them exchange their viewpoints and knowledge upon challenges, baseline practices and future development needs concerning medication and MIM. The facilitators and secretaries for each group were instructed before the workshop.

The procedure for focus groups included two working rounds. Both rounds first had a guided discussion in the groups, and then a joint session to share the results of small group discussions with all participants. Groups were given two main topics: first, to discuss and prioritize the development needs that were identified in the interviews; and second, to brainstorm and envision the future development steps for MIM.

2.3. Feedback form in evaluation of the workshop

A web based form was used in post-workshop survey to collect feedback about the workshop. Altogether 17 out of 42 participants (40,5 %) used this opportunity. For getting feedback of the workshop, ten statements with a four point likert scale were presented. Altogether 170 votes were given, of which 158 were positive (Strongly agree n=92; Quite agree n=66) and 12 negative (Strongly disagree n=0; Slightly disagree n=12). Figure 2 shows the statements and the summary of the feedback.

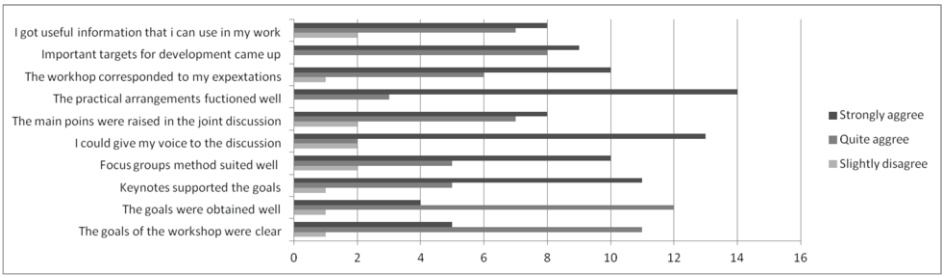


Figure 2. Summary of the given feedback.

3. Discussion

Obtaining a shared understanding of the baseline settings and needs for development is necessary, but not easy. The main result of the research was the obtained *consensual construction* of medication and MIM as a shared target of number of development activities. The research produced *practical reusable tools* and *documented practices for data gathering and analysis*. We got empirical evidence of the methodological success of our research methods that were shortly presented in this paper. The value of the research was twofold. 1) The results provide an objective starting point for further concrete regional development efforts. 2) Practically adaptable and reusable participatory methods to support multi-professional development were formalized.

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References

[1] Bassi J, Lau F, Bardal S. Use of information technology in medication reconciliation: a scoping review. The Annals of pharmacotherapy 2010; 44(5): 885-897.
[2] Bates DW, Gawande AA. Improving safety with information technology. N Engl J Med. 2003; 348(25): 2526-2534.
[3] Hämäläinen P, Reponen J, Winblad I, et al. eHealth and eWelfare of Finland. Checkpoint 2011. National Institute for Health and Welfare (THL). Helsinki.
[4] Mayoux L, Chambers R. Reversing the paradigm: quantification, participatory methods and pro-poor impact assessment. Journal of International Development, 2005; 17(2):271–298.
[5] Kivekäs E, Luukkonen I, Mykkänen J, Saranto K. Improving the coordination of patients' medication management: A regional Finnish development project. In: Proceedings of the 12th International Conference on Nursing Informatics, June 21-25. 2014, Taipei, Taiwan, forthcoming.
[6] Luukkonen I, Mykkänen J, Kivekäs E, Saranto K. Structuring Medication Related Activities for Information Management. MIE 2014; 2014 (Forthcoming).
[7] Myers MD. Qualitative Research in Business & Management. 2009; Sage Publications: London.
[8] Luukkonen I, Toivanen M, Mursu A, Saranto K, Korpela M. Researching an Activity-Driven Approach to Information Systems Development. In Miranda IM, Cruz-Cunha MM, and Gonçalves P. (eds.) Handbook of Research on ICTs and Management Systems for Improving Efficiency in Healthcare and Social Care. IGI Global 2013. p. 431 – 450.

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Fall-related Information seeking behavior of seniors on the web

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Abstract. Falls form a major health problem for older persons, and increasingly strain the healthcare system. The Internet is a potentially useful platform for empowering seniors. The aim of this study was therefore to investigate the information-seeking behavior about falls among elderly Internet users. A web-based survey was distributed among all members of an association of elderly people (> 60 years old). Fallers and non-fallers, seniors with and without experience with information seeking and the willingness of elderly for undertaking self-assessment tests on the Internet versus solely receiving information about falls were compared. In general, there was much stated interest in receiving information about conditions and medications that increase the risk of falls and information on safety in the house. Around half of the 62 respondents did not feel that they are well-informed about falls. Searching for fall-related information was not significantly associated with having falls in the previous 12 months (OR 2.11, CI: 0.55-8.16). The majority expressed higher interest in receiving fall-related information than undertaking a self-assessment test. However, only a small proportion had searched for this information already.

Keywords: information seeking behavior, information requirement, falls, Internet, information needs, elderly patients, seniors.

Introduction

Around one-third of all community-dwelling persons aged 65 years or older experience a fall each year [1]. Falls and fear of falling have serious consequences in terms of injuries leading to emergency department visits or hospital admissions, disabilities, and longstanding pain and are associated with decreased activity, reduced social contact and/or social isolation. Therefore, this multi-causal phenomenon puts substantial pressure on the health care system.

There is a need to develop feasible and easy-to-apply strategies for fall prevention, fall education and fall management for older persons living in the community. This is especially true because clinical trials, interventions and educational programs for fall prevention and management have shown varied degrees of success and costs. In the age of rapidly-evolving communication and information technology, the Internet provides a potentially cost-effective instrument for involving, educating and empowering patients, allowing patients to be provided with tailored information and preventive measures [2-4]. However, it is suggested that health communicators need to understand the nuances

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in health information seeking among older Internet users, since seniors are becoming more active health information seekers on the Internet and are relying more on online sources of health information [5]. Also, investigating differences in needs between different groups of seniors can help tailor the information based on their needs. The health communicator can then develop materials appropriate for their target group for better empowerment. There is however a lack of understanding of the information needs and seeking behavior about falls of elderly adults on the Internet. Therefore, our objectives in this study were to investigate how elderly Internet users use the Internet to get fall-related information, and to learn what kind of fall-related information is of interest to them. In addition, we wanted to know whether they are willing and prepared to undertake self-assessment tests on fall prevention on the Internet, rather than solely receiving information about falls.

1. Methods

1.1. Study setting and design

A cross-sectional descriptive survey was distributed in the last quarter of 2011 for collecting data. A web link to this survey was sent per electronic mail among 298 members of an association of Internet-using elders (> 60 years old).

The survey was organized in 4 main sections. The first and second sections elicited respectively information regarding participants' general demographic information (gender, age, education, marital status etc.) and fall-related information (number of falls during the past 12 months, self-perception of own health, having fall anxiety, reasons of having fear of falling etc.). The third section contained questions about health related Internet use including: searching information about general health or falls on Internet. If the participants indicated that they do not have interest in using the Internet to find fall-related information then the questionnaire terminated. The final part was designed for those who were interested in using the Internet to find or receive fall-related information. Questions were related to: whether seniors feel informed about falls; whether they already searched for fall-related information; where do they have specifically more interest regarding usability (having a forum, being able to contact a caregiver via e-mail (or portal) and general fall-related information, fonts and videos etc.) and whether they have interests in doing self-assessment tests on Internet.

1.2. Quantitative Data analysis

Aside from the analysis in the whole respondent group, we contrasted our findings between the subgroups fallers versus non-fallers, and those with versus those without experience in seeking fall-related information on the Internet. The term "fall-information seekers" refers to those who had already searched for fall-related information on the Internet in the past.

We excluded missing values in the responses and recalculated the total number of respondents for each question separately. Except for the demographic data, the questions were either dichotomous or designed on a 4- and 5-point Likert scale.
Continuous normally distributed variables were summarized using the mean and the standard deviation, and binary variables by percentages. Subgroups were compared using appropriate statistical tests. Differences between subgroups (all information

seekers vs. non-seekers) were quantified by odds ratios (OR) along with their 95% confidence intervals (CI).

2. Results

A total of 97 out of 298 participants completed our questionnaire (33% response rate) of which 45% were men. The average age was 72 (SD 7.7) years. Among the participants, 93% (87/94) were native Dutch (this denominator means that this item had three missing values). Of the participants, 32% (31/97) had one or more falls in the previous 12 months, which is concordant with the prevalence of falls among elderly people in the Netherlands. The most important reasons for being afraid of falling were their own pervious fall (50%, 14/28) or a fall sustained by a friend or family member (21%, 6/28).

Eighty-three respondents (86%) reported using the Internet for seeking health-related information, of which 55% (53/97) reported regular ("quite often" or "a lot") use of the Internet for this purpose. Sixty four percent (62/96) were interested in using the Internet to find fall-related information. From the 83 respondents only 13% indicated actually searching for fall-related information; 31% (26/83) were not inclined to search for/receive fall-related information on the Internet; 41% (34/83) were willing and indicated that they found falls important.

Among the 62 respondents who were willing to use the Internet to find fall-related information, respectively, 66% (39/59), 69% (41/59), and 57% (33/58) felt that they are a little or not informed about causes of falls, prevention of falls and consequences of falls. There were 68% (41/60) of respondents and 58% (35/60) expressing interest in having a website that uses respectively images or films for enhancing illustration of textual information. Only 23% (14/60) expressed interest in using forums (a possibility on a website to discuss fall-related questions or topics with caregivers or professionals electronically) and 15% (9/58) expressed interest in having a "listen button" on the website to allow for automatic reading of the textual information on the website. Figure 1 summarizes the expressed interest of elderly patients in receiving information about different subjects related to falls in older age.

Fall-information seekers were significantly better informed about causes, consequences and prevention of falls than non-seekers (mean Likert scale respectively (from 1 to 5): 3.8 vs. 3.1 p=0.01; 4.1 vs. 3.2 p=0.0015; 3.6 vs. 3.0 p=0.06). There was a significant difference between fall-information seekers and non-seekers about wanting to receive detailed information about conditions or diseases that increase the risk of falls (respectively, mean Likert scale (1 to 4) (SD): 3.60(0.48) vs. 3.08(0.89)); p=0.04).

There was no significant difference found between fallers and non-fallers in being well-informed about the causes, prevention, and consequences of falls: (mean from a Likert scale score respectively (from 1 to 5): 3.3 for fallers vs. 3.2 for non-fallers, p= 0.74; 3.1 vs. 3.1, p= 0.53; and 3.2 vs. 3.3, p= 0.74). There were no differences between considering fall information as important between the two groups (total score between 3 and 15: mean 7.9 vs. 7.9, p=0.8). In general, 95% (19/20) and 89% (55/62) of fallers and non-fallers expressed interest in receiving fall information, and 70% (14/20) and 64% (39/61) in undertaking a self-assessment test. There were significantly higher odds of having more interest in undertaking self-assessment tests for fallers vs. non-fallers (OR=4.12; CI: 1.39-12.3; p=0.01). There was, however, not significantly higher odds of having more interest in undertaking a self-assessment test for fall-information

seekers vs. non-seekers (OR=1.5; CI: 0.4-4.7; p=0.7)). Having had a fall was not associated with seeking fall-related information (OR=2.12; CI:0.55-8.16; p=0.27).

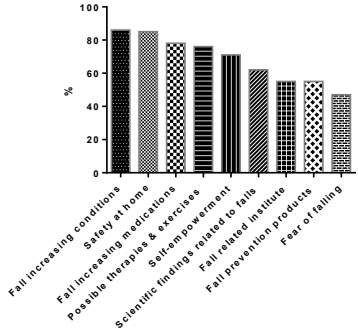


Figure 1: Chart showing percentage of elderly patients showing interest in receiving fall-related information in the total sample. In the first bar "Conditions" refer to both medical/geriatric diseases and conditions (e-g- having impaired vision), whereas in the 7th bar “Fall-related institute” refer to institutes such as physiotherapy-or fall outpatient clinics.

3. Discussion

Most elderly Internet users (85%) reported using the Internet to find health-related information. However, one in three was not willing to use the Internet to find or receive fall-related information. Moreover, from the 85% of respondents who did search for health related information, 31% did not want to search for fall-related information on the Internet. Among those willing to use Internet for searching for fall-related information (64%), more than half indicated that they feel they are not or only a little informed about falls. In addition, only about 1 in 5 had sought fall-related information. fall-information seekers felt more informed about falls in older ages than non-seekers. Fallers did not consider receiving information about falls more important than non-fallers. In general there was more interest in receiving information than undertaking an assessment test for fall prevention.

To our knowledge our work is the first study on fall-related information seeking behavior of elderly Internet users. Although the overall response rate was relatively high, many seniors did not respond to our questionnaire possibly because they may consider fall prevention as less relevant and/or had difficulty completing the survey [6;7]. It is thus plausible that the respondents were more interested in fall management than non-responders; therefore this survey may overestimate the interest of the elderly in receiving fall-related information on the Internet. We only studied the elderly Internet users. Therefore, these results may not be generalizable to the whole elderly population. Future studies should be performed to study the general senior population, particularly because there is a paucity of studies specifically investigating the information needs and the consequences of offering this information to elderly patients about health related conditions on the Internet.

About 1 in 3 seniors stated that they were not inclined to search information about falls on the Internet. This was even the case in seniors who were already health information seekers on the web. This could be due to regarding fall prevention in older age as irrelevant, being unaware of the serious consequences of falls in older people [8],

or there might be denial of the considerable fall risk [9]. In addition, elderly people may not want to be seen as aged and frail [3;10], and therefore may not be willing to participate in fall-related programs. It is also possible that the Internet itself is not seen as the most appropriate medium for receiving fall-related information. Understanding the reasons why some seniors do not state that they are interested in receiving fall-related information through the Internet is therefore important and merits further study.

Our results showed that the majority of seniors expressed more interest in receiving fall-related information on the Internet than undertaking an assessment test regarding fall prevention. Previous studies also showed that a large percentage of elderly declined to take part in interventions regarding fall prevention [11]. There are suggestions that the intention to undertake an intervention (e.g., exercise) was closely related to coping style in the elderly [12]. Given the considerable risk of falling for elders one should investigate why online assessment tests do not receive more interest from senior Internet users. Also, understanding why some seniors show no interest in seeking fall-related information on the Internet could be used to design programs for offering preventive measures using the correct medium, thereby addressing seniors' needs. We showed that there was interest in receiving information on the Internet about conditions that increase the risk of falling; safety at home; possible exercises; and medications that increase risks of falling. Therefore, websites aiming at offering fall-related information to elders should consider these items for inclusion. In addition, the usage of image and video information was considered more important than modalities and functionalities, such as a listening buttons, and it should be taken into account.

References

[1] Tinetti ME, Speechley M, Ginter SF. Risk factors for falls among elderly persons living in the community. *N Engl J Med 1988; 319(26):1701-1707*.

[2] Kreuter MW, Strecher VJ, Glassman B. One size does not fit all: the case for tailoring print materials. *Ann Behav Med 1999; 21(4):276-283.*

[3] Yardley L, Nyman SR. Internet provision of tailored advice on falls prevention activities for older people: a randomized controlled evaluation. *Health Promot Int 2007; 22(2):122-128*.

[4] Nyman SR, Yardley L. Web-site-based tailored advice to promote strength and balance training: an experimental evaluation. *J Aging Phys Act 2009; 17(2):210-222.*

[5] Akkermans M. Ouderen maken inhaalslag op het internet. *Centraal Bureau voor de Statistiek. 2011.*

[6] Vass M, Avlund K, Hendriksen C. Randomized intervention trial on preventive home visits to older people: baseline and follow-up characteristics of participants and non-participants. *Scand J Public Health 2007; 35(4):410-417*.

[7] Yang ZJ, McComas K, Gay G, Leonard JP, Dannenberg AJ, Dillon H. Motivation for health information seeking and processing about clinical trial enrollment. *Health Commun 2010; 25(5):423-436.*

[8] Simpson JM, Darwin C, Marsh N. What are older people prepared to do to avoid falling? A qualitative study in London. *Br J Community Nurs 2003; 8(4):152, 154-152, 159.*

[9] Yardley L, Bishop FL, Beyer N, Hauer K, Kempen GI, Piot-Ziegler C et al. Older people's views of falls-prevention interventions in six European countries. *Gerontologist 2006; 46(5):650-660.*

[10] Yardley L, Donovan-Hall M, Francis K, Todd C. Older people's views of advice about falls prevention: a qualitative study. *Health Educ Res 2006; 21(4):508-517.*

[11] Stevens M, Holman CD, Bennett N, de KN. Preventing falls in older people: outcome evaluation of a randomized controlled trial. *J Am Geriatr Soc 2001; 49(11):1448-1455.*

[12] Yardley L, Donovan-Hall M, Francis K, Todd C. Attitudes and beliefs that predict older people's intention to undertake strength and balance training. *J Gerontol B Psychol Sci Soc Sci 2007; 62(2):119-125.*

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Managing Complex Therapies Outside Hospitals. An Analysis of GPs Practices of how to support Medication at Home

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Abstract. Support systems for the management of prescriptions are commonplace in hospitals, whilst they are rarely found in general practice. This exploratory study draws on a qualitative survey conducted with focus groups to investigate the information needs of General Practitioners (GPs) in regard to the therapeutic management of complex patients, the purpose being to identify possible areas of application. The question addressed is whether the systems existing in hospitals can be usefully adapted and used by GPs or if a different approach needs to be adopted to design other tools. The analysis shows that the information needs of GPs relative to medication management are significantly different from those of their hospital colleagues because the former are not directly responsible for the administration but instead operate within a care network on which they cannot exercise direct control. This study suggests that support systems for therapy management should be designed on the assumption that it derives from cooperative work by a heterogeneous network of actors, and therefore with functionalities intended to satisfy the coordination needs of all the actors involved in the process.

Keywords. General Practitioners, Computer Supported Cooperative Work, medication management, focus group, qualitative methods, patient empowerment.

Introduction

Support to healthcare practitioners in medication management is a traditional area of interest for medical informatics, and one of those in which its applications are most widespread. The Computerized Physician Order Entry (CPOE) and systems to support decisions on the administration of drugs are tools used by numerous hospitals. They help among other things to reduce prescription errors [1], improve monitoring of assumptions [2], support decisions [3], and coordinate operators [4]. Nevertheless, only a small quantity of medicines are administered by the healthcare practitioners in hospitals while most consumption takes place in the home where patients self-administer medications, sometimes with the help or under the surveillance of family members or caregivers and under the supervision of a General Practitioner (GP).

Nevertheless, scant research attention has been paid to identification of systems to support GPs and patients in medication management in extra-hospital contexts, with

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the partial exception of patient reminder systems and e-prescribing. This paper investigates the information needs of GPs when managing patients with complex pharmacological therapies. The purpose is to reflect on whether medication management systems in use at hospitals should be employed in general practice, or whether other information and communication technologies should be developed to support the monitoring, education and therapy adjustment work commonly required of GPs.

1. Methods

The research work was carried out in a region of northern Italy through five focus groups consisting of GPs working in various zones of the region. The participants in the focus groups were selected from students at the local General Medicine Training School; the sessions were conducted jointly by a social scientist (principal conductor) and a student specializing in general practice. Present at each session was an average of 5.5 GPs. The focus group sessions were transcribed and analysed using template analysis [5] in order to identify emergent themes concerning information requirements in regard to medication management.

The outline of the focus group stimulated the participants to describe and discuss their professional experiences with patients undergoing complex therapies, typically elderly persons. These are patients who are particularly frail and difficult to manage [6]. The following sections describe the analysis relative to the representations of the doctors in regard to the complexities of managing complex therapies and the applications required to support them. We deliberately chose not to ask directly about desired functions of a to-be-designed system. The implications for system design described in the last paragraph of this work stem from analysis of working practices and the issues which arise in management of these patients.

2. Results. The representation of complex therapies by the GPs

In the majority of cases, complex pharmacological therapy is the result of prescriptions issued by one or more specialist doctors working at a hospital. Such therapy is first produced and tested in a controlled environment where adverse reactions can be monitored, the patient's compliance has scant importance, and the technical complexity of the treatment is not an obstacle to its administration.

The first result of the research is the conviction of the GPs that such therapy must often be remodulated and adapted to the individual patient once s/he has been discharged. One of the factors that make this work necessary is that hospital doctors formulate the therapies without sufficient information about the patient's overall history. This requires GPs to mediate between the requirements of the specialist medicine practised in clinics and hospitals and the concrete life-conditions of patients. GPs simplify the therapies prescribed by the hospital doctors by reducing or eliminating certain drugs in order to increase therapeutic compliance and prevent assumption of the drugs from obstructing the patient's normal activities. The wide array of situations foresees simplifications to render therapies more manageable in the home (e.g. too many medicines may be forgotten); make them more economically sustainable for the patient (e.g. hospital therapies do not consider the patient's economic circumstances); and protect the patient's overall well-being (e.g. an excessive number of medicines may affect the

social and cognitive abilities of an elderly patient, without giving him/her particular benefits).

A second aspect, closely connected with the first one, is the scant communication that takes place between the hospital and the GP when patients are discharged. This makes the work of the GPs more complex in various respects. For example, the GPs mentioned that elderly patients often have one or more chronic illnesses characterized by acute phases which are treated in hospital. Hospital therapy usually furnishes information specific only to management of the pathology's acute phase, without instructions on how to modify the therapy thereafter. Another example of the problems connected with scant communication concerns the activation of monitoring procedures and special care by hospital doctors that impacts on the GPs. In some cases, the GPs complained, prior consultation with them would enable more thorough evaluation of the patient's needs in light of the information that the GP could furnish.

A third aspect is that GPs are represented as key nodes in the network, but they are devoid of any real power except persuasion, and they cannot exercise control or coercion like their hospital colleagues. This complex network comprises the patients and their family members, as well as caregivers and other practitioners (district nurses, social workers), and therapy compliance depends, among other things, on the coordination of all these actors. For instance, if the patient receives home care, the GP must laboriously coordinate a variety of professional figures. Nurses and social service workers sometimes find a clear division of their tasks and responsibilities difficult to define. At the same time, the GPs seem not to have effective means with which to control and evaluate their work. On this basis GPs often reduce the therapy to make it compatible with the patient's everyday needs, the availability of family support, and his/her financial circumstances.

Finally, this set of factors explains the change that has taken place in the notion of the optimal prescription. At hospital, in the absence of issues concerning patient compliance, and in an environment regulated by healthcare personnel, medicine dosages can be maximum, and indeed augmented with the administration of further drugs (e.g. a gastrolesive drug with a gastroprotector). The need to lead a normal life entails action to reduce drug dosages from the theoretical maximum established in a controlled environment to the level most compatible with the patient's specific conditions and with the therapy's long-period sustainability in every respect.

3. Discussion

The GPs' representations evidenced that the therapy, and the medical work associated with it, assume different meanings within and externally to hospitals. There emerged a number of significant differences that can be summarized in a few closely-interrelated points.

Unlike hospitals, GPs do not have the task of directly administering drugs; nor do they need to concern themselves with supplies. The GP must rely on the patient and his/her care network for management of the medication. The GP acts on this network with education and persuasion, but s/he cannot control and verify execution of the therapy. In this context, the therapy must not only be clinically correct but also make sense to the patient and be compatible with his/her socio-material circumstances, lest it be abandoned or autonomously adapted by the patient him/herself.

In more general terms, GPs construct enduring relationships with their patients, and their work has long-term objectives. Management of complex therapies for the chronically ill is one of the most complex challenges owing to the impossibility of exercising stringent control. According to the GPs in the focus groups, this objective is achieved when the doctor can guide the care network towards a sustainable equilibrium in the medium-long period, intervening with discreet and tactful monitoring in order to induce the changes necessary [6]. We now concentrate on this point in order to suggest ways to develop systems to support the work of GPs..

3.1. Notes for the design of systems to support medication management

For several years, hospitals have had various systems in place for the management of drugs and therapies. The first question to answer is this: 'If these systems were suitably adapted, could they support the work of GPs in managing the therapies of their patients?'. The research suggests that this is not possible because of the above-described excessive differences of context between care in the home and in hospital – to which should be added that the stockage problems so important in hospitals do not exist in the domestic context.

Analysis of the focus group sessions and comparison among the systems present in hospitals makes it possible to suggest the development of tools to support complex pharmacological management. To this end, one may begin by identifying the fundamental criterion of CPOE systems, regardless of their specific functionalities. This criterion is the need to support the work of diverse practitioners by furnishing each of them with functionalities useful for their work, and by supporting coordination within the network. The doctor is thus able to use a decision support system; the nurses can be sure that the therapy has been administered and that there are no duplications; and the hospital storeroom can keep check on stocks and promptly supply the wards; and so on.

Likewise, therapy support systems outside hospitals should be designed in light of the consideration that the hoped-for benefits will derive from collaboration among different actors, each with its specific competence, rather than from the work of a single healthcare practitioner. This presupposes the creation of systems usable, in different ways, by all the actors involved in the patient's care and assistance. Like the systems present in hospitals, such systems should be integrated into the working practices of GPs, and they should help patients, relatives and caregivers in their everyday tasks, while at the same time enabling information to flow through the network and ensure its coordination. This approach would require careful analysis of these relations in order to identify the specific functionalities to furnish to each potential user of the system.

On the basis of the findings from the focus groups, we suggest the following functionalities of a system like the one outlined above. Useful for GPs would be a decision support system that helps them adapt the therapies of discharged patients, and an alert system that prompts them to conduct periodic re-assessments of those therapies. Patients could benefit from tools enabling them to verify interactions between the drugs prescribed and those for self-care (e.g. over-the-counter drugs, herbal remedies) as well as educational tools (e.g. on administration regimes) or devices that remind patients to take medicines. Such functionalities could also be beneficial to relatives and caregivers, for whom tools to coordinate patient support could also be envisaged (e.g. reminders concerning medicines about to expire or run out).

These suggestions concerning functionalities reflect just one point of view – that of GPs – who were the only category consulted in the research. Instead, a system like the

one outlined above would require analysis of the needs of all the actors involved in the therapy management process and the inclusion of other significant dimensions. When designing such systems, it would be necessary to consider domestic care practices, their intersection with forms of personal health information management [7] and taking into account medication particularities [8] also bearing in mind the emotional, and not merely functional, connotation of technical tools [9].

To conclude, systems of this kind should consider and support the fragile ecology of the formal and informal relations in the care network activated around the patient, rather than seeking their radical reconfiguration. An approach of this type would certainly be more difficult to design, but at the same time it would have the advantage of being based on already-existing relational networks and practices, and of encompassing the new forms of technologically supported patienthood and agency that now constitute a core component of healthcare models [10].

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References

[1] Bates DW, Teich JM, Lee J, Seger D, Kuperman GJ, Ma'Luf N, Boyle D, Leape L, *The impact of computerized physician order entry on medication error prevention*, Journal of the American Medical Informatics Association 6 (1999), 313-21.

[2] Overhage JM, Tierney WM, McDonald CJ. Computer reminders to implement preventive care guidelines for hospitalized patients, *Archives of Internal Medicine* 156 (1996), 1551-6.

[3] Kuperman GJ, Teich JM, Gandhi TK, Bates DW. Patient safety and computerized medication ordering at Brigham and Women's Hospital, *Joint Commission Journal on Quality and Patient Safety* 27 (2001), 509-21.

[4] Mekhjian HS, Kumar RR, Kuehn L, Bentley TD, Teater P, Thomas A, Payne B, Ahmad A. Immediate benefits realized following implementation of physician order entry at an academic medical center, *Journal of the American Medical Informatics Association*, 9 (2002), 529-39.

[5] King N, Template analysis, in Symon G., Cassel C. (Eds) *Qualitative methods and analysis in organizational research: A practical guide*, Thousand Oaks, CA: Sage, 1998, 118-134.

[6] Miele F, Coletta C, Piras EM, Bruni A, Zanutto A. GPs and elderly patients: organizing a care network, in F. Sarracino and M. Mikucka (Eds.), *Beyond money: the social roots of life satisfaction and health*, Nova Science Publishers, Hauppauge, in press.

[7] Piras EM, Zanutto A. Prescriptions, x-rays and grocery lists. Designing a Personal Health Record to support (the invisible work of) health information management in the household, *Computer Supported Cooperative Work*, 19 (2010), 585-613.

[8] Dalgaard LG, Grönvall E, Verdezoto N. Accounting for medication particularities. Designing for everyday medication management, 7th *International Conference on Pervasive Computing Technologies for Healthcare,* (2013), 137-144

[9] Piras E.M, Zanutto A. Emotions and personal health information management: some implications for design, *Studies in health technology and informatics* 169 (2010): 63-67.

[10] Danholt P, Piras EM, Storni C, Zanutto A. The Shaping of Patient 2.0: Exploring Agencies, Technologies and Discourses in New Healthcare Practices, *Science & Technology Studies* 26 (2013), 3-13.

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User Needs and Requirements Analysis for Big Data Healthcare Applications

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Abstract. The realization of big data applications that allow improving the quality and efficiency of healthcare care delivery is challenging. In order to take advantage of the promising opportunities of big data technologies, a clear understanding of user needs and requirements of the various stakeholders of healthcare, such as patients, clinicians and physicians, healthcare provider, payors, pharmaceutical industry, medical product suppliers and government, is needed. Our study is based on internet, literature and market study research as well as on semi-structured interviews with major stakeholder groups of healthcare delivery settings. The analysis shows that big data technologies could be used to align the opposing user needs of improved quality with improved efficiency of care. However, this requires the integrated view of various heterogeneous data sources, legal frameworks for data sharing and incentives that foster collaboration.

Keywords. Big data, user needs, requirements analysis

Introduction

Recent publications [1-4] highlight the potential impact of big data applications and health data analytics for the healthcare sector. However, as of today, big data technology is rarely used within health care settings. The aim of this paper is to present and discuss the results of a big data related *user needs and requirements analysis* that was accomplished in the course of a big data technology road map development for the healthcare domain. Big data technologies establish means to aggregate and analyze large sets of heterogeneous data sources, and allow generating new insights and knowledge. Thus, one essential step for developing a technology road map for big data in the healthcare domain is to determine the particular information needs of the involved user groups. The context of our work is the Big Data Public Private Forum[2] Project, which aims towards developing a technology road map for big data technologies for the European healthcare market[3].

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[2] http://www.big-project.eu/

3 Beside the healthcare sector, several other industrial sectors, such as Energy, Transport, Finance, Manufacturing, Retail and the Public Sector are addressed within the project but not focus of this publication.

The goal of our study was to identify the most relevant information needs of the various stakeholder groups in the healthcare delivery domain. They could be addressed by aggregating and analyzing large and heterogeneous data sets. Particular requirements that need to be addressed in order to foster the implementation of big data applications in the healthcare domain were identified as well.

1. Methods

As depicted in Figure 1, our study consisted of two different stages.

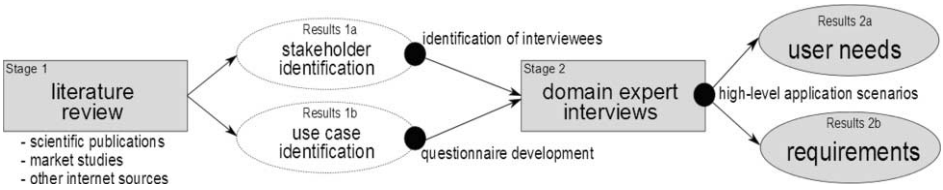


Figure 1. Two-stage approach of the presented study.

The goal of the first stage was to identify both stakeholders and use case applications of big data. Therefore, we conducted a literature review including scientific reviews, market studies and other internet sources. This knowledge allowed us to identify and select potential interviews partners, and to develop the questionnaire for the domain expert interviews. The interview guide consisted of 12 introductory questions with open response options which were clustered into three parts: a) direct inquiry of specific user needs b) indirect evaluation of user needs by discussing the relevance of the use cases identified at Stage 1 as well as any other big data applications they were aware of c) reviewing constraints that need to be addressed in order to foster the implementation of big data applications in healthcare. At Stage 2, we conducted 13 semi-structured interviews with an average length of 75 minutes. At least one expert of each stakeholder group identified in Stage 1, such as patients, clinicians, hospital operators, pharmaceutical industry, research and development (R&D), payors, and medical product providers was interviewed. To derive the user needs from the collected material respectively interview transcripts, we aggregated the most relevant and frequently mentioned use cases into high level application scenarios. Our data collection and analysis strategy was inspired by the triangulation approach [5]. Reviewing and quantitatively assessing the high-level application scenarios (see [6]), we derived a reliable analysis of user needs (see Section 0), and by examining likely constraints of big data applications the relevant requirements that need to be addressed were identified (see Section 2.2).

2. Results

In order to derive user needs and requirements from the collected data, we aggregated the most relevant and frequently mentioned use cases (53 of the 67 use cases that we had discussed with our interviewees) into six high-level application scenarios: 1) Comparative effectiveness research aiming to compare clinical and financial effectiveness of clinical care services 2) Clinical Decision Support assisting

the decision making process of clinicians 3) Clinical operation intelligence aiming to optimize clinical processes 4) Secondary Usage of health data aiming to discover new knowledge by means of data analytics 5) Public health analytics relying on comprehensive disease management of chronic and severe disease and 6) Patient engagement platforms that foster the active engagement of patients in the care process. The six high-level application scenarios established the basis for our user needs and requirements analysis.

2.1. User Needs

User needs in the context of big data can be captured by identifying the most relevant information needs of the various user groups. Within all application scenarios, any information unit that helped the involved users to improve the quality of care without increasing the costs was of great value. For instance, individualized treatment paths cannot be standardized and thus are likely to become very labor and cost-intensive without means of big data-based analytics. Thus, any information that could help to improve the quality AND the efficiency of care at the same time was indicated as most relevant and useful for the user groups. In general, those high impact insights can only be realized if the data analytics is accomplished on heterogeneous data sets encompassing data from the clinical, administrative and financial domain.

2.2. Requirements

Within our study, we identified several requirements that need to be addressed in order to foster the implementation of big data healthcare applications. We distinguished requirements a) that are business-related (BR), b) technical-related (TR) and c) requirement that are business and technical-related (BTR):

High investment needed (BR): The majority of big data applications in the healthcare sector rely on the availability of large-scale, high-quality and longitudinal health care data. The collecting and maintaining of such comprehensive data sets require not only high investments, it usually takes several years until the data sets are comprehensive enough for producing insightful analytics results. In general, such expensive and long-term based investments can rarely be covered by one single party, such that the conjoint engagement of multiple stakeholders, often including the government, is needed.

Value-based system incentives needed (BR): Current system incentives enforce “high number” instead of “high quality” of treatments. Although, it is very obvious that nobody wants to pay for treatments that are ineffective, this is still the case in many medical systems. In order to avoid low-quality reimbursements, the incentives of the medical systems need to be aligned with outcomes and thus foster cooperation between stakeholders.

Business cases with several partners needed (BR): Business cases for big data-bases solutions are difficult to identify. Several partners with diverging points of interests need to cooperate. Often, the one who is benefiting from the solution, is not the one who is in the position to drive the solution or able to pay for the complete solution. For instance, the implementation of data analytics solutions using clinical data requires high investments and resources to collect and store patient data [1]. Although, it seems to be quite obvious how the involved

stakeholder could benefit from the aggregated data sets, it remains unclear whether the stakeholder would be willing to pay or drive such an implementation.

Data security and privacy (BTR): As of today, legal frameworks defining data access, security and privacy issues and strategies are missing, and the seamless sharing and exchange of data is hindered. Simply because the involved parties lack procedures for sharing and communicating relevant findings, important data and information often remains within one department, group or organization.

Data quality (BTR): Although there exist many big data applications that are mainly looking for patterns in data, and thus do not need clean data, this is not the case for the healthcare domain. In order to derive reliable insights for health-related decision, high data quality standards need to be fulfilled. For instance, the features and parameter list used for describing the patient health status need to be standardized in order to enable the reliable comparison of patient or population data sets.

Data digitalization (TR): *S*till today, a high percentage of health related data is documented in paper-based form. However, to derive the maximum benefit from health-related data analytics, the data needs to be available in digital format. And, it needs to be complete and in good quality. In order to fulfill this requirement, the demand for standardization as well as technologies supporting the documentation process (e.g. context sensitive information extraction) is pointed out.

Semantic annotation (TR): Health data consist of very heterogeneous data, such as lab reports, medical images, clinical reports, sensor data or gene test results. Only a small percentage of this data is documented in a structured or standardized manner (e.g. International Classification of Diseases[4] (ICD) codes for diagnoses, laboratory data). It is estimated that in the upcoming years, 90% of health data will be provided in of unstructured format (e.g. medical reports) [7]. Semantic annotation facilitates automated content processing of unstructured data. This establishes the data foundation for a holistic analysis of the patient's status or the processing of complex research questions. For semantic annotation it is necessary to rely on standardized and commonly used vocabularies, terminologies or ontologies or coding schemes.

Data sharing (TR): Today a large amount of health-related data is stored in data silos. The efficient and automated data sharing is hardly possible as it faces multiple media disruptions. Although first approaches facilitating data interoperability (e.g. Health Level 7[5], OpenEHR[6], Integrating the Healthcare Enterprise[7]) are available, additional work and research is still required. At present, the health data exchange is mainly based on individualized solutions. This problem could be resolved by standardized clinical data models, commonly agreed terminologies and coding systems. Although, different coding systems are available, they are mainly used in country-specific adaptations (e.g. ICD-10) or lack usability (e.g. SNOMED Clinical Terms[8]).

[4] http://www.who.int/classifications/icd/en/
5 https://www.hl7.org/
6 http://www.openehr.org/
7 http://www.ihe.net/
[8] http://www.ihtsdo.org/snomed-ct/

3. Discussion

Our investigations showed that big health data applications indicate a high potential for improving the efficiency and quality of care delivery. However, we could identify only a limited number of already implemented big data application scenarios. Although non-advanced healthcare analytics applications - such as analytics for improved accounting or quality control - are available in a wide-spread manner [1], those do not yet make use of the potential of big data technologies. To use this potential, it is necessary that the *various dimensions of health data*, such as a) the clinical data describing the patient's history and health status b) the administrative data c) the knowledge about diseases as well as related population data d) the knowledge about changes in time are incorporated in the automated health data analysis. Hence, the highest clinical impact of big data approaches for the healthcare domain can be achieved when aggregating, comparing and relating data from the four dimensions. Therefore, big data technologies could help to produce new insights enabling personalized treatments [6].

This leads to one major problem: Health data cannot be easily accessed. High investment and efforts would be needed. As a consequence, convincing business cases are difficult to identify as the burden of initial required investments strongly reduces profit expectations [6]. In other words, one of the biggest challenges for the realization of big health data applications is the need for high investments, standards and frameworks as well as new supporting technologies to make health data available for subsequent big data analytics applications [8]. Technical and non-technical challenges need to be addressed to foster the seamless access to health data. Within our future work, we plan to elaborate these requirements in further detail.

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References

[1] Frost and Sullivan. U.S. Hospital Health Data Analytics Market [Internet]. Frost and Sullivan; 2012 [updated 2012 Aug 7; cited 2014 May 6]. Available from: http://tinyurl.com/myb2f3c.

[2] McKinsey and Company. Big data: The next frontier for innovation, competition, and productivity [Internet] McKinsey and Company; 2011 [updated May 2011; cited 2014 May 6]. Available from: http://tinyurl.com/cplxu6p.

[3] Kayyali B, Knott D, Van Kuiken S. The 'big data' revolution in healthcare [Internet]. McKinsey & Company; 2013 [updated 2013 April, cited 2014 May 6]. Available from: http://tinyurl.com/pq4dzrn.

[4] Porter M, Teisberg OE. Redefining Health Care: Creating Value-Based Competition on Results. Boston: Harvard Business Review Press; 2006.

[5] Flick U. Triangulation: Eine Einführung, Wiesbaden: VS Verlag,; 2011.

[6] Zillner S, Rusitschka S, Munne R, Lippell H, Vilela FL, Hussain K, et al. D2.3.1 First Draft of Sector's Requisites. Public Deliverable of the EU-Project BIG; 2013.

[7] Lünendonk Gmbh. Lünendonk Trendpapier: Big Data bei Krankenversicherungen: Bewältigung der Datenmengen in einem veränderten Gesundheitswesen [Internet]. 2013 [cited 2014 May 6]. Available from: http://tinyurl.com/ph6bwmh.

[8] Lobillo F. et al. D2.4.1.First Draft of Sector's Roadmap. Public Deliverable of the EU-Project BIG; 2013.

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Evaluation of the Usability of a Serious Game Aiming to Teach Facial Expressions to Schizophrenic Patients

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Abstract. In some psychological disorders such as autism and schizophrenia, loss of facial expression recognition skill may complicate patient's daily life. Information technology may help to develop facial expression recognition skill by educational software and games. We designed and developed an interactive web-based educational program with which we performed a usability study before investigating its effectiveness on the schizophrenia patients' ability of emotion perception. The purpose of this study is to describe the usability evaluation for a web-based game set that has been designed to teach facial expressions to schizophrenic patients. The usability study was done at two steps; first, we applied heuristic evaluation and the violations were rated in a scale from most to least severe and the major problems were solved. In the second step, think-aloud method was used and the web site was assessed by five schizophrenic patients. Eight experts participated in the heuristic evaluation, in which a total of 60 violations were identified with a mean severity of 2.77 (range: 0-4). All of the major problems (severity over 2.5) were listed and the usability problems were solved by the development team. After solving the problems, five users with a diagnosis of schizophrenia used the web site with the same scenario. They reported to have experienced minor, but different problems. In conclusion, we suggest that a combination of heuristic evaluation and think-aloud method may be an effective and efficient way for usability evaluations for the serious games that have been designed for special patient groups.

Keywords. Schizophrenia, video games.

Introduction

Patients with schizophrenia may have difficulties in recognition of facial expressions [1, 2] and this difficulty may cause problems in their daily life [3, 4]. Previous studies have shown that information technologies can help patients with recognition of facial expressions [1, 5, 6]. Recently, educational software or serious games have been used for patient education. Serious games are games in which education (in its various forms) is the primary goal, rather than entertainment [7]. Previous studies have indicated that patients prefer computer or web based education rather than traditional

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education [8-9]. In some studies investigating training people with schizophrenia via computer based programs for recognition of facial expressions, it has been suggested that computer based programs are very useful tools of education in recognition of facial expressions [1, 5, 10]. Apparently, it is necessary to use reliable digital facial expressions photograph sets that can be used in computer or web environment. There are many facial expressions but previous studies have shown that there are six basic facial expressions that are accepted to be universal. These are facial expressions, which display happiness, sadness, anger, disgust, surprise and fear [11-13].

The purpose of this study is to evaluate usability of this educational web site, which was developed for helping people with schizophrenia to recognize facial expressions.

1. Methods

Recognition of facial expressions may be different among cultures [11-12], so creating a new facial expressions photograph set for the Turkish people was the first thing we did as we started the study [14]. All games were designed considering some common characteristics of schizophrenia like deficiency in social cognition, difficulties in working and long-term memory, attention deficit, disturbance in executive functioning, and lower speed of processing. To evaluate the usability of our web based education software, heuristic evaluation method and think-aloud methods were used.

1.1. Heuristic Evaluation (HE)

It is a method to investigate systems' interface for usability issues by one or more experts. Evaluators examine the usability, efficiency, and effectiveness of the interface based on ten usability heuristics originally defined by Nielsen [15]. According to Nielsen, the number of the evaluators should be normally three to five, since a greater number of evaluators is not supposed to add more information [15]. For our study, eight experts completed HE questionnaires and then the feedbacks from these evaluators were used for discovering any problem of design regarding the educational web site. Experts (all have PhD in information sciences and they were unrelated to the study) were given a scenario (task list) before they started the evaluation. They reviewed the user interface of web site and generated a list of heuristic violations. The evaluators then independently rated the severity of each usability violation on the following scale [15]: 0- I don't agree that this is a usability problem at all; 1- Cosmetic problem only; 2- Minor usability problem; 3- Major usability problem; 4- Usability catastrophe.

Despite many usability problems identified in the assessments of the experts, the usability of such an instrument should be evaluated by actual users to increase the overall system quality and usability. Thus, with this consideration in mind, we used the think-aloud method with patients- in this case the actual users- soon after we fixed the major and minor problems of the web site as revealed by the experts.

1.2. Think-aloud or Protocol Analysis (TA)

This method requires from participants to verbalize their thoughts, feelings, and opinions during the test. One goal of this approach is to enable the tester to get a better understanding of the participant's mental model during interaction with the interface. It requires one usability expert and a minimum of four users who should be observed - the more users that can be observed, the better the results [16]. In our study, five patients with a diagnosis of schizophrenia participated in the TA test. Before the assessment, purpose of the research and TA were explained to the patients and they were given information about the scenario. During the evaluation, the participants were asked to think aloud while using the web site. Their expressions were recorded with handwriting by one of the authors, F.I. After the TA test, the data obtained from patients were used for the analysis of the web site and the final arrangements on serious games were then made.

2. Results

After HE, 60 usability problems were detected and "Flexibility and efficiency of use" was the first common problem among the participants (16, 26.7%), whereas "Consistency and standards" was the second (10, 16.7%). The problems that were defined by at least two experts with a severity score over 2.5 were accepted as major problems.

Table 1. Major problems detected via heuristic evaluation.

Heuristic violated	Problem	Mean	Number of Experts
Visibility of system status	Level information does not exist in the games	3,2	5
	Waiting interval between questions is too long	3,5	2
	Buttons remain selected after they were clicked	3	2
User control and freedom	There is no exit command	2,8	4
Consistency and standards	The feedbacks to users are not consistent	3,5	4
	Explanations of the games are not standard	3,5	2

Table 1 shows all the major problems, which were detected by the experts. The results of the HE were given to the software development team to help them improve the overall system usability and quality. Changes were prioritized based on the severity ratings. However, waiting interval was not shortened considering the disabilities specific to schizophrenia patients. In a second step, usability evaluation for educational web site was practiced by five patients with schizophrenia. The patients were two men and three women, between 23 and 38 years old.

After all the participants completed the task list, the data was analysed. While participants completed seven (64%) of the eleven tasks with success without any help, they needed help for the remaining four. Two of the tasks that related to "Help" options

failed because it opened another tab and the participants could not turn back to the game. In the other games, participants simply could not complete the game because they could not recognize the facial expressions. TA records were analysed and categorized for each game. Main problems were “Waiting interval between questions is too long” (Game 1), “Game description is not understandable” (Game 1), “Animations are too fast (Game 8)” and “Explanations about the site or the games are long and boring”.

3. Discussion

In this study, an educational web site that has been designed to teach recognition of facial expressions to patients with schizophrenia was assessed for usability with two different evaluation methods. As it is well known, performing a user evaluation at the end of a development phase is more effective, cheap and easy compared to the later phases. Additionally, we planned to use the software in a controlled study to see if the software had positive effects on facial expression recognition skills of the patients. Naturally, any change in software in the course of the study has a potential of distorting the study results. So, major problems of the software -if not all, must be solved before starting the study.

The educational web site was evaluated with HE method by eight experts at the end of designing phase. Since HE aims at clarifying each detected usability problem with reference to established usability principles, these findings may provide a guide for generating a revised design. Most of the experts (62.5%) found that continuous information about game level did not exist and they reported it as an important problem. In the original design, when the player passed a level, a level information message appeared at the beginning of the next level. However, according to the experts, the player might forget the level during playing game. Experts also found inconsistency of the feedbacks to the players. Each game had the same education purpose but games were different from each other in style and tasks. First, we thought that different games should have different feedback styles, but experts reminded us that consistency was a significant factor for a web site like ours. In HE methods, experts act like users and they try to find out usability problems. However, HE is not guaranteed to provide "perfect" results or to detect every usability problem in an interface user testing. Different evaluation methods have several strengths; the best evaluation of a user-interface comes from applying multiple evaluation techniques of information systems such as, usability testing, cognitive walkthrough, and TA method [17-18]. Consistent with the past studies [8-9], in this study HE method was found to be easy to use, time saving and suitable for assessing the usability of educational web sites, especially in the early phase of a development process.

HE method was quite efficient with experts, but the actual users of the system were going to be patients. Before using the system in routine use, we needed to perform a usability study with patients with a diagnosis of schizophrenia. Because of extraordinary nature of this user group, a structured usability method might have missed some usability problems specific for patients. So, we preferred to use TA method for studying with the patients. During the usability study with the patients, participants experienced some additional difficulties, especially about the help menu. This observation reminds us that serious games for these types of patients must be planned accounting for some of the common clinical features of schizophrenia patients

such as lack of attention, thought disorder or movement disorder. Evaluation of system usability by the help of experts exposes some problems related to general game and web site development design. Usability study with patients may reveal some additional problems that are related to some user specific factors. In our opinion, in usability studies of software, which is designed for special user groups, expert evaluation is not sufficient. A two-step approach may increase the quality of software, helping to detect general problems in the first step and user group specific problems in the second.

In conclusion, this study shows the outcomes of the heuristic evaluation and TA methods used in combination for identifying usability problems with an educational web site. Results suggest that using HE and TA together is very helpful to define the usability problems at the end of the development phase before it is accessed to a routine use.

References

[1] Wolwer W, Frommann N, Halfmann S, Piaszek A, Streit M, Gaebel W. Remediation of impairments in facial affect recognition in schizophrenia: efficacy and specificity of a new training program. Schizophrenia Research. 2005;80: 295–303.
[2] Bediou B, Asri F, Brunelin J, Krolak-Salmon P, D'Amato T, Saoud M, Tazi L. Emotion recognition and genetic vulnerability to schizophrenia. The British journal of psychiatry. 2007;191: 126-130.
[3] Kohler CG, Walker JB, Martin EA, Healey KM, Moberg PJ. Facial emotion perception in schizophrenia: a meta-analytic review. Schizophrenia Bulletin. 2010; 36(5): 1009-1019.
[4] Laroi F, Fonteneau B, Mourad H, Raballo A. Basic emotion recognition and psychopathology in schizophrenia. Journal of Nervous and Mental Disease. 2010; 198(1): 79-81.
[5] Silver H, Goodman C, Knoll G, Isakov V. Brief emotion training improves recognition of facial emotions in chronic schizophrenia: A pilot study. Psychiatry Research. 2004; 128: 147-154.
[6] Russell TA, Chu E, Phillips ML. A pilot study to investigate the effectiveness of emotion recognition remediation in schizophrenia using the micro-expression training tool. British Journal of Clinical Psychology. 2006; 45: 579–583.
[7] Michael DR, Chen SL. Serious Games: Games That Educate, Train and Inform. Muska & Lipman/Premier-Trade; 2005.
[8] Beranova E, Sykes C. A systematic review of computer-based softwares for educating patients with coronary heart disease. Patient education and counseling. 2007; 66(1): 21-28.
[9] Lewis D. Computer-based approaches to patient education: a review of the literature. Journal of the American Medical Informatics Association: JAMIA. 1999; 6(4): 272-282.
[10] Frommann N, Streit M, Wolwer W. Remediation of facial affect recognition impairments in patients with schizophrenia: a new training program. Psychiatry Research. 2003; 117(3): 281-284.
[11] Ekman P, Friesen WV. Constants across cultures in the face and emotion. Journal of Personality and Social Psychology. 1971; 17 (2): 124-129.
[12] Ekman P, Friesen WV, O'Sullivan M, et al. Universals and cultural differences in the judgments of facial expressions of emotion. Journal of personality and social psychology. 1987; 53(4): 712-717.
[13] Izard CE. The face of emotion. New York: Appleton-Century-Crofts; 1971.
[14] Gulkesen KH, Cinemre B, Isleyen F, Zayim N, Samur MK. What are the characteristics of people who are successful on recognizing human facial expressions on computer monitor?. Paper presented at: BMEI; 2011. Biomedical Engineering and Informatics (BMEI), 2011 4th International Conference on **4**, 2011. p. 1901-1903.
[15] Nielsen J, Mack RL. Usability inspection methods. New York: Wiley; 1994.
[16] Khannur A. Software Testing - Techniques and Applications. Pearson; 2011.
[17] Kushniruk AW, Patel VL. Cognitive and usability engineering methods for the evaluation of clinical information systems. Journal of Biomedical Informatics. 2004; 37(1): 56-76.
[18] Jeffries R, Desurvire H. Usability testing vs. heuristic evaluation: was there a contest?. ACM SIGCHI Bulletin. 1992; 24(4): 39-41.

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Supporting Elderly Homecare with Smartwatches: Advantages and Drawbacks

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Abstract. The demographic transition in industrialized countries leads to a growth of elderly population. This population is more prone to chronic diseases and puts an increasing pressure on the healthcare system. One way to reduce the cost associated to the support of this population is to improve its autonomy to keep it independent as long as possible. Many assistive technologies and environmental interventions can be implemented to achieve this goal. In this paper, we are looking at the advantages and drawbacks of smartwatches as a platform to support elderly at home. By doing a literature search and by performing expert interview, we have identified the advantages of this technology to insure the success of promising applications as well as the obstacles that should be gone beyond. Among the advantages, the ubiquity of smartwatches makes possible a continuous medical surveillance, harder to achieve with other devices. Moreover, the versatility of smartwatches provides an appropriate ground to implement a centralized platform providing multiples services facilitating elderly homecare. However, the physical constraints of the watches such as the tiny screen size, the small connectors and the limited power autonomy can be significant barriers to the adoption of these tools. In conclusion, beside the actual homecare system, improving the autonomy and the independence of elderly at home can be leveraged by a combination of environmental and assistive technologies. Smartwatches have definitively the potential to become close assistants to help elderly in their daily life. However, this will not be achieved without dedicating a significant effort in designing appropriate user interfaces and certainly dedicated hardware to respond to the constraints associated with potential physical and cognitive impairments.

Keywords. Aged, Home Care Services, Health Services for the Elderly, Mobile Health, Medication Adherence, Personal Autonomy, Frail Elderly

Introduction

The increasing population lifespan generates a growing pressure on the health care system in industrialized countries. As people get older, they naturally get prone to chronic diseases, to physical and cognitive impairments and often need to be monitored more closely [1].

There are strong assumptions that the high costs associated with the hospitalization or care in specialized structures of this population can be diminished by prevention measures, encouraging home care and improving autonomy [2,3]. Moreover, many studies show that elderly prefer strongly homecare over hospitalization as it allows to

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maintain their independence and has usually a beneficial effect on their health [4]. Improving autonomy and independence of elderly population can be leveraged with assistive technologies (AT) and environmental interventions [5]. Among the first group, personal emergency response system, such as alarm watches, can be use as a way to reduce the fear associated with falling [6,7]. This fear is relevant as studies show both the incidence of falls and the severity of complications increase with age, increased disability and functional impairment [8]. Other technologies, such as medication reminders, are central to prevent the high costs and risk of death associated with medication low adherence [9]. Finally, a bunch of sensors such as blood pressure monitor [10] and glucose meter can be used to support people global heath evolution [11].

Whereas some specialized solutions are already available on the market, they still have limited applications. The association of mobile and personal monitoring associated with modern communication devices has the potential to create better integrated tools that may change radically the situations. We are particularly interested to look at the potential of smartwatches to see if they can be employed as an efficient assistant by elderly populations. By conducting a literature review and interviews with a gerontechnology specialist, we attempted to identify the key problems toward the adoption of this technology.

1. Method

This is an exploratory study that aims to identify the opportunities created by the use of smartwatches as a tool to favor home care of elderly. In order to identify the advantages and drawbacks of such scenario, we have looked at three sources of information. A search of the literature by querying Medline with keywords such as “fall detection”, “home care”, and “technology adoption” provided us with a more than dozens of articles that the authors have read in order to extract the key findings. A survey of specification pages of the existing smartwatches helped us to identify the capabilities and limitations of these tools such as the available sensors, the autonomy and so on. Finally, we have confronted our findings with a specialist by conducting some interview with local domain experts from the Geneva public home care organization.

2. Results

2.1. Key advantages:

Ubiquity: If ubiquitous computing is a broadly used expression to characterize the use of smartphones, tablets and other ultraportable devices, this is a malapropism. Indeed, there are still many situations where people do not carry their faithful digital companion [12]. Indeed, not everyone carries its smartphone at home; it is not exceptional that instead of keeping the device in their pocket, people let their smartphone at their home entrance. More importantly, at nighttime, the smartphone will be more likely found connected to a power plug as almost all devices currently on the market necessitate several hours power load daily. This is a real concern as a typical situation requiring alert is a fall of elderly during night. The alerting device has to be reachable and effective. If the smartphone is still on the bedside table, loading, it will

not detect any fall, nor will it be reachable to generate alerts manually. On the other hand, a smartwatch, beside the remaining constraint of charging, can be worn during night and use to generate alarms or detect incidents.

Integrated captors: Similarly to modern smartphones, smartwatches are a concentrate of technology. The most advanced one possess accelerometer, GPS as well as gyroscope. The accelerometer makes it possible to detect the fall of a person based on the unusual acceleration pattern recorded. This application has already shown promising results, even if the false positive rate is often cited as a barrier toward its adoption [13–15]. The GPS has also undeniable potential when people leave their home. Numerous conditions can produce cognitive impairments and weaken the sense of orientation [1]. In such situations, the GPS allow to be localized and propose help, such as generating alarms outside a given area or instructions to go back home. GPS can also be employed to monitor people activity. It can be use to evaluate the level of physical activity. More importantly, the activity sensors such as GPS, accelerometer, gyroscopes, and compass can be employed conjointly to identify unexpected modification in activity patterns and generate alerts accordingly to the detected change.

Safety: Personal emergency response system, such as portable alarm button, is not a novelty [16]. It has been demonstrated to be an efficient way to improve elderly independence [17]. Most of the commercial systems currently available are dedicated tools. Their advantage is a very long autonomy, but they often require a receiver box at home which limits the autonomy of the carrier to its immediate environment. Another disadvantage of the current system is that they are usually very recognizable, such as a big red button at the wrist, and are sometimes perceived as stigmatizing [18]. Using modern smartwatches could address some of the disadvantages of existing systems, while raising the question of power autonomy.

Development potential: There is an unlimited potential regarding the range of applications that can be installed on smartwatches. Whereas other devices are often limited to a specific use, smartwatches have the potential to act as a central platform to leverage numerous functionalities around elderly. We can imagine providing applications recalling people to take their medications [19], recalling medical appointments [20], or reminding to remain hydrated [21].

Personalization: Not all elderly have the same skills and needs. Some need to control their glucose level, other feel unsecure when they have to leave their home and other just need to be reminded to take their mediations. The modularity of smartwatches that works under the concept of apps (similarly to smartphones) allows to install only the required components and to offer a tailored tool responding to the specific user needs, including all the things that are not relevant to health but just desired.

2.2. Key problems

User adoption: The elderly feeling regarding the use of a watch to provide assistance goes in two opposite directions. On the one hand, watches are not intrusive in elderly life. Many of them are already accustomed to wear one. On the other hand, the large amount of money that can be invested to buy watches shows that they are not only worn as a utility tool, but also as a jewel. This is especially true among elderly. Even the most fashionable watch may meet resistance among elderly that are emotionally attached to the watch they have always carried. Another important reason playing against the adoption of such innovative tool is the stigmatization feeling that old people

can have when they wear such a device. The only fact of wearing such device is admitting that something goes wrong [22].

Usability: Most of the interfaces conceived today for the old people tend to display large interacting elements with large font to help people with reduced mobility and impaired eye to be able to effectuate the required task [23]. On a smartwatch the very limited size of the screen doesn't help the manipulation by impaired people [24].

Disruptive technology: The actual generation of people over 70 has not grown with the technologies that seem so natural for the newer generations. For many old people, managing digital interfaces with submenu and complicated gestures is not trivial. Moreover, the instructions provided by manufacturer are often not devoted to elderly and work on assumed implicit knowledge. However, some studies show that if elderly are convinced by the utility of the tool, they are likely to adopt it independently of their age. Therefore, the resistance toward such technology should diminish with the apparition of appropriate services [25,26].

Autonomy: Depending on the number of applications running on the device and on the number of sensors that are used, the battery of the watch can get empty pretty quickly. If users forget to charge their device or do not realize that the battery is empty, it might stop functioning at a critical moment. Another specific problem linked to the autonomy is the size of the connectors that must be plugged in order to charge the watches. Indeed, smartwatches have usually small connectors that are difficult to be manipulated by people with reduced dexterity.

Price: We can expect that smartwatches will cost less in the near future. However, many elderly living with limited resources are price sensitive and spend their money carefully. For them, buying a smartwatch is a significant investment that will have to bring significant added-value and substantial improvement on their life quality.

3. Conclusion

The increasing numbers of seniors from the current demographic transition creates a strong pressure on the healthcare system. There are strong assumptions that maintaining this population at home as long as possible is a way to reduce the associated cost and to improve their life quality. Maintaining elderly at home can be leveraged with a large palette of assistive technologies and environmental interventions. In this paper, we attempt to assess the interest of smartwatches to be use as assistant, to maintain elderly population at home as long as possible. A study of the advantages and drawbacks shows that the high technological nature of these tools opens many opportunities to maintain elders at home (fall detection, medication plan follow up, activity tracker…). However, we raise some concerns about the usability of the watches that should be addressed. The elderly cognitive and physical limitations can be a serious barrier toward the use of these tools. Consequently, the probable potential of smartwatches will not be expressed without serious effort to imagine dedicated interfaces and maybe dedicated watches more adapted for the target population.

References

[1] Salthouse T a. When does age-related cognitive decline begin? Neurobiol Aging. 2009 Apr;30(4):507–14.

[2] Landers SH. Why health care is going home. N Engl J Med. 2010 Oct 28;363(18):1690–1.
[3] Hammond J. Home health care cost effectiveness: an overview of the literature. Public Health Rep. 1979;94(4):305–11.
[4] Hellström Y, Persson G, Hallberg IR. Quality of life and symptoms among older people living at home. J Adv Nurs. 2004 Dec;48(6):584–93.
[5] Mann WC, Ottenbacher KJ, Fraas L, Tomita M, Granger C V. Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly. A randomized controlled trial. Arch Fam Med. 2008;8(3):210–7.
[6] Delbaere K, Crombez G, Vanderstraeten G, Willems T, Cambier D. Fear-related avoidance of activities, falls and physical frailty. A prospective community-based cohort study. Age Ageing. 2004 Jul;33(4):368–73.
[7] Vellas BJ, Wayne SJ, Romero LJ, Baumgartner RN, Garry PJ. Fear of falling and restriction of mobility in elderly fallers. Age Ageing. 1997 May;26(3):189–93.
[8] Kannus P, Parkkari J, Koskinen S, Niemi S, Palvanen M, Järvinen M, et al. Fall-induced injuries and deaths among older adults. JAMA. 1999 May 26;281(20):1895–9.
[9] Maclaughlin EJ, Raehl CL, Treadway AK, Sterling TL, Zoller DP, Bond CA. Assessing Medication Adherence in the Elderly Which Tools to Use in Clinical Practice ? 2005;22(3):231–55.
[10] Stergiou G, Mengden T, Padfield P. Self monitoring of blood pressure at home. Bmj. 2004;329(October):870–1.
[11] Klonoff DC. Benefits and limitations of self-monitoring of blood glucose. J Diabetes Sci Technol. 2007 Jan;1(1):130–2.
[12] Kjeldskov J, Skov MB. Exploring context-awareness for ubiquitous computing in the healthcare domain. Pers Ubiquitous Comput. 2006 Nov 7;11(7):549–62.
[13] Abbate S, Avvenuti M, Bonatesta F, Cola G, Corsini P, Vecchio A. A smartphone-based fall detection system. Pervasive Mob Comput. Elsevier B.V.; 2012;8(6):883–99.
[14] Mubashir M, Shao L, Seed L. A survey on fall detection: Principles and approaches. Neurocomputing. Elsevier; 2013 Jan;100:144–52.
[15] Bagalà F, Becker C, Cappello A, Chiari L, Aminian K, Hausdorff JM, et al. Evaluation of accelerometer-based fall detection algorithms on real-world falls. PLoS One. 2012 Jan;7(5):e37062.
[16] Heinbüchner B, Hautzinger M, Becker C, Pfeiffer K. Satisfaction and use of personal emergency response systems. Z Gerontol Geriatr. 2010 Aug;43(4):219–23.
[17] Mann WC, Belchior P, Tomita MR, Kemp BJ. Use of personal emergency response systems by older individuals with disabilities. Assist Technol. 2005 Jan;17(1):82–8.
[18] Zwijsen S a, Niemeijer AR, Hertogh CMPM. Ethics of using assistive technology in the care for community-dwelling elderly people: an overview of the literature. Aging Ment Health. 2011 May;15(4):419–27.
[19] Becker S, Kribben A, Meister S, Diamantidis CJ, Unger N, Mitchell A. User profiles of a smartphone application to support drug adherence--experiences from the iNephro project. PLoS One. 2013 Jan;8(10):e78547.
[20] Car J, Gurol-Urganci I. Mobile phone messaging reminders for attendance at healthcare appointments. … Database Syst Rev. 2012;(7).
[21] Ferry M. Strategies for ensuring good hydration in the elderly. Nutr Rev. 2005;63(6):22–9.
[22] Boström M, Kjellström1 S, Björklund A. Older persons have ambivalent feelings about the use of monitoring technologies. Technol Disabil. 2013;25(2):117–25.
[23] Marcus A. Universal, ubiquitous, user-interface design for the disabled and elderly. Interactions. 2003 Mar 1;10(2):23.
[24] Plaza I, Martín L, Martin S, Medrano C. Mobile applications in an aging society: Status and trends. J Syst Softw. Elsevier Inc.; 2011 Nov;84(11):1977–88.
[25] Mallenius S, Rossi M, Tuunainen V. Factors affecting the adoption and use of mobile devices and services by elderly people–results from a pilot study. 6th Annu Glob Mobil …. 2007;
[26] Tang PC, Patel VL. Major issues in user interface design for health professional workstations: summary and recommendations. Int J Biomed Comput. 1994 Jan;34(1-4):139–48.

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Development of Structured Clinical Process Model of Dementia

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Abstract. As Japan is aging rapidly with more people with dementia, healthcare providers need to develop and share the care delivery model in order to respond to the need of not only the patients' but also of the families' and society's. The authors have developed a disease management and care system of the people with dementia based on the previous model developed by us for other diseases. Through the case reviews of the patients, this model proved to be useful in visually describing the patients' courses. We are going to develop as a next step a model to foresee the patients' progress so that we may be able to make timely interventions. Additionally, we have a plan to use it to improve the Japanese guideline of dementia care.

Keywords. Clinical process model, dementia, visualization, structuring, standardization

Introduction

Japan is aging rapidly and the aging ratio in 2013 was 25.1%. It is estimated to be 33.4% in 2035 and 39.9% in 2060. This means that one out of every 2.5 persons is of age 65 or over. The older the person is, the more likely he or she develops dementia. Though the figures differ from study to study, the prevalence of dementia at the moment is 3.0% to 8.8% and the figure may rise up to 10% in 2026. It was thought that the number of patients were about two millions in 2010, but some specialists now tells that 10 % of the people of 65-year old or over are with dementia, meaning 2.42 millions. They also say that this figure may again rise up to 3.25 millions in 2020 [1]. This kind of trend is common all around the world, especially in the developed countries.

As we have a limited number of care facilities for the people with dementia, it is an imperative for us to build up a social system to help those people living in the community including their own home without having much trouble physically, emotionally and socially.

This study aims at developing a "clinical process model" that facilitates the better disease management for the people with dementia. This clinical process model describes the process which the people with dementia follow and assist the healthcare providers to better address to their needs.

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1. Methods

The authors have developed the clinical process model for the people with dementia based on the Patient Condition Adaptive Path System (PCAPS). PCAPS is a structured knowledge model for healthcare delivery [2]-[6]. It consists of the clinical process chart (CPC) and the Unit Sheet (US). CPC is a comprehensive scheme that describes the disease progression, or disease process. And the CPC is made up of several units which represent the phases of disease progression. For each unit, healthcare providers set the goals of intervention and develop care plans. Thus, PCAPS visualizes and clarifies what the healthcare providers do in a logical and structured manner.

Tsuru et al already identified six disease management modes in the area of paediatrics. They are: (1) healthy or no awareness, (2) managed living without medical supervision, (3) managed living with medical supervision, (4) management by the GPs (outpatient departments), (5) management by the specialists, and (6) specialty intervention [7].

The authors utilized these six modes to develop the disease management model of the people with dementia. The process of development was as follows (Fig. 1):

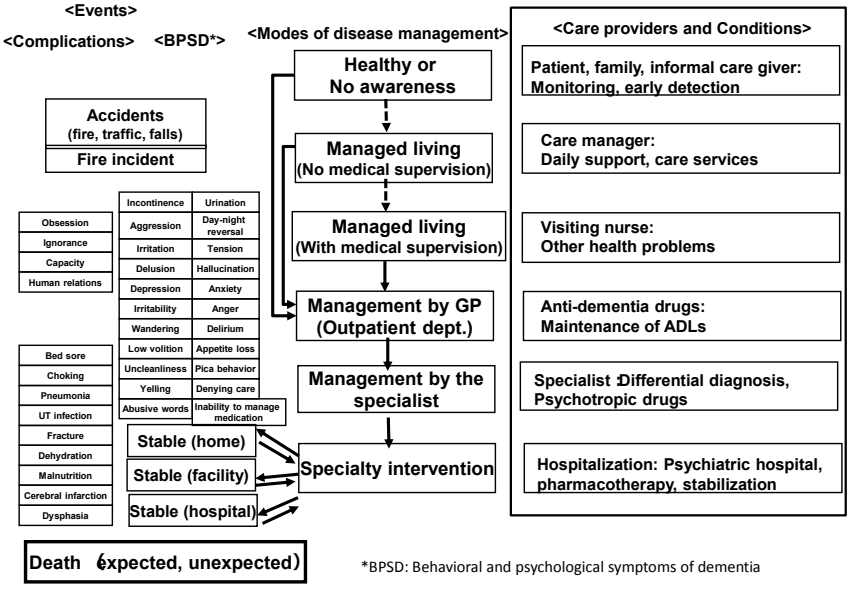


Figure 1. The six modes of disease management and events

- The first step: we applied the six modes of the paediatric disease management to that of dementia.
- The second step: Usually, the modes (1) to (3) are not under medical intervention. However, when dementia is suspected in either of this mode, the person moves to the mode (4) and sees the GP to get anti-dementia medication. In the mode (5), the patient gets psychotropic medicine because he or she shows some disturbing behaviour (s). At this mode, intervention is often performed by the psychiatrist. As the modes (4) to (6) accompanies medical interventions, they are to be managed under the PCAPS, which is a tool to

guide medical process. In the CPC of the PCAPS for dementia, we set the units according to the severity of dementia including the one which describes the post-death events.

- The third step: We put down the events caused by the disease. These events include family relationship, complications of the disease and the behavioural and psychological symptoms of dementia (BPSD) [8].
- The forth step: We developed the transitional logic between units, which shows when the patient moved to the next unit.
- The fifth step: We performed the validation study of our model through the case reviews of eight patients taken care at an internal and mental clinic in Tokyo. We actually followed their course of illness on the CPC.

The eight patient were selected so that they might cover the various types of the patient profiles such as those under appropriate medical supervisions, those with comparatively long course of dementia, those taken care of at home by spouses or children.

2. Results

The CPC for dementia with ten units were built up. The core part consists of 12 units which show the illness course. The CPC also includes 4 family relation events, 11 complication events and 22 BPSD events.

In the validation study, one patient was excluded as the person was not diagnosed as dementia. Of the rest of the seven patients, two were finally taken care at care facilities (Fig. 2) while five stayed at home (Fig.3). It was thought that patients might be taken care at home unless they get severely demented. Though one person was severely demented, she could stay home because she was bed-bound and did not show wandering. The patients tended to experience more events (family relation, complications of illness and/ or BPSD) as the severity went up.

The CPC was successful to describe the patients' profiles with the information on the disease severity and events caused by the disease. It was suggested that the CPC may provide a model to visualize the disease progression of the people with dementia.

3. Discussion

The eight patients with whom we developed and validated the clinical process model of dementia covered a wide variety of patient profiles empirically assumed. Therefore, we may conclude that this study encompasses diverse states of the patients with dementia irrespective of the small number of the subjects, ensuring the significance of the validation.

It was suggested that the PCAPS was well applied for dementia, as the CPC was successful in describing the disease progress of the patients. The PCAPS may be utilized as a tool to determine the effectiveness of interventions in the clinical settings.

The contents of the PCAPS may be turned into electronic data with the aid of the PCAPS Builder, which is an assistive tool to develop the clinical knowledge contents.

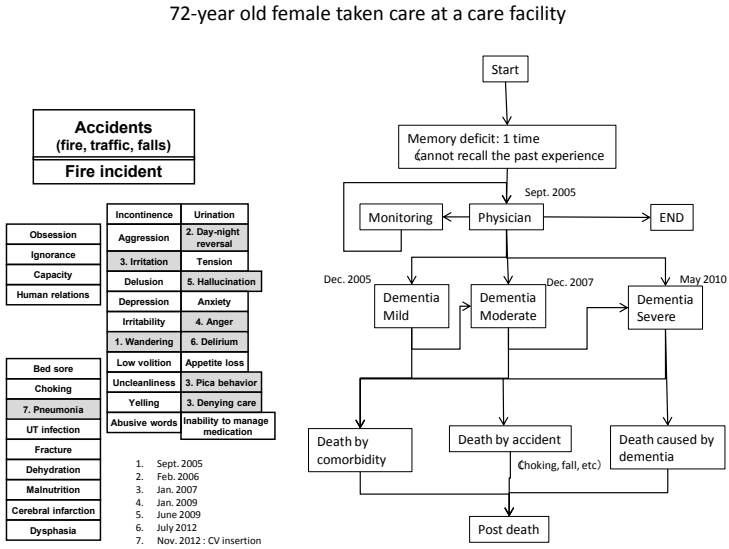


Figure 2. The CPC for a patient taken care at a care facility

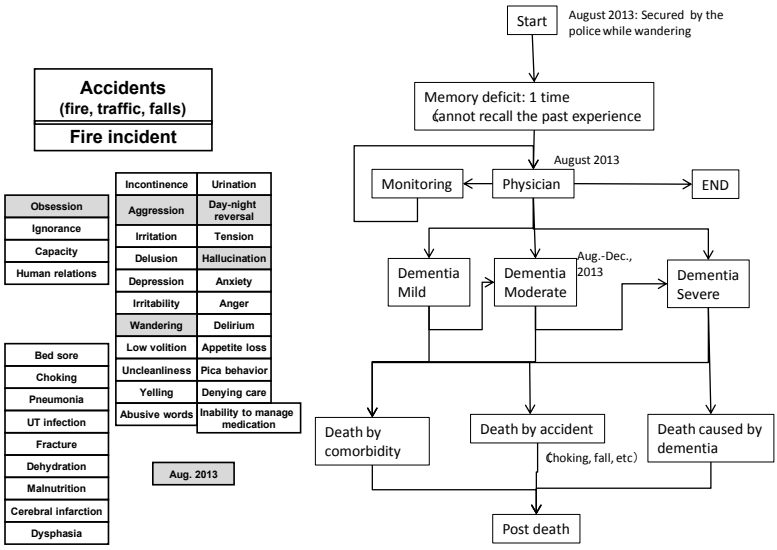


Figure 3. The CPC for a patient taken care at home

Once turned into electronic data, the contents may be clinically utilized with the use of the PCAPS Administrator, which is an assistive tool to administer the knowledge contents. The PCAPS Administrator helps us accumulate the clinical process data prospectively in daily practice.

The authors plan to embed the national guidelines for the dementia care into the electronic contents. Then we may compare the actual interventions, e.g. administration of medications, with the guidelines to assess the gap between the recommendations in the guidelines and the actual practice. Further, we may evaluate the effectiveness of the standard interventions in the guidelines for their improvement.

The clinical process modes for dementia in this study deals with those who has been diagnosed as dementia. We are planning to develop the clinical process models for the screening phase and diagnosis phase of dementia with the PCAPS.

Through the accumulations of the case reviews with the aid of EHR, we may build a model to see the future course of the patient.

In addition, the PCAPS may facilitate the development of clinical analysis methods because it enables comparison among patients' disease courses. We are going to construct an ICT system based on the PCAPS for dementia to develop such methods.

References

[1] Cabinet Office of Japan, *White Paper for aging society in 2014*, Koshu-eisei kyokai, Tokyo, 2014.

[2] S. Tsuru, Y. Iizuka, M. Munechika, A Framework for Structured Clinical Knowledge – PCAPS, *Proceedings of 53rd EOQ Congress, scientific paper total* (2009) 8, CD-ROM..

[3] S. Tsuru, Y. Iizuka, M. Munechika, Structuring Clinical Nursing Knowledge using PCAPS: Patient Condition Adaptive path System, *Proceedings of NI2009(Connecting Health and Humans IOS-Press ISBN 978-1-60750-024-7), scientific paper* (2009) 391-395.

[4] S. Tsuru, Y. Iizuka , M. Munechika, Clinical Process Standardization Method Using PCAPS, *Proceedings of ASQ World Conference on Quality and Improvement, scientific paper* (2010) 1-6, CD-ROM.

[5] S. Tsuru, Y. Iizuka , M. Munechika, Structured Model for of Clinical Processes: PCAPS-CPC, *Proc. of the 54th European Organization for Quality Congress, scientific paper* (2010) 1-8, CD-ROM.

[6] S. Tsuru, Y. Iizuka , M. Munechika, Structured Clinical Knowledge and its Application as a Socio-technology – PCAPS, *Proc. of the 55th European Organization for Quality Congress, scientific paper* (2011), 1-8.

[7] S.Tsuru, M. Fujiwara, T. Motoki, T. Minoura, T. Kobayashi, K. Tanizaki, R. Shimono, Development of the Modes of Disease Management for Infants and Children, *Proc. MIE2014* (2014) (in submission)

[8] M. Mizuki, S. Tsuru, M. Omori, F. Wako, Developing a Model of the Care Management for the Elderly with Dementia, *Proc. MIE2014*, (2014) (in submission).

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Vision and Challenges of a Cartographic Representation of Expert Medical Centres for Rare Diseases

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Abstract. In Germany, many highly specialized facilities for the diagnosis and treatment of rare diseases exist. However it is quite difficult for patients to find the required specialists because of the fact that information on the internet is scattered and of variable quality. The German Federal Ministry of Health initiated several activities to address this issue. This paper describes the project *se-atlas* which aims at presenting the medical care options for people with rare diseases on an interactive map and in a list format. Potential users of this resource will be patients and their relatives, doctors, non-medical personnel and the general public. Most information derived from the data sets is already listed in ORPHANET. The project's primary goals are to steadily increase the data set and to ensure its quality. This paper presents the goals and measures taken in this project. It gives an overview of the challenges implementing such a new service and the visions behind.

Keywords. Rare Diseases, Cartographic Visualization, Patient Empowerment, Patient Involvement, Patient Information.

Introduction

Diseases with a particularly low prevalence are called rare diseases. The European Union considers diseases to be rare when they affect not more than 5 per 10,000 persons. It is estimated that there are between 5,000 and 8,000 different rare diseases, affecting nearly 29 million people in the European Union and 4 million people in Germany alone [1], [2].

It is often difficult for patients and other healthcare professionals to know where to find these specialists as the diseases experts are also rare. To overcome this difficulty, the French Ministry of Health and the National Institute of Health and Medical

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Research (INSERM) jointly launched ORPHANET (www.orpha.net) in 1997, a multilingual information portal on rare diseases and orphan drugs. Since 2001 Germany became a partner and provides data for the international dataset.

In 2009 the Council of Ministers of the European Union recommended to the EU countries to identify rare disease expert centres and to make the information available to the end users. Recommendations on the definition of what is a centre of expertise have been published by the EU Committee of Experts on Rare Diseases [3]. Following the European Council recommendations, Germany published a National Plan for Rare Diseases (RD) in August 2013 which includes 52 policy proposals to guide and structure actions in the context of rare diseases within their health and social systems [4]. One of these proposed action fields focus on information management and has the goal to improve the level of information available to and information procurement by those afflicted, their relatives, doctors, therapists and caretakers. This action field led to the recommendation to establish a central information portal with an overview of experts in a map format which motivates the project *se-atlas* (section 3.5.3 [4]). Funded by the Federal Ministry of Health (Germany), the goal of the project *se-atlas* is to focus on an innovative representation of medical care options for people with rare diseases in Germany derived from the ORPHANET data set. In addition to the name and address of an institution, also information like the rare disease treated, individual contact data including telephone numbers, opening hours, etc. are stored. Data will be presented in both the format of an interactive map and a detailed listing. The project is intended to help completing the existing data set and to improve the accessibility by enhancing search functions and by testing new ways of interaction in order to keep the data relevant and up to date. Potential users of the information platform are patients and their relatives, practitioners, non-medical personnel and the general public.

The project *se-atlas* started in June 2013 and is scheduled to be completed by the end of May 2015. In the following we will give an overview about the goals and measures taken in this project, the intended realization and some of the challenges.

1. Goals and Measures

Based on the entered search term and the estimated or provided location of the user, relevant expert centres will be presented by the website in form of a map and a detailed listing. The user shall be able to filter the presented health care providers by different criteria such as distance, specification and quality. The goal is to provide a fast and intuitive overview about the different facilities. *se-atlas* intends to incorporate both categorization concepts described in the following and will provide a visualization of the different categories. The achievement of these goals should be supported by an early inclusion of representatives of the target group in the development process. The results have been summarized in a requirement specification document and discussed within the project partners. For the end of the project exemplary usability and acceptance tests are planned.

1.1. Quality Criteria

It is important that the listed institutions and experts fulfil defined quality criteria. ORPHANET Germany has implemented for this purpose an advisory board of experts.

Additionally a criteria checklist provided by the European Union Committee of Experts on Rare Diseases (EUCERD) has been in use since June 2013 [5].

Besides the so-called EUCERD-criteria, which are used for quality control by ORPHANET, a new German criteria catalogue, called NAMSE-criteria, has been developed differentiating between three types of centres for rare diseases, namely types A, B and C [4]. Distinctions are made among others between facilities which provide out-patient or in-patient services, have a focus on specific disease groups, and conduct or participate in research.

In addition to these official criteria new ideas based on the idea of Web2.0 shall be implemented, tested and evaluated within the project. The user shall have the opportunity to easily report if an entry or a search result is misleading or missing. Additionally, centres of rare diseases and patient organizations will be empowered to grant affirmations of quality by approving list entries in an internal area of the website.

The concept considers that the *se-atlas* map can be included as a web widget to any other webpage; for example to a page of a patient organization, which only visualizes expert centres covering one or more specific diseases. This way higher visibility of the project can be reached and the interest in keeping the data up-to-date by the corresponding community is increased.

1.2. Classifying address data and linkage to ORPHANET

To find the relevant expert centres, the address data have to be classified and linked with the corresponding diseases and their synonyms. *se-atlas* uses the ORPHANET classification to classify address data [6], [7]. The ORPHANET classification has a hierarchical structure and contains 8.945 diseases and synonyms grouped in 31 categories, e.g. *rare cardiac diseases*, *developmental anomalies during embryogenesis*, *inborn errors of metabolism*, r*are gastroenterological diseases*, *rare neurological diseases*, etc. [8]. Additionally, further classifications and listings such as the German modification of ICD10 and the German translation of MeSH will be integrated for the classifying of the centres for the operating medical experts. A project run by the German Institute of Medical Documentation and Information (DIMDI) currently maps the alpha-ID of the ICD10GM to the ORPHANET classification, so that the ICD10GM codes could be considered for classification in an easier way in future. The linkage of medical expert centres to multiple diseases is very complex and time consuming. *se-atlas* will offer new tools to support this process technically.

The basis for the underlying data set of the eligible facilities will be provided by the project partner ORPHANET Germany. The project's primary goals are to consistently increase the data set and to ensure its quality. If address data or the linkage to the corresponding diseases changes in one system, these changes will be adapted in the other database. Full correspondence between these two services is intended.

2. Realization and Challenges

The website is realized by using common technologies like JSP/JSF, JavaScript, HTML5, and CSS. The underlying database is MySQL on a Tomcat Server. First functionalities are implemented as a prototype already. For the cartographic visualization Google Maps, Nokia Here and OpenStreetMap (OSM) [9] have been tested. The quality of the data provided by OSM for Germany is very high and without charge, so

the decision was made to use OSM in *se-atlas*. Coming along with this decision is that an own OSM-server has to be hosted and a higher effort for familiarization is necessary.

One important challenge is to classify the registered specialists with their forte. The basis for the underlying data set of the eligible facilities as well as the classification of rare diseases will be provided by the project partner ORPHANET Germany (see section 1.2). For better understanding and research in the classification a java-based browsing tool was developed for internal use.

The number of diseases per category varies considerably. The category *rare genetic diseases* contains the most diseases, *rare intoxications* the fewest. Some diseases of the ORPHANET classification cannot be allocated to a distinct parent disease but fit different categories. For better search results, in consultation with ORPHANET International, a functional classification is provided, which contains a subset of the original classification and which links those diseases to their main categories.

In discussion with clinical experts and representatives of the users, scenarios and mock-ups describing the overall functionality of the website have been created. Figure 1 shows the mock-up for the cartographic view of the search results for the rare *Gaucher disease*. The different building symbols at the map represent the different categories (see figure 1). On the right side a short overview of the results in a list format is provided. The results can be limited to a maximum value of distance, which can be calculated with the help of the Geolocation API [9] or a minimum level of specificity. The specificity is calculated based on the relation between the diseases typed in and the assigned diseases.

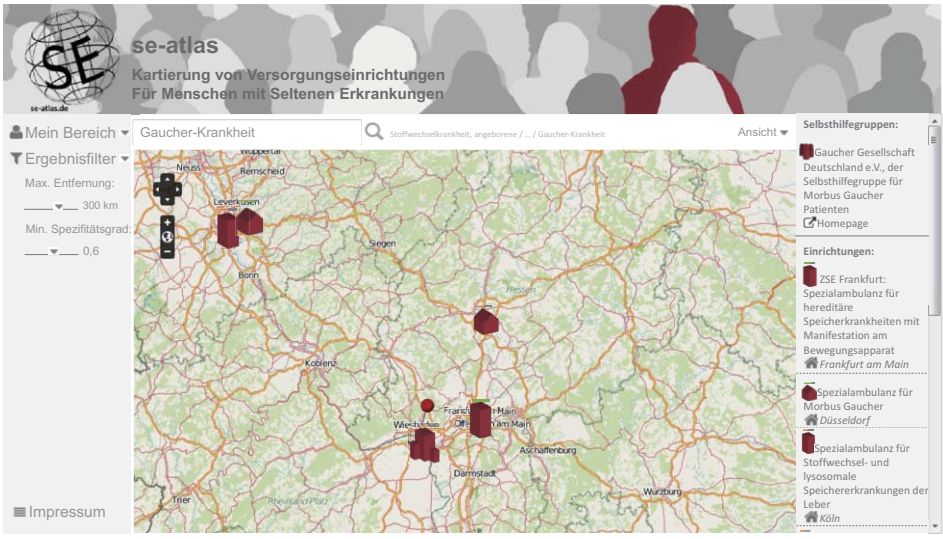


Figure 1. Mock-up of the website, not the final design.

Because names of diseases are often difficult to spell and not very common, errors like interchanges of letters or left outs should be covered by the search engine. For example for the disease *ichthyosis*, also the entry *ichtyosis*, *ichthoysis*, or *ichtiosis* should be possible. For this example, algorithms like Soundex, (Double-) metaphone, Kölner Phonetic, Levenshtein-Distance, or N-gramme (Dice-coefficient) have been tested and analysed. Based on terms extracted from the different classifications and listings (ORPHANET classification, ICD10GM, and MeSH) using autocomplete in combi-

nation with these algorithms, we obtained useful results in form of dropdown listings. A combination of Levenshtein and Kölner Phonetic seemed most promising. Even with over 20,000 terms in our database, feasibility und usability were satisfying.

3. Conclusion and Outlook

In the previous sections, we described the actual status and the emerging challenges of the project *se-atlas*. For this project it is very important that a consequent exchange of experiences between the interdisciplinary partners takes place. New concepts, for example representing data or including patient feedback are valuable contributions from other project partners. A close cooperation within the consortium will be necessary, but more importantly a conclusion as to who will operate the system after the funding period will need to be made.

In general, there are already several options for expansion of the system. The technical concepts and quality assurance strategies developed could be transferred to other European countries.

The next steps in the project *se-atlas* will be to complete the first running prototype of the system in spring 2014. Access will initially be restricted to a limited number of test persons and the available number of searchable expert centres will be small in this phase. In parallel the process of generating new data and the updating of existing data will start with the help of the partner organizations.

References

[1] Commission of the European Communities. Communication from the commission to the European Parliament, the council, the European economic and social committee and the committee of the regions - on Rare Diseases: Europe's challenges. Brussels: 2008.
[2] Federal Ministry of Health (Germany) [Internet]. Bundesministerium für Gesundheit, Seltene Erkrankungen; [last visited Apr 2014]. www.bmg.bund.de/praevention/gesundheitsgefahren/seltene-erkrankungen.html.
[3] Aymé, S. State of the art of rare disease activities in Europe: a EUCERD perspective. In: Orphanet J. Rare Dis. 2012; 7.
[4] NAMSE [Internet]. National Plan of Action for People with Rare Diseases - Action Fields, Recommendations, Proposed Actions, 2013. [last visited Apr 2014]. http://namse.de/images/stories/Dokumente/Aktionsplan/national plan of action.pdf.
[5] European Union Committee of Experts on Rare Diseases, EUCERD Recommendations on Rare Disease Patient Registration and Data Collection, 2013.
[6] Orphanet [Internet]. Free access data from Orphanet, [last visited Apr 2014]. www.orphadata.org.
[7] Maiella S, Rath A, Angin C, Mousson F, Kremp O. Orphanet and its consortium: where to find expert-validated information on rare diseases. Rev. Neurol. 2013;169.
[8] Orphanet [Internet], 2012 Activity Report Orphanet Report Series, Reports collection. 2013. [last visited Apr 2014]. www.orpha.net/orphacom/cahiers/docs/GB/ActivityReport2012.pdf.
[9] Hartz T, Ückert F. Nutzung der Geolocation API bei der kartographischen Darstellung von Versorgungslandschaften bei Seltenen Erkrankungen. Paper presented at the 58. GMDS Jahrestagung; 2013 Sept 1-5; Lübeck.
[10] Neis P, Zielstra D, Zipf A. The Street Network Evolution of Crowdsourced Maps: OpenStreetMap in Germany 2007–2011. Futur. Internet. 2011;4:1-21.

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Contrastive conversational analysis of language production by Alzheimer's and control people

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Abstract. Alzheimer's disease is characterized by memory disorders, although it affects also other cognitive functions (executive functions, attention, gnosia, praxia and language) and the communication ability. Our objective is to study verbal communication of people affected by the Alzheimer's disease at early to moderate stages. One particularity of our approach is that we are working in ecological conversational situations: people are interviewed by persons they know and in non-artificial environment. We propose a contrastive study of verbal productions of five people affected by the Alzheimer's disease and of five control people, both over 80 years old. To obtain quantitative and qualitative results, the oral corpora are transcribed and processed with the NLP methods and tools, and manually. Our results indicate that the Alzheimer's patients present lexical and semantic deficit and that their conversation is reduced comparing to the control people.

Keywords. Conversation, Linguistics, Natural Language Processing, Language of Patients, Alzheimer's disease, Loss of Language, Speech and Language Therapy, France

Introduction

It is estimated that currently over 850,000 people are affected by the Alzheimer's disease (AD) in France, and that the number may reach up to 1,200,000 in 2020 [1]. Most of the time, AD patients present a satisfactory communication skills at early stages of the disease: disorders concern language production, although its understanding is preserved [2]. The main disorder, relative to the lexical production, shows lexical and semantic deficiency due to progressive loss of semantic knowledge [3]. Phonological and morpho-syntactic skills are preserved at this step [2]. While pathology is developing, lexical and semantic troubles become more important, with the increasing of semantic paraphasia, loss of lexical understanding and morpho-syntactic disorders. Disorders gain then both language production and understanding, which makes the communication increasingly difficult [2]. Gnosic disorders (such as prosopagnosia) [1], as well as other cognitive and functional troubles [4,5] can appear. Decrease in language competence and in cognitive functions lead to muteness [2] and

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progressive social isolation. Maintaining the communication is the major challenge of speech and language therapists.

Studies of healthy old people indicate that: language performance depends on their education and age [6]; they show more frequently approximate and incoherent discourse, ambiguous references, periphrases and redundancies [7]; they do grammatical errors more frequently than younger persons [8,9]; they often speak about past events to maintain the conversation; they become egocentric and are not attentive to what other people are saying, which can lead to monologues; discussed topics are respected but with very frequent digressions and loss of the main idea [10]. Some existing work also proposed analysis of semi-supervised or supervised conversations of old people with AD. Concerning the comparative studies of language communication of healthy and AD persons, this existing work reveal that: AD persons produce syntactically poorer sentences [8,9], mention lesser number of ideas and words [11], produce redundant, less precise and informative discourse [12,13,14,15], rare use of the modalizers [12], pronouns miss the reference, which implies a loss of the semantic cohesion [14,15].

Our objective is to propose a contrastive study of verbal conversation of the AD and healthy patients. We want to propose additional diagnostic and therapeutic elements: define specific criteria of the conversational AD language and distinguish deficient and preserved elements. We work with transcribed spoken corpus of AD and healthy persons collected in ecological and non-artificial context (known interlocutor, non-supervised conversation). This is one of the specificities of our study. The other one is that the corpus is processed with Natural Language Processing (NLP) tools and through manual analysis.

1. Methods

The corpus is collected with ten people: five AD patients (89 to 99 years) and five healthy people (83 to 102 years). The average age is 90 years. These people are chosen in order to build as homogeneous as possible cohort concerning their age, gender (females), social and cultural level, and residence place. Concerning the AD patients, they have early to moderate disease stage and they can communicate (both, speak and understand). All of them have gone through a neurological test at most six months before the recruitment. They do not present other neurological or psychiatric history. To start the conversation, two pictures are proposed (train departure for vacations and bicycle ride). First the preferred picture and then the other one are discussed. The conversations can last for 20 to 40 minutes. The conversation are then transcribed with the Transcriber software [16]. Both text transcription and annotations *(eg,* disfluencies, hesitations, pauses) can be encoded. The transcription process needed over 100 hours. The transcribed corpus is processed with the NLP tools: POS tagging and lemmatization with TreeTagger [17] and Flemm [18]. The lemmas are morphologically analyzed Dérif [19]. These tools are used in their usual settings: no adaptations have been done.

Several aspects, covering intra and inter-individual communication, are studied. The objective is to provide comparative analysis of the conversation of AD and healthy people as exhaustively as possible. Among the studied aspects, we have the following: individual and overlapped time of speech (participation of person in the conversation), turns of speaking (dynamics of language exchange), language disfluencies (such as

empty and non-empty (*heu, hmm*) pauses, primes, repetitions and stutters, self-corrections, incomplete sentences) [20,21], breath groups, average length of sentences, informativity of sentences (use of discourse elements such as *oh, ah, bon (well), là (here)*), sentences containing only *yes* and *no* statements (up to ten occurrences), use of modalizers (cover non referential elements such as *je pense que (I think that)* and indicates that the person has some perspective and is detached from what he is saying [12]); personal pronouns (number of occurrences and their percentage comparing to the number of nouns); verbs (we distinguish the tenses of verbs and compute the percentage of a given tense among all the verbs); distribution of lemmas according to POS tags; reported speech and interpolated clauses (both allow to observe the detachment of the person from what he is saying); morphological complexity (observed further to the morphological analysis of words into bases and affixes); lexical diversity (computes the number of different words within the POS categories); lexical frequency (frequency of a given lemma for a given speaker).

2. Results and Discussion

Table 1. Quantitative results and salience of the aspects studied.

Aspects studies	AD patients	Healthy people
Time of speech	*11.26 min*	*14..20 min*
Overlaps of speech	*0.59 min*	*1.01 min*
Empty pauses	*65*	*31*
Non-empty pauses	*13*	*34.60*
Disfluencies	*2.80*	*8.40*
Number of words per breath group	3.90 words	4.31 words
Average length of sentences	*4.79 words*	*7.26 words*
Sentences containing only yes and no statements	*88.80*	*52.40*
Personal pronouns (total percentage)	*1%*	*0.65%*
Personal pronouns (1st person singular percentage)	*36%*	*23%*
Verbs	*377*	*553*
Distribution of lemmas according to POS tags	10	14
Lexical diversity	*168.60*	*302.40*

In Table 1 we indicate the average quantitative results for AD and healthy people groups. In italic and larger characters we indicate those aspects that show salient differences and may be involved in the diagnosis of the disease at early stages.

The results obtained describe extensively the discourse produced by AD patients. We can observe the following differences by comparison with the healthy people: AD patients produce a lesser number of words for the same speaking time; they show a higher number of turns of speaking; they speak with lesser speed; they have a greater number of stutters, self-corrections and incomplete sentences; they produce shorter sentences; they have an important number of *yes* and *no* sentences; they have a greater number of empty pauses and lesser number of non-empty pauses; they seldom use reported speech and interpolated clauses; they have poorer lexicon; they show a very high percentage of personal pronouns, especially of pronouns like *je (I)*. In general, we can notice that the discourse produced by the AD patients is less fluent and rich than the discourse of healthy people. It misses several aspects that mark the spontaneous and

natural speech (disfluencies, reported speech and interpolated clauses). Nevertheless, several elements typical of the spoken language are present, which means that the AD discourse begins to show structural and conceptual disorders at this level. We can see that several salient aspects are related to the NLP features (*eg*, lexicon, syntax). Notice that in an existing study [22], dedicated to the analysis of aphasia discourse, the authors observed that classical features (and not NLP features) are relevant to the diagnosis. The fact that the NLP tools can efficiently help the analysis and diagnosis of the Alzheimer's disease at early stages is a very positive result of our study.

Yet, the results obtained are to be taken with precaution because the variability within each group is very high. This is due to the personality of each participant, their habits and ways of life. In future work, it is necessary to study a larger group of people to reduce the influence of the inter-personal variability.

3. Conclusion and Perspectives

We proposed a comparative analysis of spoken corpora produced by Alzheimer's disease patients and by healthy people, all over 80 years old. The data allowed to perform an extensive study of conversation of these two categories of people and to compare them. Up to now, such analysis was difficult due to several aspects involved and to the fact that the existing studies seldom addressed the conversation analysis of people with AD: these studies usually analyze discourse produced in supervised and artificial contexts (supervised description of images in artificial settings). Our study mends this situation.

During our study, we observed that lexical and semantic deficits are indeed specific to AD patients. They can be observed through the poor lexical diversity. Even if these people are considered to have the communication skills, the language loss has already started (decreasing number of sentences, of words, of speaking time...). The analysis we propose also shows that AD patients is less detached from what they are saying. The speech becomes non-natural and one can wonder whether the AD patients can still manage their discourse or whether they just exploit the speech reflexes they learned previously in their lives. We think that the obtained results are interesting and that they can help the speech care of such people. Such care should start as soon as possible in order to maintain the communication skills as long as possible.

Since the communication loss of the AD patients is going increasing with the evolution of the disease and causes their isolation, our study allows to better understand, at the level of language production, what are the specific language deficiencies of AD patients at early to moderate stages. Besides, the comparison of AD patients discourse with healthy people discourse provides a better analysis and evaluation, and also it provides a basis for the diagnosis and a better speech care. The conclusions of our study help to better understand the development of the disease. In future work, we plan to study larger corpora collected with additional participants within similar ecological context.

The use of the NLP tools allows to systematically process larger amounts of data and to observe several specificities of the AD patients speech. Nevertheless, it is necessary to adapt some NLP tools to the processing of the data we use (to complete the morphological analysis with other morphological rules) and to use additional tools (*eg*, syntactic analysis). Complementary study of verbal and non-verbal (gesture) communication is an interesting issue. If similar data are available in other languages,

the approach proposed can be applied to process them. Finally, the automatic categorization of speakers as AD-suffering or not and the automatic diagnosis of this disease as early stages is another important perspective of the current work.

References

[1] Dubois, B. Actualités de la maladie d'alzheimer. *Annales Pharmaceutiques Françaises 2009*, **67**(2), 116-126.

[2] Joanette, Y., Kahlaoui, K., Champagne-Lavau, M. et Ska, B. Troubles du langage et de la communication dans la maladie d'Alzheimer : description clinique et prise en charge 2006, 223-241.

[3] Tran, T., Dasse, P., Letellier, L., Lubjinkowic, C., Thery, J. et Mackowiak, M. Les troubles du langage inauguraux et démence : étude des troubles lexicaux auprès de 28 patients au stade débutant de la maladie d'Alzheimer. *SHS Web of Conferences 2012*, **1,** 1659-1672.

[4] Traykov, L., Rigaud, A., Cesaro, P. et Boller, F. Le déficit neuropsychologique dans la maladie d'Alzheimer débutante. *L'Encéphale 2007*, **33**(1), 310-316.

[5] Fryer-Morand, M., Delsol, R., Nguyen, D. et Rabus, M. Le syndrome dysexécutif dans la maladie d'Alzheimer: à propos de 95 cas. *Neurologie-Psychiatrie-Gériatrie 2008*, 8, 23-29.

[6] Mackenzie, C. Adult spoken discourse: the influences of age and education. *International Journal of Language and Communication Disorders 2000*, **35**(2), 269-285.

[7] Feyereisen, P. et Hupet, M. *Parler et communiquer chez la personne âgée*. PUF, Paris 2002.

[8] Kynette, D. et Kemper, S. Aging and the loss of grammatical forms: A cross-sectional study of language performance. *Language and Communication 1986*, **6,** 65-72.

[9] Kemper, S., Rash, S., Kynette, D. et Norman, S. Telling stories: The structure of adults' narratives. *European Journal of Cognitive Psychology 1990*, **2** 205-228.

[10] Rousseau, T., De Saint-André, A. et Gatignol, P. Évaluation pragmatique de la communication des personnes âgées saines. *Neurologie Psychiatrie Gériatrie 2009*, **9,** 271-280.

[11] Croisile, B., Ska, B., Brabant, M., Duchene, A., Lepage, Y., Aimard, G. et Trillet, M. Comparative study of oral and written picture description in patients with alzheimer's disease. *Brain and language 1996*, **53,** 1-19.

[12] Duong, A., Tardif, A. et Ska, B. Discourse about discourse: What is it and how does it progress in Alzheimer's disease? *Brain and cognition 2003*, **53,** 177-180.

[13] Berrewaerts, J., Hupet, M. et Feyereisen, P. Langage et démence : examen des capacités pragmatiques dans la maladie d'Alzheimer. *Revue de Neuropsychologie 2003*, **13**(2), 165-207.

[14] Ska, B. et Duong, A. Communication, discours et démence. *Psychologie et NeuroPsychiatrie du Vieillissement 2005*, **3**(2), 125-133.

[15] Lee, H. (2011). Vieillissement normal et maladie d'Alzheimer : analyse comparative de la narration semi-dirigée au niveau lexical. *In Colloque international sur les méthodes et analyses comparatives en sciences du langage*.

[16] Barras, C., Geoffrois, E., Wu, Z. et Liberman, M. (1998). Transcriber: a free tool for segmenting, labeling and transcribing speech. *In Conference on Language Resources and Evaluation (LREC)*, 1373-1376.

[17] Schmid, H. Probabilistic part-of-speech tagging using decision trees. *In ICNMLP 1994*, 44-49, Manchester, UK.

[18] Namer, F. FLEMM : un analyseur flexionnel du français à base de règles. *Traitement automatique des langues (TAL) 2000*, **41**(2), 523-547.

[19] Namer, F. Morphologie, Lexique et TAL: l'analyseur DériF. TIC et Sciences cognitives. Hermes Sciences Publishing, London 2009.

[20] Bove, R. *Analyse syntaxique automatique de l'oral: étude des disfluences*. Thèse de doctorat, Université d'Aix-Marseille I, Marseille 2008.

[21] Pallaud, B. Les amorces de mots comme faits antonymiques en langage oral. *Recherches sur le français parlé 2002*, **17,** 79-102.

[22] Gaspers, J., Thiele, K., Cimiano, P., Foltz, A., Stenneken, P. et Tscherepanow, M. An evaluation of measures to dissociate language and communication disorders from healthy controls using machine learning techniques. *In IHI 2012*, 209-218.

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Assistive System for People with Apraxia Using A Markov Decision Process

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Abstract. CogWatch is an assistive system to re-train stroke survivors suffering from Apraxia or Action Disorganization Syndrome (AADS) to complete activities of daily living (ADLs). This paper describes the approach to real-time planning based on a Markov Decision Process (MDP), and demonstrates its ability to improve task's performance via user simulation. The paper concludes with a discussion of the remaining challenges and future enhancements.

Keywords. Markov Decision Process, Task Model, Cognitive Assistive System, Activity of daily living.

Introduction

Stroke survivors suffering from neurophysiological disorders [1, 2] such as Apraxia or Action Disorganization Syndrome (AADS) may be unable to perform simple activities of daily living (ADLs). For example, when making a cup of tea or preparing a snack, patients might perform a wrong sequence of actions, skip steps, or misuse objects with possible safety implications. Caregivers can provide assistance, but patients may be unwilling to accept this as a long-term solution, considering it to be an intrusion into their privacy. Hence, assistive technologies for cognition (ATC) are a key objective in helping stroke survivors to regain independence. This is the goal of the CogWatch system [3], and this paper focuses on its Task Model (TM): a real-time planning system based on a Markov Decision Process (MDP), which can guide and provide meaningful feedback to patients during ADLs. To be more precise, the TM's aim is to make the patients aware of their errors, suggest what should be done to successfully complete the task, and alert them in case of danger.

The potential of ATCs for patients with cognitive impairments in task accuracy and independent task completion has been demonstrated in several studies. Levinson [4] describes an ATC using artificial intelligence (AI) called PEAT, which automatically generates the best plan to complete a task, and assists the user with visual and auditory cues. This project has been enhanced with the integration of sensors [5]. Other computer-based guidance systems, such as Cogorth [6] or Coach [7] were also developed as prototypes before being improved with new technologies. Nevertheless, despite this growing interest in incorporating sensing capabilities and AI techniques in

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ATCs, the studies rarely focus on the effects of the devices on patient performance, and the implication of involving clinical specialists in the system development have also received little attention.

We aim to show that a planning system integrating AI technics can also take into account clinical specialists' knowledge in order to make ATCs' guidance more meaningful. Moreover, even if CogWatch is at its early stage and data involving stroke survivors are still being gathered, we can still demonstrate the ability of its Task Model to improve task performance via user simulation.

1. System Architecture and Method

CogWatch's current goal is to re-train patients with cognitive impairments providing them autonomous guidance during tea making. The complete system (Figure 1) comprises sensorized objects (mug, kettle, milk jug), an Actions Recognition System (AR), the TM and a Prompting System. First, the patient or the clinician chooses the type of tea (i.e. black tea, black tea with sugar, white tea, or white tea with sugar) for which training is believed to be needed. This information is then passed to the TM that enables the system to begin interacting with the patient. When moving the objects, the patient triggers the sensors attached to them; the outputs of the latter, together with estimates of the patient's hand positions, are communicated wirelessly to the AR that tries to comprehend what action has just been performed. Synchronized with Kinect, the AR is a probabilistic system based on Hidden Markov Models. It is implemented as a set of parallel detectors, so that actions occurring at the same time can be identified. It outputs its observations to the TM, which keeps in its memory the patient's actions history, so it can constantly analyses it in order to find potential errors. Flexible, the TM allows the patient to perform the chosen task following all possible valid variations of actions. However, when it detects an error, it determines its type and what action should be performed by the patient for the task to be succeeded. Finally, the TM sends this information to the Prompting System that decides when, how and at which frequency cues (e.g verbal, auditory, visual cues) should be delivered to the patient.

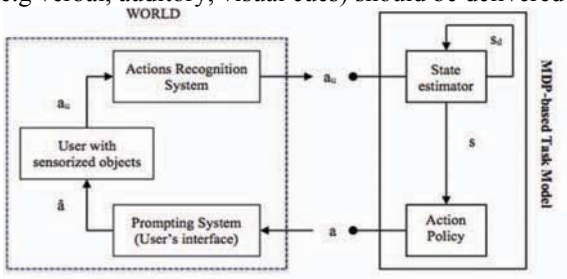


Figure 1. Structure of CogWatch: a_u and a denote the user's action and the TM's strategy, s_d is the user's actions history, s being factorized with a_u and s_d. The circumflex indicates an estimate.

As explained previously, the TM is based on a Markov Decision Process. The MDP is a mathematical tool for planning, learning and describing decision-making in probabilistic environments. It is defined as a four-tuple *(S, A, P, R)* [8], where: *S* is a finite set of states, *A* is a finite set of actions, *P* is the transition function (*P(s, a, s')* denotes the probability of reaching state *s'* from *s* given that action *a* was taken), and *R(s, a)* is replaced by *C(s, a)*, the cost of taking *a* in state *s*. Given an MDP, the

problem is to find the optimal strategy π^* which is a mapping from states to actions, where $\pi^*(s)$ is the best action to perform in state s. Its computation is based on the policy value $V^*(s)$, which is the expected sum of costs incurred by a session starting in state s at time $t=0$, and following π^*, until the final state is reached at T_F.

$$V^*(s) = < \sum_{t=0}^{T_F} c(s_t, a_t) >, \quad (1)$$

where $s_0 = s$ and $a_t = \pi^*(s_t)$. It can also be expressed as:

$$V^*(s_t) = min_a[< c(s_t, a) > + \sum_s P(s, a, s_t) V^*(s)]. \quad (2)$$

π^* is then defined by:

$$\pi^*(s_t) = argmin_a[< c(s_t, a) > + \sum_s P(s, a, s_t) V^*(s)]. \quad (3)$$

Those strategies are computed using a Monte Carlo Algorithm [11]. To do so, the four-tuple *(S, A, P, C)* needs to be defined following CogWatch's context:

- **The action space A:** Using the principles of task analysis [9], each type of tea is decomposed into a hierarchy of sub-goals, tasks and sub-tasks. CogWatch currently focuses on the first level, where eight sub-goals have been identified, plus one common error (9), and one potentially hazardous activity (10). These are: *{1. "Fill kettle", 2. "Boil water", 3. "Pour boiling water from kettle into mug", 4. "Add teabag", 5. "Add sugar", 6. "Add milk", 7. "Stir", 8. "Remove teabag", 9. "Pour cold water from jug into mug", 10. "Toy with kettle"}*.
- **The state space S:** States of the MDP-based TM directly correspond to user's states. Specifically, a state is a sequence of actions performed while completing the task that has been chosen by the clinician or the patient.
- **Transition function:** CogWatch is currently used with real participants under the supervision of a clinician. Thus, we make the assumption that the transition function *P(s, a, s')* is binary. Suppose that the current state s corresponds to the sub-sequence $g_1, g_2, \ldots, g_n$, that a is the sub-goal g, and s' is $g_1, g_2, \ldots, g_n, g$. Then $P(s, a, s')=1$ and $P(s, a, t)=0$ for all states $t \neq s'$.
- **Cost function:** The cost function *C(s, a)* is a mechanism to incorporate human judgment about the importance of different types of behaviour into the MDP. In our case, it includes a penalty based on the time taken to achieve the task, and a penalty for not doing a specific action in a state where this action is considered to have highest priority. The first type of penalty allows the TM to compute the fastest strategy. However, the fastest strategy is not necessarily the most psychologically plausible. To deal with this, we analysed data from control participants in order to determine which actions are performed most frequently in each state during the task. This knowledge allows the TM to suggest strategies that are not only correct but that clinical specialists also consider being plausible.

2. User Simulation and Results

This section describes an evaluation of the MDP-based TM and measures its ability to guide a virtually impaired simulated user *(SimU)* that interacts with a simulation of CogWatch to make cups of tea. The evaluation with real users is the ultimate measure for the usefulness of a system, we have started it but do not report the data as it is yet in its pilot stages.

Based on real participants data, the *SimU* incorporates a complete psychologically plausible behavior, which allows it to deal with all possible situations encountered while interacting with the CogWatch Simulator. It can output all the sub-goals part of the MDP action space and virtually interact with the Prompting System from which it can receive cues or ask for help. The CogWatch Simulator follows the same structure of the real system described in Figure 1; the *SimU* replacing the module corresponding to the 'user with sensorized objects'. During this experiment, the *SimU* tried to make each type of tea 1189 times. Table 1 shows its success rates when being compliant to the TM (i.e when executing the strategy suggested by it) and when ignoring it, which means to perform the task by itself. The results highlight the fact that the use of the CogWatch Simulator increases the ability of the *SimU* to succeed each type of tea. In other words, when the MDP-based TM detects a recoverable error made by the *SimU*, the strategy it suggests and to which the *SimU* complies helps the latter to succeed each task more often.

Table 1. Simulated User's success rates when interacting with the CogWatch Simulator.

Type of tea	Assisted by TM	Ignoring TM
Black tea	86.7%	79.1%
Black tea with sugar	35.4%	16.3%
White tea	63.3%	43.9%
White tea with sugar	64.5%	19.1%

Table 2 shows the error rates of specific types of errors made by the *SimU* when trying to make a white tea with sugar, complying with and ignoring the Task Model. One can see that the TM's assistance results in significantly fewer toying and omission errors being made by the *SimU*. Defined by specialists working with cognitively impaired people, the errors highlighted in this table are part of the thirty errors the MDP-based TM is able to detect and to compensate with its strategy.

Table 2. Error rates of specific types of errors made by Simulated User's when making a white tea with sugar. E30 – sequence error: removing the teabag from the mug before adding hot water to it; E13 – toying error: misusing the water jug; E29 – omission error: omitting to stir the tea (if pre-defined as compulsory).

Type of error	Assisted by TM	Ignoring TM
E30	12.6%	12.7%
E13	9.4%	61.3%
E29	0.6%	0.9%

3. Discussion

In our experiments, we have shown that the assistance of the MDP-based Task Model integrated in a simulation of the current CogWatch System permits to increase the success rates of a virtually impaired simulated user for each type of tea. It also decreases the error rates of specific types of errors commonly performed by people suffering from apraxia. Thus, following the strategy provided by the TM helps the *SimU* to increase its task performance. We believe that similar results will be observed when experiments being run with real participants will come to an end. From an architectural and computational point of view, to have implemented this virtual simulation of CogWatch allowed us to validate the Task Model's capability to fulfill the requirements needed for the system to be an intelligent assistive device. In the future, the TM will be extended to other types of tasks, such as snack making and teeth brushing. The flexibility of its current structure already allows such extensions, but

specific errors definitions will have to be defined and integrated. Another issue that will be tackled is the granularity of the actions the TM analyses. Indeed, we would like to deal with actions that are at a lower level of hierarchy. For example, we would like the TM to understand that if the patient fails adding an ingredient it is because an object is hold with a wrong grip, or because he/she fails other complex dexterous movements. Beyond these examples, numerous challenges remain such as the amount of human supervision needed by CogWatch.

Currently, when used with real participants, a clinician supervises CogWatch. This allowed us to make the assumption that the observations made by the AR of the user's state are always correct. As our goal is to have a fully automatic assistive device with as little human supervision as possible, in the next prototypes we will have to take into account the uncertainties associated to the AR. Indeed, the AR may misrecognize some actions performed by the user during the task, which means that the observations of the user's state received by TM might not be true all the time. Such uncertainties are inevitable, and as a MDP-based Task Model cannot cope with them, a solution will be to replace the MDP with a Partially Observable MDP (POMDP) [10] that can accommodate uncertainties in the state space. So, when the AR will output an observation, instead of choosing a strategy based on the most probable state, a POMDP-based TM will base it on a probability distribution over all states. In the context of a fully automatic system, we believe that such enhancements will permit obtaining a more accurate representation of the environment, and a more robust guidance under uncertainty.

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References

[1] Liepmann H. Drei Aufsätze aus dem Apraxiegebiet. Berlin: Karger; 1908.
[2] Schwartz MF, Reed ES, Montgomery M, Palmer C, Mayer NH. The quantitative description of action disorganization after brain-damage: a case-study. Cogn Neuropsychol. 1991;8(5):381-414.
[3] Hermsdorfer J, Bienkiewicz M, Cogollor JM, Russel M, Jean-Baptiste E, Parekh M, Wing AM, Ferre M, Hughes C. CogWatch - Automated Assistance and Rehabilitation of Stroke-induced Action Disorders in the Home Environment. HCI Aspects of Optimal Healing Environments. 2013;8020(2):343-350.
[4] Levinson R. PEAT : The planning and execution assistant and training system, Journal of Head Trauma Rehabilitation. 1997;12(2):769-775.
[5] Modayil J, Levinson R, Harman C, Halper D, and Kautz H. Integrating Sensing and Cueing for More Effective Activity Reminders. AAAI Fall 2008 Symposium on AI in Eldercare: New Solutions to Old Problems; 2008.
[6] Levine S, Kirsch N. Cogorth : A programming language for customized cognitive orthoses, Proceedings of the Rehabilitation Engineering Society of North America (RESNA); 1985.
[7] Mihailidis A, Fernie G, Barbenel JC. The use of artificial intelligence in the design of an intelligent cognitive orthosis for people with dementia. Assistive Technology. 2001;13(1):23-39.
[8] Puterman M. Markov Decision Processes: Discrete Stochastic Dynamic Programming. In: John Wiley & Sons, Inc; 1994.
[9] Hughes CM, Baber C, Bienkiewicz M, Hermsdorfer J. Application of human error identification (HEI) techniques to cognitive rehabilitation in stroke patients with limb apraxia. Access in Human-Computer Interaction. Applications and Services for Quality of Life. Springer Berlin Heidelberg; 2013.
[10] Williams JD, Poupart P, Young S. Factored partially observable Markov Decision Processes for dialogue management. Computer Speech and Language. 2005; 21(2):393-422.
[11] Levin E, Pieraccini R, Eckert W. A stochastic model of human machine interaction for learning dialogue strategies. IEEE Transactions on Speech and Audio Processing. 2000;8(1):11-23.

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Enabling Person-Centric Care using Linked Data Technologies

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Abstract. Patient-Centric Care requires comprehensive visibility into the strengths and vulnerabilities of individuals and populations. The systems involved in Patient-Centric Care are numerous and heterogeneous, span medical, behavioral and social domains and must be coordinated across government and NGO stakeholders in Health Care, Social Care and more. We present a system, based on Linked Data technologies, taking first steps in making this cross-domain information accessible and fit-for-use, using minimal structure and open vocabularies. We evaluate our system through user studies.

Keywords. Patient Centered Care, Smarter Care, Information Sharing, Integration

Introduction

Organizations seeking to improve health outcomes and lower costs are facing unique challenges such as aligning care delivery to population needs, creating and managing holistic, individualized care plans and care coordination to produce positive and sustainable outcomes at reduced cost. In [1], it is reported that 5% of individuals face complex issues spanning multiple domains and accounting for 50% of the cost. Identifying these individuals early on is key to reducing costs. The impact of social determinants for health dictates that multi-domain information is needed for holistic and individualized care delivery [2]. Furthermore, coordination across care agencies and stakeholders requires an integrated view of the individual, their vulnerabilities and their environment [3].

The common denominator is the need for *fit-for-use* information spanning *multiple domains*. In general, needs span six core areas: health, food, shelter, safety, education and income. Potential information sources are diverse and numerous (e.g. the American Hospital Association numbers 5724[2] members and the number of homeless shelters surpasses 4000[3]). The complexity of Health Care data is vast and Social Care systems have a very broad scope.

Relevant use-cases are abundant: In a New York hospital, a survey has shown that 9.2 minutes out of a 15-minute doctor's visit were spent on social needs, crowding out clinical care [4] and illustrating that "social context" of individuals is critical in improv-

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[2]http://www.aha.org/research/rc/stat-studies/fast-facts.shtml, retrieved 19/04/2013

[3]http://www.shelterlistings.org/

ing care (for example, consider asthma triggered by sub-standard housing, depression or chemical dependency affecting medication adherence, lack of food impacting diabetes). A single social worker may be responsible for thousands of people [4]. Providing timely, relevant, multi-dimensional and fit-for-purpose information about vulnerability to all care workers is critical.

1. Methods

Typical Health Care data integration approaches use an all-or-nothing model, i.e. data is either part of the (mediated) model or not accessible at all [5]. We argue that this is unrealistic in the Care Coordination domain and propose a Linked Data-based approach, in which a *minimal model is used to provide a high-level navigation structure* and users are able to *further explore* the entire data space, adapted to user expertise. We concede that a shared model capturing all information that needs to be shared is unrealistic. We develop an approach relying on *readily available vocabularies or ontologies* and a *navigational model* for minimal integration. We use *exploration* to access the rest of the information, based on this model. In addition, information is made *fit-for-use* across specialist domains by exploiting domain ontologies, published as open data.

1.1. Vocabularies and Ontologies as drivers for integration

Given that we do not develop a full model for the data to be exchanged, or at least a single centralized model, how do we effectively retrieve and process relevant data? In our approach, we rely on a set of *reference ontologies*, acting as integration points across systems and providing context for users, although we make little use of their formal semantics. In general, these ontologies should have good coverage of the domains (e.g. health, social services, homelessness), but we do not expect them to be fully integrated or to cover the full spectrum of the information exchanged. In addition, re-using existing ontologies reduces both the development and integration cost. Some examples of the ontologies/taxonomies we have used are WSG84[4] and the Time Ontology[5] for spatiotemporal representation, the human disease ontology[6], FOAF and VCARD for basic personal information, the family ontology [6], the social care subject taxonomy[7] as well as ontologies derived from HL7.

1.2. Minimal model-driven presentation

Although reference models are enough to provide basic linking of information, they make information consumption challenging, since they do not capture the relative importance of various pieces of information or the user task, as we will also show in our evaluation. On the other hand, a presentation layer, such as a collection of views that can be rendered on the screen, would nullify any advantage of not having a rigid, central model and would essentially reduce the addressable information space to what is covered by those views. We propose using a business rule-like structure to unify models and help users quickly assess the severity and navigate through vulnerabilities of individuals. Such a structure can be seen in Figure 1. At the top level, we have a logical model, consisting, in this case, of a hierarchy of weighted factors contributing to an individual's vulnerability. Each node on top is connected by means of SPARQL queries to the Semantic Layer

[4] http://www.w3.org/2003/01/geo/
[5] http://www.w3.org/TR/owl-time/
[6] http://disease-ontology.org/
[7] http://www.scie.org.uk/publications/misc/taxonomy.asp

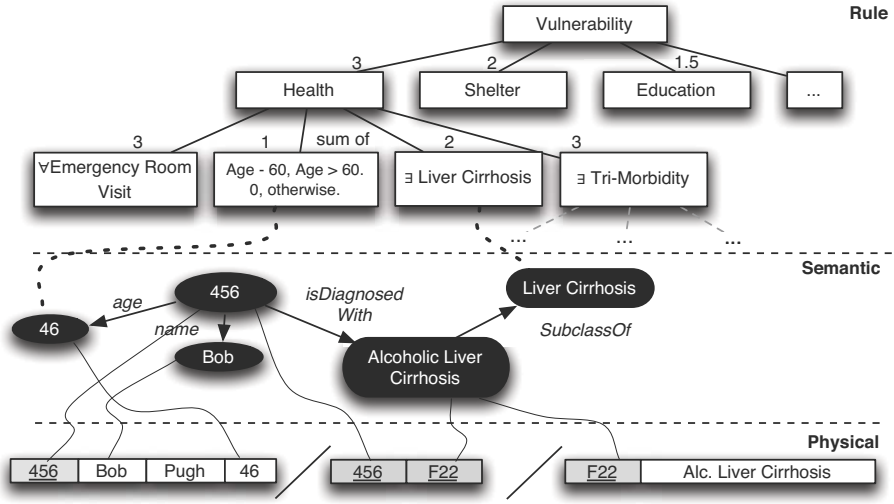


Figure 1. Example model for vulnerability

in the middle. The Semantic Layer abstracts from the representation of the information in the source systems (systems for Social Care, EHRs etc). We elaborate using Figure 2:

Conciseness. The structure shown on Figure 2(α) shows a concise navigational structure of the vulnerabilities of an example individual. The circles represent the relative importance of the vulnerabilities in a set of dimensions that are deemed important in the domain of the user (in this case, a multi-disciplinary team worker). Clicking on a circle expands it so as to display its contributing factors. In this way, the user gets an immediate impression of the key weaknesses of an individual (in this case, it would be problems regarding Health and Food) and retains the capability to explore further (in this case, the user has chosen to expand on the main factors affecting income).

Exploration. Our reference ontologies and navigation structure do not cover the entire information space, since we impose no restriction to the models used by each organization. To get more fine-grain information, an exploration pane (Figure 2(β)) is used to navigate the entire space, based on the Linked Data structure and potential ontology overlap. In the example, the user can see that the individual is receiving child benefit amounting to 170 euros weekly. In addition, it displays relevant information from Linked Open Data, such as complicating factors for diseases (not shown in example).

Fitness-for-use. Specialist knowledge inhibits information consumption across domains. For example, although *Pica Disease* may be the most appropriate term to describe a condition to a physician, it has little fitness-for-use for a social care worker. For the latter, the super-class *Eating Disorder* is more useful. In our system, based on the clicks of each user group when exploring data, we adapt the terminology presented by default (not shown in example).

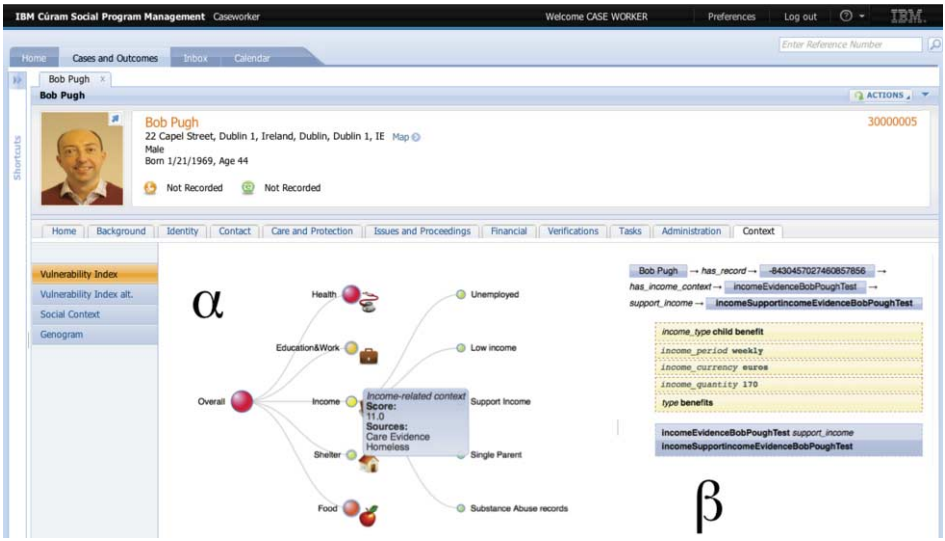


Figure 2. User interface for navigation and exploration

1.3. Realization and Deployment

We developed a prototype implementation on top of enterprise IBM systems for Social Care and Health Care. The IBM Cúram Social Program Management Platform[8] is a business and technology solution that delivers prebuilt social program components, supporting users from multiple disciplines. IBM software Patient Care and Insights[9] integrates and analyzes patient information providing information such as care plans, risk assessment and clinical summaries. We have integrated information from the above systems, along with Open Data sources and other data (e.g. information typically managed by a homeless shelter), for a total of 3 relational databases (some enterprise systems have multiple databases), 1 non-relational database, 1 RDF data source and 12 ontologies.

2. Results

We have performed a user study to evaluate the time required to get a business result. We use a standard Web-based exploration tool for RDF[10] as a baseline, also addressing the entire information space (i.e. using the same input). Table 1 shows a set of questions, taken from an actual intake for coordinated care, for general vulnerability and risk of homelessness. Also shown is the average time to retrieve an answer using our system and the average time to retrieve an answer using the baseline Web-based RDF exploration tool, using a randomized question order. Results for one-way ANOVA ($F(1,104)=8.366, p=0.005$) for 10 respondents indicate a statistically significant difference. The baseline system took 54.1% more time to retrieve an answer than our system, on average. The number of clicks was comparable while, for the baseline, on 3 occasions the user gave an incorrect answer and on 3 more they gave up without giving an answer. We note that our models and system have in no way been adapted for the particular tasks.

[8] `http://www-03.ibm.com/software/products/en/social-programs/`
[9] `http://www-01.ibm.com/software/ecm/patient-care/`
[10] http://wifo5-03.informatik.uni-mannheim.de/pubby/. Deployed on the same platform as our approach.

ID	Domain	Question	Baseline	Ours
A1	Employment	When did you last work?	51 *sec*	**43** *sec*
A2	Education	What is the highest level of education completed?	85 *sec*	**32** *sec*
A3	Income	What type of services is your family receiving?	76 *sec*	**40** *sec*
A4	Housing	What is your current housing situation?	**37** *sec*	51 *sec*
A5	Substance abuse	Have you ever had a problem with alcohol or drugs?	**42** *sec*	51 *sec*
A6	Physical health	Do you have any health or medical conditions?	157 *sec*	**42** *sec*
B1	Housing	What is your primary reason for homelessness?	41 *sec*	**15** *sec*
B2	Housing	How long have you been living on the street?	**32** *sec*	46 *sec*
B3	Child Welfare	Do you currently have children in foster care?	70 *sec*	**62** *sec*
B4	Mental health	Do you have emotional, personal problems or stress?	30 *sec*	**19** *sec*

Table 1. Intake questions. A1 to A6 refer to vulnerability, B1 to B4 refer to homelessness.

We show in isolation that adapting terminology yields improved results for the user. We start from a condition in the Human Disease Ontology, and ask the user whether they are familiar with the term. If not, we select the more generic condition (i.e. the parent in the hierarchy of diseases) and repeat. For 10 non-specialist users (with a computer science background), and 21 distinct terms, there was user agreement on what the understandable term is in 120 out of 210 observations. As a consequence, adapting the original term to the most identifiable term means that 57% of the time, users would immediately identify the term. When we do not, the corresponding percentage was 21%.

3. Discussion

We have shown some first steps towards information sharing for Person-Centric Care across highly diverse and challenging domains, using Linked Data. Our results show that we can address the same information space as a generic graph exploration approach while reducing the time to reach a business result. To put our results into context, consider the study reporting that 9.2 minutes were spent on social needs in each doctor's visit [4].

There are many remaining challenges in the area. Although current practice in Care Coordination follows a blanket consent model (i.e. persons need to agree to share all their data across care agencies), privacy and consent management is a challenging and exciting direction. In addition, better exploration interfaces that hide the complexity of the RDF graph, yet remain generic, are needed. User context (e.g. location) can be taken into consideration and the context captured by our system can be used as input for analytics.

References

[1] Conwell LJ, Cohen JW. Characteristics of persons with high medical expenditures in the US civilian non-institutionalized population, 2002. Medical Expenditure Panel Survey, Agency for Healthcare Research and Quality; 2005.

[2] Marmot M, Wilkinson R. Social determinants of health. Oxford University Press; 2009.

[3] Kodner DL, Spreeuwenberg C. Integrated care: meaning, logic, applications, and implications–a discussion paper. International journal of integrated care. 2002;2.

[4] Onie R, Farmer P, Behforouz H. Realigning health with care. Stanford Social Innovation Review. 2012;10:28–35.

[5] Nodine M, Hee A, Ngu H, Bohrer W. Semantic Brokering over Dynamic Heterogeneous Data Sources in InfoSleuth. In: ICDE; 1999. .

[6] Stevens R, Stevens M. A Family History Knowledge Base Using OWL 2. In: OWLED; 2008. .

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Nutritional Alert in hospitalized patients

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Abstract. The objective of the study is to assess a nutritional risk alert using an Informatics System in hospitalized patients versus the conventional methodology. Method: we studied 400 medical patients at the Belgrano Hospital Critical Care Unit. We considered two groups of 200 patients. In the first the group (Control Group), nutritional risk was diagnosed in a traditional way. In the second group (Alarm Group), nutritional risk was diagnosed with an alert system. The alert was triggered when a patient showed low levels of, at least, two of the following variables: albumin, cholesterol, triglyceride, lymphocyte or low body mass index (BMI). Results: nutritional risk was detected in 20.3% of the Control Group patients while, in the Alert Group, nutritional risk was detected in 34.3% of the patients; the difference between the two groups was significant ($p<0.001$), with a sensitivity rate of 99% and a specificity rate of 98%.Conclusion: malnutrition is more easily detected when using an alert system.

Keywords. Malnutrition in hospital, HL7,Alert, Informatics System

Introduction

Malnutrition prevalence upon hospital admission is higher than generally believed. The prevalence rate of malnutrition problems in intensive care is approximately of 30%, out of which 70% is undiagnosed. [1], [2].[3] Malnutrition increase morbidity. This, in turn, results in longer hospitalizations. Hospitalized patients are subject to stress, infections and organic dysfunctions. [4],[5] Physicians in critical care units usually neglect nutritional aspect of patients. They tend to focus on the major disease. [6],[8],[9].
Hospital costs incurred for malnourished patients are 60% higher than those incurred for patients in good nutritional condition [10]. Bernstein and Col showed that the lack of a timely nutritional intervention may cost approximately U$S 500,000 on a yearly basis [11].

1. Methods

Objective: The objective of this work is to prove that an alert is a helpful tool for doctors to better detect malnourishment in hospitals. This was a randomized experimental design work with a control group. This research was carried out over a 1-year time span where patient data were gathered in a sequential manner. For this study we worked with two groups of patients: one was the control group and the other was the one in which an alert was applied.Though all the doctors were informed about the

study beforehand, both groups of doctors who assisted these patients performed their tasks in the habitual way during the study, and just the doctors who assisted patients who were in alert intervention were informed if patients had two variables (albumin, cholesterol, triglyceride, lymphocyte) or BMI under normal values. The data for this study were collected in the Intensive care unit of Belgrano Hospital. The 8-bed critical care unit is staffed by 10 physicians and 20 nurses. The average patient discharge was 32 patients on a monthly basis. The sample bottom line was established in 323 patients.

We selected 400 patients at the Belgrano Hospital Intensive Care Unit who were hospitalized from September 2011 until September 2012. These patients were categorized in two groups through a routine random number generation. These two groups were called Control Group and Alert Group. In the first one, nutritional risk was detected with the traditional way whereas in the latter, nutritional risk was detected with the help of an automatic alert system. (See Figure 1)

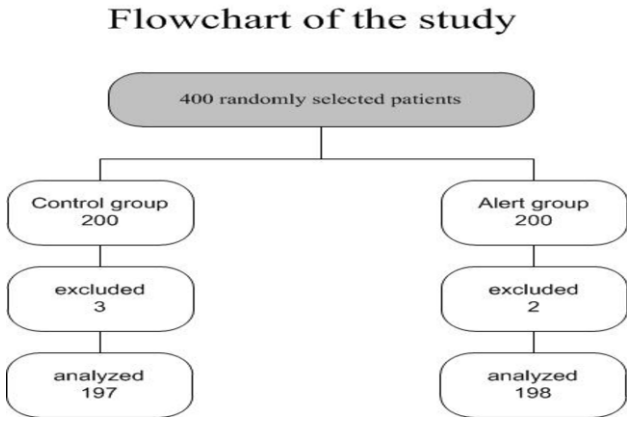


Figure 1: Flowchart of the study.

The Gold Standard was created by a committee of experts who analyzed retrospectively all the information available in the medical records in order to determine whether the patients of both Groups were malnourished or not. **Inclusion criteria**: patients who had albumin, cholesterol, triglyceride, lymphocyte and body mass index (BMI) tests done. Deceased patients were also included. **Exclusion criteria**: patients who did not have lab and BMI tests done were excluded from this study. The Informatics System is a standard supported by Health Level Seven International (HL7). The alert is triggered when a patient shows low levels of, at least, two of the following variables: albumin, cholesterol, triglyceride, lymphocyte or low body mass index (BMI). The Alert engine feeds data in from the Laboratory Information System (LIS) and from the Health Information System (HIS). When the alert is triggered a warning message displays on the HIS system screen.

2. Results

The average age of the study population of both samples was 67.05 years old, with a maximum of 96 and a minimum of 22 years old (see table 1). The rate of male population in the study was 45.03 % and female, 54.70 %.

Table 1 – population

	Alert	Control	Both
Total	200	200	400
Age max	**96.00**	90.00	**96.00**
Age min	34.50	**22.00**	**22.00**
Age rate	67.34	66.76	67.05

Nutritional risk was detected in 34.3 % of the Alert group patients while, in the Gold standard, nutritional risk was detected in 33.8 % of the patients, a non-significant difference between the two groups, as shown in Table 2. The sensitivity was 0.99 and the specificity was 0.98, as shown in Table 3.

Table 2 – Results Alert group

	Alert	Gold St
Total	198	198
Undetected nutritional risk	130	131
Detected nutritional risk	68	67
% N Risk	34.3	33.8

Table 3 – Results

	Alert	true	false
Undetected nutritional risk	130	129	1
Detected nutritional risk	68	66	2
Sensitivity	0.99		
Specificity	0.98		

Nutritional risk was detected in 20.3 % of the Control Group patients while, in the Gold standard, nutritional risk was detected in 32 % of the patients; the difference between the two groups was significant ($p<0.001$) as shown in Table 4. The sensitivity was 0.62 and the specificity was 0.82 shown in Table 5.

Table 4 – Results Control group

	Control	Gold Standard
Total	197	197
Undetected nutritional risk	157	134
Detected nutritional risk	40	63

Table 5 – Results Control group

	Control	True	False
Undetected nutritional risk	157	128	39
Detected nutritional risk	40	39	1
Sensitivity	0.62		
Specificity	0.82		

In our work malnutrition was more easily detected in patients who were controlled with an alarm system (34.3%) than in those patients who were not (20.3%). The difference between the two groups was significant ($p<0.001$) as shown in Table 6.

Table 6 – Comparative results of the Alert and the Control Groups

	Alert	Control
Total	198	197
Undetected nutritional risk	130	157
Detected nutritional risk	68	40

3. Discussion

Results have shown that the nutritional risk alert we built was of significant help. The rate of malnutrition detection was lower in the group with no alert system than in the group with an alert system (34.3% versus 20.3%) (See table 6). The alert had a high sensitivity and specificity and this fact helped doctors to diagnose malnutrition (See table 3). However, there was a bias in our method: Control Group doctors knew that we were carrying out a research on the nutritional status of patients in the unit and that they were being monitored. This might have affected their behavior and, consequently, the outcome of this research. Malnourishment in hospitalized patients is often undiagnosed. In spite of the fact that there are well-developed scores to detect hospital malnourishment, we belief that alert systems based on medical knowledge might be a great help. After a thorough research, we have not found precedents of this tool being used in the healthcare industry. In the area of intensive care at our Hospital we observed malnutrition was higher than we thought, so we considered some strategies to find a method to avoid this problem. Many times doctors worry about certain pathology a patient in hospital may have and they underestimate some aspects as nutrition or feeding. We think clinical alerts are useful to solve specific problems in a certain area, for a specific group of professionals or in a certain point in time. We think they cannot be used without any control. For example, in our hospital, intensive care physicians did not pay great attention to nutritional aspect of patients and the alert was useful for this.

After some time doctors learn to do it and they do not need alerts anymore. We think diagnosis problem of under nutrition does not exist in other areas as in the nutrition or in the pediatric departments, because physicians in those services pay more attention to this aspect in patients. For this reason we think alerts in electronic reports do not need to be applied to all services and physicians. We designed a study on nutritional alerts using interfaces with electronic and laboratory reports to collect information which allows to register an alert on a possible malnutrition. In our study we observed that this kind of clinical alert makes the physician think of possible malnutrition and diminish that possibility of the patient's malnourishment. We think it is very important to use alerts, and in our study we managed to show their usefulness: physicians using alerts could diagnose more problems than the ones without them. We highly recommend paying attention to the systems design: it is important to be careful in overabundance of alerts in electronic clinical reports because the excess of information generates frustration in doctors who may skip reading some useful information.

References

[1] Fetter RB, Shin Y, Freeman JL, Averill RF, and Thompson JD. Casemix definition by diagnosis-related groups. Med Care 18 (2 Suppl), (1980), 1-53.
[2] Zadeh LA. Is probability theory sufficient for dealing with uncertainty in AI: a negative view. In: Kanal LN and Lemmer JF, eds. Uncertainty in Artificial Intelligence. Amsterdam: Elsevier, (1986), 103-116.
[3] Weed L. Medical Records, Medical Education and Patient Care. 2nd ed. Cleveland: Case Western Reserve University Press, 1971.
[4] Strunk W, White EB, and Angell R., Elements of Style. 4th ed. New York: Allyn & Bacon, 1999.
[5] University of Chicago Press Staff. The Chicago Manual of Style. 15th ed. Chicago: University of Chicago Press, 2003.
[6] Mike Lean, Martin Wiseman, Malnutrition in hospitals BMJ (2008), 290-336.
[7] Gabriel Ricardo Monti, Desnutrición hospitalaria: una patología subdiagnosticada, Revista de la Asociación Médica Argentina, Vol. 121, Número 4, (2008), 20-22.
[8] Baccaro F, Sánchez A., Determination of hospital malnutrition: a comparison between the subjective global assessment and body mass index, Rev Gastroenterol Mex. (2009),105-109.
[9] Correia MI, Waitzberg DL., The impact of malnutrition on morbidity, mortality, length of hospital stay and costs evaluated through a multivariate model analysis. Clin Nutr (2003), 235-239.
[10] Kruizenga HM, Van Tulder MW, Seidell JC, et al.: Effectiveness and cost-effectiveness of early screening and treatment of malnourished patients. Am J Clin Nutr 82 (2005),1082-1089.
[11] Bernstein LH, Shaw-Stiffel TA, Schorow M, et al.: Financial implications of malnutrition. Clin Lab Med 13 (1993), 491-507.

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Online Information Seeking for Cardiovascular Diseases: A Case Study from Mayo Clinic

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Abstract. The objective of this study is to understand the types of health information (health topics) that users search online for Cardiovascular Diseases, by performing categorization of health search queries (from Mayoclinic.com) using UMLS Metamap based on UMLS concepts and semantic types.

Keywords. Health Information Seeking, Search Log analysis, UMLS Metamap

Introduction

Since early 2000, Internet literacy and the number of Internet users have increased significantly, including using the Internet for health information[1,2]. According to the latest 2013 Pew Survey[2], one in three American adults have gone online to find out information about a medical condition. One of the most common ways to seek online health information is via Web search engines, such as Google, with approximately 8 in 10 online health inquiries originate from a search engine[2]. Since cardiovascular disease (CVD) is one of the most common chronic diseases[3], in this work we perform a categorization of CVD-related queries into selected health categories to understand the types of information related to CVD sought by Internet users.

This study provides a better understanding of what Online Health Information Seekers (OHIS) search for and gives us better insights into their health information needs. Such information can empower us with knowledge to improve the health search experience as well as to develop advanced knowledge and content delivery systems. Previous studies have used different approaches for the classification of health search queries based on diverse categorization objectives[4-6]. This study distinctively uses a semantic approach to understand "consumer oriented" health categories for CVD-related searches. With data from MayoClinic.com[7], we categorized 10 million CVD queries into 17 health categories using UMLS Metamap[8] based on UMLS concepts and semantic types. As per our study, 'Vital Signs', 'Symptom', 'Treatment', 'Drugs and Medications', 'Diet', and 'Cause' are the top health categories that users search for concerning CVD. We also identified that 80% of the CVD search queries are categorized into either one or two health categories.

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1. Methods

1.1. Data Source and Dataset Creation

In this study, we collected CVD-related search queries that direct an OHIS from Web search engines to the Mayo Clinic's consumer health information portal[7], which is one of the top online consumer-centric health information portals in the US. Our recent Web analytics statistics indicate that the MayoClinic.com portal is on average visited by millions of unique visitors every day. The MayoClinic.com Web Analytics tool (IBM Netinsight on Demand) keeps detailed information about web traffic such as input search query, time of visit, and landing page. MayoClinic.com has several CVD-related webpages that are organized by health topics and disease types. Using the Web Analytics tool, we obtained 10 million CVD-related anonymized search queries originating from Web search engines that "land on" CVD webpages within MayoClinic.com and are related to CVD. These queries are in the English language and were collected between September 2011-August 2013. Our final analysis dataset consists of 10,408,921 search queries.

1.2. Data Analysis

Mapping of search queries to UMLS: We performed a semantic analysis of health search queries by mapping all the search queries from the dataset to UMLS concepts and semantic types using UMLS Metamap[8]. Metamap is a tool for recognizing UMLS concepts in text. For a given search query, Metamap identifies one or more UMLS concepts, their semantic types, concept unique identifiers (CUIs), and other details. For example, 'Symptoms of heart attack' is mapped to the 'Symptom' and 'Heart Attack' concepts, and 'SOSY' and 'DSYN' semantic types. Refer to Table 1 for semantic type abbreviations used in this paper.

Selection of health categories: There are many possible health categories of interest. In this work, based on empirical evidence we selected 17 health categories **(Table 1)** that are more "consumer oriented" as well as can reveal details about what OHISs generally search for in the context of CVD. While selecting the health categories, we also considered 1) the health categories on popular health websites (Mayo Clinic, WebMD, etc.), 2) the types of information mentioned along with CVD search queries such as vital signs (blood pressure, heart rate), quantitative measurements (blood pressure readings, medication dosage), age groups (infants, adult, elder), and 3) the most frequent semantic types that surfaced from a semantic analysis of the CVD query log dataset using UMLS Metamap. Note that there can be possible overlaps between some health categories, for example 'Drugs & Medications' can be considered as part of 'Treatment', but in our analysis we considered both as separate health categories in order to study search traffic for each topic separately.

Categorization Approach: After mapping CVD queries to UMLS, we categorized the search queries into 17 different health categories as following:

1) UMLS has 140 semantic types and some of them directly mapped to health categories that we selected; for example, 'AGGP' (Age-group) semantic type is directly mapped to the 'Age group' category. In this case, we categorized all the search queries with semantic type 'AGGP' into the 'Age group' category.
2) For a few health categories ('Test & Diagnosis') we utilized multiple semantic types ('DIAP','LBPR','LBTR'). In this case, we categorized all the search queries

with at least one semantic type ('DIAP', 'LBPR', 'LBTR') into 'Test & Diagnosis' category.

3) For a few health categories ('Food & Diet'), certain concepts that are closely associated with the health topic are not mapped to the selected semantic type. In such cases, we utilized both semantic types and well as semantic concepts for categorization. For example, the 'FOOD' semantic type does not include concepts such as 'meal', 'menu', 'diet', 'recipe', 'lunch', etc. as they are not actually food items. We categorized all the search queries that have a 'FOOD' semantic type or at least one concept ('menu', 'diet', 'recipe', etc.) into a 'Food & Diet' category.
4) For a few health categories (e.g., 'Cause') there are no directly associated semantic types. In such cases, we utilized semantic concepts associated with search queries. For example, we categorized all the search queries which have either 'Cause' or 'Reason' semantic concepts into the 'Cause' category.
5) For 'Living with' and 'Side effect' health categories, apart from semantic concepts, we also considered the presence of keywords ('Living with' and 'Side effect') within the search query as 'Living with' is not a concept in UMLS and we found that few search queries with side effects are not mapped to 'Side effect' concept.

A search query can be categorized into zero, one, or more than one health category depending on the mapping of the query to UMLS concepts and semantic types. While selecting semantic types and concepts for a health category we considered their frequency in the dataset and their scope. We manually evaluated search queries in each categories and added/removed some semantic types and concepts. We performed several iterations evaluating the semantic type/concepts for each category and we defined the categorization scheme **(Table 1)**.

Table 1. List of health categories and their respective UMLS semantic types/concepts used categorization. **Abbreviations**: SOSY-Signs and Symptoms, ORCH-Organic Chemical, PHSU- Pharmacologic Substance, TOPP- Therapeutic or Preventive Procedure, FTCN-Functional Concept, CNCE-Conceptual Entity, DIAP-Diagnostic Procedure, LBPR-Laboratory Procedure, LBTR- Laboratory Test Result, FOOD-Food, MEDD-Medical Device, DSYN-Disease or Syndrome, QNCO-Quantitative Concept, AGGP-Age Group, TMCO-Temporal Concept, Ref- Reference

Health categories	UMLS Semantic Types (**ST**), UMLS Concepts (**CC**) and Keywords (**KW**)	**Examples Search Queries**
Symptom	**ST**: SOSY **CC:** symptoms, signs, Heart murmur	Stroke symptoms
Cause	**CC**: cause, reason	Stroke cause
Risk-Complication	**CC**: risk, complications	Stroke complications
Drugs and Medications	**ST**: ORCH|PHSU, CLND, PHSU **CC**: medication, medicine, drugs, dose, dosage, remedy, tablet, pill	aspirin, Tylenol, blood pressure medication
Treatment	**ST**: TOPP, FTCN(treat*, surgery), CNCE(treatment)	Stroke treatments
Test & Diagnosis	**ST**: DIAP, LBPR, LBTR	Echocardiogram
Food and Diet	**ST**: FOOD CC**:** caffeine, recipe, meal, menu, diet, eat, breakfast, lunch, dinner, alcohol	heart healthy recipes, alcohol blood pressure
Living with	**CC:** control, manage, reduce, lower, coping, survive, survival, cure **KW:** living with	Living with high blood pressure
Prevention	**CC:** prevent, Avoidance, low risk	Stroke prevention
Side effect	**CC:** side effect **KW:** side effect	blood pressure medicine side effects
Medical device	**ST**: MEDD	Pacemaker risks
Diseases	**ST**: DSYN, **CC:** arrhythmia, avascular necrosis	Heart failure, Stroke
Quantitative	**ST**: QNCO	blood pressure ranges
Age-group Ref.	**ST**: AGGP	hypertension in children
Body part Ref.	**ST**: BPOC, BLOR	heart ablation
Vital signs	**CC:** blood pressure, heart rate, pulse rate, temperature	Blood pressure
Temporal Ref.	**ST**: TMCO	Morning high blood pressure

2. Results

Table 2. Categorization of CVD search queries into 17 health categories and their percent distribution

Sr. No	Health categories	Total Queries	% Distri-bution	Sr. No	Health categories	Total Queries	% Distri-bution
1	Vital signs	4,824,220	29.09	10	Test & Diagnosis	538,387	3.25
2	Diseases	3,436,391	20.72	11	Quantitative	377,475	2.28
3	Symptom	1,423,663	8.58	12	Living with	370,645	2.23
4	Body parts Reference	1,151,465	6.94	13	Risks and Complications	277,294	1.67
5	Treatment	1,008,587	6.08	14	Temporal Reference	184,055	1.11
6	Drugs and Medications	739,177	4.46	15	Prevention	136,428	0.82
7	Food and Diet	739,045	4.46	16	Age-group Reference	87,929	0.53
8	Medical device	665,484	4.01	17	Side effect	25,655	0.15
9	Cause	599,895	3.62		**Total**	16,585,795	100

Based on **Table 2**, the most popular health category while searching for CVD information is 'Vital signs', which includes search queries related to blood pressure, heart rate, etc. One in every five searches explicitly mentions at least one disease in the search query (such as stroke, heart failure). Other popular health categories that users search for included 'Symptom', 'Treatment', 'Drugs and Medications', 'Diet', and 'Cause'. We observe that many CVD related search queries have reference to body parts (left arm, stomach, heart), medical devices (pacemaker), quantitative measures (blood pressure readings, medication dosage), temporal reference (night, morning), and age-group (infant, child, adult, elders). Although CVD can be prevented with some lifestyle and diet changes, interestingly very few OHISs search for CVD 'Prevention'.

Table 3. A search query can be categorized into one or more health categories. The table shows the distribution of search queries by the number of health categories in which they are categorized.

Number of health categories	Number of search queries	Percentage Distribution		Number of health categories	Number of search queries	Percentage Distribution
0	615,186	5.91		5	20,313	0.20
1	4,746,969	45.60		6	4,376	0.04
2	3,561,248	34.21		7	39	0.0003
3	1,254,924	12.06		**Total**	10,408,921	100
4	205,866	1.98				

Using our categorization approach, we categorized 94% of the search queries, out of 10 million CVD related queries, into at least one health category (Table 3). Most of the queries are categorized into either one (45%) or two (34%) categories (Table 3). Very few CVD queries are categorized into 4 or more categories (2%). Our approach did not categorize 6% of the queries into any health categories. After studying the uncategorized search queries, we found that there are few queries that do not fit into any of the selected 17 categories for example, cardiac surgeon, cardiology mayo, video on cardiovascular, pediatric cardiology, and orthostatic.

3. Discussion

In this study, we categorized 94% of 10 million CVD related search queries into 17 health categories using UMLS Metamap and based on UMLS concepts and semantic types of the queries. We found using Metamap and UMLS concepts/semantic types is a very good approach for categorization of health related search queries as UMLS incorporates a variety of medical vocabularies and concepts, and mapping of each concept to semantic types. For example, using UMLS we can annotate text with a large number of drugs such as aspirin and Tylenol. However one disadvantage in using some UMLS semantic types for categorization is that some undesired concepts (in the context of our customized categorization, not in terms of UMLS concept hierarchy) are included in the semantic type. For example, semantic types 'ORCH/PHSU' and 'ORCH' are associated with the 'Drugs and Medication' category. These semantic types include some concepts that are not considered drugs to a consumer/lay population: caffeine, alcohol, fruit, prevent, etc. At the same time, if we do not consider 'ORCH/PHSU' and 'ORCH' in the drug category then we miss out on important drugs such as aspirin, and Tylenol. Online health information plays a vital role in improving health literacy and help OHIS to make more informed health decisions. Therefore, it is crucial to understand what health topics an online user may search for, as it gives us better understanding about their information needs, which can be utilized to alleviate health information search processes. This study identifies frequently searched health categories for CVD and demonstrates utility of UMLS MetaMap, semantic types and concepts for customized categorizations. The study extends our knowledge about online health information seeking and information needs in chronic diseases and particularly in CVD. Such knowledge can be used to improve Web search engines and do a better organization of health information content on health websites/applications.

Acknowledgement:

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References

[1] Tustin N. The role of patient satisfaction in online health information seeking. *Journal of Health Communication.* 2010;15(1):3-17.
[2] Fox S, Duggan M. Health online 2013. *Pew internet & American Life Project* 2013.
[3] National Center for Health Statistics. Health, United States, 2010: With special feature on death and dying. Hyattsville, MD. 2011.
[4] Cartright M-A, White RW, Horvitz E. Intentions and attention in exploratory health search. *SIGIR* 2011.
[5] Spink A, Wolfram D, Jansen MB, Saracevic T. Searching the web: The public and their queries. *Journal of the American society for information science and technology.* 2001;52(3):226-234.
[6] Dogan RI, Murray GC, Névéol A, Lu Z. Understanding PubMed® user search behavior through log analysis. *Database: the journal of biological databases and curation.* 2009.
[7] Mayo Clinic health information portal http://www.mayoclinic.com/ (Accessed on Feb 3, 2014)
[8] Aronson AR. Effective mapping of biomedical text to the UMLS Metathesaurus: the MetaMap program. *Proceedings of the AMIA Symposium* 2001.

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Virtual Patients in a Real Clinical Context using Augmented Reality: Impact on Antibiotics Prescription Behaviors

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Abstract. The research community has called for the development of effective educational interventions for addressing prescription behaviour since antimicrobial resistance remains a global health issue. Examining the potential to displace the educational process from Personal Computers to Mobile devices, in this paper we investigated a new method of integration of Virtual Patients into Mobile devices with augmented reality technology, enriching the practitioner's education in prescription behavior. Moreover, we also explored which information are critical during the prescription behavior education and we visualized these information on real context with augmented reality technology, simultaneously with a running Virtual Patient's scenario. Following this process, we set the educational frame of experiential knowledge to a mixed (virtual and real) environment.

Keywords. Antibiotics, Antimicrobial Resistance, Guidelines, Virtual Patient, Augmented Reality, Mobile Education

Introduction

Antibiotics have been considered as a determining factor for saving lives and minimizing the suffering of patients for more than sixty years. The widespread inappropriate use of antibiotics provoked the manifestation of antibiotic resistance organisms. Antimicrobial resistance is one of the biggest public health challenges [1]. Previous studies [2]-[5] have shown that combining educational methods and intervention strategies to general practitioners can reduce the antibiotics prescription in the range between 3% and 12% [4],[5]. Developing effective educational methods in the healthcare workers' context could therefore further lower unnecessary prescriptions. Two types of technologies could be appropriate: virtual patients (VPs) defined as "interactive computer simulations of real-life clinical scenarios" [4] and Augmented Reality (AR), a technology that provides the opportunity to computer-generated virtual imagery information to be overlaid onto a live directly or in-directly real world environment in real time [7]. AR bridges the gap between the real and the virtual in a seamless way [8]. AR technology embeds digital artifacts in physical setting. Both of these technologies seem to provide a complementary approach, but interestingly, we

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have found a limited number of studies that have investigated this combined educational method in health care education.

The aim of this study was to design and evaluate an innovative educational method (vpAR) that includes VPs embedded in mobile mediated contextual environment (AR). The hypothesis is that such an educational method would bring the best of both worlds into an effective educational intervention that could optimize the prescription behavior of healthcare professionals. The following research questions were investigated:

- What educational aims are addressed using vpAR?
- What are the technological affordances of vpAR?
- What are the pedagogical affordances of vpAR?

1. Methods

Two research methods were examined for the development of the prototype: the ''Model'' methodology, which focuses on defining an abstract model for a real system [9] and the Design Based Research Methodology (DBR), which informed our study design [10] . We carried out the empirical process in continuous cycles of design and evaluation. The design decisions were justified through theory, formative and summative evaluation and in a close interaction with healthcare practitioners. We conducted the study in the authentic learning environment [12].

1.1. Selection of educational challenges relevant to rational drug prescription and tools for the literature review.

We selected the appropriate educational challenges as following: first we investigated the existing educational processes for improving prescription behaviors, in which the healthcare professionals participated. Next, we reviewed the literature to find learning objectives that have an influence on improving prescription behaviors. For the literature review we used the databases: PubMed, Web of Science, CINAHL, for medical and healthcare material, by using the keywords: resistance, antibiotics, antibiotic education, educational tools in antibiotic education, antibiotic guidelines, antibiotic policies, virtual patients in antibiotic education, clinical pharmacology. For the technological material IEEE and Scopus databases were used. A significant number of papers found by the keywords: mobile, mobile educational tools, augmented reality, mixed reality, augmented reality and education, mixed reality and education, augmented reality integration, contextual learning.

1.2. Pedagogical framework

We reviewed several educational theories to find the best approach for the pedagogical design. Three dominant theories have been reported as relevant in healthcare education: authentic learning [13], situated learning [14] and experiential learning [15]. The theories informed the design iterations.

1.3. Participants and context of the study

We focused on healthcare professionals with prescription experience ≤ 2 years, to reach the recently graduated students that have been in contact with contemporary educational methods. The participants' role was to provide their insights in the design of the research and potential solutions to the educational problems. We used a room at the Medical Simulation Department at Karolinska University hospital, Stockholm as the context of our study. We conducted two ''think aloud'' groups with nine Resident Practitioners.

1.4. Development of the vpAR prototype

The design process aimed at developing the vpAR prototype. The specific characteristics of digital patient were drawn from the typology of Huwendiek [15]. We used Metaio AR platform to develop the digital artifacts and to track the learning context. Metaio platform is based on AREL (Augmented Reality Experience Language) and is structured on a JavaScript binding in combination with XML content.

2. Results

The design based research iterative methodology resulted in three outcomes: the educational challenges that may be addressed using vpAR, the technological and pedagogical designs for the vpAR application.

2.1. Educational aims that may be addressed using vpAR

Table 1 shows the educational goals that are important to address by the combination of VP and AR with a vpAR application.

Table 1. Educational aims that can be targeted with each type of technology

Competency addressed	Educational goal	VP only	AR only	vpAR (VP+AR)
Knowledge	Prescribing antibiotic therapy according to national/local practice guidelines	Clinical Reasoning	Visualization of objects and guidelines real-time	Examination of VP and real-time visualization of related guidelines
Skills	Definitions and indications of empiric/directed therapy vs. prophylaxis	Student's Assessment		VP and object visualization in real context for student's assessment
Attitude	Clinical situations when not to prescribe an antibiotic	Clinical Reasoning		Real-time feedback

2.2. Technological affordances of vpAR



Figure 1. Shows the different components of the vpAR application

Fig. 1 shows the user interface of our prototype, which was deployed in a tablet device. Two trackable drugs were used as markers. Additional information was visualized when the objects scanned by the augmented reality software (Junaio) which was installed in the tablet device. From the prototype's evaluation process it was observed that the user understood completely the process and the educational purposes. The data for the VPs and for pharmacology were unsupervised, anonymized and collected from an IT-system.

The Metaio platform includes the following components that allowed the integration of VPs into augmented reality: XML to load VP data and antibiotic information data; an HTML5 layer to provide a graphical user interface. The user interacts with the VPs and the context by the using the camera (Fig. 1).

2.3. Pedagogical affordances of vpAR

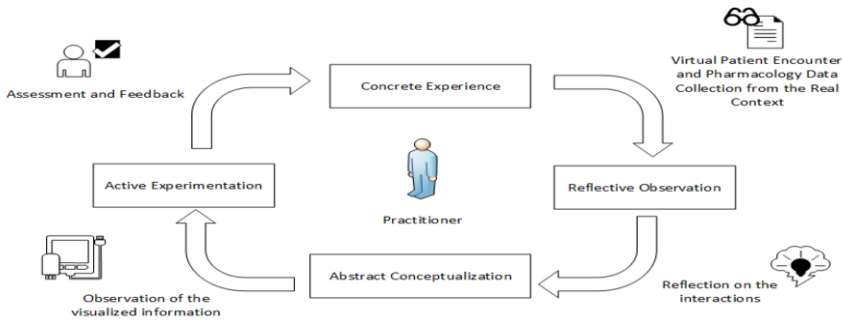


Figure 2. The educational process that is driven in vpAR application

The experiential theory was [15] used as the blueprint for the educational design. *Concrete experience:* The practitioner encounters a VP and collects pharmacology data from the real context. *Reflective observation:* The practitioner reflects on the effects of his interactions. *Abstract conceptualization:* The user runs assessment based on his/her choices and gets feedback; the user also examines the changes of the predicted outcome when we change the variables of VP.

3. Discussion

We presented the vpAR application from the technological and pedagogical perspectives. VpAR is the result of an iterative design based methodology, where the practitioners were involved and combines the best of both modalities. An observed limitation of this prototype is the need to use a tablet device; as AR technology improves, the findings of this study will be instantiated in new solutions (e.g. wearable devices, google glasses) to improve the usability of the interaction. This study needs to extend the research of the educational outcomes that VP and AR provide and explore the educational dynamics of this integration. We plan to conduct more think aloud groups with healthcare professionals to improve the testing prototype and to explore how this solution could be implemented in different medical departments to enrich the educational process of inter-professional skills and behavioral change. Finally, VP scenarios should be created for antibiotics' education, considering the fact that they will be used in real context.

References

[1] Rammanan L, Adriano D, Chand W, Anita M, Zaidi K, Heiman F et al. Long-lasting improvement in general practitioners' prescribing of antibiotics by means of medical audit. Scand J Prim Health Care, 2013; 85-90.
[2] Munck AP, Gahrn-Hansen B, Sogaard P, Sogaard J. Long-lasting improvement in general practitioners prescribing of antibiotics by means of medical audit. Scand J Prim Health Care 17**,** 1999; 85-90.
[3] Butler CC, Simpson SA, Dunstan F, Rollnick S, Cohen D, Gillespie D, et al. Effectiveness of multifaceted educational program to reduce antibiotic dispensing in primary care: practice based randomized controlled trial. BM J 2012;344
[4] Welschen I, Kuyvenhoven MM, Hoes AW, Verheij TJ. Effectiveness of a multiple intervention to reduce antibiotic prescribing for respiratory tract symptoms in primary care: randomized controlled trial. BMJ 2004; 329 - 431
[5] Flottorp S, Oxman AD, Havelsrud K, Treweek S, Herrin J. Cluster randomized controlled trial of tailored interventions to improve the management of urinary tract infections in women and sore throat. BMJ 2002;325- 367.
[6] Cook D, Triola M. Virtual patients: A critical review and proposed next steps. Med Educ. 2009;43:303–11
[7] Azuma, RT. A survey of augmented reality. Presence: Teleoperators and Virtual Environments 1997;6(4):355-85. Cambridge, MA: The MIT Press.
[8] Chang G, Morreale, P, Medicherla, P. Applications of augmented reality systems in education. In D. Gibson & B. Dodge (Eds.), Proceedings of Society for Information Technology & Teacher Education International Conference Chesapeake, VA: AACE.2010; 1380-5.
[9] Amaral JN, Buro M, Elio R, Hoover J, Nikolaidis I, Salavatipour M, et al, About Computing Science Research Methodology 2011.
[10] Pernaa J, Aksela M, Model-Based Design Research: A practical Method for Educational innovations, (ABSRJ) 2013;4:1
[11] Dana H, Dolman M, Tigelar D, ,Building bridges between theory and practice in medical education using a design-based research approach: AMEE Guide No. 60,, Maastricht University, The Netherlands
[12] Gulikers JTM, Bastiaens TJ, Martens R. The surplus value of an authentic learning environment, Computers in Human Behavior, 2005;21:509-21
[13] Rule AC. Editorial: The components of authentic learning, Journal of Authentic Learning 2006;3(1):1-10
[14] Anderson, JR, Reder, LM, Simon HA. Situated Learning and Education. Educational Researcher. 1996;25(4):5-11
[15] Kolb DA, Experiential learning: experience as the source of learning and development. Englewood Cliffs, N.J: Prentice-Hall (1984).
[16] Huwendiek S, de Leng BA, Zary N, Fischer M, Ruiz J, Ellaway R. Towards a typology of virtual patients, Medical Teacher 2009;31:743-48

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8. Quality and Privacy

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Automatic Variance Analysis of Multistage Care Pathways

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Abstract. A care pathway (CP) is a standardized process that consists of multiple care stages, clinical activities and their relations, aimed at ensuring and enhancing the quality of care. However, actual care may deviate from the planned CP, and analysis of these deviations can help clinicians refine the CP and reduce medical errors. In this paper, we propose a CP variance analysis method to automatically identify the deviations between actual patient traces in electronic medical records (EMR) and a multistage CP. As the care stage information is usually unavailable in EMR, we first align every trace with the CP using a hidden Markov model. From the aligned traces, we report three types of deviations for every care stage: additional activities, absent activities and violated constraints, which are identified by using the techniques of temporal logic and binomial tests. The method has been applied to a CP for the management of congestive heart failure and real world EMR, providing meaningful evidence for the further improvement of care quality.

Keywords. Care Pathway, Variance Analysis, Hidden Markov Model, Temporal Logic, Care Quality Improvement

Introduction

A care/clinical pathway (CP) is a complex intervention for the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period [1]. The aim of a CP is to enhance the quality of care by improving patient outcomes and promoting patient safety. A CP may consist of multiple care stages corresponding to different disease progression conditions, where each stage contains various clinical activities such as diagnoses, medications and lab tests, as well as the temporal dependencies and numeric preconditions of the activities.

Although a CP defines a standardized care process for a specific clinical condition, actual care will inevitably deviate from the planned CP [2]. Clinicians may ignore expected activities and violate constraints during actual care. Moreover, new activities that are not defined in the CP can also be executed. Variance analysis is the process of collecting and analyzing these deviations, aimed at evaluating and revising the CP as well as reducing medical errors. However, it is difficult and error-prone for clinicians to report deviations manually [2]. Since electronic medical records (EMR) track the real care progression of patients, a potential improvement for variance analysis is to identify deviations automatically by comparing the medical records against the CP [3].

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It is a challenging problem, however, to detect the deviations for a complex CP with multiple care stages. A clinical activity can be planned in different stages (e.g., ACEI, or angiotensin-converting enzyme inhibitors, are medications targeted at every stage of CHF care) and the stage information is normally unavailable in EMR, which may result in ambiguity of mapping a care event to the activity of the correct stage. An existing solution for CP variance analysis [3] is designed for CPs that can be represented as single directed graphs, without considering CPs with multiple stages. In the neighboring field of business process management, the conformance checking method [4] that can be used to detect deviations is also limited to non-hierarchical process models and cannot distinguish duplicate activities defined in different stages.

In this paper, we address this issue by proposing a variance analysis method to identify the deviations for a multistage CP. Given a CP and a set of patient traces from EMR, we first create a hidden Markov model (HMM) from the CP, with the purpose of annotating each care event with a stage. From these aligned patient traces, we statistically examine three categories of deviations: additional activities, absent activities and violated constraints, based on the techniques of first-order linear temporal logic (FO-LTL) and binomial tests. The identified deviations can provide valuable information for the further improvement of patient safety and care quality.

1. Methods

In this section, we introduce our CP variance analysis method in detail. The inputs of our method are a CP and patient traces of a cohort in EMR, while the output is a variance analysis report including the deviations. Since there is no agreed standard for modeling a CP [3], we use a general CP representation. Other formats that have the ability to define activities and their relations can be converted to our representation easily. Let A be the universal set of clinical activities, where each activity is defined as a unique string (e.g., a code from a standard terminology, or a use-defined value such as "ACEI"). Then a CP is represented as $M = (A_M, S, \Delta, C)$, where $A_M \subset A$ is a set of CP activities, S is a set of care stages, Δ: $A_M \rightarrow S$ is a many-to-many mapping between activities and stages, and C is a set of constraints (see Section 1.2). In EMR, a care event is represented as $e = (p, a, g, v, t)$, where p is the patient ID, $a \in A$ is the care activity (e.g., "ACEI"), g is the activity type (e.g., "medication"), v is the numeric value (e.g., the drug dose), and t is the occurring time. For a specific patient p, his/her care events can be sorted by t to generate a patient trace $\sigma = \langle e_1, e_2, \ldots, e_l \rangle$. As illustrated in Figure 1, our method consists of two phases: alignment and variance identification.

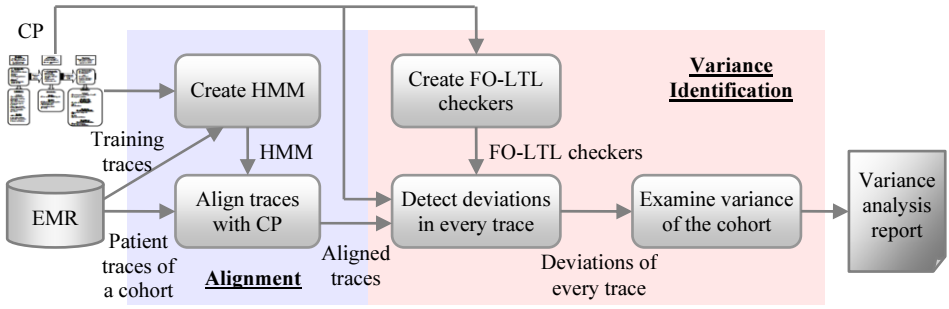


Figure 1. Method flowchart of CP variance analysis

1.1. Alignment between Patient Traces and CP

Notice that the care stage of an event is not available in EMR, and there is a many-to-many mapping between activities and stages in a multistage CP. In order to identify the deviations, we must first decide when an event matches one of alternative stages. Furthermore, in real patient data, many events that are not defined in the CP may occur frequently. The care stages of these additional events should also be determined. This ambiguity cannot be resolved correctly by independently annotating each event. To address the problem, we use a HMM [5] to model the stage transitions of a CP, by which a globally optimal stage sequence can be found for a given patient trace.

The structure of HMM for variance analysis is derived from the CP. We first create a hidden state for each care stage $s \in S$, and an observation for each activity $a \in A_M$. As new activities that are not defined in the CP can be observed in patient traces, we also create an "additional" observation for each activity type (e.g., "Additional medication"). The probabilities of the HMM are initially assigned according to the CP, where the start probabilities $P(s)$ and the transition probabilities $P(s'|s)$ satisfy the temporal constraints defined in C, and the emission probabilities $P(x|s)$ conform to the activity-stage mapping Δ. Figure 2 shows an example of HMM, where HTN (hypertension) is defined in both stages and MI (myocardial infarctions) is defined in Stage B.

Based on the HMM structure, each patient trace $\sigma = \langle e_1, e_2, \ldots, e_l \rangle$ is converted to an observation sequence $o = \langle x_1, x_2, \ldots, x_l \rangle$. For every event $e_i = (p_i, a_i, g_i, v_i, t_i)$ in σ, if $a_i \in A_M$ then $x_i = a_i$, otherwise the additional observation for g_i is assigned to x_i. Then we train the HMM using a set of training patient traces, by applying the Baum-Welch algorithm [5]. After training, we can align a given patient trace σ with the HMM by using the Viterbi algorithm [5], which finds the most likely sequence of care stages $\tau = \langle s_1, s_2, \ldots, s_l \rangle$ by maximizing $P(s_1) \cdot P(s_2|s_1) \cdot \ldots \cdot P(s_l|s_{l-1}) \cdot P(x_1|s_1) \cdot \ldots \cdot P(x_l|s_l)$.

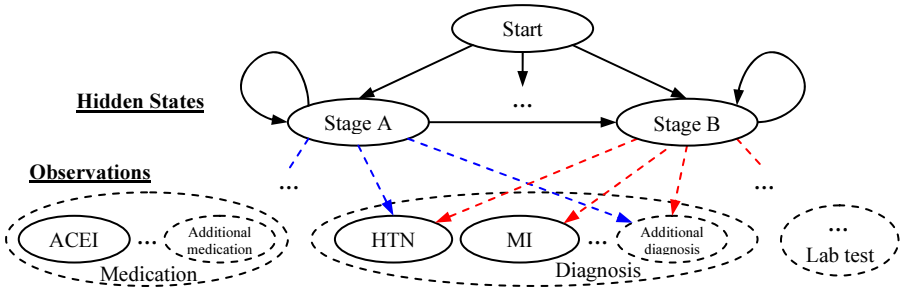


Figure 2. HMM structure derived from a CP

1.2. Variance Identification

Given an aligned patient trace, we can detect three categories of deviations. The first category is additional activities, which are executed in the patient trace but *not* defined in the CP. The second is absent activities, which are defined in the CP but *not* executed in the patient trace. To identify these activity deviations, we first build a null set $A_+(s)$ for every stage s, as well as a set $A_-(s)$ that contains all pre-defined activities in s. Then for each event e_i in the patient trace σ and its annotated stage s_i in τ, if $a_i \notin A_M$ then a_i is added to $A_+(s_i)$, otherwise a_i is removed from $A_-(s_i)$. After the iteration, $A_+(s)$ contains the additional activities for the stage s, while the absent activities remain in $A_-(s)$.

The third category is violated constraints, which are defined in the CP but *not* satisfied in the patient trace. Notice that in a CP, both temporal dependencies and numeric conditions of the activities should be formally represented. For this purpose, we use FO-LTL to define the constraints, which is constructed by combining first-order formulas by temporal and Boolean operators [6]. For detecting the violated constraints, we translate each FO-LTL constraint $c \in C$ into a Büchi automaton B_c [6], which is a non-deterministic finite automaton with an acceptance condition for input sequences. If the patient trace σ cannot be accepted by B_c, then c is a violated constraint for σ. Figure 3 shows an example automaton derived from a FO-LTL constraint, which means that "stop using ACEI if Creatinine (CR) increases to >3.0 (mg/dL)".

Based on the deviations identified in every trace of a patient cohort, we can examine the deviations of the whole cohort. Because deviations occurring by chance alone are less meaningful, we should check whether each deviation is statistically significant for the cohort. Given a deviation δ in the stage s, let n be the number of patients who experienced s, and n_δ the number of patients for whom δ is identified, the support degree of δ is defined as $d_\delta = n_\delta / n$. Then we perform a one-tailed binomial test to check its statistical significance. Since different categories of deviations may have different variabilities, we define a local variance threshold for each category. Let θ be the threshold for the category of δ, and H_0: $d_\delta \leq \theta$ be the null hypothesis. If $d_\delta > \theta$ with p-value < 0.05, then δ is significant for the cohort and will be reported to clinicians.

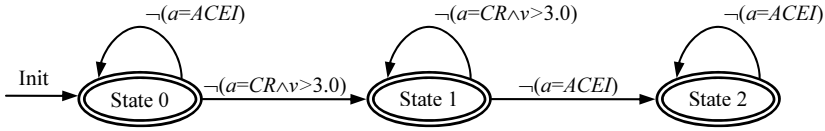


Figure 3. Büchi automaton for "$\forall a, v.\ \Upsilon((a=ACEI) \rightarrow \Box((a=CR \wedge v>3.0) \rightarrow \Box(\neg(a=ACEI))))$"

2. Results

In this section we present the details of our experiments on a multistage CP and real world EMR data. The CP is derived from a clinical guideline for the management of CHF [7], including 3 stages, 64 activities (24 diagnoses, 22 medications and 18 lab tests) and 86 constraints among the activities (e.g., the constraint shown in Figure 3). The EMR data contains 134,902 care events (79,966 diagnoses, 35,384 medications and 19,552 lab tests) that have occurred over the course of 4 years, from a cohort of 430 CHF patients with COPD (chronic obstructive pulmonary disease) condition. In the experiment, we set the variance thresholds for additional activities, absent activities and violated constraints to 0.2, 0.9 and 0.2 respectively. Then the three categories of deviations are identified accordingly. The statistics of the deviations is shown in Table 1. Notice that in Stage C, much more additional activities are identified, while pre-defined activities are seldom absent. That is probably because the disease condition of Stage C is more severe and complex, and more interventions were given.

Table 1. Statistical results of the variance analysis

Stage	#Activities	#Constraints	#Additional Activities	#Absent Activities	#Violated Constraints
Stage A	18	28	6	8	15
Stage B	22	28	4	6	14
Stage C	24	30	26	1	16

The analysis of the deviations reveals that, most of the additional activities are relevant to the target condition. For example, the top 10 additional activities (except COPD) in Stage C include: Glucocorticoids (GCs), Bronchodilators, Quinolones and Statins, which are useful medications for treating CHF with COPD; Anemias and Joint disorders, which are possible complications of COPD; and HbA1c, which is usually monitored when using GCs. These deviations are helpful in developing the CP specific to the management of CHF with COPD. Besides, a majority of the absent activities and violated constraints are due to the non-compliance to the pre-defined lab tests. Many indicators planned in the CP were not monitored on schedule. These non-compliance situations could be reported to clinicians to promote the safety and quality of care.

3. Discussion

Variance analysis forms a critical part of the quality improvement cycle for CPs [2]. Unfortunately, healthcare organizations rarely collect and analyze variance data when using CPs due to the difficulty in identifying deviations [2]. This paper proposed a novel approach to automate the process of CP variance analysis, particularly for CPs with multiple stages. Experimental results show that our method has the potential to provide meaningful information for refining CPs and improving care practices.

One limitation of our current approach is that we do not distinguish positive deviations from negative ones in terms of patient outcomes, which may provide additional evidence for further improvement. To address this problem, we are planning to develop an approach to rank the identified deviations according to their correlation with a particular outcome. Another limitation is that the time intervals between adjacent events are not modeled in HMM. The intervals, however, may vary between 0 day and several years, which should be taken into account during trace alignment. A potential improvement is continuous-time HMM, where the transition probabilities are defined as functions of time. Other future work includes run-time CP recommendation, which aims to provide decision support during CP execution, by suggesting new activities or alerting violations according to the results of variance analysis.

References

[1] Vanhaecht K, De Witte K, Sermeus W. The impact of clinical pathways on the organisation of care processes [dissertation]. Belgium: Katholieke Universiteit Leuven; 2007.
[2] Hyett KL, Podosky M, Santamaria N, Ham JC. Valuing variance: the importance of variance analysis in clinical pathways utilisation. Aust Health Rev. 2007 Nov; 31(4): 565-70.
[3] Ainsworth J, Buchan I. COCPIT: a tool for integrated care pathway variance analysis. Stud Health Technol Inform. 2012; 180: 995-9.
[4] de Leoni M, Maggi FM, van der Aalst WMP. Aligning event logs and declarative process models for conformance checking. In: Proceedings of the 10th international conference on Business Process Management; 2012 Sep 3-6; Tallinn, Estonia. Berlin: Springer; 2012. p. 82-97.
[5] Rabiner LR. A tutorial on hidden Markov models and selected applications in speech recognition. Proc IEEE. 1989 Feb; 77(2): 257-86.
[6] De Masellis R, Su J. Runtime enforcement of first-order ltl properties on data-aware business processes. In: Proceedings of the 11th International Conference on Service Oriented Computing; 2013 Dec 2-5; Berlin, Germany. Berlin: Springer; 2013. p. 54-68.
[7] Hunt SA, Abraham WT, Chin MH, Feldman AM, Francis GS, Ganiats TG, et al. ACC/AHA 2005 guideline update for the diagnosis and management of chronic heart failure in the adult. Circulation. 2005 Sep 20; 112(12): 154-235.

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Abbreviations in Swedish Clinical Text - use by three professions

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Abstract. A list of 266 abbreviations from dieticians' notes in patient records was used to extract the same abbreviations from patient records written by three professions: dieticians, nurses and physicians. A context analysis of 40 of the abbreviations showed that ambiguous meanings were common. Abbreviations used by dieticians were found to be used by other professions, but not always with the same meaning. This ambiguity of abbreviations might cause misunderstandings and put patient safety at risk.

Keywords. Abbreviations, health records, dietetic records, ambiguity

Introduction

Abbreviations and acronyms are frequently used in patient records, and become a patient safety risk as many abbreviations are ambiguous [1, 2]. The word abbreviation originates from *brevis*, latin for short, and this is precisely the purpose of abbreviations in several ways. Not only are they quicker to write and read for the professionals using electronic health records (EHRs), they also make the whole text shorter and easier for the reader to overview. Abbreviations in EHRs are often domain specific but can also belong to general language use [3]. There are standard acronyms established in the medical community that can be found in medical terminologies, but often abbreviations are created ad hoc, not following standards, and ambiguous. For English medical abbreviations, a third of the short abbreviations in the UMLS terminology are ambiguous [3]. Furthermore, a word or expression can be shortened in several different ways. These features can depend on subdomains such as specialty or profession.

Interpreting abbreviations and acronyms can be troublesome even for different health care professionals and they are one of the biggest comprehension barriers for patients reading their EHRs [4, 5]. Ambiguous and unexplained abbreviations in patient records can lead to misunderstandings that put patient safety at risk [2]. According to Swedish legislation, the patient record must be understandable for safe health care, and should also enable the patient to follow her/his health care process.

There are not many studies on abbreviations in Swedish EHRs, and for an emerging profession such as dietitians there is almost nothing written about documentation. A categorization of abbreviations is informative when developing

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automated abbreviation detection systems for improved information extraction. The aim of this study was to analyse the use of some abbreviations in clinical text by three professions in Swedish health care; dietitians, nurses and physicians.

1. Methods

Abbreviations from dietetic EHRs were collected by the first author in a dietetic corpus. These abbreviations were used to extract matching abbreviations from EHRs written by three different professions. A sample of these extracted abbreviations were then analysed in their context to study the level of ambiguity.

1.1. Data

The original dietetic corpus consisted of 147 systematically collected notes, about 30 000 words. They were all written by dietitians in 2009-2010 in hospitals and primary care centers in three different counties in central Sweden.[2]

Three subsets from the Stockholm EPR Corpus[3] [6] from the years 2009-2011 were used in this study: dietetic notes (DIET), daily notes written by nurses (NURSE) and radiology notes written by physicians (X-RAY). The total number of words was 9 516 625 (DIET), 13 925 899 (NURSE) and 15 370 134 (X-RAY), respectively.

1.2. Extracting and matching abbreviations

A manual content analysis of the original dietetic corpus was performed by a dietitian, identifying and interpreting all abbreviations found in the 147 dietetic notes. The analysis resulted in a list of 266 abbreviations. The three subsets (DIET, NURSE, X-RAY) were tokenized using Stagger [7], a Swedish tokenizer and part-of-speech tagger. Modifications were made in Stagger in order to properly handle tokenization of the domain-specific abbreviations. Each word was then matched with the list of abbreviations in order to compute the frequencies in each subset.

1.3. Context analysis

In a context analysis of the original dietetic corpus, the abbreviations were classified in different categories depending on their meaning. From the list of 266 abbreviations, 40 abbreviations were selected on the basis of being promising for analysis; either because they were short (1-2 letters) and therefore could be expected to be ambiguous, or because they were highly subdomain specific for dieticians and therefore could be expected to mean something else for the other two professions. For each of these 40 abbreviations, 20 sentences were randomly extracted from each of the three subsets (DIET, NURSE, X-RAY), and read by two of the authors (a dietitian and a physician) taking note of the different meanings. The disambiguated abbreviations were then classified in regards to their meanings, using the same categories as for the original dietetic corpus.

[2] Deemed exempt by the Regional Ethical Review Board in Uppsala

[3] Ethical approval by the Regional Ethical Review Board in Stockholm, permission number 2012/2028 31/5

2. Results

2.1. Frequency analysis

Most abbreviations from the original corpus were found in all three subsets (72%, see table 1). Some abbreviations (8%) were used exclusively by dieticians, almost all concerned food and diet. There was also a small number of abbreviations (n=24) that were not found in the other subsets. Most of these concerned variations of non-standardized general abbreviations, medical assessment and intervention, and food/meals.

Table 1. Frequencies of shared abbreviations, not taking into account that they may be ambiguous. Abbreviations from the original dietetic corpus were matched against DIET, NURSE AND X-RAY.

SEPR Corpora with matched abbreviations	Number of instances	%
DIET + X-RAY + NURSE	191	72
DIET + X-RAY	9	3,4
DIET + NURSE	12	4,5
X-RAY + NURSE	7	2,6
DIET only	21	7,9
X-RAY only	0	0
NURSE only	2	0,8
None (original dietetic corpus only)	24	9,0
total	266	100

2.2. Context analysis of the original dietetic corpus and the three subsets

The classification of the 266 abbreviations in the original dietetic corpus is shown in table 2. Some abbreviations had multiple meanings and therefore five abbreviations were placed in more than one category. Table 2 also shows the classification of the three subsets regarding the analysis of the 40 selected abbreviations, where the abbreviations in the DIET subset more often concerned food and medical assessment or treatment while the same abbreviations in the X-RAY subset more often concerned diseases and body parts.

Almost all of the 40 selected abbreviations had ambiguous meanings, both within and between professions (1-13 meanings, mean 4.3). The abbreviations in the DIET corpus were least ambiguous (mean 1.8 meanings/abbreviation), while the NURSE (mean 2.7) and X-RAY (mean 2.7) subsets showed more ambiguity, figure 1.

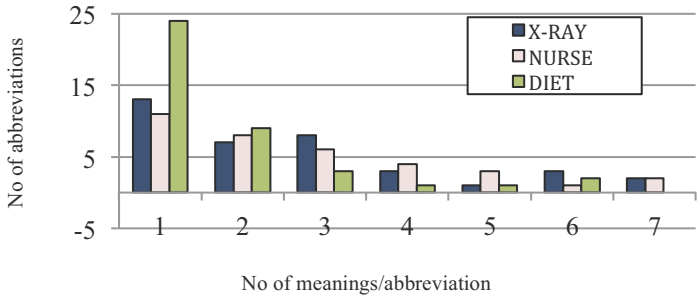


Figure 1. Multiple meanings is manifested for many of the 40 abbreviations for each of the three subsets

Table 2. Categorization of abbreviations found in the original dietetic corpus and the three subsets.

Categories	No of abbreviations				Explanation
	Original corpus (n=266)	DIET (n=40)	NURSE (n=40)	X-RAY (n=40)	
General non-standardized	90	20	27	21	Not classified in any of the specific categories below, non-standardized but common in everyday Swedish
General standardized	12	4	5	6	Found in the Swedish Writing Rules (SWR) [8]
General standardized, punctuation mistakes	25	2	2	1	Found in the SWR, with minor punctual deviations
Food/meals	36	10	8	1	Meals, food and cooking
Medical assessment and intervention	33	13	11	3	Assessment methods and scales, treatments, medicines
Diseases	18	7	6	17	Diseases
Units	17	4	9	8	Length, volume and other units
Institutions/hospitals	16	8	3	3	Names of institutions
Laboratory values	16	3	2	2	Blood lipids, iron status etc
Health care professionals	5	1	1	1	Professions within health care
Body parts	0	0	1	6	Organs and other body parts
Names of persons or products	0	6	8	6	Names of persons or products
Probable spelling mistakes	3	5	13	16	No identified meaning, interpreted as spelling mistake

An example of this ambiguity is the abbreviation “gr” which has in total seven different meanings: gram (*gram*), Celsius degree (*grader*), group (*grupp*), times (*gånger*), angular degree (*grader*), level of disease (*grad*), due to (*p gr a, på grund av*).

A certain expression can have many different abbreviations, and the abbreviations may be dependent on profession, for example six different abbreviations for the disorder Diabetes Mellitus were found in the three subsets (table 3). While dietitians and physicians used different abbreviations for the two main types of the disorder, nurses predominantly used “diab”. There may be other abbreviations specific for nurses and physicians, e.g. DM 1 and DM 2, not found in this analysis.

Table 3. Frequencies of abbreviations for different expressions of the disorder diabetes mellitus. Abbreviations from the original dietetic corpus were matched against DIET, NURSE AND X-RAY. Note that the subsets are of different sizes and that the different frequencies therefore are not directly comparable.

		No of instances found		
Abbreviation	Original expression	DIET	NURSE	X-RAY
diab	diabetes	118	965	158
dm	diabetes mellitus	432	38	290
DM	Diabetes Mellitus	597	69	4219
DMT1	Diabetes Mellitus type 1	71	0	0
DMT2	Diabetes Mellitus type 2	39	0	0
IDDM	Insulin Dependent Diabetes Mellitus	416	0	36

3. Discussion

In this study we have characterized the use of abbreviations in Swedish patient records among three health care professions. Ambiguous abbreviations were common both within and between the different professions. A limitation of the study is that it was based upon an exact matching of the 266 abbreviations found in the original dietetic corpus, meaning that no other abbreviations than those we looked for were found. A more open collection of all abbreviations in the corpora, followed by categorization, might have revealed even more synonymous abbreviations as well as more ambiguity.

There seems to be somewhat different abbreviation cultures among the three professions, such as the use of different abbreviations for Diabetes Mellitus, or the more frequent food abbreviations among dieticians. However, there are also many similarities, and many of the different meanings of the analyzed abbreviations were common for all three professions.

The frequent ambiguity of abbreviations, as well as the use of many different abbreviations for the same word, may have implications for patient safety as it increases the risk of misunderstandings of the EHR. It also hampers the possibilities for patients to understand their own patient records. Our main contribution is the categorization and analysis of abbreviation types used by different professions, which could be informative when developing automated abbreviation detection systems.

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References

[1] Friedman C, Kra P, Rzhetsky A. Two biomedical sublanguages: a description based on theories of Zellig Harris. *J of Biomed Informatics* 2002; 35: 222–235.

[2] Paparella, S. Avoiding dangerous abbreviations and dose expressions. *J of Emergency Nursing* 2004; 30(1):54-58.

[3] Liu, H, Lussier, YA, Friedman, C. A study of abbreviations in the UMLS. In *Proceedings of the AMIA Symposium* (p. 393): 2001. American Medical Informatics Association

[4] Laippala V, Danielsson-Ojala R, Aantaa K. et al. Vocabulary in Discharge Summaries–The Patients' and the Nurses' Perspective. The 4th International Louhi Workshop on Health Document Text Mining and Information Analysis: 2013

[5] Keselman A, Slaughter L, Arnott-Smith C et al. Towards consumer-friendly PHRs: patients' experience with reviewing their health records. In *AMIA Annual Symposium Proceedings* (Vol. 2007, p. 399): 2007. American Medical Informatics Association.

[6] Dalianis H, Hassel M, Henriksson A et al. Stockholm EPR Corpus: A Clinical Database Used to Improve Health Care. Proceedings of the Fourth Swedish Language Technology Conference, (SLTC-2012), Lund, Sweden, October 25-26, 2012, pp. 17-18.

[7] Östling R. Stagger: an Open-Source Part of Speech Tagger for Swedish. Northern European Journal of Language Technology, 2013; 3:1–18.

[8] The Swedish Language Council (Ed.). *Svenska skrivregler* [Swedish Writing Rules]. Stockholm:Liber;2000.

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Machine learning-based detection of chemical risk

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Abstract. Chemical risk appears with chemical substances that are dangerous for human or animal health, or for environment, such as with Bisphenol A and phtalates. Chemical risk causes several severe health disorders and is particularly dangerous for human health. Specific agencies are involved in the verification of the suitability of products and goods to be marketed. For this, a large amount of scientific and institutional literature is manually analyzed to study the current knowledge on the associated chemical risk. We propose to use machine learning and dedicated classification for the automatic detection of chemical risk statements. We test several algorithms and features and obtain between 0.60 and 0.95 F-measure.

Keywords. Natural Language Processing, Public Health, Machine Learning, Chemical Risk, Uncertainty, Evaluation

Introduction

Chemical risk appears when chemical substances, dangerous for human or animal health or for environment, are used. For instance, substances like Bisphenol A and phtalates are endocrine disrupters that, at certain doses, can interfere with the endocrine (or hormone system) in mammals [1,2]. They cause a great number of severe disorders such as sexual development problems (feminizing of males or masculine effects on females), breast cancer, prostate cancer, thyroid and other cancers, brain development problems and deformations of the body [3]. Although controversial, the effect of endocrine disrupters occupies an important place in medical and economical spheres. For these reasons, authorization for marketing of some products and goods may depend on their chemical composition. Such authorizations are delivered by specific agencies like European Food Safety Authority (EFSA) [4]. People working in these agencies have to analyze a great amount of literature to provide scientifically-based arguments for decision-makers on possibility and appropriateness of marketing of these products and goods. We propose an automatic approach for the analysis of literature and for detection of sentences related to chemical risk. In the following of this paper, we present first the material used, we then introduce the methods, discuss the results obtained and conclude with some future work.

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1. Material

Processed corpus. The corpus processed [5] proposes review of scientific literature on Bisphenol A-related experiments and known experimental results. It contains over 80,000 word occurrences. The corpus contains typical statements that may be found in scientific and institutional literature. The arguments provided are used for supporting the decisions for managing the chemical risk uncertainties.

Linguistic resources. Linguistic resources contain linguistic *markers* for describing several aspects of the content of scientific writings: *negation* [6] (*eg, no, not, neither, lack, absent, missing*), which indicate that experimental results have not been observed in a study, that a study did not respect the norms, etc.; *uncertainty* [7] (*eg, possible, hypothetical, should, can, may, usually*), which indicates doubts about the results, their interpretation, significance, etc.; *limitations* (*eg, only, shortcoming, small, insufficient*), which indicate limits, such as small size of a sample, small number of tests or doses, etc.; *approximation* (*eg, approximately, commonly, considerably, estimated*), which indicates limits due to an imprecise or approximate values of substances, samples, doses, etc. Such markers are frequent in the scientific writings, especially negation and uncertainty that have been quite well studied in previous work [8,9]. The limitation and approximation markers do not seem to have been used in existing work.

Classification. The classification describes types of chemical risk factors and uncertainties like causal relationship between the chemicals and the induced risk, such as laboratory procedures, human factors, animals tested, significance of results, form of reporting, natural variability, control of confounders, exposure, dosage, assumptions, performance of the measurement and analytical method, etc. [10].

Reference data. The reference data are obtained thanks to a manual annotation by a specialist of chemical risk: 425 segments are assigned to 55 classes of risk factors. The classes to not overlap. The reference data are a subset of the whole corpus.

2. Methods

Machine learning, or supervised categorization, is exploited for performing the automatic detection of sentences that mention chemical risk uncertainties and different classes of the chemical risk uncertainties.

Pre-processing and Annotation. Corpus is pre-processed with the Ogmios plateform [11] through tokenization into words, POS-tagging and lemmatization by Genia tagger [12]. The corpus is also annotated with the linguistic resources.

Supervised categorization. For the automatic detection of risk factors, we use the reference data and supervised categorization [13]. The categories to be recognized are positioned at two levels: first, we want to detect sentences concerned with the chemical risk uncertainties; second, we want to detect to which classes of chemical risk these sentences belong. In the first case, we address a more general problem, while in the second case, we try to perform a fine-grained classification of sentences. For each experiment, we build datasets with equal numbers of positive and negative examples. For instance, when sentences are to be categorized at the level of chemical risk uncertainties, we recruit the 425 positive sentences related to chemical risk and 425 negative sentences non-related to chemical risk. We proceed similarly when recruiting data for different classes, but in this case, the negative set combines both sentences that are non-related to chemical risk and sentences that are related to other classes of risk.

Features used. The features used for the categorization are issued from the semantic annotation: *forms* (words as they occur in the texts: *uncertain, risks*); *lemmas* (lemmatized words: *uncertain, risk*); *lf* (combination of forms and lemmas: *uncertain/uncertain, risks/risk*); *tag* (morpho-syntactic or POS tags of the words: *adj, noun*); *lft* (combination of forms, lemmas and tags: *uncertain/uncertain/adj, risks/risk/noun*); *stag* (semantic tags of the words, such as *uncertainty, negation, limitations, approximation*); *all* (combination of all the features). The features are selected according to the number of documents they occur within. We test several values, going from 1 to 4 documents. The objective is to reduce the decision space and to select the most relevant features.

Feature weighting. These features are weighted in three ways: *freq* (row frequency of features); *norm* (normalization of the frequency by the document length); *tfidf* (weighting of the frequency by term frequency*inverse document frequency [14]).

Evaluation and Baseline. We apply the cross-validation [15], designed to use two distinct data sets during training and test steps. We perform a three-fold cross-validation. We compute three evaluation measures: precision (percentage of sentences that are correctly categorized among all the sentences categorized in a given category); recall (percentage of sentences correctly categorized comparing to those that should be categorized in a given category); f-measure (their harmonic mean). We also exploit a *baseline,* that corresponds to the assignment of sentences in the default category. For instance, with a two-category test (*eg* sentences related to the chemical risk uncertainties and sentences non-related to the chemical risk uncertainties) and the equal number of sentences in each category, this kind of *baseline* would generated 50% performance, as all sentences would be assigned to the same category. Comparing to this *baseline,* we also compute the obtained gain, that corresponds to the real improvement of the performance *P* by comparison with the *baseline BL* [16]: (*P-BL)/(1-BL).*

3. Results and Discussion

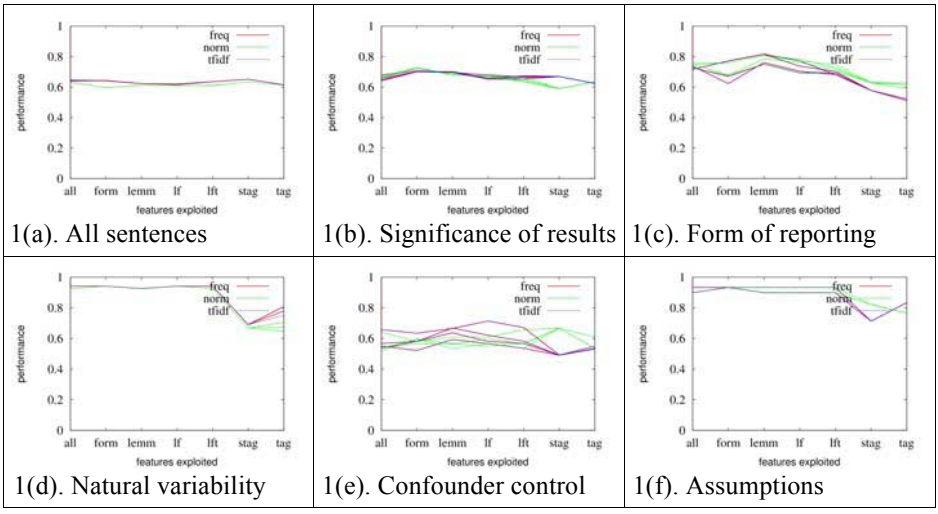


Figure 1. Performance (F-measure) obtained on different datasets with J48.

We tested several algorithms provided by the Weka platform. The decision-tree algorithm J48 [17] is rapid and provides competitive results. We present here the results obtained with this algorithm. Figure 1(a) shows the results obtained when distinguishing sentences related to the 55 classes from the reference data. The x-axis indicates the features used (forms, lemmas, semantic tags, POS tags or their different combinations). The y-axis indicates the performance values (F-measure). Different colors of the lines correspond to the weighting of the features (row frequency, normalization by the document length, normalization with the tfidf). Moreover, for each normalization, different thresholds for the feature selection are applied. Figure 1(a) indicates that the performance is stable (between 0.61 and 0.64), with different features used. Exploitation of forms, semantic tags and combination of all the features give slightly better results. Although very simplistic, the POS tags *(eg* nouns, verbs, adjectives) appear to be quite efficient to the task. Concerning other settings of the method: we obtain similar results with different normalization methods (row frequency, normalization by the document length, normalization with the tfidf); the feature selection has no impact of the results. Compared to the baseline (0.50 F-measure), we obtain 0.24 points of improvement.

Classes that contain at least ten sentences are treated. We present here the results obtained on five classes: *Significance of results* (Figure 1(b)), *Form of reporting* (Figure 1(c)), *Natural variability* (Figure 1(d)), *Control of confounders* (Figure 1(e)) and *Assumptions* (Figure 1(f)). We can observe that there is no direct and observable dependance between the size of the datasets and the performance obtained: the results are similar for several classes whichever the feature selection and weighting, while with other classes the variability of the results is important. Similarly, the results may depend on the feature selection, especially with the class *Confounder control*. In general, we can observe poorer performance with semantic tags (stag) and POS tags (tag). Usually, forms, lemmas and their combinations with other features appear to be efficient. Compared to the baseline, the highest gain is obtained with the class *Natural variability*, which means that this class shows specific linguistic features (lexicon, markers) by comparison with the rest of the sentences. The automatic detection is then facilitated by this fact. Here is an example of sentence related to the class *Natural variability*: "*Based on the re-analysis the Panel considered that no conclusion can be drawn from this study on the effect of BPA on learning and memory behaviour due to large variability in the data."* Among the salient features, we can find words such as *variability, differences* for the class *Natural variability*; *factor, uncertainty* for the class *Choice of uncertainty factors*; *contamination, not, confounders, confounding* for the class *Control of confounders*. They are often evocative of the semantics of the corresponding class.

4. Conclusion and Perspectives

The presented work provide experimental insights into the automatic detection of sentences related to the chemical risk uncertainties. We proposed to perform the extraction of sentences concerned by chemical risk at two levels: detection of sentences potentially concerned by the chemical risk uncertainties; detection of sentences potentially concerned by specific classes of chemical risk uncertainties. Several classes from the reference data contain but a small number of sentences: their automatic categorization is not performed currently. One possible solution is to perform the over-

sampling [18]. Still, with the current experiments, the limitation due to the size of classes is partially overcome by the fact that sentences under these classes can be detected without specifying their category *(ie,* general relation to the chemical risk uncertainties and not to a given class of chemical risk uncertainties). The performance obtained is respectable: it varies between 0.60-0.70 for classes that are difficult to detect, and up to 0.82-0.95 for classes that show lexical and semantic specificities.

Our future work will address the current limitations of the presented experiments: building the dedicated lexicon, application of over-sampling algorithms, use of other methods (topic modeling, information retrieval). Besides, the proposed methods will be applied to a larger corpus of documents from the chemical risk area, as well as corpora concerned with other chemical substances. The extracted results will be presented for evaluation and assessment to experts working in environmental agencies.

5. References

[1] Testai E, Galli CL, Dekant W, Marinovich M, Piersma AH, Sharpe RM. A plea for risk assessment of endocrine disrupting chemicals. *Toxicology*. 2013;**314**(1), 51-9.

[2] Andersson AM, Bay K, Grigor KM, Rajpert-De Meyts E, Skakkebaek NE. Special issue on the impact of endocrine disrupters on reproductive health. *Int J Androl*. 2012;**35**(3), 215.

[3] Crisp TM, Clegg ED, Cooper RL, Wood WP, Anderson DG, Baetcke KP, Hoffmann JL, Morrow MS, Rodier DJ, Schaeffer JE, Touart LW, Zeeman MG, Patel YM (1998). Environmental endocrine disruption: An effects assessment and analysis. *Environ. Health Perspect*. **106.** (Suppl 1), 11–56.

[4] www.efsa.europa.eu/

[5] EFSA Panel. (2010). Scientific opinion on Bisphenol A: evaluation of a study investigating its neurodevelopmental toxicity, review of recent scientific literature on its toxicity and advice on the danish risk assessment of Bisphenol A. *European Food Safety Authority (EFSA) journal*, **8**(9), 1-110.

[6] Chapman, W., Bridewell, W., Hanbury, P., Cooper, G., Buchanan, B. A simple algorithm for identifying negated findings and diseases in discharge summaries. *J Biomed Inform*. 2001, **34**(5), 301-10.

[7] Périnet, A., Grabar, N., Hamon, T. Identification des assertions dans les textes médicaux: application à la relation {patient, problème médical}. *TAL* 2011 **52**(1), 97-132.

[8] Mutalik, P., Deshpande, A., Nadkarni, P. Use of general-purpose negation detection to augment concept indexing of medical documents: a quantitative study using the UMLS. *J Am Med Inform Assoc 2001*, **8**(6), 598-609.

[9] Light, M., Qiu, XY., Srinivasan, P. The language of bioscience: facts, speculations and statements in between. In *ACL WS on Linking biological literature, ontologies and databases 2004:* 17-24.

[10] Maxim L and van der Sluijs JP. Qualichem In Vivo: A Tool for Assessing the Quality of In Vivo Studies and Its Application for Bisphenol A. PLOS one 2014. In press

[11] Hamon, T., Nazarenko. Le développement d'une plate-forme pour l'annotation spécialisée de documents web: retour d'expérience. *TAL 2008,* **49(2),** 127-154.

[12] Tsuruoka, Y., Tateishi, Y., Kim, J., Ohta, T., McNaught, J., Ananiadou, S., Tsujii, J. Developing a robust part-of-speech tagger for biomedical text. *LNCS 2005,* **3746,** 382-392.

[13] Witten, I., Frank, E. *Data mining: Practical machine learning tools and techniques*. Morgan Kaufmann, San Francisco, 2005.

[14] Salton, G. Developments in automatic text retrieval. *Science 1991,* **253,** 974-979.

[15] Sebastiani, F. Machine learning in automated text categorization. *ACM Computing Surveys 2002*, **34**(1)**,** 1-47.

[16] Rittman, R. *Automatic discrimination of genres.* Saarbrucken, Germany: VDM, 2008.

[17] Quinlan, J. *C4.5 Programs for Machine Learning*. San Mateo, CA: Morgan Kaufmann, 1993.

[18] Chawla, N.V., Bowyer, K.W., Hall, L. O., Kegelmeyer, W.P. Synthetic minority over-sampling technique. *Journal of Artificial Intelligence Research 2002*, **16,** 321-357.

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Blood Bag Temperature Monitoring System

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Abstract. Storage and transportation of red blood cells (RBCs) outside the standard temperature range as defined by guidelines can lead to hemolysis. One of the main factors believed to cause hemolysis is temperature.Infusion of the corrupted RBCs leads to haemolytic reactions which are severe and life-threatening. We developed a temperature monitoring system to monitor temperature changes of each blood bag during storage and transportation. The main objective of the present study was evaluating the accuracy of the temperature monitoring system and studying its feasibility. Validating the system relied on accurate digital thermometers that latch on a blood bag. To evaluate the feasibility, a case study was performed on 20 RBC bags transported from hospital blood bank to the cardiac surgery intensive care unit and the heart operating room. The results indicated that 12% of 25605 recorded temperatures (per minute) were outside the standard range. Minimum and maximum temperatures were 0.5℃ and 16℃ that were below and above the standard, respectively. The system was shown to be easily handled by users. The system is capable to alarm when a blood bag's temperature is outside the standard temperature and prevents blood corruption. This system can be used as a decision support system in blood transfusion services to improve storage and transportation conditions of the blood bags.

Keywords. Transfusion, hemolysis, temperature change, temperature monitoring system, decision support system

Introduction

Blood transfusion can save many patients' lives and has many clinical benefits, but it's not without risk. According to the 2012 annual SHOT report that covers the UK nine people out of 2466 have lost their lives due to blood transfusions. Compared with similar findings in 2011, there was an increase of about 12.5% [1]. Most cohort studies showed transfusion can cause adverse patient outcomes; including death, organ failure progression, infection and prolonged hospital stay [2]. Acute and delayed hemolytic

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reactions are one of the deadly reactions caused by blood transfusions and their occurrence should be prevented as much as possible [1].

One of the main factors that cause hemolysis is temperature [3]. Storage and transportation of RBCs outside the specific defined temperatures leads to hemolysis via blood biochemical changes [4]. Infusion of these RBCs can be fatal due to severe symptoms that may occur [5].In order to preserve the quality of RBCs, they should be kept at a specified temperature range during storage and transportation [6, 7]. The use of a proper refrigerator with interior temperature between 1℃ to 6℃ is essential for storage. Also based on European and American guidelines, temperature of RBCs during transportation must be kept between 1℃ to 10℃ [8-10].

Concern about blood products' temperature begins when they are dispatched from the blood bank to different wards within the hospital and placed out of refrigerator in ambient temperature for an undetermined length of time. According to the 30-minutes rule, if a blood product is placed out of refrigerator longer than 30 minutes it must be taken out of use cycle [11]. But it is hard to determine the length of time that they were placed in out-of-range temperatures. The limited blood supply doesn't allow discarding them without confirming their length of stay outside the standard temperature.

In recent years, there has been an increasing interest in using temperature-sensitive indicators to address the problem of temperature monitoring during storage and transportation. Two types of these indicators are available for this purpose. Type 1 is a temperature indicator that determines if a bag's temperature has exceeded a defined maximum. Type 2 is a time-temperature indicator that determines the length of time in which a bag's temperature has exceeded a defined maximum. None of these indicator types can continuously record temperature changes and also control for the minimum temperature. We hence designed a device that is attached to a blood bag and continuously monitor temperature during storage and transportation and record them on embedded memory.

This study aimed to test the accuracy of the new temperature monitoring system and evaluate its feasibility during storage and transportation for RBCs transported from the hospital blood bank to the cardiac surgical intensive care unit (CSICU) and the heart operating room.

1. Materials and Methods

According to a need assessment performed in the hospital, the monitoring temperature system was designed and developed by the authors. This system is equipped with an accurate thermometer sensor and a memory unit to save temperature in pre-specified time intervals when attached to the blood bag. One of the main features of this system is its connectivity to an external reader to display the recorded data in a graphical form and to save them in an external memory for computer use. In addition the system compares the recorded temperatures with the standard ranges and gives appropriate alarms. In order to test the accuracy of the system, we used different standard digital thermometers to be attached to the blood bag including one with the accuracy of ±0.3℃. For this purpose we used standard blood bags that were filled with water at different temperatures. Then we compared the standard digital thermometers recorded temperature with our system.

For evaluating the feasibility of the system, a case study was performed on 20 RBC bags transformed from the blood bank to the CSICU and heart operating room for

transfusion. Alarm capability of the device was disabled and only temperature of the blood in the bag during storage and transportation was saved on the embedded memory.

There were up to six stages of transportation and storage for each blood bag: transportation from blood bank to OR, storage in OR, transportation to CSICU if not used in OR, storage in CSICU, and finally transportation to blood bank if not used.

2. Results

We achieved ±0.5℃ accuracy for the temperature monitoring system. These systems recorded a total of 25605 measurements (one per minute) of data, of which12% were abnormal (out of range).Table 1 displays minimum, maximum and average of blood bag temperatures during storage and transportation.

Table 1. Minimum, maximum and average of blood bag temperature in degrees Celsius

	Blood Bank	Transportation	Operating Room	ICU
Minimum	3	1	1	0.5
Maximum	12.5	16	13	9
Average	4.4	5.3	4.5	3.5

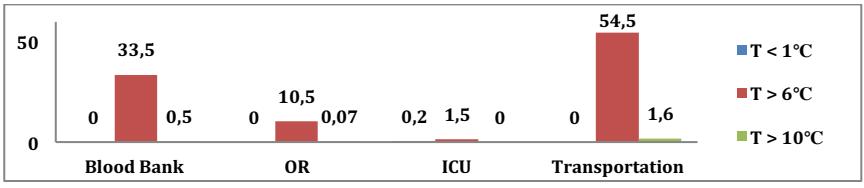


Figure 1. Percentage of abnormal data in different stages of storage and transportation

The results of the preliminary analysis assessed the percentage of abnormal data measurements in different stages (Figure 1). We were able to identify 7 cases out of 20 in which temperature was outside the 1℃ to 10℃ range and should be taken out of use cycle based on the 30 minutes rule. Other 13 out of 20 bags had exceeded defined temperature during storage. Our findings showed undesired fluctuations in blood bag temperatures in one domestic refrigerator due to its thermostat function. If the warning system of the designed device would have been activated, it would have announced critical conditions with appropriate timely alarms. We used a questionnaire to evaluate the users' satisfaction. The questionnaire was answered by 30 users. They were satisfied and found the system easy to handle. We did not record any issue for attaching and detaching the device from the blood bags and did not also have any gap in recording the bags' temperature and extreme values (below -10℃ and above 40℃).

3. Discussion

The results of this study showed that a considerable percentage of RBC bags have out-of-range temperatures during storage and transportation and it requires corrective action. Our designed and developed temperature monitoring system has hence the potential to improve the quality of blood bag storage and transformation, especially after utilization of alarms. Also feedback from staff showed that the device was easy to handle. The cost of the device (approximately $30) indicates it should be affordable especially in the coming years.

Our study has some limitations. First turning on the device before connecting to the bag or turning it off after separating it from the bag could cause the device to record ambient temperature; data cleaning techniques should be able to address this limitation. Second, like other temperature indicators this device can just provide surface temperature [12]. Despite these limitations, we found that this system can provide more information in comparison to standard temperature and time-temperature indicators due to its continuous monitoring and recording. For example results in one of the domestic refrigerators indicated regular fluctuation in blood bag temperatures during storage with 3℃ peak to peak amplitude. After preliminary analysis we found these fluctuations are due to the thermostat function. In addition we could measure and record the temperatures which were below the range. Below 1℃ temperature as important as above 6℃ for storing and transporting blood bags but none of the usual indicators can control for the minimum temperature.

Another main feature of the temperature monitoring system is its capability of remote monitoring. It can be connected wirelessly to a central system and a central system can monitor the temperature conditions and expiry date of a blood bag.

Further research should be done to investigate the utilization of this system as a decision support system in different blood services. In this way two types of alarms can be employed. These alarms can be used to declare critical conditions before and after blood corruption and prohibit the use of the corrupted blood bag.

4. References

[1] SHOT annual report and summary 2012.
[2] Marik PE, Corwin HL. Efficacy of red blood cell transfusion in the critically ill: a systematic review of the literature. Crit Care Med. 2008;36(9):2667-74.
[3] Sowemimo-Coker SO. Red blood cell hemolysis during processing. Transfus Med Rev. 2002;16(1):46-60.
[4] Sawant RB, Jathar SK, Rajadhyaksha SB, Kadam PT. Red cell hemolysis during processing and storage. Asian J Transfus Sci. 2007;1(2):47-51.
[5] Nurasyikin Y, Leong CF, Fadhlullah TM, Hafiz WM, Nadiah Z, Atieqah AN, et al. Role of blood bag temperature indicators in maintaining patent temperature of the returned unused blood bags in blood bank. Clin Ter. 2011;162(1):19-22.
[6] Perry HE, Prasad P, Kirwan S, Huang YQ. Core temperature changes in resuspended red blood cells (RBCs) and pediatric RBCs removed from refrigerated storage. Transfusion. 2010;50(1):174-7.
[7] Thomas S, Hancock V, Cardigan R. The 30 minute rule for red blood cells: in vitro quality assessment after repeated exposure to 30°C. Transfusion. 2013;53(6):1169-77.
[8] AABB Standards Program Committee.Standards for blood banks and transfusion services. 28th ed. Bethesda: AABB; 2012.
[9] Joint UKBTS/NIBSC Professional Advisory Committee. Guidelines for the blood transfusion services in the United Kingdom. 7th ed. London: The Stationery Office; 2005.

[10] Council of Europe. Guide to the preparation, use and quality assurance of blood components. 16th ed. Strasbourg: European Directorate for the Quality of Medicines & Healthcare of the Council of Europe; 2010.
[11] Pick P, Fabijanic J. Temperature changes in donor blood under different storage conditions. Transfusion. 1971;11(4):213-5.
[12] Johnson V, Langeberg A, Taye-Makuria A, Sandler SG. Temperature-sensitive labels for containers of RBCs. Am J Clin Pathol. 2006;126(3):406-10.

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Computational Study of the Potential role of Chemotaxis in Enhancing the cell Seeding of Tissue Engineering Scaffolds

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Abstract. Chemotaxis is a morphogenetic mechanism that consists of cell movement along a concentration gradient. Since cell adhesion is essential for cell migration and tissue integrity, and morphogenesis also involves chemotactic cell movement, we conducted a study of the influence of adhesion and chemotaxis on cell seeding of scaffolds. We built three-dimensional models of a cell aggregate, respectively of a cell suspension, in the vicinity of a porous scaffold that contained a chemoattractant substance. We assumed that the chemoattractant is released at a steady rate, creating a constant concentration gradient. To study the interplay of adhesion and chemotaxis, we simulated cell seeding using an algorithm based on the Metropolis Monte Carlo method. We varied the chemotactic strength, which describes the extent to which cells tend to move along the chemoattractant gradient. We found that, for the same energetic and geometric conditions, the distribution of cells within the scaffold hinges on the chemotactic strength. Our study suggests that cell seeding of tissue engineering scaffolds may be enhanced by incorporating chemoattractants of controlled release rate into the scaffold.

Keywords. Tissue engineering, cell seeding, scaffold, chemotaxis, cell adhesion

Introduction

When tissue function is impaired due to injury, disease or congenital malformations, tissue replacement or regeneration is desirable. Recent progress in tissue engineering and regenerative medicine offered certain solutions, but also raised exciting questions [1]. While sheet-like replacement tissues (such as skin or bladder) are being produced for clinical applications, the fabrication of bulky tissue constructs remains a challenge.

In a classical approach to tissue engineering [1] [7], cells are first expanded in conventional cell culture dishes; then they are seeded on porous scaffolds made of biocompatible, degradable materials. For weeks, the tissue construct is cultured in the laboratory, and, finally, it is implanted and gradually restores tissue function [2].

The functionality of the tissue construct hinges on the success of cell seeding [3]. Ideally, the scaffold should be populated by a large number of uniformly distributed cells. To identify conditions of optimal cell seeding, we have developed Metropolis

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Monte Carlo simulations [4][5]. Here we extend our simulations to also take into account chemotaxis [7].

Our working hypothesis is that a suitable chemoattractant gradient will lead the cells into the depth of the scaffold, favouring uniform cell seeding. To test this hypothesis, we simulate seeding by a cell aggregate and then by a cell suspension, of a scaffold with spherical pores, which contains a chemoattractant substance distributed with a constant concentration gradient. The cell aggregate model is relevant because cohesive cells in suspension tend to reaggregate during seeding, and scaffolds are actually populated by cell aggregates that attach to their surface [3].

Our study is motivated by the emergence of solid free-form fabrication techniques for building scaffolds with desired microstructure [8] that incorporate chemoattractants and growth factors with controllable gradients and release rates [9][10].

The available computational models have proven their efficiency in characterizing the process observed in embryology, focusing on a small number of cells subjected to a variety of factors such as cell cycle, cell shape changes and the influence of chemicals that are present in their environment. In the context of tissue engineering applications, however, it is necessary to simulate the evolution of a large number of cells (10^5-10^7 cells), in order to study their self-organization in artificial tissue structures. The existing programs are limited regarding the size of the multicellular systems which they characterize [12][13].

1. Methods

We model the biological systems on a lattice of 50×50×150 nodes, the *OZ* axis representing the longitudinal axis of the system. The length unit is the distance between two nodes, equal to one cell diameter. In the area $Z \leq Z_0$ (Z_0=80) lattice nodes are occupied by scaffold or cell culture medium. The porosity of the scaffold is specified by the radius of the pores *R* as well as the radius of the circular orifices that connect the pores, *r* [4]. In the area $Z > Z_0$ we either represent a cell aggregate bathed in cell culture medium, or a cell suspension. The cell aggregate is represented by a sphere of 20 length units in diameter (*D*=20); the elements of the sphere are lattice sites associated to individual cells. Lattice sites associated to the cell suspension are occupied either by a cell, or by a medium particle [4].

We simulated the cell seeding of scaffolds, taking into account the interactions between the elements of the system (cell adhesion to the substrate, cohesion of the cells), as well as chemotaxis, using our SIMMMC application [4], based on the Metropolis Monte Carlo (MMC) method, extended to also account for chemotaxis.

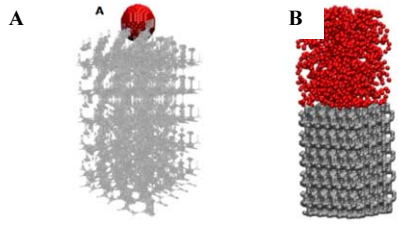


Figure 1. A. Model of a cell aggregate (*D*=20) on the surface of a porous scaffold (*R*=5, *r*=2); **B.** Model of a cell suspension in the neighborhood of a porous scaffold (*R*=5, *r*=2); visualized using VMD [11].

The principle that guides cell movement in our simulations is the differential adhesion hypothesis, which states that cells move in their medium until they reach the minimum energy state of the system [6]. The total energy of the system is given by $E = E_{adh} + E_{chemo}$, where E_{adh} is the energy of adhesion [4,5], and E_{chemo} is the energy associated to chemotaxis [7]:

$$E_{chemo} = -K \cdot \sum_{i=1}^{N} C_i \quad (1)$$

Here i labels cells (N is the total number of cells), C_i denote the chemoattractant's concentration in the vicinity of cell i and K represents the chemotactic strength, which describes the extent to which cells tend to move along the concentration gradient.

According to the MMC algorithm, a biologically relevant random move is made, which is accepted with the probability $P = \min\left(1, \exp\left(-\frac{\Delta E}{E_T}\right)\right)$. Here, E_T is the biological analogue of the energy of thermal motion [4], and $\Delta E = \Delta E_{adh} + \Delta E_{chemo}$, where ΔE_{adh} is the change in the adhesion energy of the system, whereas ΔE_{chemo} is the change in the energy associated with chemotaxis. For efficiency, the energy change is only computed for the region affected by the move.

2. Results

Our study of cell seeding is based on running a number of Monte Carlo steps (MCS). The input parameters of the simulations are:

- the cohesion energy between cells, ε_{cc}
- the adhesion energy between cells and substrate, ε_{cs}
- the radius of the pores, R
- the radius of the orifices between the pores, r
- the minimum and maximum concentration of the chemoattractant C_1 and C_2, respectively; C_1 is the concentration at the top of the scaffold (next to the aggregate or the cell suspension), whereas C_2 is the concentration at the bottom of the scaffold (farthest from the cells); for simplicity, here we assume that the concentration gradient is constant along the OZ axis.
- the chemotactic strength associated to cells, K.

First we considered a cell aggregate on the surface of a scaffold (Figure 1A). Shown in Figure 2 are the configurations obtained during 4×10^5 MCS for different values of K.

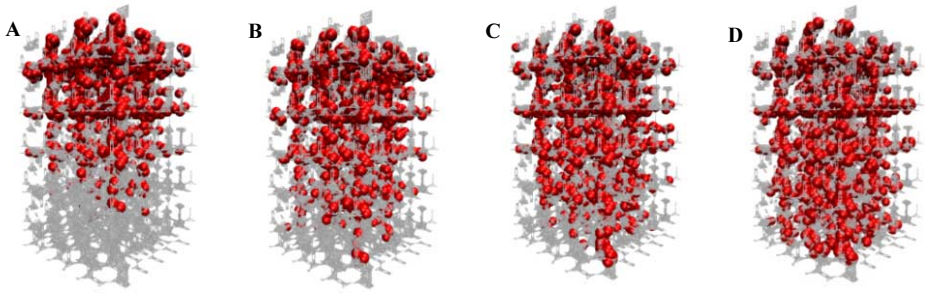


Figure 2. Results of cell seeding obtained after running 4×10^5 MCS (parameters: ε_{cc} =1; ε_{cs} =1.4; R=5; r=2; C_1=1; C_2=10). **A**. K=0; **B**. K=400; **C**. K=700; **D**. K=1000; visualized using VMD [11].

During the second set of simulations, we considered the model of a cell suspension in the neighborhood of the scaffold (Figure 1B). Figure 3 shows the configurations obtained after running 10^4 MCS for different values of the chemotactic strength, .

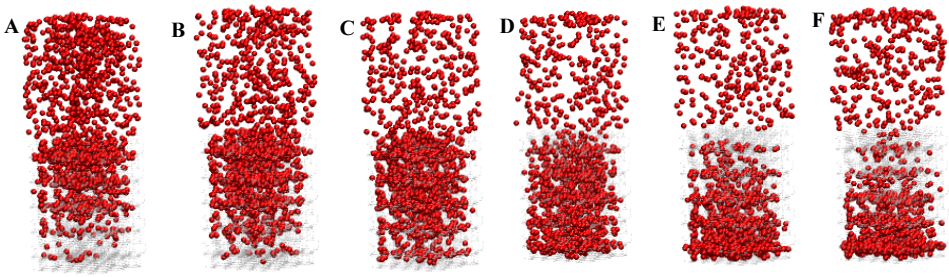


Figure 3. The results of cell seeding obtained after running 10^4 MCS (parameters: ε_{cc} =0; ε_{cs} =0.6; R=5; r=2; C_1=1; C_2=10). **A**. K=0; **B**. K=200; **C**. K=500; **D**. K=1000; **E**. K=1300; **F**. K=1500; visualized by VMD [11].

To characterize cell seeding quantitatively, we followed the evolution of the Z coordinate of the cells' centre of mass for different values of K (Figure 4).

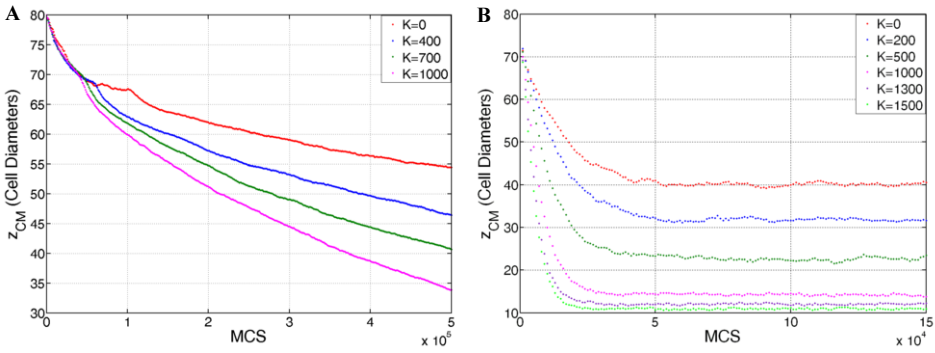


Figure 4. The evolution of the Z coordinate of the cells' centre of mass for different values of K: **A**. for a cell aggregate (first set of simulations) and **B**. for a cell suspension (second set of simulations).

3. Discussion

Our results confirm the hypothesis that the stronger is chemotaxis, the faster is the penetration of the cells into the scaffold.

Figure 4 gives a quantitative assessment of the impact of chemotaxis on cell seeding. In the first set of simulations (Figure 4 A), we observe that as K is larger the coordinate of the centre of mass of cells decreases faster, indicating that more and more cells enter the scaffold. For = 1000 , within 4×10^5 MCS the Z coordinate of the cells' centre of mass approaches 40, which is the Z coordinate of the scaffold's centre of symmetry, indicating a uniform distribution of the cells within the scaffold (Figure 2D). A similar behaviour is observed also in the second set of simulations (Figure 3D).

Prolonged evolution under the influence of chemotaxis or too strong chemotaxis leads to the accumulation of cells in the lower layers of the scaffold (Figure 4).

4. Conclusions

In this work we studied three-dimensional computational models of two biological systems: a cell aggregate and a cell suspension, located in the vicinity of a porous scaffold that incorporates a constant chemoattractant gradient. Based on these models, we simulated cell seeding by a Metropolis Monte Carlo algorithm [4], which was extended to also take into account chemotaxis.

To identify the optimal conditions for a rapid and uniform cell seeding, we varied the chemotactic strength at constant energetic and geometric input parameters.

We analyzed the results of the simulations quantitatively by following the evolution of the Z coordinate of the cells' centre of mass. The results indicate that strong chemotaxis favors the migration of cells into the bulk of the scaffold, eventually giving rise to a uniform distribution. Ideally, chemotaxis should cease at this stage.

Our *in silico* study suggests that if chemotaxis is employed to attract cells into deep layers of a scaffold, a suitable gradient needs to be provided for an optimal interval of time. Controlled drug release systems developed recently [9, 10] might be appropriate to assure such conditions.

References

[1] Langer R, and Vacanti JP. *Tissue engineering*. Science 1993:260(5110):920-26.

[2] Lanza RP, Langer R, and Vacanti JP, eds. *Principles of Tissue Engineering*. 3rd ed. Burlington: Elsevier Academic Press, 2007.

[3] Vunjak-Novakovic G, Obradovic B, Martin I, Bursac PM, Langer R, and Freed LE. *Dynamic Cell Seeding of Polymer Scaffolds for Cartilage Tissue Engineering*. Biotechnology Progress 1998:14 (2):193-202.

[4] Robu A, Neagu A, Stoicu-Tivadar L. *Cell seeding of Tissue Engineering Scaffolds studied by Monte Carlo simulations*. In: Moen A, Andersen SK, Aarts J, Hurlen P, eds. Studies in Health Technology and Informatics, Volume 169, 2011, User Centred Networked Health Care - Proceedings of MIE 2011. IOS Press; pp. 882-6.

[5] Neagu A, Kosztin I, Jakab K, Barz B, Neagu M, Jamison R, and Forgacs G. *Computational Modeling of Tissue Self-Assembly*, Modern Physics Letters B 20(20):1217-31.

[6] Foty RA, and Steinberg MS. *The differential adhesion hypothesis: a direct evaluation*, Developmental Biology 2005:278(1):255-63.

[7] Savill NJ, and Hogeweg P. Modelling Morphogenesis: *From Single Cells to Crawling Slugs*. Journal of Theoretical Biology 1997:184(3):229-35.

[8] Griffith LG, and Naughton G. *Tissue Engineering--Current Challenges and Expanding Opportunities*. Science 2002: 295 (5557):1009-14.

[9] Tayalia P, and Mooney DJ. *Controlled Growth Factor Delivery for Tissue Engineering*. Advanced Materials 2009:21(32-33):3269-85.

[10] Biondi M, Ungaro F, Quaglia F, and Netti PA. *Controlled drug delivery in tissue engineering*. Advanced Drug Delivery Reviews 2008: 60 (2):229-42.

[11] Humphrey W, Dalke A, Schulten K. *VMD – Visual Molecular Dynamics*, J. Mol. Graphics 1996:14:33-8. (www.ks.uiuc.edu/Research/vmd/ accessed Feb. 2nd, 2014).

[12] Swat M.H., Hester S.D., Balter A.I., Heiland R.W., Zaitlen B.L., Glazier J.A., *Multicell Simulations of Development and Disease Using the CompuCell3D Simulation Environment*, Systems Biology 2009, 361-428.

[13] Newman T.J., *Modeling multicellular systems using subcellular elements*, Mathematical Biosciences and Engineering 2, 2005, 613-624.

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A framework for privacy-preserving access to next-generation EHRs

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Abstract. Although personalized medicine is optimizing the discovery, development and application of therapeutic advances, its full impact on patient and population healthcare management has yet to be realized. Electronic health Records (EHRs), integrated with data from other sources, such as social care data, Personal Healthcare Record (PHR) data and genetic information, are envisaged as having a pivotal role in realizing this individualized approach to healthcare. Thus, a new generation of EHRs will emerge which, in addition to supporting healthcare professionals in making well-informed clinical decisions, shows potential for novel discovery of associations between disease and genetic, environmental or process measures. However, a broad range of ethical, legal and technical reasons may hinder the realization of future EHRs due to potential security and privacy breaches. This paper presents a HIPAA-compliant framework that enables privacy-preserving access to next-generation EHRs.

Keywords. Next-generation Electronic Health Records, HIPAA, Privacy, Attribute-based Access Control

Introduction

Personalized medicine has emerged as an essential strategy of modern practice to drive the most effective clinical decisions for optimal patient and population health [1]. A personalized medicine approach to providing health services may involve integrating genomics technologies and advances with clinical and family histories in order to more coherently tailor therapeutics to individual patients [2]. Thus, a key supporting component to effecting personalized medicine is the Electronic Health Record (EHR) providing the non-genetic factors.

In addition to the traditional clinical narrative, EHRs are currently capturing structured data relating to all aspects of care, including diagnosis, medication, laboratory test results and radiological imaging data containing integrated patient data. However, much potential can be realized if a broader set of information were incorporated in EHRs such as: (a) patient information contained in Personal Health Records (PHRs), (b) health information from medical devices connected to patient such as from assistive telecare systems, (c) social care information retrieved on request from social care organizations, (d) health information extracted from various healthcare

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systems such as primary and hospital care electronic medical records - EMRs; and (e) genomics information such as genotype and sequence data extracted from biobanks and genetic databanks. This can introduce a new era of personalized medicine where this new generation of EHRs will constitute a computable collection of fine-grained longitudinal phenotypic profiles, facilitating cohort-wide investigations and knowledge discovery on an unprecedented scale, thus leading to more effective prevention, diagnosis and treatment of diseases.

Despite the foreseen potential of next-generation EHRs, their multi-owner and multi-user nature raises severe privacy concerns. A number of approaches for addressing similar concerns have been proposed solely for EHR or PHR systems [3]. To address these issues in next-generation EHRs, as defined above, an innovative framework is required under which data will be pulled together from all the data sources in a privacy preserving manner. This paper presents such a framework which enables EHR data to be processed fairly, for specific purposes (clinical practice and research) according to the privacy policies set by different owners, and, where needed, based on consent of the persons concerned. Thus, clinical practice can be supported (a) by providing healthcare professionals with a readily available rich picture of patient data at the bedside, and (b) by enabling researchers to perform population-wide research in order to obtain EHR-derived knowledge that will bridge the translational gap between bench and bedside and will contribute to the a realization of personalized and stratified medicine. The proposed framework is deployed on a trusted cloud environment and draws upon Attribute-based Access Control (ABAC) paradigm for providing fine-grained access control to users. For research purposes, the proposed framework provides unrestricted access to data hosted in entities (health and social care organizations, etc) covered by Health Insurance Portability and Accountability Act (HIPAA) which are previously de-identified according to the HIPAA Privacy Rule. Hence, the likelihood of breaching patient privacy is reduced.

1. Methods

Figure 1 illustrates a high-level architectural view of the proposed framework which is described by a three-tier model, comprising the data layer, the client layer and a trusted cloud layer.

The client layer is a web portal, whereby medical professionals and other researchers request access to next-generation patient EHRs.

The data layer comprises the remote data resources providing the various chunks of data comprising a next-generation EHR. These resources are heterogeneous and reside at different settings. In particular, for the purposes of this paper, it is assumed that PHR data are stored in a cloud-based PHR system and, while EMR and social data are stored in data repositories of geographically distributed and organizationally disparate health and social care providers, respectively. In addition, information from medical devices attached to patients are uploaded to the PHR through a special-purpose mobile application. Finally, genomic information is assumed to be hosted in several research centers. The various parts of a next-generation EHR are accessible by relevant web services and are owned by different entities according to the specific security policy (e.g. owner of PHR and genomic data is the patient, while owner of the clinical/social data is the health/social provider where the patient has received care). Hence, each part of the EHR may be governed by different institutional or personal

policies and practices with respect to confidentiality, security and release of information. However, as health and social care organizations constitute covered entities under the HIPAA Privacy Rule, they must comply with the Rule's requirements for safeguarding the privacy of protected health information.

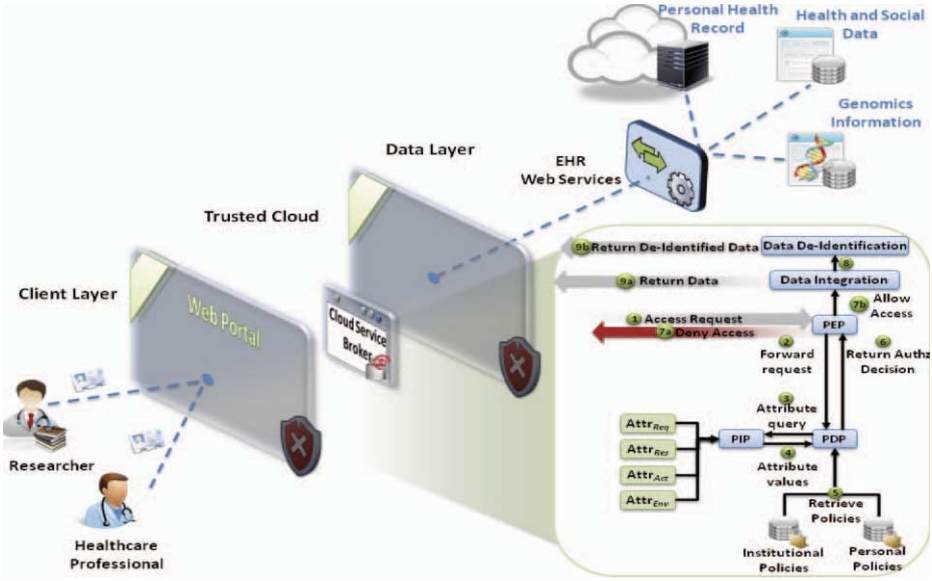


Figure 1. System Architecture

The middle tier is a cloud service broker which serves as a mediation gateway that handles interactions between users and data resource providers. It is deployed on a trusted cloud and provides access to integrated patient EHR data while ensuring compliance to the relevant HIPAA and patient-defined policies by properly authorizing users of the system, i.e. medical doctors and researchers. In doing so, the service broker draws upon the Attribute-based Access Control (ABAC) paradigm. In essence, the Service Broker mediates between requestors (healthcare professionals, researchers) and resources (EHR web services) to decide whether access of a given requestor to given resource should be permitted or denied by taking into account the attributes of the requestor, the resource, the action and the context holding at the time of the attempted access (operational, technical, or situational).

Essentially, access control is enforced through attribute-based access control policies which are defined as 4-tuples (*Req*, *Act*, *Res*, { p-Attr$_{Req}$, p-Attr$_{Res}$, p-Attr$_{Act}$, p-Attr$_{Env}$}) stating that a requestor *Req* is allowed to perform action *Act* to an asset *Res* subject to constraints {p-Attr$_{Req}$, p-Attr$_{Res}$, p-Attr$_{Act}$, p-Attr$_{Env}$} imposed by the attributes of *Req*, *Act*, *Res* and *Env*. The attributes of each entity participating in an access control decision are:

- Requestor attributes: User ID, Department of hospital and/or university where he belongs, user roles, group memberships etc.
- Resource attributes: Uniform Resource Identifier (URI) of the web service to be invoked, specific method of the web service to be executed.
- Action attributes: type of request (read, write, update EHR), purpose of request (clinical practice, research).

- Environment attributes: Time and location of attempted access, type of communication channel (e.g. protocol), client type (e.g. smart phone, etc).

Each request for gaining access to a resource is received by the Policy Enforcement Point (PEP) protecting it. The PEP makes an authorization call to the Policy Decision Point (PDP), which in turn queries for additional subject, resource, action and environment attributes from the appropriate Policy Information Point (PIP)**.** After acquiring the requested attributes, the PDP retrieves the relevant policies from the policy repository and the policies created by the PHR owner, evaluates the request against these policies (function illustrated in Figure 2) and returns a response (and applicable obligations) to the PEP in the form of an authorization decision to grant or deny access. An obligation is information returned with the decision upon which the PEP may or may not act (e.g. an obligation may contain additional information concerning a decision to deny). If access is permitted, the PEP grants the requester access to the resource; otherwise, access is denied.

```
1  ISSUE access_request(Req, Act, Res)
2  BEGIN attribute_collection
3     FOR each Entity in {Req, Act, Res, Env}
4        FOR each Attr_Entity,1 in Attr_Entity
5           Acquire attribute value
6           Add attribute to the Entity attribute set
7        END FOR
8     END FOR
9  END attribute_collection
10 BEGIN make AC decision based on attribute vales and user-defined policies
11    PDPdecision = PDP_make_AC_decision(Req request to Act on Res under Env)
12       PHRSysPolicy= retrieve user-defined policies related to Req
13             IF (PDPdecision = 'permit' and PHRSysPolicy = 'permit') THEN
14                   Forward the request to the relevant Web Service
15             ELSE
16                   Deny the request
17             END IF
18 END make AC decision based on attribute vales & user-defined policies
19 FUNCTION PDP_make_AC_decision(Req request to Act on Res under Env)
20    retrieve policies(Req, Act, Res)
21    evaluate policies (Req, Act, Res, Env)
22    return decision
23 END FUNCTION
```

Figure 2. Function for access control policy evaluation

In case that the user is a researcher, s/he can obtain unrestricted access to the sets of data required for his specific research purpose. However, in order to prevent access to unauthorized patient data, EHR data are de-identified in accordance with the HIPAA Privacy Rule once it is retrieved from the various data resources. In particular, the "Safe Harbor" method is used according to which 18 specific identifiers are removed (names, geographic subdivisions smaller than a state, all elements of dates, biometric identifiers etc) [6]. Although genomic data can uniquely identify a person, in the proposed framework, these data are not totally excluded from the data set returned to the researcher. In particular, during the de-identification process, specific parts of these data which can be used for identifying a person are removed, while the remaining information is made available for research. Due to the large volume of data usually required for research purposes, Quality of Service (QoS) needs to be ensured. In the proposed mechanism, this is ensured by detecting and rejecting bad queries, and/or throttling datasets, for example by enforcing limitations on data query size.

2. Results

To illustrate the functionality of the proposed framework, a prototype system was implemented that draws on the ePrescribing healthcare process depicted in Figure 1. Prototype system implementation was based on the Oracle 11g SOA and, in particular, on (i) Integrated Service Environment (ISE) for EHR web services development and (ii) an enterprise portal for healthcare professionals, collaborating healthcare organizations and researchers to access content. The system was deployed on a laboratory cloud computing infrastructure. The platform used for the generation of sample patient PHRs is Tolven ePHR where health information from medical devices (i.e. weight, blood pressure and blood glucose measurements) are uploaded automatically via a relevant Android application [5][6]. Semantic interoperability between all pieces of information comprising a next-generation EHR is achieved by means of ontologies. The ABAC policies have been defined using eXtensible Access Control Markup Language (XACML) [7]. Due to lack of space, a comprehensive description of the prototype implementation will be provided elsewhere.

3. Discussion

Next-generation EHRs comprising clinical, non-clinical and genomic data, hold great promise for improving patient safety as they can support well-informed decision making by providing readily access to richer patient information at the bedside. Moreover, they also constitute a vast repository of data that could be mined in the context of population-wide research aiming at bridging the translational gap between bench and bedside and moving towards a realization of personalized and stratified medicine. This paper presents a framework that sets the ground to realize these goals by facilitating privacy-preserving access to next-generation PHRs. System evaluation is a task to be undertaken in the near future aiming at determining the system usability. Thus, its potential weaknesses may be revealed suggesting alterations in the system design and directions for future work.

References

[1] Waldman SA, Terzic A. Patient-centric clinical pharmacology advances the path to personalized medicine, Biomarkers Med. 2011 Dec;5(6):697–700.
[2] Issa AM. Personalized Medicine and the Practice of Medicine in the 21st Century, Mcgill J Med. 2007 Jan;10(1):53–57.
[3] Heinze O, Birkle M, Köster L, Bergh B. Architecture of a consent management suite and integration into IHE-based regional health information networks. BMC Med Inform Decis Mak. 2011 Oct; 11:58.
[4] Oracle 11g SOA suite [Internet]. [cited 2014 Jan 15]. Available from: http://www.oracle.com/us/products/middleware/soa/suite/overview/index.html
[5] Tolven Healthcare Innovations[Internet]. The electronic Personal Health Record. [cited 2014 Jan 15]. Available from: http://www.tolven.org/ephr.html
[6] Koufi V, Malamateniou F, Vassilacopoulos G. An Android-Enabled Mobile Framework for Ensuring Quality of Life through Patient-Centric Care. Paper presented at MIE; 2012, Aug 26 – 29; Pizza: Italy.
[7] OASIS [Internet]. eXtensible Access Control Markup Language (XACML) [cited 2014 Jan 14]. Available from: https://www.oasis-open.org/committees/tc_home.php?wg_abbrev=xacml

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Secure Teleassistance towards endless medical litigations: Identification of liabilities through a protocol using Joint Watermarking-Encryption Evidences

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Abstract. Teleassistance is defined by the help provided through a telemedicine network by a medical practitioner to one other medical practitioner faced to a difficult case. One of the main limiting factors of its development is the fear of the practitioners to be involved in a litigation. In such a situation, the main issue is to determine as quick and as certain as possible if the damage is in relation with the tort of negligence and the liabilities of each involved physician. After a brief summary of the legal context, we present a protocol combining joint watermarking-encryption and a third party to enforce exchange traceability and therefore to bring valuable electronic evidence in case of teleassistance litigations.

Keywords. teleassistance, proof of data exchange, watermarking, encryption.

Introduction: teleassistance legal framework and medical litigations

The development of teleassistance began more than 20 years ago and has since demonstrated its efficiency [1]. Even though, technology strongly increased the quality and speed of image transmission, telemedicine only got a legal recognition in France in 2009 and its legal framework being defined in 2010 [2-3]. In this context, when a patient suffers of a prejudice related to a diagnostic error, it is necessary to determine the respective liabilities of the practitioners involved in the diagnostic/therapeutic process. Professional negligence will be argued if one of the practitioners involved in the teleassistance has had a negligent attitude, i.e. falling short of what might have been expected from him regarding his field of competence. To assess this possible lack of professionalism, and, thus, possible legal liability of one or both involved practitioners (joint liability), several questions will arise to allow the judge to reach a conclusion: Who made the request? What was requested? When? For whom? What documents were provided/requested? Who answered? What? When? Regarding which documents?

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In order to discover the process that originated the error and to give it a value of legal evidence [2-4], all the elements involved in the transaction must be stored; elements which can be identified according to the following needs [4]:

- ***N1***- Whole transmitted data have to be saved with the identity of all practitioners, the name of the patient, the date and the time of the transaction.
- ***N2-*** The date, time and substance of the answer of the referent practitioner must be strongly linked to the documents he received before sending it.
- ***N3-*** Save the substance of the answer of the referent with the identifiers of the physician, the specialist, the date and the time of the transaction.
- ***N4-*** Both practitioners must be identified in such a way they cannot repudiate their respective messages;
- ***N5-*** all elements involved in the transaction must be stored, with no means of modification, and rendered unreadable from an unauthorized access.

In this paper, in order to provide an appropriate response to these security needs, we propose a new secure tele-assistance protocol. This one takes advantage of Joint Watermarking-Encryption (JWE), a recent mechanism for digital content (e.g. images, medical report) protection which simultaneously offers confidentiality, integrity, authenticity and traceability functionalities [5-6]. The remainder of this paper is organized as follows. In section 1, we give a brief overview of JWE technique before presenting our protocol in section 2, and analyzing its security in section 3.

1. An overview of joint Watermarking-Encryption

Recently introduced in [5-6], a JWE algorithm conducts data encryption and data watermarking in a single operation process (see Fig.1). If encryption ensures data confidentiality, watermarking on its side can be used so as to verify data integrity and authenticity. We recall that watermarking [8] relies on two processes: embedding and reading. At the embedding stage, the message is inserted by modifying the host document (e.g. image, text) in an "imperceptible" way. "Imperceptible" means that the watermarked document can be used instead of the original document without interferences. Applied to an image; embedding consists in slightly modifying its pixel gray level values so as to insert the message in it. Image pixels are modified or modulated so that they can be interpreted/demodulated by the reader to gain access to the message. As depicted in Fig. 1, for digital images, the originality of JWE is that it allows the user to insert two messages, Ms and Me, which can be read/extracted in the encrypted and spatial domains, i.e. in the encrypted and decrypted image, respectively. The watermarking extraction functions fs and fe give access to Ms in the spatial domain and to Me in the encrypted image, respectively. Ms and Me can be security attributes (e.g. digital signature, unique identification number) that allow one user to verify the image integrity and authenticity even if this one is encrypted. If we consider the JWE function W_{emb}, the joint watermarked-encrypted version I_{we} of an image I is given as:

$$I_{we} = W_{emb}(I, M_s, M_e, K_e, K_{ws}, K_{we}) \quad (1)$$

where K_e, K_{ws} and K_{we} are the encryption key and the watermarking keys in the spatial and encrypted domains, respectively. Embedded messages M_s and M_e can be extracted from I_{we} and its decrypted version I_{wd}, respectively as follows:

$$M_e = f_e(I_{we}, K_{we}); M_s = f_S(I_{wd}, K_{ws}) \quad (2)$$

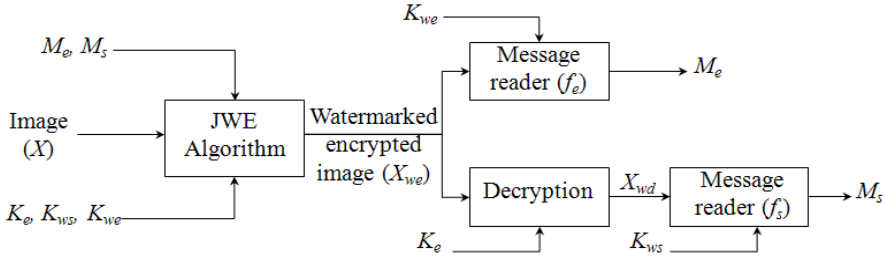


Figure 1. General system architecture of a JWE algorithm. M_e, M_s, K_e, K_{ws} and K_{we} are the message available in the encrypted domain, the message available in the spatial domain, the encryption key and the watermarking keys in the spatial and the encrypted domain, respectively.

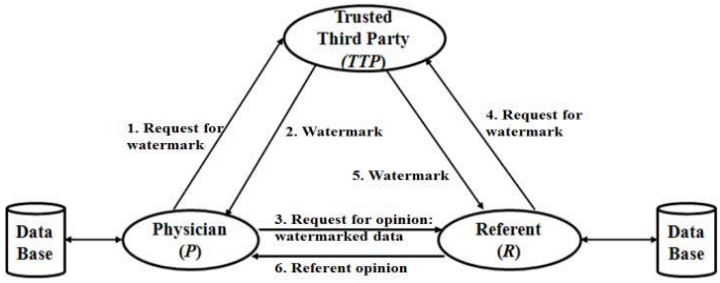


Figure 2. Teleassistance scenario and interactions between actors in the proposed protocol.

2. Liabilities identification through a secure teleassistance protocol based on JWE

In the proposed protocol, for one document, encryption ensures data confidentiality (*N5*) while the watermarking functionality contributes to: i) protect the document integrity (*N1*) by inserting into the document a proof of its integrity, ii) assess the document's origin and its attachment to one patient (*N1,N2*) by embedding the identifiers of the different entities involved in the exchange, iii) prove the identifier of the practitioner who received the document (*N3*) by inserting his identifier. We also suggest exploiting watermarking so as to introduce a secure link in between exchanged data not only for linking one document to the users and the transactions but also between the documents themselves. To do so, we embed within one document: practitioners and patient identifiers, its unique identifier (e.g. the DICOM UID), the transaction timestamp and a digital signature of the documents to which it is related with (*N2*). *N*on-repudiation need (*N4*), is commonly achieved with digital signatures.

To simplify the presentation of our protocol, let us consider the case where a physician (*P*) asks a Referent Physician (*R*) for a 2nd opinion (see fig. 2). The initial request may consist in images and any other elements that can participate to the decision making. Let's consider *X* is one element of this request. *R* analyzes the request and returns his answer by means of a report *Y* sent to *P*. Herein, we assume that each actor *u* involved in the transaction possesses its own public-private key pair (pK_u,sK_u). For reason of simplicity, we consider in the sequel that *X* and *Y* are images. Our protocol takes advantage of a third tierce party (*TTP*) considering that *P* and *R* can be dishonest trying, to falsify transaction data. Our protocol consists in three sub-protocols, we describe thereafter: "Request for Opinion", "Opinion Response" and "Verification" which is called in case of litigation and where all evidence are sent to the *TTP*.

2.1. "Request for Opinion" sub-protocol

This three step sub-protocol allows *P* to securely send to *R* a document *X* while securely linking this latter to the recipient and the transaction by means of a watermark.

Step1: *Generation of the watermark* W^X*: P* requests the *TTP* for a watermark W^X by sending to it into an encrypted form: its identifier as well as those of *R,* the document and the patient; along with a digital signature. Based on this signature, the *TTP* verifies the origin and the integrity of the request before secretly generating W^X based on the received data and the transaction timestamp. Then, the *TTP* sends to *P*, W^X encrypted with pK_P along with its digital signature (DS_{TTP} (W^X)). From W^X, the *TTP* will be able to re-link *X* to *P*, *R*, the patient and the transaction time and date (*N1*). When *P* receives the message, it decrypts W^X and verifies its signature so as to be sure that W^X was issued by the *TTP*.

Step2: *Request transmission phase:* Using the JWE algorithm (see section 1), *P* embeds within *X* two watermarks: W^X, which will be available in the spatial domain (i.e. M_s=W^X) and W^{eX}, which contains a reliability proof of *X* that will be available in the encrypted domain (i.e. $M_e = W^{eX}$). The obtained encrypted watermarked version X_{we} of *X* is then sent to *R*. *P* also saves $DS_{TTP}(W^X)$ and X_{we} in its database so as to ensure *N1*. DS_{TTP} (W^X) will serve as evidence proving that W^X was generated by the *TTP* and that it is the watermark we should retrieve into the decrypted version X_{wd} of X_{we}.

Step 3: Transmission of receipt acknowledgement: Using K_{we}, *R* extracts W^{eX} from the received encrypted data and verifies their integrity and origin without decrypting them. If it is ok, *R* returns to *P* an acknowledgement receipt which corresponds to the digital signature of X_{wd}: $DS_R(X_{wd})$. Notice that *R* cannot access to W^X because he does not know the spatial domain watermarking key K_{ws}. On its side, *P* save $DS_R(X_{wd})$ so that *R* will not be able to deny the reception of the request (*N4*).

2.2. "Opinion Response" sub-protocol

This three step sub-protocol aims at linking the different data involved in the response with the entities involved in the transaction as well as linking documents involved in the request and the response (*N3*). To do so, two watermarks are used.

Step1: *Generation of the watermark* W^Y: like *P*, *R* request the generation its watermark W^Y. After having generated W^Y based on the transaction timestamp and the identifiers of *P, R* and *Y* received from *R*, the *TTP* sends it along with $DS_{TTP}(W^Y)$ to *R*.

Step2: *Referent opinion transmission:* Before sending its answer *Y*, *R* generates a watermark *W* so as to link *Y* with *X*, using as example a digital signature of *X*. Then, he concatenates *W* with reliability proof of *Y* so as to build the watermark W^{eY}. W^{eY} and W^Y are next embedded using the JWE algorithm. The obtained watermarked encrypted document, Y_{we}, is transmitted to *P*. *R* securely also sends the watermarking key in the encrypted domain, K^r_{we}. *P* saves DS_{TTP} (W^Y) and Y_{we} (*N2*).

Step3: *Transmission of receipt acknowledgement:* After having verified the integrity/origin of *Y* and its link with *X* based on W^{eY}, *P* confirms the message reception by sending to *R* the digital signature the decrypted version Y_{wd} of Y_{we}: $DS_P(Y_{wd})$.

2.3. "Verification" sub-protocol

In case of litigation, *P* and *R* have to send their respective evidences to the *TTP*, it means: {DS_{TTP} (W^X), X_{wd}, $DS_R(X_{wd})$, DS_{TTP} (W^Y), Y_{wd}, $DS_P(Y_{wd})$}. Based on these

elements of proof, the *TTP* verifies that: 1) the watermarks it has generated and embedded by *P* and *R* are the good ones. This task is conducted by comparing the watermarks' digital signatures extracted from X_{wd} and Y_{wd} to $DS_{TTP}(W^X)$ and $DS_{TTP}(W^Y)$; *2)* X_{wd} and Y_{wd} brought as evidence by *P* and *R* correspond to those really exchanged. For this, it is sufficient enough to verify DS_R (X_{wd}) and DS_P (Y_{wd}).

3. Security analysis

Among the issues and attacks to be considered [7], our protocol is more concerned by: the "*issue of non-repudiation*" and the "*collusion attack*". Regarding non-repudiation issues, both physicians cannot deny they sent/received data due to the facts: i) they embed their own identifiers (available in the encrypted domain) while signing encrypted data (see [5]); ii) each of them has acknowledged good data reception of data. In the case of a collusion attack- *P* and *R* may repeat the steps of the protocol in order to build evidence that innocent them. This can be detected through the timestamps and the images' identifiers, which will not correspond to those presented by the colluders.

4. Conclusion

In this paper, we have proposed a new secure teleassistance protocol. It takes advantage of Joint Watermarking-Encryption algorithm which simultaneously allows: securing communication in terms of confidentiality; providing proof of data reliability even if these ones are encrypted; providing evidence an exchange occurred and which data were involved by means of secure links established between them. With our protocol it is possible to retrieve documents that are content related. It is resistant to non-repudiation issue and collusion attack.

References

[1] C. Quantin, D.O. Jaquet-Chiffelle, G. Coatrieux, E. Benzenine, F.A. Allaërt, Medical record search engines, using pseudonymised patient identity: An alternative to centralised medical records, *International Journal of Medical Informatics* 80 (2011), 6-11.

[2] Décret n° 2010-1229 du 19 octobre 2010 relatif à la télémédecine.

[3] A. Allaert, C. Quantin, Responsabilités et rémunérations des actes de télé-expertise, *Journal de Gestion et d'Economie Médicales* 30 (2012), 219-229.

[4] G. Coatrieux, C. Quantin, F.A. Allaert, B. Auverlot, Ch. Roux, Watermarking- a new way to bring evidence in case of telemedicine litigation, *Stud Health Technol Inform* 169 (2011), 611-615.

[5] D. Bouslimi, G. Coatrieux, M. Cozic, Ch. Roux, A joint encryption/watermarking system for verifying the reliability of medical images, *IEEE Transactions on Information Technology in Biomedicine* 16 (2012), 891–899.

[6] D. Bouslimi, G. Coatrieux, M. Cozic, Ch. Roux, A joint encryption/watermarking algorithm for verifying the reliability of medical images: Application to echographic images, *Computer Methods and Programs in Biomedicine* 106 (2012), 47-54.

[7] M. Deng, B. Preneel, Attacks on Two Buyer-Seller Watermarking Protocols and an Improvement for Revocable Anonymity, *Proc. ISECS* (2008), 923-929.

[8] G. Coatrieux, W. Pan, N. Cuppens-Boulahia, F. Cuppens, Ch. Roux, Reversible Watermarking Based on Invariant Image Classification and Dynamic Histogram Shifting, *IEEE Transactions on Information Forensics and Security* 8 (2013), 111-120.

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Balancing the need for big data and patient data privacy – an IT infrastructure for a decentralized emergency care research database

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Abstract. Emergency rooms of hospitals provide care to a lot of patients and have great impact on their outcome, so researching the quality of care seems important. Research using registries has yielded impressive results in other areas of medicine. However centralized data-storage has its pitfalls, especially regarding data privacy. We therefore drafted an IT infrastructure that uses decentralized storage to ensure data privacy, but still enables data transfer between participating hospitals. It implements an independent information broker to ensure anonymity of patients. Still it provides a way for researchers to request data and hospitals to contribute data on an opt-in basis. Although not an entirely new approach, the emphasis on data privacy throughout the design is a novel aspect providing a better balance between the need for big sample sizes and patient privacy.

Keywords. Emergency medicine, routine care research, registry, database, data privacy

Introduction

The emergency room (ER) is a special department for hospitals. It represents the initial point of contact with patients who mostly have multiple ERs to choose from. A visit to the ER is usually unplanned and the diseases presented are acute. Records from ER patients can hence serve as a good metric or signal for the surveillance of acute traumatic or infectious diseases, like the flu or EHEC.

The assessment of symptoms and test results is most critical in the ER. Even though many patients don't require immediate or extensive therapy, the key is to identify the few that do [1]. Missed opportunities at this point can only be rectified with a lot of effort during the following treatment in the hospital. The decisions and plans

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for specific therapies made in the ER can greatly impact the patient's health. For instance, admission or transferal to the correct department (i.e. surgery, gynecology or cardiology) determines the focus of the therapy and by extension the probable outcome of the patient. The quality of the initial diagnosis is crucial, not only to the patient, but also to the hospital. If it is wrong, the patient potentially has to suffer from his disease longer and endure unnecessary diagnostics. The costs for the therapy rise substantially, which in Germany means losses for the hospital. Hence, researching performance and enabling quality management in this area is important – for patients and hospitals alike. [2]

Usually, this involves building regional or nationwide registers focusing on specific illnesses or patient groups [3]. Registers are usually designed with a centralized database using a specialized dataset – a subset of patient data specific for the investigated group. However, concerns about patient data privacy and the potential leak of business secrets for hospitals have been raised and need to be addressed when building a new infrastructure for research in the realm of emergency care.

This work aims to sketch out an IT infrastructure concept that employs decentralized data storage honoring Germany's data privacy laws but still enables data export and analysis using the entire patient record data set of the emergency department. It also empowers hospitals to participate in a network of research sites contributing their patient data for studies. Hospitals can decide about participation for each individual study.

1. Methods

1.1. Requirements for research

For most studies observing patients, sample size is key. Gathering more data can be facilitated by collecting data from multiple study sites. To support big data applications, huge data pools are required – like a nation-wide registry. Once collected, a standardized way for data-retrieval and analysis is needed. This requires semantically comparable and syntactically compatible data. The logical place to ensure these requirements for routine care data is at the point of entry into the (computer-) system. Only if the medical workers (physician, nurse, emergency technician) use the same concepts to document their findings, data can be used for analysis. Strict adherence to a standard is needed to ensure comparability and terminological bindings should exist to clearly define the concepts.

A potential study site needs a way to contribute its data to the pool. For electronic submission, this requires a technical protocol and semantic encoding or annotation. For many study sites to contribute, it takes a standardized protocol and implementation guidelines. Patients, who seek help in an emergency room, receive care from a variety of medical professionals. Every caregiver documents his findings and performed procedures in a file. Hence, these files contain all the information needed to perform care analysis. Most hospitals have neither a defined structure for documentation nor a digital file that spawns over multiple specialties. Fortunately, we can rely on prior work by experts in the field of emergency care and documentation. Their German emergency room protocol was concerted by 18 medical societies of different specialties in Germany [4]. On top of standardized content within the files, a standardized way for (digital) transport of such documents is needed.

A researcher has to be able to query the data in the repository. A real time answer or short response time is not required. Most studies take month of preparation, applying for funding and required permissions, so an additional delay seems acceptable.

1.2. Ethical and legislative principles, requirements and constraints

In the European Union and in Germany, data privacy is a right guaranteed by law. Regulations for a nationwide emergency register are numerous – even outside the EU [5]. An institution or hospital providing care is not allowed to hand patient information over to a third party, unless it is anonymized. We are prohibited from creating a centralized database of all patients from all the participating hospitals, because the data set contains many sensible variables. Building a centralized register with the complete emergency care dataset is not possible according to German data privacy laws. Also a patient's entry in the dataset contains too many data items allowing for de-anonymization. Therefore the result of a query needs to be k-anonymized, l-diversified [6] and must only be stored by the researcher who requested it. Every query to the register has to be logged, creating an audit trail. Also, every query has to be reviewed regarding ethical principles and data privacy.

Trust among hospitals participating in a registry and between scientists in general can be a big issue and should therefore be addressed. Decentralized IT-based infrastructures have been shown to reduce friction by making data- and sample-sharing strictly opt-in [7]. Financial interest could also hinder sharing, since handing over full records to an external party might help competitors to gain market share (especially in lucrative niches).

2. Results

2.1. Concept for a data query process

To honor the patients' data privacy, we only store their data in a local data warehouse on the premises of the hospital they were treated at (see figure 1). Only local ER personnel and local administrators have access to this system. To create a bigger registry of records spanning multiple hospitals, the local data warehouses can enter a network – either over a secured connection or asynchronously via encrypted file transfer. This network (as shown in Figure 1) enables researchers to file applications for data (1) that need approval by an ethical, scientific and data privacy board (2). Queries are formalized (3), sent to each of the participating data warehouses (4) and can be run automatically after a local data manager has consented. Results of a query are encrypted and packaged to be transported to an independent data broker (5) – not to the entity formulizing the query. This broker has to ensure that no individual patient can be de-anonymized due to a specific combination of attributes (like sex, age, location, illness, operation date). To achieve this, he will enforce a set of predefined metrics for k-anonymity and l-diversity on individually encrypted field contents. This involves blurring the data (at the local data warehouse) or completely deleting records from the set (at the data broker) in case the minimum requirements are not met. As a last step, the data is sent to the researcher and decrypted (6). A study log containing meta-data (research question, query, clinics that consented) is kept throughout the process.

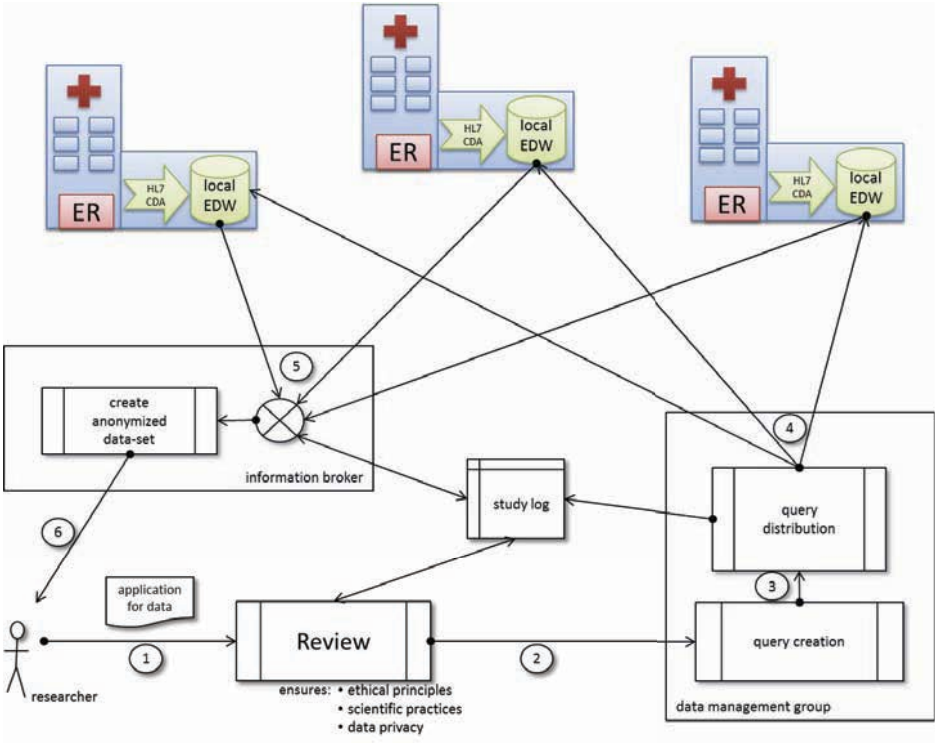


Figure 1. schema of information and data flow according to the concept presented. (ER = emergency room, EDW = emergency data warehouse).

2.2. Software Architecture

The local data warehouses will be implemented using i2b2 software to store patient information exported from an electronic medical record system, like Murphy et al. have described before [8]. The local emergency data warehouse will run on a dedicated (virtual) machine and communicate with other clinical systems using the HL7 protocol. Our preferred technique for importing a patient record from the ER will be an HL7 version 3 Clinical Document Architecture (level 3) document [9]. Such an XML file contains both a defined structure with human readable information and terminological bindings. To map concepts to standard terminologies or classifications, we will employ a process similar to a project for pre-hospital emergency care [10]. Only accepting documents that comply with this standard would ensure only importing and storing information with the correct concepts. However, we have to acknowledge that most hospitals will currently not be able to support the creation of HL7/CDA-documents. Therefore we will – upon request only – enable importing HL7 version 2 messages, but also demand terminological encodings.

3. Discussion

We have designed an IT system and organizational process that honor patients' data privacy. Though complicating data extraction and explorative analysis, they don't necessarily hinder data export and analysis. The organizational oversight implemented in our infrastructure should prevent fraud and ensure patient data privacy.

Connecting multiple i2b2 instances to form a potentially nationwide network to execute research queries is not a new idea. The Data Sharing Network (SHRINE) was used in multiple projects using multiple i2b2 installations to achieve distributed data extraction [11]. In contrast to our architecture, each participating site had to translate a standard query to match the local database of concepts. Additionally, to account for our very specific requirements, we cannot simply adopt a generic approach. At the very least, we will have to implement certain check points where the consent of the local hospitals CIO (chief information officer) is – at least implicitly - needed.

Other approaches, similar to ours, to build an infrastructure for registries by extracting data from medical records have been proposed. It appears our solution is unique regarding the implementation of an information broker (or data broker) as an independent entity. This is both an organizational and technical challenge. Implementing and evaluating the presented infrastructure is the goal of our publicly funded research project "AKTIN".

With regard to actual implementation, we believe data extraction from electronic medical records using HL7 CDA to be the hardest challenge. We need software creators' cooperation to implement features into their products as well as administrators at each site to ensure necessary configuration with terminological bindings.

Altogether, we believe the presented infrastructure and the defined processes provide considerably more data privacy assurances and better balance the need for big sample sizes and data privacy.

References

[1] C.H. D. Jones et al., The safety netting behaviour of first contact clinicians: a qualitative study, *BMC family practice (*2013), 140.
[2] J.M. Pines et al., Exogenous predictors of national performance measures for emergency department crowding, Annals of emergency medicine 3 (2012), 293–298.
[3] A.L. Asher et al., The National Neurosurgery Quality and Outcomes Database and NeuroPoint Alliance: rationale, development, and implementation, Neurosurgical focus 1 (2013), E2.
[4] F. Walcher et al., Medizinische Dokumentation: Kerndatensatz „Notaufnahme", Dtsch Arztebl International 12 (2011), 626–628.
[5] A.L. Asher et al., Regulatory considerations for prospective patient care registries: lessons learned from the National Neurosurgery Quality and Outcomes Database, Neurosurgical focus 1 (2013), E5.
[6] A. Machanavajjhala et al., L -diversity, ACM Transactions on Knowledge Discovery from Data 1 (2007), 3–es.
[7] M. Lablans et al., Providing trust and interoperability to federate distributed biobanks, Studies in health technology and informatics (2011), 644–648.
[8] S.N. Murphy et al., Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2), Journal of the American Medical Informatics Association : JAMIA 2 (2010), 124–130.
[9] R.H. Dolin et al., The HL7 Clinical Document Architecture, Journal of the American Medical Informatics Association 6 (2001), 552–569.
[10] B. Edeler et al., LOINC in Prehospital Emergency Medicine in Germany - Experience of the `DIRK´-Project, Methods of information in medicine 6 (2013),
[11] A.J. McMurry et al., SHRINE: Enabling Nationally Scalable Multi-Site Disease Studies, PLoS ONE 3 (2013), e55811.

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Patient Information, Consents and Privacy Protection Scheme for an Information System Dedicated to Pervasive Developmental Disorders

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Abstract. Patients explicit and unambiguous information, patients consents and privacy protection are reviewed in this article, in the frame of the deployment of the information system TEDIS dedicated to autism spectrum disorders. The role of the Delegate to the Protection of Data is essential at this stage. We developed a privacy protection scheme based on storing encrypted patients personal data on the server database and decrypting it on the Web browser. It tries to respond to the end-users request to manage nominative data in a human readable form and to meet with privacy protection framework.

Keywords. TEDIS, privacy protection, patient consent, pervasive developmental disorder, autism spectrum disorders, patient information system

Introduction

An information system TEDIS [1,2], dedicated to patients with Pervasive Developmental Disorder (PDD), also called Autism Spectrum Disorders (ASD) [3,4, 5,6], was developed by the Department of Child Psychiatry and the department of Biostatistics and Medical Informatics in Necker University Hospital, Paris. It aims to support the medical community and public health decision makers to improve knowledge about the psychopathological, physio-pathological and etiological processes related to ASDs, to follow-up incident patient cohorts and to support decision making, patient's care and research. Systematic, exhaustive and continuous multi-centric patient data collection will then be developed in the nine ASD patient assessment centers in Ile-de-France district (about 600 ASD patients evaluated every year).

Information collected for ASD patient assessment includes social environment and life events, birth context and development during the first years of life. The actual

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assessment consists of a battery of diagnosis instruments, and developmental tests with specific scores and developmental age for each test. ASD patient assessment also includes additional information in genetics, neurology, electro-encephalography and radiology. The political and social context concerning ASD justifies the attention of the legislator at the National Commission Computing and Freedom (CNIL) [7] and at the Advisory Council for Information Processing in the Domain of Health Research (CCTIRS) [8]. Despite the robustness and rigor of user authorization, access control protection and security built in TEDIS, the CCTIRS expressed some reserves. The CCTIRS asked further questions concerning patient privacy protection, information and consents to participate to TEDIS study and to authorize secondary use of her/his personal and clinical data.

TEDIS end users are child psychiatrists, residents, psychologists, medical secretaries and authorized team members. They requested the functionality to directly manage patient personal information in a human readable form to link and check reliably clinical data.

We will present in this article the privacy protection scheme we developed to meet with the CCTIRS criteria and the end-users claimed functionalities. We will also point out major modifications introduced in the patient information notice and consent forms.

Literature review and related work

The 1973 Report of the Secretary of Health, Education and Welfare Advisory Committee on Automated Personal Data System [9] recommendations about policies dealing with Fair Information Practices insisted on individual rights to find out what information about him or her was recorded, if it is used for its original purpose and right to amend identifiable information. In direction of companies and organizations, the report insisted on their obligations to guarantee reliability of personal data for their intended use and to prevent misuse.

The EU directive on processing personal data specifies the right to privacy with respect to processing of personal data [10,11]. It distinguishes: *"Privacy can be defined as the ability of an individual or group to keep their lives and personal affairs out of public view... Confidentiality is more concerned with the responsibility of individuals, companies or organizations that may collect and store such information on others, and the need to ensure that only authorized individuals are allowed access to that information".*

A survey of 20 OECD countries explored the extent to which countries have developed and use personal health data. In conclusion, the authors pointed out the potential role of OECD in supporting building law and policy frameworks *"to strengthen national health information infrastructure so that privacy-respectful uses of data for health, health care quality and health system performance monitoring and research become widespread, regular activities"* [12].

O'Kane and al. [13] reported a study results where "*further exploration of both temporarily-sensitive privacy perspectives and new options in consent management that support shifting privacy concerns over one's lifetime*". Jing Jin et al.[14] suggested an application *"to collect a patient's access control policies as patient consents, and uses these consents to selectively share the patient's medical information".*

Privacy protection also relies on architectural organization of medical and personal data. As example in favor of distributed versus centralized organization [13]: *"this allows the medical data to stay at the place of origin – GP-thus allowing for changes requested by patients, perhaps based on changing privacy attitudes, to be fulfilled at their local GP' office* […] *This decentralized architecture will have to allow privacy-preserving statistical data aggregation of data to be transmitted to the researchers to support medical studies"*.

In a different context [15], patient privacy infringement may occur at the server side which makes the server-side untrusted. The authors suggested to encrypt patient privacy data and to save them on the server database. The privacy scheme runs on the client side. It comprises: an index generator to encrypt privacy data, a query translator built on privacy data and runs at the server side, and a query executor that has to process through the query translator before accessing decrypted privacy data.

1. Methods

TEDIS information system was organized into a production database, permanently updated by end-users and a data warehouse, periodically fed by the production database with consolidated, de-identified aggregated patient data. Only de-identified data of the data warehouse will be used for TEDIS future research projects. Such organization matches with the CCTIRS request. Our concern in the present work is related to the TEDIS production database.

1.1. Participant consents:

The second group of the CCTIRS questions concerned participant information notice, participant informed consent and participant consent for secondary use of her or his data. We asked for an expert counselling from a Privacy Officer or PO. We introduced the following modifications to the original documents:

In the patient information notice, TEDIS objectives were strictly conforming to the CCTIRS authorization application. A special information statement made it explicit that the participant agreement or refusal to participate in TEDIS study project will not affect in anyway, her or his care.

"Non-opposition" consent was added to the participant approbation. It explicitly stated that the participant is not opposed to the secondary use of her or his medical data collected for another purpose than for TEDIS project. A special mention of medical data drawn from genetics, electro-encephalography and imagery was made explicit in the non-opposition consent.

1.1.1. Participant privacy protection scheme:

Authentication and access control: TEDIS information system is intended to be used in a multi-centric approach by child psychiatrists and team members. Only authorized users with username and password may use TEDIS system. Access control procedures are built around the assessment centres: authorized users may only access to the assessment centre where they are in charge of the PDD patients care and follow-up.

Patient personal data encryption: It is easier to automatically manage patient personal data than to manually maintain a patient list with personal information and the corresponding TEDIS identifiers.

In order to meet with the CCTIRS request and to respond to the end users claim to manage personal data in a human readable form, we propose a solution consisting of saving encrypted patient personal data on TEDIS server database and decrypting it, in a human readable form at the end-user interface on the Web-browser.

We selected a high-security data encryption solution called JavaScrypt© which runs entirely in the Web browser [16]. Encryption facilities use the Advanced Encryption Standard (AES) and support symmetric encryption. An interesting feature consists of capturing the instant when the user presses a key or performs various events for which we can request notification and add the time in 255ths of a second to the data array and encryption algorithm.

The encrypted personal information are saved on the server on a separated database we call "patient_iddb". Encrypted information are linked to the clinical database with TEDIS unique patient identifier. To make the access to the link less trivial, we decided to encrypt at the server side, the patient identifier associated with the encrypted personal information. We used a Java™ AES strong encryption algorithm to encrypt in unidirectional way, the patient identifier augmented with additional information saved in the patient clinical database.

When the end-user requests a patient record, the query sent to the server uses the patient identifier to retrieve related clinical data. The query uses the same added information from the clinical database and the same Java™ encryption algorithm, to regenerate on the fly the encrypted patient identifier. This latter will serve to retrieve the appropriate record of the personal encrypted information from the "patient_iddb". The decryption of the personal information occurs at the client side interface using JavaScript tools.

At the client-side, the information brought from the server is displayed sequentially: first the clinical information is displayed. It needs no further processing. Then the decryption of personal information with the paired encryption key occurs on the HTML page layer which supports JavaScript language instructions.

2. Results

The encryption program of personal information is fully functional for the creation, encryption, update, retrieval and correct display of patient personal information appropriately linked to clinical data. Retrieval and correct display works for individual patient record as well as for a list of patients treated at the child psychiatry department.

The sequential processes of data retrieval, decryption and display in the Web browser are fast, less than one millisecond per record, and transparent to the end-user.

The overall solution including modifications of patient information notice, participant consents, data control access procedures and the encryption scheme was validated by the PO at the Juridical Affairs Office of the University Paris Descartes. The overall solution was accepted by the CCTIRS.

3. Discussion and Conclusion

Free text TEDIS participant personal information is easy to manage and link to the clinical data. Data quality control is facilitated and the system remains safe for the protection of patient privacy [13]. In case of illegal access or intentional database misuse at the server side, the intruder will not be able to access to the free text participant personal data.

Personal information encryption however, prevents from using phonetics to anticipate detecting potential duplicates.

The PO profile is emerging into companies and organizations which manage personal and private data particularly in health care settings. The European directive [11] allows country members to create the function of Delegate to the Protection of Data. The tendency is to systematize the recruit of such profile in European countries [17].

References

[1] Ben Said M, Robel L, Pellegrin-Touati M, Rousselot-Pailly B, Golse B, Jais JP,Landais P.TEDIS, Pervasive Developmental Disorder' patients information system, preliminary results. *Stud Health Technol Inform*. 2012;180:285-9.

[2] Ben Said M, Robel L, Vion E, El Ghazali A, Golse B, Jais JP, Landais P.Implementation and experimentation of TEDIS: an information system dedicated topatients with pervasive developmental disorders. *Stud Health Technol Inform*.2011;169:270-4.

[3] Amaral DG. The promise and the pitfalls of autism research: An introductory note for new autism researchers. Brain Res. 2011 Mar 22;1380:3-9. Epub 2010 Dec 1.

[4] Wilson HS, Skodol A. Special report : DSM-IV : overview and examination of major changes. *Arch. Psych. Nurs.* 1994 Dec.

[5] Chamak B. Autism and social movements : french parents' associations and international autistic individuals' organisations. In: Sociology of Health & Ilness Vol. 30 N. 1 2008 ISSSN 0141, pp. 76- 96.

[6] Vohra R, Madhavan S, Sambamoorthi U, St Peter C. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. *Autism* December 18, 2013 1362361313512902- [Epub ahead of print]

[7] http://www.cnil.fr (last visited on May 2nd 2014)

[8]http://www.enseignementsup-recherche.gouv.fr/cid20537/cctirs.html last visited on May 2nd 2014

[9] Rutherfoord RH, Rutherfoord JK. Privacy and Ethical Concerns in Internet Security. SIGITE'10, October 7-9, 2010, Midland, Michigan, USA. ACM 978-1-4503-0343-9/10/10.

[10] ETSI EG 202 487 V1.1.2 (2008-02)Human Factors (HF);User experience guidelines; Telecare services (eHealth)http://docbox.etsi.org/STF/Archive/STF355_eHealth_UserServiceModels/PrepMeet/STF%20initial%20documents/TC%20HF/eg_202487v010102p.pdf (last visited May 2nd 2014)

[11] Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and of the free movement of such data. http://ec.europa.eu/justice/policies/privacy/docs/95-46-ce/dir1995-46_part1_en.pdf (last visited on Jan 31st/2014).

[12] Oderkirk J, Ronchi E, Klazinga N, International Comparisons of Health systemPerformance Among OECDCountries: Opportunities and Data Privacy Protection Challenges, *Health Policy.* 2013 Sep;112(1-2):9-18.

[13] O'Kane AA, Mentis HM, Thereska, Non-Static Nature of Patient Consent: Shifting Privacy Perspectives in Health Information Sharing. *CSCW '13,*February 23–27, 2013, San Antonio, Texas, USA - *ACM* 978-1-4503-1331-5/13/02.

[14] Jing Jin, Gail-JoonAhn, Hongxin Hu, Michael J. Covington, Xinwen Zhang, Patient-centric Authorization Framework for SharingElectronic Health Records, *SACMAT'09,* June 3–5, 2009, Stresa, Italy.*ACM* 978-1-60558-537-6/09/06, pp :125-134

[15] Chenglang Lu · ZongdaWu ·Mingyong Liu ·Wei Chen · JunfangGuo, A Patient Privacy Protection Scheme for Medical Information System, *J Med Syst* (2013) 37:9982, pp 1-10.

[16] http://www.fourmilab.ch/javascrypt/ last visted on May 2nd 2014

[17] http://ec.europa.eu/dataprotectionofficer/index_en.htm last visited on May 2nd 2014

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9. Research and Education

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Clustering physical activity phenotypes using the ATLAS index on accelerometric data from an epidemiologic cohort study

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Abstract. While many studies have identified associations of physical activity with both mortality and morbidity, the effects of different dose-patterns are still unclear. Employing the recently introduced ATLAS index, the aim of the research work for this paper was to investigate whether physical activity phenotypes can actually be extracted from a large-scale epidemiological accelerometer data set, and if these match the ones proposed. The ATLAS parameters were computed for 6386 data sets from the NHANES 2005-2006 cohort study, and x-Means clustering was performed on the results. Thus, four distinct clusters were identified, named: 'insufficiently active', 'irregularly active', 'busy bee' and 'physical worker/ weekend warrior'. In conclusion, it is possible to identify different activity phenotypes using the ATLAS index. More research is necessary with regard to the regularity component and the relation of activity patterns and medical parameters in the groups identified.

Keywords. Accelerometry, physical activity, cohort studies, pattern recognition

Introduction

Physical activity is well known to be associated with a person's cardiovascular risk factor profile and also influences the prevalence of musculoskeletal diseases [10; 11]. The beneficial effects of increased physical activity have been demonstrated in numerous studies [5]. While a general beneficial association has been established, its causes, their effects and the pathways in-between are still under investigation. Despite this, on the basis of epidemiologic data and empirical studies, several recommendations for physical activity for different population groups are in effect. These include those of the American Heart Association (AHA) and the American College of Sports Medicine (ACSM) [3] as well as of the World Health Organisation (WHO) [8]. While these recommendations refer to rough measures of intensity (e.g. "moderate" or "vigorous"), duration and frequency, it remains unclear which dose patterns of daily life activities will have an optimal effect on risk factors, and ultimately on clinical outcome parameters.

Large scale cohort studies such as NHANES, UK BIOBANK or the upcoming German National Cohort may provide researchers with data to facilitate the investigation of detailed dose-effect relationships. Most recent cohort studies use

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actimetry devices, primarily triaxial accelerometers, to record activity over extended periods of time, usually at least one week. State-of-the-art devices feature triaxial measurements and high sampling rates (100Hz), allowing for much more detailed motion analysis than just for determining the active energy expenditure (AEE) or counting steps [2; 7]. As there is some evidence, that not only intensity and duration influence clinical outcome parameters [4], but also the distribution of the activity events across time, in other words their regularity, the author has recently introduced the three-dimensional ATLAS index (*Activity Types from Long-term Accelerometric Sensor data*), aiming to enable identification of activity patterns using regularity, duration and intensity as characteristic parameters [6]. Along with the index, five archetypal activity phenotypes have been proposed. Thus far, however, it remains unclear if the ATLAS index is useful to distinguish between different physical activity groups, and if the proposed or other archetypal phenotypes can be identified in large scale, real-world data sets.

With regard to these research questions, the aim of the work for this paper was to apply the ATLAS index on a large cohort accelerometer data set to investigate whether physical activity archetypes can actually be extracted and whether these match the ones proposed by the author.

1. Methods

1.1. Data set, preprocessing and computation of ATLAS index parameters

The mathematical and computational details of the ATLAS index have been presented in [6]. To validate the physical activity groups, a large and freely-available data set was obtained from the NHANES 2005-2006 investigation [1]. Within this cohort study, the ActiGraph device was used, providing accelerometer-based data, aggregated to minute values. For further data analysis on an individual basis, and to improve handling, the large data set was split into small sets, each for one individual participant. For each of these files, the ATLAS parameters (regularity, duration and intensity) were computed by intensity-threshold-based identification of activity events lasting for at least five consecutive minutes, and by subsequent extraction of the regularity parameter. All analyses were performed on a high-performance computer system using scripts developed by the author with the R statistics package. The resulting data set contains the three ATLAS parameters for each study participant.

1.2. Physical activity phenotype analysis

To identify archetypical activity phenotypes in the accelerometer data sets, the author has chosen to use a clustering technique. As the actual number of distinct activity types is yet unknown, conventional clustering techniques such as k-Means, which demand setting the number of clusters before applying the algorithm, had to be ruled out. Thus, the author chose to use the x-Means algorithm first introduced by Pelleg et al [9], expanding the well-known k-Means approach by an efficient way of determining the number of clusters automatically. The clustering algorithm was applied using its implementation in the WEKA open source data mining toolkit (version 3.6).

2. Results

From the original NHANES data set, 6386 single data sets – one for each participant – were extracted. The *x-Means* clustering algorithm yielded four distinct groups within the data based on the ATLAS parameters. Table 1 shows the characteristics of these groups with regard to their clustering centroids.

Table 1. Results of x-Means clustering on ATLAS parameters: duration, intensity and regularity.

	N	duration [minutes * 1/1000]	intensity	regularity
Cluster 1	158 (2%)	3.12	1.1	3.55
Cluster 2	4264 (67%)	5.83	1.09	0.2
Cluster 3	72 (1%)	199.56	1.78	0.01
Cluster 4	1892 (30%)	27.97	1.23	0.07

3. Discussion

First of all, the results show that it is indeed possible to identify distinct clusters of persons on the basis of their ATLAS index scores. Thus, we can conclude that the ATLAS parameters provide relevant information which may be useful to actually identify different activity phenotypes in populations. Regarding the distribution of the study population, it is obvious that the majority of this population was – to a large extent – inactive. This is also reflected by the largest cluster found – Cluster 2 – which is characterized by very low mean activity duration (3.1 per 1000 minutes) and very low intensity and regularity scores (1.09, 0.2). This cluster group comprises two thirds of the entire population (N=4264) and could be named "insufficiently active", as proposed by Lee at al [4]. This first result confirms the fact known from literature that a large part of the population – in this particular case from the U.S. – has an inactive, sedentary lifestyle. Located close to Cluster 2 is Cluster 4, making up for another 30% of the study population (N=1892). This group is characterized by a low regularity score (0.07), but higher mean activity duration (28 per 1000 minutes) and a higher intensity score (1.23) than the previous group. These persons engage in physical activity for a mean duration of 40 minutes per day, but very irregularly. This group was not yet proposed by the author, and may be termed "irregularly active".

In contrast to the two large cluster groups presented so far, Clusters 1 and 3 represent only 3% of the study population. Cluster 1 members (N=158) show low scores for mean activity duration (3.12 per 1000 minutes) and intensity (1.1), yet these activity events are regularly distributed over time. This group might be the proposed "busy bee" group, but the author would have expected a higher duration level. One reason for the observed low mean duration level could be that only events of at least five consecutive minutes were considered for potentially effecting a relevant metabolic activation, and that thus shorter events (e.g. walking a flight of stairs, walks between offices, etc.) may have been disregarded. Another reason may be that the threshold values used for identifying activity events – for which there are no default values yet – are still too high to detect low-intensity daily-life activity, which may also be relevant.

The final Cluster 3 is the smallest one (N=72), yet exhibits distinct characteristics: The mean duration amounts to 200 per 1000 minutes, in other words 287 minutes per day. The intensity level is very high (1.78), and the regularity is low (0.01). Considering the extremely high duration of nearly five hours a day as well as the high intensity level, is seems likely that the persons in this group are workers engaged in intensive physical work, e.g. in construction or road work. Irregularity can be attributed to their rest periods, e.g. on weekends. The pattern also matches that of the so-called "weekend warrior", and this type is likely part of the cluster group, however with a lower than mean activity duration.

The author was not able to identify the proposed "athlete" group with high values for all three parameters (duration, regularity and intensity).

3.1. Limitations

While the current ATLAS index parameters allow for identifying physical activity groups, the regularity parameter, which is currently defined as the normalized inverted variance of time periods between detected activity events – may be too "strict" to grasp normal human behavior. The author therefore suggests two improvements: firstly, within the event detection algorithm to distinguish between high intensity activities, as performed by an athlete or a physical worker, and low-intensity activities, and secondly, by using a running mean filter on the event distribution periods for the high-intensity events. Furthermore, based on mean duration, a reasoning component should be integrated for distinguishing between physical workers and persons with sportive activities, because these groups might exhibit completely different risk profiles and currently cannot be separated from each other with the ATLAS index.

4. Conclusion

This paper has shown that using the ATLAS index on large scale data sets of epidemiological cohort studies is feasible, and that it enables researchers to identify different activity phenotype groups. It was not possible to identify all the groups proposed by the author previously [6]. Further research work is necessary to adjust the regularity parameter for more closely reflecting human behavior. In addition, the identified groups need to be tested for associations between their activity parameters and their medical risk profile. Finally, studies have to be performed with regard to clinical outcome parameters such as mortality or the prevalence and incidence rates of specific disease conditions.

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References

[1] Centers for Disease Control and Prevention (CDC). National Center for Health Statistics (NCHS), National Health and Nutrition Examination Survey Data, in, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Hyattsville, MD, 2013. Accessed Oct 30, 2013, http://www.cdc.gov/nchs/nhanes/nhanes2005-2006/PAXRAW_D.htm.

[2] M. Gietzelt, K.H. Wolf, M. Kohlmann, M. Marschollek, and R. Haux, Measurement of Accelerometry-based Gait Parameters in People with and without Dementia in the Field. A Technical Feasibility Study, Methods Inf Med 52 (2013), 319-325.

[3] W.L. Haskell, I.M. Lee, R.R. Pate, K.E. Powell, S.N. Blair, B.A. Franklin, C.A. Macera, G.W. Heath, P.D. Thompson, and A. Bauman, Physical activity and public health: updated recommendation for adults from the American College of Sports Medicine and the American Heart Association, Circulation 116 (2007), 1081-1093.

[4] I.M. Lee, H.D. Sesso, Y. Oguma, and R.S. Paffenbarger, Jr., The "weekend warrior" and risk of mortality, Am J Epidemiol 160 (2004), 636-641.

[5] M.F. Leitzmann, Y. Park, A. Blair, R. Ballard-Barbash, T. Mouw, A.R. Hollenbeck, and A. Schatzkin, Physical activity recommendations and decreased risk of mortality, Arch Intern Med 167 (2007), 2453-2460.

[6] M. Marschollek, A semi-quantitative method to denote generic physical activity phenotypes from long-term accelerometer data--the ATLAS index, PLoS One 8 (2013), e63522.

[7] M. Marschollek, M. Gietzelt, M. Schulze, M. Kohlmann, B. Song, and K.H. Wolf, Wearable sensors in healthcare and sensor-enhanced health information systems: all our tomorrows?, Healthc Inform Res 18 (2012), 97-104.

[8] W.H. Organization, Global Recommendations on Physical Activity for Health, WHO Press, Geneva, 2010.

[9] D. Pelleg and A.W. Moore, X-means: Extending K-means with Efficient Estimation of the Number of Clusters, in: Proceedings of the Seventeenth International Conference on Machine Learning, Morgan Kaufmann Publishers Inc., 2000, pp. 727-734.

[10] J. Sattelmair, J. Pertman, E.L. Ding, H.W. Kohl, 3rd, W. Haskell, and I.M. Lee, Dose response between physical activity and risk of coronary heart disease: a meta-analysis, Circulation 124 (2011), 789-795.

[11] J. Woodcock, O.H. Franco, N. Orsini, and I. Roberts, Non-vigorous physical activity and all-cause mortality: systematic review and meta-analysis of cohort studies, Int J Epidemiol 40 (2011), 121-138.

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Towards a Trial-Ready Mobile Patient Questionnaire System

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Abstract. Gathering patient-reported data enables physicians to know a patient and his/her health-related needs in a more comprehensive way. One method to collect these data is to let the patient fill out electronic questionnaires on a mobile device, e.g. a tablet. Although having successfully implemented a prototype, the mobile questionnaire system at this site has been stretched to its limits within both routine care and clinical trials. By collecting user feedback and analysing the capabilities and limits of the underlying framework, we identified key issues of the prototype. A new implementation addresses these obstacles while keeping the overall application logic and usability. This leads to a trial-ready mobile patient questionnaire system.

Keywords. Questionnaires, Quality of Life, m-health, patient reported outcomes, medical documentation

Introduction

To guarantee the best treatment in patient-centred care settings, medical experts need to know not only a patient's clinical picture, but also his/her social context and preferences, which implies collecting all relevant information. Unfortunately, due to the increasing workload of clinicians, the available time at the bedside and thus the possibility to collect this information is decreasing.
Patient Reported Outcomes (PRO), i.e. patient data gathered and provided by him-/herself or the patient's relatives without the physician's assistance, can be helpful to get a better understanding of the patient's context and his/her perception. This information is useful to find the precise diagnosis and the best therapy for the individual patient, which can lead to improved, personalized healthcare.

Gathering patient-based data is usually done via paper-based questionnaires that are filled out by him/her in the waiting room. There are two different approaches to transfer the questionnaire results into the Electronic Health Record (EHR). First a medical staff member can typewrite it into the EHR, to make it electronically available for both routine care and research purposes (following the Single Source approach [1]). The second approach is to scan the paper-based questionnaire and make it available within the EHR documentation of the patient. The approaches contain several drawbacks: typewriting or interpretation errors might occur, the data of scanned questionnaires is not accessible in a structured way, delivery of patient data to the physician is delayed and the task itself is both cumbersome and cost-ineffective. To

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overcome the media disruption, some projects already implement an electronic questionnaire system that allows the patient to answer a digital survey [2]. At this site, such a system called "Mobile Patient questionnaire (MoPat)" has been implemented prototypically in 2010 and was evaluated regarding usability and cost-efficiency [3]. The implementation provides web-based patient questionnaires. In contrast to other systems, completed questionnaires are exported to the EHR System instantaneously in a data format that is both re-usable and compliant to the EHR system's data structure.

Although being successfully deployed, the prototype has been stretched to its limits, not only because of the recent security issues of the underlying programming framework [4], but also in terms of infrastructural conditions. To make the system future-proof and scalable, the existing prototype, its usage and the underlying infrastructure have been analysed and changed accordingly. This manuscript describes the issues identified and the newly implemented solutions.

1. Methods

During usage of the MoPat system in the participating clinics, we asked ten clinicians about occurring problems and feature requests for additional scenarios. Either direct, open interviews via telephone or email have been conducted. The interviews were unstructured to give the users the possibility to describe their impressions and features comprehensively. The information given by the users were analysed and the issues and feature requests were prioritized by importance.

After gathering the user's feedback, we conducted code reviews to estimate the amount of work that had to be invested to solve the issues addressed and features requested. The code review considered recent issues like security, feature potential of the underlying programming framework and the staff's knowledge about it.

After analyzing on the one hand the user requests and on the other hand the potential of the programming framework, we decided to develop a new version of MoPat. As the use of a web-based approach turned out to be a good choice we decided to follow the approach.

We introduced test automatisms that check the source code with unit tests each time a new version is built or a code review has been conducted. Additionally, monitoring services that observe the currently running version and check basic features automatically using the Selenium framework on a frequent basis were deployed.

2. Results

2.1. Issues of the prototype and feature requests

The users mainly reported one issue and one feature request: missing network connectivity and readiness for the conduction of clinical trials.

Although network connectivity is increasing within the hospital, a wireless network connection is only consistently available at the registration desk. Unfortunately, the web-based prototype was built to only request a single question from the server, present it to the patient, send the answer(s) back to the server and request the next question consecutively. Due to this implementation, a network connection is necessary during the patient's survey. Since the patient usually conducts

the survey in the waiting or patient room, network connectivity at the registration desk alone is not sufficient. Two obvious solutions might be to provide wireless network at the waiting/patient room or to use cellular data. The first one does not cover the scenarios of deployment in additional clinics or moving patients. The second one does not comply with the local and probably most data protection guidelines as long as the tablet computer displays patient data. Thus, the implementation has to be adapted.

The prototype was already able to export PRO data in an XML format, which is both human readable and machine processable. Since patient data that is available in such a format is well-structured, it can be both imported into an EHR and be used within clinical trials. However, the availability of structured data alone is not sufficient for utilizing a tool within clinical trials. Data formats acknowledged by the Food and Drug Administration (FDA), e.g. CDISC ODM [5], are necessary to enable researchers to submit their trial results. Additionally, regulatory requirements, such as documentation of the development, extensive software tests and code reviews, have to be met as well.

The technical analysis of the prototype led to two results: (1) the underlying framework is still vulnerable to common web-based attacks, such as Cross-Site-Scripting (XSS) or Denial-Of-Service (DOS), which in part allows the attackers to gain information of/from the application or even compromise the system; (2) new features, like additional types of questions, export to CDISC ODM files or full audit logs would consume a lot of programming effort. The utilized framework is designed for rapid software prototyping, which means that requirements are quickly implemented by following the "convention over configuration" pattern and creating modern graphical user interfaces automatically. This property supports the development of prototypes, but makes it cumbersome for developers to implement complex additional application logic. Additionally, the local knowledge about the framework was not as extensive as about other programming languages and frameworks.

2.2. Solutions in the new mobile questionnaire system

The resulting new version of the MoPat system covers all features of the prototype: It supports questions for which the patient can choose one to several answers (multiple choice), write a free text answer, pick a certain date, choose a value on a visual analogue scale (both horizontally and vertically) or Likert scale. Each question is presented separately on a single screen to guarantee high usability.

To address the connectivity issues, the questionnaire(s) is/are completely transmitted in the beginning of the survey, and network connectivity is only necessary at the end of the survey. Until then, each new answer given by the patient is sent to the server following the "fire and forget pattern", which means that the request is fired to the server but the server's response is ignored. The jQuery-based business logic at the client-side takes care of displaying the next question and storing the given answers as long as the server did not confirm the latest update in the background. This implementation has even been successfully tested within an investigator-initiated trial (IIT) at another site. The application server deployed at this site delivers the complete questionnaire via a VPN-secured cellular connection to the remote client; no lag could be identified while answering the questions.

A template-based export allows administrators to upload an empty file either in the XML structure already known or ODM. The application detects placeholders to put the patient's responses into and exports these PRO data following the given template.

The issue of the utilized programming framework is solved by the use of a well-known and better supported programming framework for Java, Spring [6]. Java is a commonly used programming language, hence the further development of the redeveloped application is ensured.

Since MoPat is developed as a web-based application, the user interface's look and feel is not like a native application. The new MoPat version uses the jQuery Mobile Framework to improve the look and feel and the input elements. This framework enhances the web site elements with touch-improved behavior. As you can see in figure 1 the graphical user interface is well structured with navigation at the top and providing one single question on every screen.

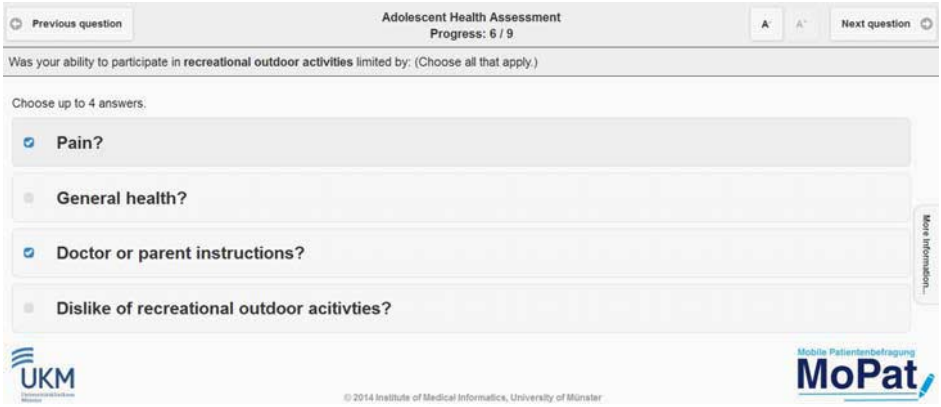


Figure 1. Screenshot of the new version of MoPat used by the patient.

Most clinics provide a single sign-on service to authenticate users within the incorporated software systems. The new MoPat version provides the ability to authenticate users within MoPat via a configurable LDAP (Lightweight Directory Access Protocol) implementation. This simplifies user management and authentication for the clinical users, because no additional passwords are needed.

The application contains a complete audit logging mechanism. It logs the user's and system's action each time a patient's data point is read, written, updated, deleted, transferred or received, together with the calling function and date of processing. The application is only permitted to add additional log entries into the separate database. In summary all identified features and issues are listed in Table 1 including their implementations in the different MoPat versions.

Table 1. Features/issues identified and addressed by the MoPat versions

Feature / issue	MoPat	MoPat redesigned
network connectivity	Required constantly	Required selectively
XML export	Supported	Supported
EDC-compliant export	Not Supported	Supported
XSS vulnerability	Strong	Weak
Adding new question types	Difficult	Easy
Audit logging	Not Supported	Supported
Touch capabilities	Weak	Strong
LDAP authentication	Not Supported	Supported

3. Discussion

The user's feedback has shown that the existing prototype already covered all functional and usability requirements. Nevertheless, additional infrastructural and security issues have been discovered and regulatory needs have been identified. Thus, the existing implementation was not sufficient for a routine, multicenter utilization (within clinical trials) that is both scalable and sustainable.

Although dealing with an infrastructural problem, we were able to solve the mainly reported issue with a design pattern within the program. This does not only enable the application to behave more robustly to connectivity problems, it also takes off the patient's impression of not using the application in the right way due to non-respondence.

In theory the old MoPat could support the documentation process within clinical trials, but the export abilities where not sufficient to transfer the stored data in MoPat to an electronic data capture (EDC) system for clinical trials. In addition a system used in clinical trials has to fulfill certain requirements in code quality, e.g. comprehensive documentation or testing of source code. The new source code is tested with unit tests and the running application, especially the client-side implementation, is automatically tested with Selenium. Thus, the chance to achieve a qualified software certification is higher for the new developed system. To handle the export of the stored data to an EDC system, the new implementation has an integrated ODM export mechanism. This XML data format can be imported by several EDC systems, e.g. OpenClinica, hence no additional transformation has to be performed to make PRO data gathered with MoPat available to EDC systems. By improving the software quality and data export capabilities, we achieved to provide a PRO system that can be utilized in clinical trials.

In conclusion, the new implementation addresses all identified issues both from organizational/infrastructural and development point of views. This leads to a mobile questionnaire system for PRO that is – due to its new capabilities and configurability - ready to be utilized in different scenarios. Both routine PRO data collections in connection with an EHR system and standalone implementations with (direct) exports to an EDC system are now possible and successfully tested.

References

[1] Dugas M, Breil B, Thiemann V, Lechtenbörger J, Vossen G. Single source information systems to connect patient care and clinical research. Stud Health Technol Inform. 2009;150:61–5.

[2] Rogausch A, Sigle J, Seibert A, Thüring S, Kochen MM, Himmel W. Feasibility and acceptance of electronic quality of life assessment in general practice: an implementation study. Health Qual Life Outcomes. 2009;7:51.

[3] Fritz F, Balhorn S, Riek M, Breil B, Dugas M. Qualitative and quantitative evaluation of EHR-integrated mobile patient questionnaires regarding usability and cost-efficiency. Int J Med Inf. 2012;81(5):303 – 313.

[4] Rubyonrails Ruby On Rails: CVE security vulnerabilities, versions and detailed reports [Internet]. [cited Feb. 3rd 2014]. Available at: http://www.cvedetails.com/product/22568/Rubyonrails-Ruby-On-Rails.html?vendor_id=12043

[5] Clinical Data Interchange Standards Consortium (CDISC). ODM Certification & Archiving and Interchange of Metadata [Internet]. 2013 [cited Nov. 12th. 2013]. Available at: http://www.cdisc.org/odm

[6] Walls C. Spring in action. 3rd ed. Shelter Island: Manning; 2011. 400 p.

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Health Information Research Platform (HIReP) – An Architecture Pattern

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Abstract. Secondary use or single source is still far from routine in healthcare, although lots of data are available either structured or unstructured. As data are stored in multiple systems, using them for biomedical research is difficult. Clinical data warehouses already help overcoming this issue, but currently they are only used for certain parts of biomedical research. A comprehensive research platform based on a generic architecture pattern could increase the benefits of existing data warehouses for both patient care and research by meeting two objectives: serving as a so called single point-of-truth and acting as a mediator between them strengthening interaction and close collaboration. Another effect is to reduce boundaries for the implementation of data warehouses. Taking further settings into account the architecture of a clinical data warehouse supporting patient care and biomedical research needs to be integrated with biomaterial banks and other sources. This work provides a solution conceptualizing a comprehensive architecture pattern of a Health Information Research Platform (HIReP) derived from use cases of the patient care and biomedical research domain. It serves as single IT infrastructure providing solutions for any type of use case.

Keywords. Clinical data warehouse, secondary use, primary use, architecture, single source

Introduction

More and more clinical information is available electronically within modern healthcare environments [1]. However reusing clinical information for research based upon a data warehouse infrastructure is still rare. Only few projects doing that do exist [2, 3]. One issue is data availability as electronic medical/health records (EMRs/EHRs) are designed for clinical documentation and restrict access to data on patient care settings. Another issue is data quality. Data are captured in different settings redundantly and hence it is unclear which data are representing the truth.

A clinical data warehouse might help integrate different data sources and thus enable physicians to get a holistic view of the patient. Concerning patient care it would also enable the treating physician to compare the patient's visit to similar visits and make the right conclusions. A clinical data warehouse could also be the single point-of-truth required to improve data quality and hence be a data source for biomedical research.

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An architecture pattern of a research platform has to implement patient care and medical research requirements to better integrate both parts. A clinical data warehouse is meant to be one component of a research platform. Further components necessary for integration of patient care and biomedical research are identified in this study. The objective is to define a generic architecture pattern called *Health Information Research Platform (HIReP)* is defined to better integrate both parts.

1. Methods

The Design and Creation strategy as described by Oates [4] was used. Three data sources were combined in a triangulation to minimize weaknesses in the results. Data sources were use cases, laws and guidelines and an expert panel discussion. First, use cases, which the architecture pattern of a research platform is supposed to implement, were defined. Afterwards, an analysis of German data privacy laws and data privacy guidelines by the *Technology, Methods, and Infrastructure for Networked Medical Research* [5, 6] (acknowledged non-profit association) (TMF e.V.) was performed. This literature analysis was conducted to find out about the specific regulations for research in healthcare settings. Finally the resulting architecture pattern was discussed with an expert panel (TMF working group on data privacy). All results were merged and resulted in the architecture pattern described in the following chapter.

2. Results

2.1. Use cases driving the HIReP approach

The HIReP approach is driven by two major use cases derived from enquiries of the National Center for Tumor Diseases Heidelberg (NCT), the Biomaterial Bank Heidelberg (BMBH) and various departments at Heidelberg University Hospital.

One use case is care-oriented and describes the combination of two different information sources to support patient treatment. This primary use of biomedical information includes a clinical data warehouse and a biomaterial bank. The intended purpose of the clinical data warehouse is to provide an integrated view on patient's health information to support physicians at Heidelberg University Hospital in medical treatment. It integrates structured and unstructured data from multiple data sources and allows for analyzing unstructured documents. Additionally, data can be extracted from unstructured documents and transformed to structured data for further use. All clinical information can be found in the clinical data warehouse. A context integration between EMR/EHR and clinical data warehouse allows for a holistic view of the currently in the EMR/EHR selected patient. The clinical data warehouse also has functionality for comparison of the selected patient's current visit to similar visits of other patients in an anonymized view. In addition to the health information captured in the context of treatment it is of use for the physicians to query the BMBH for available biomaterial like patient's tissue or liquor samples. The query's results should be integrated into the patient's health information view of the clinical data warehouse. This additional information fosters the physicians' decision on further analysis of available biomaterial in support of patient treatment.

The second use case driving the HIReP approach is research-oriented and based on needs of the NCT which is interested in patients' health information captured in the context of treatment as well as in information on available biomaterial. This information is used for research purposes, therefore it has to be either anonymized or - in case there is an informed consent of the patient - pseudonymized medical information. This is contrary to the first use case which requires personalized medical information for patient care. Within the research-oriented use case the information providers are the clinical data warehouse at Heidelberg University Hospital and the BMBH, whose interaction with the information consumer (NCT) could be either separated or combined. The separated mode means that the consumer queries each provider individually whereas the combined mode allows querying various sources with a single request. This request gets forwarded to the addressed information providers and the results of all providers get fused and returned to the consumer. E.g. as a biomaterial bank does not include additional health information of the patient a sample belongs to, the combined approach allows querying for biomaterial of patients with specific health criteria. The identification of patients matching to the given health criteria takes place in the clinical data warehouse.

The HIReP approach provides an integrated and extensible solution for both mentioned use cases.

2.2. High-level architecture of HIReP

Based upon the described use cases and with the prospective extension by additional systems in mind, a generic architecture for HIReP not limited to the initial use cases' scope was designed. Furthermore, it was decided to comply with the restrictive German and European data protection and security guidelines [5-7] for networked medical research. The combination of these guidelines allows for the integration of patient care and research in one platform and results in conformance to the required informational separation of powers. As the second use case matches to the research category and the designed architecture also supports the care-oriented first use case, the HIReP slogan *"primary use enabled, secondary use compliant"* was composed.

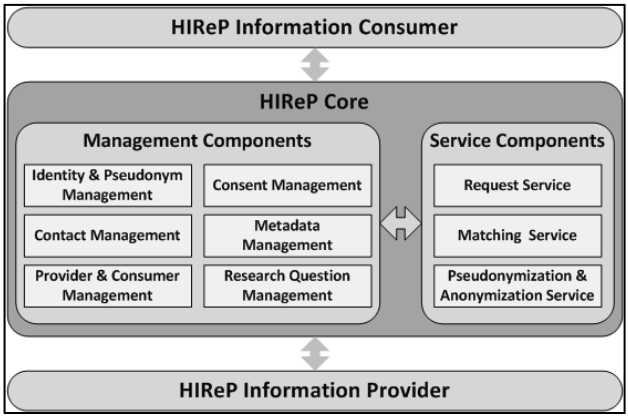


Figure 1. High-level architecture of HIReP

The HIReP architecture shown in Figure 1 is divided into three parts: *HIReP Information Consumer*, *HIReP Information Provider* and the joining *HIReP Core*. The *HIReP Core* is divided into the interconnected sections *Management Components* and *Service Components*. The *Management Components* [8] are characterized by low data variability and low data throughput. Patient's identifying data and related pseudonyms resulting from the dissemination of patient's health information for research purposes are administered by the component *Identity & Pseudonym Management*. This allows for de-pseudonymization in justified cases, e.g. major research breakthroughs supporting further treatment of the patient. The component *Consent Management* keeps track of patients' informed consents related to the further dissemination of their health information for medical research. Based upon an informed consent the health information can be disseminated pseudonymized otherwise anonymized. The *Contact Management* [9] component allows addressing and informing patients in case of justified de-pseudonymization. As HIReP enables flexible information consumer and information provider extension the architecture includes on the one hand a *Provider & Consumer Management* and on the other hand a *Metadata Management*. The *Provider & Consumer Management* is a service registry with an extension to define and administer permitted connections between consumers and providers. This is necessary due to data security reasons as for example a research-oriented information consumer shall only be allowed to connect to information providers relevant to the consumer's research question. The component *Metadata Management* is a dictionary enabling an integrated view on the data that could be provided via HIReP. All information providers have to add information about their data to this dictionary which can be browsed by information consumers to determine if relevant information will be available. The final component within the section *Management Components* is the *Research Question Management*. As a research-oriented information consumer has to apply for access to health information relevant for research it has to define the research question and has to justify the necessity to access the information. Such an application can be prepared via the component *Research Question Management*. Subsequently, this application gets evaluated by an expert panel and in case of acceptance all necessary HIReP configurations to setup the information flow will be carried out.

In contrast to the *Management Components* the *Service Components* are characterized by high data throughput. The component *Request Service* is responsible for handling unique information requests or information subscriptions from information consumers and involves the additional components *Matching Service* and *Pseudonymization & Anonymization Service*. The *Matching Service* supports the *Request Service* at handling complex information requests comprising various information providers and returns a merged result to the *Request Service*. Finally, the *Pseudonymization & Anonymization Service* gets involved in case the requested health information is used for research purposes. Therefore the service must work closely with the components *Consent Management* and *Identity & Pseudonym Management*. If an informed consent of the patient is available via *Consent Management* the health information can be delivered pseudonymized and the service removes the patient's identifying data from the health information and adds a pseudonym. To keep track of all pseudonyms generated for a patient the service adds each new pseudonym to the *Identity & Pseudonym Management*. In case there is no informed consent available the service removes all identifying data from the health information and delivers it anonymized.

2.3. Initial HIReP setup

According to the driving use cases the initial setup of HIReP includes the clinical data warehouse at Heidelberg University Hospital and the BMBH as information providers. Information consumers are the NCT's research database and the clinical data warehouse at Heidelberg University Hospital for care purposes. As the clinical data warehouse acts as provider and consumer the term *prosumer* is used to emphasize its combined role. Furthermore the initial *HIReP Core* includes only the four components *Identity and Pseudonym Management*, *Request Service*, *Matching Service*, and *Pseudonymization and Anonymization Service*. Based upon this setup the feasibility of the HIReP approach can be verified, especially the operability of the designed interfaces between information providers/consumers and the realized components of the *HIReP Core* can be tested and the initial HIReP use cases can be configured and executed.

3. Discussion

In contrast to other system architectures supporting secondary use of biomedical data [2, 3], the *HIReP approach* replicates data only once prior to making it available for research. The *Provider & Consumer Management* as part of the *HIReP Core* allows for new services to be registered and - in combination with adding metadata to the *Metadata Management* - can be queried for data. This functionality helps to easily add/remove or change modules in the architecture. Thus each data store can be consumer, provider or prosumer of data.

References

[1] Köpcke F, Trinczek B, Majeed RW, Schreiweis B, Wenk J, Leusch T, Ganslandt T, Ohmann C, Bergh B, Röhrig R, Dugas M, Prokosch HU. Evaluation of data completeness in the electronic health record for the purpose of patient recruitment into clinical trials: a retrospective analysis of element presence. *BMC Med Inform Decis Mak.* 2013; **13**(2013):37-44.

[2] Prokosch HU, Beck A, Ganslandt T, Hummel M, Kiehntopf M, Sax U, Uckert F, Semler S. IT Infrastructure Components for Biobanking. *Appl Clin Inform,* 2010, **1**(4), 419-429.

[3] Gerlich MG, Moller A, Schafer C, Strohbach AK, Krafczyk-Korth J, Hoffmann W. Epidemiology of multi-resistant organisms - challenges to a regional data management system. *GMS Krankenhhyg Interdiszip,* 2011, **6**(1), Doc26.

[4] Oates BJ. Researching Information Systems and Computing. London: Sage; 2006.

[5] Simon JW, Paslack R, Robienski J, Goebel JW, Krawczak M. *Biobanking – legal framework.* Berlin: MWV; 2006.

[6] Reng CM, Debold P, Specker C, Pommerening K. *Generic data protection solutions for medical research networks*. Berlin: MWV; 2006.

[7] European Commission, Proposal for a DIRECTIVE OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL on the protection of individuals with regard to the processing of personal data by competent authorities for the purposes of prevention, investigation, detection or prosecution of criminal offences or the execution of criminal penalties, and the free movement of such data. Brussels; 2012.

[8] Schwanke J, Löhnhardt B, Bahls T, Borg A, Drepper J, Geidel L, Heinze O, Lablans M, Langner D, Muscholl M, Quade M, Schreiweis B, Pommerening K. Standpunktpapier für die Notwendigkeit der Harmonisierung von Lösungsansätzen für das Probandenmanagement in medizinischen Forschungsnetzen. 2013.

[9] Schwanke J, Rienhoff O, Schulze TG, Nussbeck SY. Suitability of customer relationship management systems for the management of study participants in biomedical research. *Methods Inf Med,* 2013; **52**(4); 340-350.

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Can Physicians Recognize Their Own Patients in De-identified Notes?

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Abstract. The adoption of Electronic Health Records is growing at a fast pace, and this growth results in very large quantities of patient clinical information becoming available in electronic format, with tremendous potentials, but also equally growing concern for patient confidentiality breaches. De-identification of patient information has been proposed as a solution to both facilitate secondary uses of clinical information, and protect patient information confidentiality. Automated approaches based on Natural Language Processing have been implemented and evaluated, allowing for much faster text de-identification than manual approaches. A U.S. Veterans Affairs clinical text de-identification project focused on investigating the current state of the art of automatic clinical text de-identification, on developing a best-of-breed de-identification application for clinical documents, and on evaluating its impact on subsequent text uses and the risk for re-identification. To evaluate this risk, we de-identified discharge summaries from 86 patients using our 'best-of-breed' text de-identification application with resynthesis of the identifiers detected. We then asked physicians working in the ward the patients were hospitalized in if they could recognize these patients when reading the de-identified documents. Each document was examined by at least one resident and one attending physician, and with 4.65% of the documents, physicians thought they recognized the patient because of specific clinical information, but after verification, none was correctly re-identified.

Keywords. Natural Language Processing, Patient Data Confidentiality, Electronic Health Record De-identification, United States department of veterans affairs.

Introduction

The adoption of Electronic Health Record (EHR) systems is growing at a fast pace in the United States and in Europe. In the former, it reached more than 50% of physician practices and 80% of hospitals in April 2013, when only 17% of physician practices and 9% of hospitals were using an EHR in 2008. [1] This growth results in very large quantities of patient information becoming available in electronic format, with tremendous potentials, but also equally growing concern for patient confidentiality and privacy breaches.[2]

Confidentiality of the information entrusted by a patient to a healthcare provider has been a foundation of the confidence relationship established between them for centuries.[3] Breaching this confidentiality not only damages this relationship, but also

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exposes the patient to financial, reputation, employment, and other identity theft disastrous consequences. In the U.S., the Health Insurance Portability and Accountability Act (HIPAA) protects the confidentiality of patient data [4] and requires informed consent of the patient and approval of the facility's Institutional Review or Ethics Board to use clinical data for research purposes, but this requirement can be waived if the data is de-identified.

The de-identification of patient information has been proposed as a solution to both facilitate secondary use of clinical information, and protect patient information confidentiality. Most clinical information found in the EHR is represented as narrative text,[5] and de-identification of text consists in the application of the HIPAA "Safe Harbor" rule, removing all protected health information (PHI). This is a tedious and costly manual endeavor,[6] and automated approaches based on Natural Language Processing (NLP) have been implemented and evaluated, allowing for much faster de-identification than manual approaches.[7] These approaches started with Sweeny's system [8] and focused on various selections of PHI, ranging from patient names only,[9] to all PHI categories defined in the Safe Harbor rule, or even everything that was not recognized as clinical information.[10]

The text de-identification process is composed of two main steps: PHI *detection*, and then PHI *removal or transformation*. The latter typically consists in replacing PHI with some tags or characters (e.g., 'Mr. Smith' becomes '<Patient_name>'), but another option is to replace PHI with synthetic but realistic substitutes (e.g., 'Mr. Smith' becomes 'Mr. Jones'). This second option is often called "PHI resynthesis" and has been experimented by our team [11] and Aberdeen et al.[12] It adds computational complexity but offers the advantage of allowing the rare instances of PHI that could have been missed to "hide in plain sight," notably improving the effectiveness of de-identification.[13]

The U.S. Veterans Healthcare Administration (VHA) Consortium for Healthcare Informatics Research (CHIR) is a multi-disciplinary group of collaborating investigators affiliated with VHA sites across the U.S. In the context of the CHIR, a de-identification project focused on investigating the current state of the art of automatic clinical text de-identification,[7,14] on developing a best-of-breed de-identification application for VHA clinical documents,[11] and on evaluating its impact on subsequent text analysis tasks [15] and the risk for re-identification of this text. When evaluated, most automatic clinical text de-identification systems allowed for a sensitivity of 88 to 99% when detecting PHI.[7,12] This means that some PHI is missed by these systems, and even if quite rare, does this matter? Would researchers using the de-identified clinical documents, or even healthcare providers who took care of the patients mentioned in the documents, be able to recognize these patients when examining the documents? All methods to assess the risk for re-identification were applied to a small number of structured and coded data only (e.g., demographics, location),[16,17] not to narrative text, and clinical documents are rich in clinical and social information that can be unique and could be used to re-identify a patient.

The following sections describe our effort to evaluate this risk for re-identification of automatically de-identified clinical documents.

1. Methods

A corpus of 86 discharge summaries was automatically de-identified with 'BoB' (our *B*est-*o*f-*B*reed automatic clinical text de-identification application) and using PHI resynthesis. This application is described in more details in other publications.[11,18] The discharge summaries were extracted from the most recent documents in the EHR of 86 randomly selected patients hospitalized at the Salt Lake City VHA Medical Center, in the Acute Medicine Department, between 1 and 3 months before the beginning of our study.

A group of 5 attending physicians, 2 chief medical residents, 1 subspecialty fellow, 7 second or third year medical residents, and 4 interns (1st year medical residents) examined our corpus of de-identified discharge summaries. These medical providers were involved in the care of patients hospitalized in the Acute Medicine Department, and details of their recent rotations in the medicine wards are listed in Table 1.

Table 1. Physicians examining the de-identified discharge summaries

Identifier	Role	Service in Acute Medicine during the past 6 months (before the interview)
P1	Chief medical resident	2 weeks
P2	1st year resident (intern)	2 weeks
P3	3rd year resident	6 weeks
P4	3rd year resident	2 weeks
P5	3rd year resident	2 weeks
P6	1st year resident (intern)	5 weeks
P7	Subspecialty Fellow	2 months
P8	1st year resident (intern)	2 weeks
P9	3rd year resident	2 weeks
P10	Attending	Full-time (6 months)
P11	Attending	Full-time (6 months)
P12	Attending	Full-time (6 months)
P13	Attending	Full-time (6 months)
P14	Attending	Full-time (6 months)
P15	2nd year resident	6 weeks
P16	3rd year resident	7-8 weeks
P17	3rd year resident	6 weeks
P18	Chief medical resident	3 months
P19	1st year resident (intern)	3 weeks

Each de-identified discharge summary was examined by at least one resident or fellow and one attending physician (sometimes more), during 188 interviews when we presented the printed de-identified document to the physician, waited for them to read it, and then asked them if they recognized the patient presented in the document. We recorded their answer and if positive, verified the accuracy of the patient identity they proposed.

2. Results

The corpus of discharge summaries was automatically de-identified and the physician interviews were then administered during a period of about 2 months.

Three physicians (a chief medical resident and two residents) thought they had recognized a patient when reading their de-identified discharge summary. Their reasons to have this impression included specific procedures, diagnoses, signs, and imaging results, as listed in Table 2 below.

For these patients, the physicians suspected that they recognized the patient because of clinical details that reminded them of their patient. They often couldn't give any identifying information about the 'recognized' patient, but when they could, we verified this information, and eventually no patient was correctly recognized. (Table 3).

Table 2. Patients 'recognized' in de-identified discharge summaries

Patient identifier	Healthcare provider	Reason(s) to have 'recognized' the patient	Patient identity confirmed?
874	Resident (P4)	Procedures (no patient name remembered)	No
874	Resident (P2)	Diagnosis (wrong patient name)	No
975	CMR (P1)	Treatment, Diagnosis, Signs (wrong patient name)	No
994	CMR (P1)	Imaging (no patient name remembered)	No
996	CMR (P1)	Treatment (wrong patient name)	No

CMR = Chief medical resident

Table 3. Patient de-identified discharge summaries identification results

Identification type	Count	Proportion of patients
Patient identity unknown	82/86	95.35%
Patient identity incorrectly recognized (or without any patient identifier)	4/86	4.65%
Patient identity correctly recognized	0/88	0%

3. Discussion

As reported above, none of the 86 automatically de-identified discharge summaries could be re-identified. A few patients had characteristics that made the physician reviewing the discharge summary suspect that they had recognized the patient, but none was correctly identified.

Considering that physicians currently working in or who recently rotated through a hospital ward would be the most likely to recognize a patient described in a de-identified discharge summary, these results are encouraging in terms of risk for re-identification of de-identified clinical documents. Even if automatic de-identification applications are unable to reach perfect accuracy, the resynthesis of the detected PHI allows it to "hide in plain sight" and greatly reduces the risk of re-identification. More interesting is the recognized richness of unique or unusual clinical details that are noted in discharge summaries; these details were the reasons given for 'recognizing' a patient in our study. These details were eventually found not to be precise and specific enough to correctly re-identify patients in this study.

This study was limited to one department in a VHA hospital in the U.S. and one clinical document type, and might not generalize easily to other similar settings. The number of de-identified documents examined was not large, but sufficiently powered to clearly give us an estimation of the risk for re-identification of automatically de-identified discharge summaries. Further studies are needed to validate and extend our results across hospital departments and document types. An important reason for re-identification is clinical information, especially when rare and unique, and larger studies with a higher likelihood of such rare and unique information would allow for a more accurate assessment of the risk for re-identification. Results of large studies

would form the basis for informing institutional policy on large-scale de-identification of medical records and sharing of those records for secondary purposes.

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References

[1] U.S. Department of Health and Human Services, Doctors and hospitals' use of health IT more than doubles since 2012, www.hhs.gov, (2013).
[2] J.K. Taitsman, C.M. Grimm, S. Agrawal, Protecting patient privacy and data security, *N. Engl. J. Med*, **368** (2013) 977–979.
[3] National Library of Medicine, The Hippocratic Oath, (2002).
[4] CFR Title 45 Subtitle A Part 164: Security and Privacy, GPO, 2008.
[5] A.W. Pratt, Medicine, Computers, and Linguistics, *Advanced Biomed Eng*, **3** (1973) 97–140.
[6] D.A. Dorr, W.F. Phillips, S. Phansalkar, S.A. Sims, J.F. Hurdle, Assessing the difficulty and time cost of de-identification in clinical narratives, *Methods of Information in Medicine*, **45** (2006) 246–252.
[7] S.M. Meystre, F.J. Friedlin, B.R. South, S. Shen, M.H. Samore, Automatic de-identification of textual documents in the electronic health record: a review of recent research, *BMC Med Res Methodol*, **10** (2010) 70.
[8] L. Sweeney, Replacing personally-identifying information in medical records, the Scrub system, *Proc AMIA Annu Fall Symp*, (1996) 333–337.
[9] R.K. Taira, A.A. Bui, H. Kangarloo, Identification of patient name references within medical documents using semantic selectional restrictions, *AMIA Annu Symp Proc*, (2002) 757–761.
[10] J.J. Berman, Concept-match medical data scrubbing How pathology text can be used in research, *Archives of Pathology & Laboratory Medicine*, **127** (2003) 680–686.
[11] O. Ferrandez, B.R. South, S. Shen, F.J. Friedlin, M.H. Samore, S.M. Meystre, BoB, a best-of-breed automated text de-identification system for VHA clinical documents, *Journal of the American Medical Informatics Association*, **20** (2013) 77–83.
[12] J. Aberdeen, S. Bayer, R. Yeniterzi, B. Wellner, C. Clark, D. Hanauer, B. Malin, L. Hirschman, The MITRE Identification Scrubber Toolkit: design, training, and assessment, *Int J Med Inform*, **79** (2010) 849–859.
[13] D. Carrell, B. Malin, J. Aberdeen, S. Bayer, C. Clark, B. Wellner, L. Hirschman, Hiding in plain sight: use of realistic surrogates to reduce exposure of protected health information in clinical text, *Journal of the American Medical Informatics Association*, **20** (2013) 342–348.
[14] O. Ferrandez, B.R. South, S. Shen, F.J. Friedlin, M.H. Samore, S.M. Meystre, Evaluating current automatic de-identification methods with Veteran's health administration clinical documents, *BMC Med Res Methodol*, **12** (2012) 109.
[15] S.M. Meystre, O. Ferrandez, F.J. Friedlin, B.R. South, S. Shen, M.H. Samore, Text De-Identification for Privacy Protection: a Study of its Impact on Clinical Text Information Content, *J Biomed Inform*, (2014, in press).
[16] K. Benitez, B. Malin, Evaluating re-identification risks with respect to the HIPAA privacy rule, *Journal of the American Medical Informatics Association*, **17** (2010) 169–177.
[17] K. El Emam, E. Jonker, L. Arbuckle, B. Malin, A systematic review of re-identification attacks on health data, *PLoS ONE*, **6** (2011) e28071–e28071.
[18] O. Ferrandez, B.R. South, S. Shen, S.M. Meystre, A Hybrid Stepwise Approach for De-identifying Person Names in Clinical Documents, *Proceedings of the 2012 Workshop on Biomedical Natural Language Processing (BioNLP 2012)*, Montreal, Canada, 2012: pp. 65–72.

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The use of DRG for Identifying Clinical Trials Centers with High Recruitment Potential: a Feasability Study

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Abstract. Recruitment of large samples of patients is crucial for evidence level and efficacy of clinical trials (CT). Clinical Trial Recruitment Support Systems (CTRSS) used to estimate patient recruitment are generally specific to Hospital Information Systems and few were evaluated on a large number of trials. Our aim was to assess, on a large number of CT, the usefulness of commonly available data as Diagnosis Related Groups (DRG) databases in order to estimate potential recruitment. We used the DRG database of a large French multicenter medical institution (1.2 million inpatient stays and 400 new trials each year). Eligibility criteria of protocols were broken down into in atomic entities (diagnosis, procedures, treatments …) then translated into codes and operators recorded in a standardized form. A program parsed the forms and generated requests on the DRG database. A large majority of selection criteria could be coded and final estimations of number of eligible patients were close to observed ones (median difference = 25). Such a system could be part of the feasability evaluation and center selection process before the start of the clinical trial.

Keywords. Clinical trials, Recruitment Support Systems, DRG, Patient selection

Introduction

Clinical trials (CT) are necessary to enhance standards of care. Recruitment of large samples of patients is crucial for gaining external validity. But accrual of patients, and economic efficacy of the study, are hampered when trials are opened in centers with low recruitment capabilities. According to the literature, only about a third of medical research studies recruit their planned number of patients within the time originally specified [1]. Several attempts have been made to use Clinical Trial Recruitment Support Systems (CTRSS) to estimate patient recruitment in CTs. However, only few papers reported an evaluation of the effectiveness on more that a dozen of CTs [2]. Moreover, these CTRSS generally requires proprietary Hospital Information Systems (HIS) which reduces their applicability [3].

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Thus our aim was to assess, on a large number of CTs, the usefulness of converting CT eligibility criteria into requests performed on commonly available data as Diagnosis Related Groups (DRG) databases in order to estimate potential recruitment.

1. Methods

Assistance Publique – Hôpitaux de Paris (AP-HP) is one of the largest european healthcare institutions, with 38 hospitals and around 1.2 million admissions in acute care per year. In France, as in several other western countries, all hospitals, either public or privately funded, have to transmit standardized data about each acute hospital stay into the DRG system for budget purposes.

Coding of data is done by dedicated professionals who follow national guidelines and perform regular quality checks. Diagnoses are coded according to WHO ICD-10 while procedures, mainly surgical or imaging, are coded since 2004 using the CCAM (Classification Commune des Actes Médicaux) a national nomenclature that, as snomed, is multidimensional. Excepted for the most expensive ones such as chemotherapeutic agents, drugs are not recorded, nor lab results. According to French laws, access to the national database was done with the authorisation of the French watchdog authority for data privacy, called CNIL (Commission Nationale Informatiques et Libertés).

AP-HP clinical research activity encompasses around 900 academic sponsor trials and more than 1300 industry sponsor trials, with 400 new each year. For homogeneity of coding nomenclatures, we focused on drug trials that began in the 2005-2010 period and ended in 2010-2011. Eligibility criteria were retrieved from the detailed protocol.

We selected CT in various therapeutic domains. AP-HP Clinical Research department records CT administrative data so we were able to identify multicenter trials and retrieve annual realized recruitment volume.

We planned a strict separation between the data that described a CT in a standardized form and the computer program that interprets the forms then performs the requests on the database.

To identify eligible patients from the DRGs data, narrative criteria from the detailed protocol must be converted to computable criteria. Such computable criteria include entities, attributes, logical (ie, ‘and’ and ‘or’) or time operators (i.e. 'last stay', 'since x time units') and codes. We identified nine data categories, defined as entities, from CT protocols and DRGs that are useful for clinical research: demographics , medical history, clinical scores and symptoms, diagnoses, laboratory tests, procedures, treatments, adverse events and others. We then defined attributes of these entities (eg, ICD code, date for a diagnosis). Medical concepts of the protocol were mapped onto atomic entities and converted into entity-level criteria. Complex conditions were expressed by means of logical and also time operators since protocols frequently used longitudinal criteria that addressed several stays of the same patient (eg, for establishing a minimal duration between two events). Thus, all high-level inclusion criteria were linked by a conjunction operator while high-level non inclusion criteria were linked by a disjunction operator, but a high-level criterion could be expressed by various combinations of entry-level criteria. At last, lists of codes for diagnoses (ie, ICD-10), procedures (CCAM), drugs and DRG were created, and the period of treatments and others were defined. All codes, conditions and operators were recorded on a standardized sheet. This task was manually performed by two coding professionals

(NB, TT) with consensus meetings when difficulties. Additionally, a library of pre-coded common conditions (eg, cancer) was created for re-usability purposes.

We used SAS software (SAS Institute, Cary, NC) to develop a parser of the standardized sheet which translates them into requests on the database using either SQL queries or procedural programs. SAS was chosen according to its ability to manage large amount of data and perform queries but any other language with these characteristics will do the job, due to the independence between data and program.

2. Results

To date, we converted 85 protocols, from 12 large medical fields (mainly cardiovascular, endocrinology and metabolism, neurology, oncology and haematology, pneumology, rheumatology) reflecting the diversity of CT performed in AP-HP. Duration of conversion for one protocol from literate form to standardized form is about one day while retrieval of data on a one year DRG AP-HP database (1.2 million inpatient stay records) takes less than one hour.

Main results concerning most represented fields and the whole set of 85 trials are presented in Table 1. The median number of eligibility criteria per protocol was around 40, one third being inclusion criteria, without large disparities between fields. The proportions of criteria that we could translate were good for inclusion criteria (around 60%) and better for non inclusion criteria (around 80%). Considering entities, diagnostic criteria accounted for more than a half, followed by drugs and lab tests. Translation was effective for more than 9 diagnoses out of 10.

Initial selection of stays considered demographics characteristics (age, sex) as defined in the protocol and a very broad definition of the main diagnosis (eg, breast cancer) and led to subsets of 500 to 20,000 stays for year 2010, depending on pathological domains. After complete application of all coded criteria in the protocol, the final sample was considered as an estimation of potential recruitment for the trial. Sample sizes were generally low with a global median of 34 stays (interquartile range = 6-160), but higher for few domains, notably cardiovascular pathologies. Potential recruitment estimated by our system was generally optimistic. Thirty-seven % of trials showed a positive difference between estimation and realized recruitment less than or equal to 25 patients, and 61% a positive difference smaller than 100 patients. Some discrepancies could be larger, in some domains, notably cardiovascular. But for oncology-haematology trials, the estimations were generally closer to the observed recruitments, due to the large proportion of therapeutic criteria that could be coded. Situations where no potential patient was identified whereas the real recruitment was at least one, were few (13% of trials, i.e. a 87% sensitivity) and differences were mainly less then 10.

3. Discussion

From a sponsor point-of-view, a decision support system aiming to a better selection of participating centers in clinical trials should be operational in all candidate hospitals, whatever their information system. Our system exploits the ubiquitous DRG databases and despite simplicity of the DRG coding semantics, more than two-thirds of eligibility

criteria for trial could be coded and used for request on the DRG database. We analyzed 85 protocols from various fields. Estimated recruitment sizes, although greater than observed accrual, were generally low (less than 100 patients), so that a complementary manual check of patient charts for final eligibility could be easily performed. Sensitivity was high and we think that it could allow not to select inefficient centers with low recruitment potential.

Several points desserve discussion. Our system concerns only inpatients and ignores ambulatory information since this activity is often not recorded in a standardized and exploitable format. However, trials on inpatients are the most demanding, this restriction could be considered minor. Proportion of encoded criteria was not 100% since not all concepts of a protocol could be represented using standard vocabularies, notably symptoms, lab tests and treatments, although such nomenclatures exists (i.e. LOINC, ATC) but these data are not yet part of the DRG file. It is noteworthy that when encoding is feasible, as in oncologic chemotherapy, performance was good while when scores could not be translated into ICD-10, eg for some levels of the New York Heart Association (NYHA) functional classification, final subsets of patients were very large. But, if our proportion of encoded criteria compared favorably to other works, this measure is somewhat inadequate since all criteria are not equal in terms of discriminating power [4, 5]. Specificity of the system will be assessed in a next phase of the project : by performing manual review of medical files of selected patients, we will determine a true eligibility. Then we should be able to model which trial characteristics explain these discrepancies in order to finely tune our estimations.

In the era of automatic process through the use of semantic interoperability services that identify semantically-equivalent protocol/HIS data elements [6], our pragmatic system may appear « low-tech », but it gives some useful insights on the level of performance that automatic CTRSS may reach in the analysis of protocol eligibility criteria. In a near future, improvements in the accuracy and performance of patient selection by CTRSS should more likely come from the automatic analysis of narrative data contained in myriads of electronic health records, rather than from the automatic translation of protocols [7]. Unlike others CTRSS, our tool is designed for identification of potentially large-recruitment centers before start of the trial and not for real-time automatic screening of eligible patients, so its retrospective functioning is well suited. It could be part of the feasability evaluation and center selection process before the beginning of the clinical trials involving inpatients.

Table 1. Description of protocols and performance of retrieval system according to medical domains.

	CARV	ENDM	NEUR	ONCH	PNEU	RHUS	Total
Protocols (n)	10	7	14	16	7	7	85
Criteria number	42	39	38	40	41	57	41
% of inclusion criteria	22	28	33	42	29	30	30
% of coded inclusion crit.	50	60	83	70	67	36	61
% of coded non inclusion crit.	83	83	80	75	84	70	78
% of longitudinal criteria	13	15	12	18	7	10	14
% of diagnosis criteria	59	54	52	42	65	42	53
% of procedures criteria	3	0	0	0	0	3	0
% of adverse events criteria	4	3	2	2	2	4	3

% of score criteria	4	0	4	1	0	5	0
% of lab test criteria	10	10	3	16	11	7	8
% of drugs criteria	9	13	12	24	7	14	12
% of coded diagnosis criteria	95	96	95	94	95	83	94
% of coded procedures criteria	84	100	100	100	100	100	100
% of coded adverse events criteria	100	100	100	100	100	100	100
% of coded score criteria	25	100	95	100	0	20	69
% of coded lab test criteria	29	33	25	28	50	40	33
% of coded drugs criteria	43	33	0	72	50	16	33
Initial selection (patients)	4153	1265	2404	1734	787	2512	2512
Final potential recruitment (patients)	460	17	34	10	11	16	34
Final potential recruitment (IQR)	38-1940	5-1094	12-72	2-78	2-98	3-481	6-160
Investigator anticipated recruitment	12	8	7	5	6	12	8
Real observed recruitment	4	2	1	2	5	2	2
Potential vs real : difference	454	10	24	10	-1	9	25
Potential vs real : false negative	0	0	0	0	-1	0	0

All numbers are median calculated on the corresponding protocols elsewhere stated ; IQR = interquartile range ; CARV : cardio-vascular, ENDM : Endocrinology and metabolism, NEUR : Neurology, ONCH : Oncology and haematology, RHUS : Rheumatology and systemic disease

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References

[1] M Dugas, S Amler, M Lange M *et al.*, Estimation of patient accrual rates in clinical trials based
[2] on routine data from hospital information systems, *Methods Inf Med.* **48** (2009), 26-36.
[3] M Cuggia,P Besana, D Glasspool *et al.*, Comparing semi-automatic systems for recruitment of
[4] patients to clinical trials, I*nt J Med Inform* **80** (2011), 371–388.
[5] K Yamamoto, E Sumi, T Yamazaki *et al.*, A pragmatic method for electronic medical record-based observational studies: developing an electronic medical records retrieval system for clinical research, *BMJ Open* **2** (2012), pii: e001622.
[6] F Köpcke, D Lubgan, R Fietkau *et al.*, Evaluation of data completeness in the electronic health record for the purpose of patient recruitment into clinical trials: a retrospective analysis of element presence, *BMC Medical Informatics and Decision Making* **13** (2013), 37-44.
[7] E Sumi, S Teramukai, K Yamamoto *et al.*, The correlation between the number of eligible patients in routine clinical practice and the low recruitment level in clinical trials: a retrospective study using electronic medical records, Trials **14** (2013), 426-434.
[8] A El Fadly, B Rance, N Lucas *et al.*, Integrating clinical research with the Healthcare Enterprise: From the RE-USE project to the EHR4CR platform, *J Biomed Inform.* **44** (2011), 94-102.
[9] C Coorevits, M. Sundgren, G Klein *et al.*, Electronic health records: new opportunities for clinical research, *J Intern Med.* **274** (2013), 547-60.

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Virtual Patient Repositories - A Comparative Analysis

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Abstract. Virtual Patients (VPs) are an important component of medical education. One way to reduce the costs for creating VPs is sharing through repositories. We conducted a literature review to identify existing repositories and analyzed the 17 included repositories in regards to the search functions and metadata they provide. Most repositories provided some metadata such as title or description, whereas other data, such as educational objectives, were less frequent. Future research could, in cooperation with the repository provider, investigate user expectations and usage patterns.

Keywords: virtual patient, repository, metadata, Healthcare LOM, eViP

Introduction

Virtual Patients (VPs) are defined as "specific type of computer-based programs that simulate real-life clinical scenarios; learners emulate the roles of health care providers to obtain a history, conduct a physical exam, and make diagnostic and therapeutic decisions" [1]. Today, VPs are an important component of medical education, but the amount of labor and expense involved in their creation and maintenance is high [2].

Addressing the issue of labor and expense, recent VP-related research has been focused on enabling faculties to share VPs to reduce effort and costs. This can be realized in different ways: To foster the exchange of VPs, the MedBiquitous Virtual Patient (MVP) standard has been developed and implemented over the past years [3, 4]. Moreover, medical schools have undertaken efforts to collaboratively develop and use VPs in the recent past. For example, Berman et al. [5] describe the creation of pediatric VPs that were used by more than 70 medical schools. Finally, web-based repositories allow faculties to either access VPs directly or download, adapt and further use them.

Concerning the latter, little has been published to date about available repositories, which resources they provide and how teachers and learners can use them. For example, a PubMed search for "virtual patient collection" and "virtual patient repository" in title/abstract returned no results.

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To be able to use and search such repositories in an efficient way, the provision of meaningful metadata and a sophisticated search and filter functionality are indispensable components.

A widely adopted standard to describe metadata in healthcare education is the Healthcare Learning Objects Metadata standard [6], which extends the Learning Objects Metadata (LOM) standard [7], adding healthcare specific descriptions such as keywords from medical taxonomies. Healthcare LOM was also the basis for the development of the eViP profile [8] – a selection of relevant metadata to describe and exchange VPs.

The aim of our research was to provide an overview of VP repositories and the metadata they provide for users.

1. Methods

1.1. VP repositories

We systematically searched PubMed, Scopus, EMBASE, PsycINFO, CINAHL/EBSCO, and ERIC using the search terms "virtual patients" and "virtual patient" in title and/or abstract. The last date of our search was May 30, 2013. We excluded all non-educational and non-English-language articles, as well as articles not mentioning the word “virtual patient” within the text. All articles were scanned for references to VP repositories. In addition, we checked cross-references from repositories to other repositories.

1.2. Analysis of repositories

For our analysis, we included publicly accessible repositories (with or without registration) that contained at least one virtual patient. We analyzed the repositories with regard to the metadata, search functionality and filter criteria they provide. As a basis, we used the metadata defined in the Healthcare LOM Standard. We also counted the number of VPs by applying filter and search functions provided. If "virtual patient" was not available as a criterion, we used similar terms, such as "cases". The analysis was done in August 2013.

2. Results

2.1. VP repositories

We identified 573 citations, applying our search strategy. We included and scanned 289 articles for our study, excluding 21 non-English-language and 263 non-educational articles. Overall, we discovered references to 31 repositories from which 14 were excluded – six were not (publicly) available and eight did not contain any VPs. Table 1 gives an overview of the 17 included repositories.

Table 1: Overview of the 17 repositories.

Repository	Number of VPs (languages)	VPs only	Search/ Filter	Feedback/ Evaluation
BMJLearning [9]	745 (en)	No	Yes	comments, rating
CHEC_CESC [10]	86 (en, fr)	No	Yes	comments
EHLS [11]	5 (en)	No	No	comments
e-MedEdu [12]	23 (en)*	No	Yes	comments
eViP [13]	340 (en, de, pl, se, ro)	Yes	Yes	-
HEAL [14]	1 (en)	No	Yes	-
IML [15]	22 (de)	No	Yes	-
Jorum [16]	79 (en)	No	Yes	-
KELDAmed [17]	304 (en, de)	No	Yes	-
LRSMed [18]	118 (en, de)	No	Yes	evaluation
MedEdPortal [19]	36 (en)	No	Yes	comments
MedU [20]	145 (en)	Yes	Yes	-
Meducator [21]	32(en, gr)	No	Yes	-
MERLOT [22]	16 (en)	No	Yes	comments, rating
MyCourses [23]	70 (en)	No	Yes	-
PINE [24]	60 (en)	Yes	Yes	-
VirtualPatient-Work.net [25]	89 (en, de, es)	Yes	No	-

* Other resources were in Korean and could not be evaluated.

None of the repositories indicated how many users had accessed a VP.

2.2. Analysis of repositories

Basic descriptive data - for example, title, author and description - are provided by more than 50% of the repositories, whereas metadata such as target group or educational objectives were less prominent. Table 2 gives an overview of the metadata most often provided by the 17 collections.

Table 2: Overview of most the common metadata provided by the 17 repositories, based on the eViP profile and the LOM / Healthcare LOM (HLOM) standards.

Metadata	Number of repositories	in eViP profile	(H)LOM
Title	17	Yes	LOM 1.2
Author/Institution/Contact details	15 / 10 / 3	Yes	LOM 2.3
Description	14	Yes	LOM 1.4
Date of Upload / Last Update	10 / 3	Yes	LOM 2.3
Discipline	10	Yes	HLOM 1.5
Language	10	Yes	LOM 1.3
Keywords	9	No	LOM 1.5
Learning Resource Type	10	No	LOM 5.2
Copyright Information	9	Yes	LOM 6.2
Target group	7	No	HLOM 10.1.4
Educational objectives	4	No	HLOM 9.3
(Typical) Learning time	3	No	LOM 5.9

Further metadata are covered by single collections only. These are: level of interactivity (LOM 5.1 & 5.3), version and status of VP (2.1 & 2.2), costs (LOM 6.1, eViP profile), and other non-LOM- (but eViP-profile-) covered data, such as age and sex of the VP, and the VP system in which the VP was developed.

Not included in any collection were metadata like difficulty (LOM 5.8), description of how a VP can be used (LOM 5.10), and the user's role within the VP (LOM 5.5).

3. Discussion

3.1. VP repositories

We identified 17 publicly available repositories that contained at least one virtual patient. 12 of these contained many other e-learning resources, but four provided VPs only. For our study, we focused on the identification of metadata and search functionalities, but future research could target other aspects, focusing particularly on the specialized VP collections. Interesting aspects might include, for example, usability, usage pattern and statistics (who is using the collections and how). This type of analysis could give important input into the discussion of whether and how such collections support the exchange and sharing of virtual patients among institutions.

An advantage of sharing VPs through a repository is the possibility to provide tools for feedback (e.g., commenting or rating), which are implemented in seven repositories. Teachers and students who have used a VP can provide feedback on the quality or share their experience on how they integrated the VP into the curriculum. We did not systematically investigate whether and how such feedback tools are used, but our impression was that it is rarely used in most repositories. Reasons for this could be that the VPs have not yet been accessed very often (this information is not provided by the repositories), or that users do not go back to the repository after accessing a VP.

3.2. Analysis of repositories

In order to efficiently support an exchange of VPs, a repository should, apart from other aspects, be easy to use and efficient in providing the VP that a user (teacher or student) is looking for. This means that both search functionality and the metadata describing the VP need to be designed carefully.

Our study showed that "basic" metadata, such as title, description or author information, are available in most of the repositories. Surprisingly, other metadata, such as target group or educational objectives, are neither included in the eViP profile nor frequently provided in the repositories. We did not conduct a survey on user expectations or usage patterns to judge user preferences. However, we expect that such data is indeed relevant for users in assessing whether a VP is suitable for a required purpose. To further elucidate this, a survey of user expectations is required. Using medical taxonomies, such as ICD-10 or MeSH, which have also been recommended for the eViP profile, can improve the quality of free text metadata, such as keywords or discipline. It is also important to note that even if repositories support the structured entry of all relevant metadata, it is still up to the VP provider to enter all data in a meaningful way. So far, it remains unclear which way of sharing VPs – collaborative development, repositories, or direct exchange via MVP – is more frequent or more conducive to fostering an exchange. Some collections, such as MedU [5,20], have been developed through a collaborative interfaculty approach, while others, such as eViP [13], offer VPs for both direct access and download as MVP packages. In our opinion, such combinations of approaches could give direction to future repository concepts.

The aim of our study was to give a rough overview of the existing repositories containing VPs and the metadata they provide. We did not, however, investigate details of the VPs (e.g., characteristics or quality of content) provided in the repositories or evaluate user expectations and usage patterns. These interesting aspects could be addressed in cooperation with the repository providers in future studies.

References

[1] Candler C. Effective use of educational technology in medical education. Washington D.C.: *AAMC* Institute for Improving Medical Education. 2007; 7p.

[2] Huang G, Reynolds R, Candler C. Virtual patient simulation at U.S. and Canadian medical schools. *Acad Med*. 2007; 82(5): 446-451.

[3] Kononowicz AA, Heid J, Donkers J, Hege I, Woodham L, Zary N. Development and validation of strategies to test for interoperability of virtual patients. *Stud Health Technol Inform*. 2009; 150: 185-189.

[4] Smothers V, Azan B, Ellaway R. ANSI/MEDBIQ VP.10.1- 2010 MedBiquitous Virtual patient standard. *MedBiquitous Consortium* [Internet]. 2010 Apr 6 [cited 2014 Jan 18]. Available from: http://tinyurl.com/noy2xdt

[5] Berman NB, Fall LH, Chessman AW, Dell MR, Lang VJ, Leong SL, Nixon LJ, Smith S. A collaborative model for developing and maintaining virtual patients for medical education. *Med Teach*. 2011; 33(4):319-24.

[6] Smothers V. ANSI/MEDBIQ LO.10.1-2008 Healthcare learning object metadata specifications and description document. *MedBiquitous Consortium* [Internet]. 2009 Sep 30 [cited 2014 Jan 18]. Version No.: 1.1. Available from: http://tinyurl.com/l7w9gv

[7] Institute of Electrical and Electronics Engineers, Inc. Draft standard for learning object metadata. IEEE-Standards Association Learning Technology Standards Committee [Internet]. 2002 Jul 15 [cited 2013 Nov 18]. IEEE 1484.12.1-2002 Available from: http://tinyurl.com/6rwxxha

[8] eViP Technical Reference Group. VP Profile implementation and conformance testing. [Internet] 2009 Jan 1 [cited 2014 Jan 18]. Deliverable number: D2.2. Available from: http://tinyurl.com/okb4l39

[9] BMJ Learning [Internet]. UK: BMJ Publishing Group [cited 2013 Aug 15]. Available from: http://www.bmjlearning.com

[10] CHEC-CESC [Internet]. CA: The Association of Faculties of Medicine of Canada [cited 2013 Aug 15], Available from: http://chec-cesc.afmc.ca/library

[11] EHLS [Internet]. US: University of Utah [cited 2013 Aug 15]. Available from: http://library.med.utah.edu/km/onlinetutorials.php

[12] E-MedEdu [Internet]. Korea: Sungkyunkwan University School of Medicine [cited 2013 Aug 15]. Available from: http://www.mededu.or.kr/

[13] Electronic virtual patients (eViP) [Internet]. EU: Evip Electronic Virtual Patients [cited 2013 Aug 15]. Available from: www.virtualpatients.eu

[14] HEAL [Internet]. US: University of Utah [cited 2013 Aug 15] Available from: http://library.med.utah.edu/heal/

[15] IML [Internet]. CH: University of Bern [cited 2013 Aug 15]. Available from: http://e-learning.studmed.unibe.ch/

[16] Jorum [Internet]. UK :University of Manchester [cited 2015 Aug 15]. Available from: http://dspace.jorum.ac.uk/xmlui/

[17] KELDAMed [Internet]. DE: University of Heidelberg [cited 2013 Aug 15]. Available from: http://www.umm.uni-heidelberg.de/apps/bibl/KELDAmed/

[18] LRSMed [Internet]. DE: Essen University Hospital [cited 2013 Aug 15]. Available from: http://www.lrsmed.de/

[19] MedEdPortal [Internet]. US: Association of American Medical Colleges [cited 2013 Aug 15] Available from: https://www.mededportal.org/

[20] MedU [Internet]. US: MedU [cited 2013 Aug 15]. Available from: http://www.med-u.org/

[21] Meducator [Internet]. GR: mEducator consortium [cited 2013 Aug 15]. Available from: http://www.meducator2.net/searching/

[22] MERLOT [Internet]. US: California State University [cited 2013 May 11]. Available from: www.merlot.org

[23] Mycourses [Internet]. US: Harvard Medical School [cited 2013 May 11]. Available from: http://mycourses.med.harvard.edu/public/

[24] PINE [Internet]. CA: Inukshuk Wireless, Northern Ontario School of Medicine, Laurentian, McMaster, and Ryerson Universities and Confederation College [cited 2013 Aug 15]. Available from: http://pine.nosm.ca/pine/

[25] Virtual-Patient-Work.Net [Internet]. DE: Institute of Occupational and Environmental Medicine, University of Munich [cited 2013 Aug 15]. Available from: http://www.networm-online.eu/

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Virtual Patients in Massive Open Online Courses – Design Implications and Integration Strategies

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Abstract. Massive Open Online Courses (MOOCs) are raising extensive attention across disciplines, while it becomes evident that rethinking of learning designs that work well in these environments is needed. In the field of medical education, where the technology of MOOCs is not widely adopted yet, we wish to investigate the potential offered by virtual patients for the purpose of clinical reasoning skills training. In this paper we describe three use case scenarios employing virtual patients' features in MOOCs: (1) collective evaluation of decision making in the context of uncertainty; (2) collective repurposing of cases and division of discussion into subgroups focusing on local variances in healthcare; (3) division of content in short cases for flexible selection and adaptive learning with virtual patients. We also present technical requirements for implementing the use case scenarios and future work plans.

Keywords. Massive open online courses, virtual patients, e-learning, medical education, integration.

Introduction

Massive Open Online Courses (MOOCs) form a recent trend in education, raising extensive attention across disciplines. Heralded as the new disruptive innovation, it promises open access to prestigious universities' courses, on an unprecedented scale [1]. The rise of MOOCs is fuelled by rapid advances in the development of Internet technologies, predominantly offered by cloud computing infrastructure [2]. Yet, for many communities, including healthcare education, the true added value in terms of educational benefits remains uncertain [3].

Despite the fact that the first MOOCs were created taking an innovative, connectivist stance featuring collaborative learning, many of the massive courses that followed took a behaviouristic approach that emphasizes individual learning and passive knowledge transmission [4]. This is regarded by many as a step back in the evolution of education that calls for rethinking of MOOCs' learning designs [5]. For instance, Chris Dede argued that from the three features required in high quality

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teaching – cognitive knowledge, situated learning and a learners' community – MOOCs provide only the first one [6]. Another issue raised by Grünewald et al. regards the need of MOOCs to provide opportunities for experiential learning [4].

The healthcare education community has noticed with curiosity the emergence of the MOOC technology [7], however in terms of implementation the discussion has just begun. In this paper we wish to focus the attention of the discussion on the potential offered by MOOCs to foster clinical reasoning – a skill fundamental for the quality of healthcare services. In a seminal paper Cook et al. suggested virtual patients (VPs) as the key technology to enhance the skills of clinical reasoning [8]. VPs defined as "interactive computer simulations of real-life clinical scenarios" [9] have potential features to remedy some of the problems addressed currently in MOOCs, enabling interactivity, experiential learning and fostering specific medical skills.

The purpose of this study is to discuss the opportunities of extending MOOCs with VPs focusing on clinical reasoning. We aim to leverage and combine the unique benefits provided by both educational environments. We investigated in particular:

- How can VP features leverage MOOC possibilities?
- What are the technical requirements for implementing VPs in MOOCs?

1. Methods

1.1. Exploring scenarios for use of VP features in MOOCs

The starting point of our analysis was a framework for design and evaluation of MOOCs by Grover et al [10]. Maximization of utility for utmost diverse learners' groups was set in that paper as the imperative for effective construction of MOOCs. From the indicated approaches we selected two for further research on the possibility of their implementation using VPs at massive scale: a) Distributed nature of intelligence; in particular, moving the instructors' roles from the instructors to the participants, to enable greater learner self-organisation and opportunities for sharing knowledge. b) Mass customization; understood in the context of education as offering different learning outcomes for different learning groups. Next, we made a thematic literature review of VP features, known from previous projects, and potentially addressing the desired MOOC qualities. Analysed were in particular outcomes of the eViP project, a pan-European initiative aimed at adaptation of VPs for diverse context [11]. This led finally to the presentation of scenarios for utilizing the explored VP features in MOOCs.

1.2. Investigation of technical requirements

The identified scenarios were further analysed to elaborate technical requirements for their practical implementation as MOOC learning activities. We have systematized this task by the activity theory – already applied before in the analysis of VP activities [12]. In order to focus on the required technical tools we selected a variant of the framework proposed by Wilson, being a harmonization of Bedny and Engeström approach [13].

At this stage we also considered technical requirements imposed by the context of the planned application: the integration of the edX MOOC platform with Open Labyrinth VP system. Access to the MOOC platform was enabled by the joining of the

authors' institution in 2013 to the edX initiative [14]. Open Labyrinth [15] is at the moment of writing the most advanced, free available, open-source VP system. We looked also into existing standards to support the integration task, and our previous experience in (non-massive scale) integration of Virtual Learning Environments (VLEs) with VPs [16].

2. Results

2.1. Scenarios for using VP features in MOOCs

Use Case A: Collective evaluation of decision making in the context of uncertainty. In this scenario we provide the wide audience with VPs containing ill-defined clinical problems: i.e. with sparse or conflicting clinical data. In such situations even experts are not uniform in their decisions. The unfolding of the case will stop at this stage for a few days enabling collection of responses in an answer format following the Script Concordance Testing (SCT) approach [17], implemented already in some VP systems (e.g., CASUS; "Network Answer" [18]). In the resolution of the case, participants in the course are presented with a summary of answers given by the mass audience, may discuss their responses on-line, and benchmark their overall performance based on a scoring process adopted from SCT [17]. This requires that weights of experts' answers are high and fixed. For regular users it may evolve starting from the zero level and increase based on the learner's performance. In that way the distributed intelligence of the MOOC audience informs the individual clinical reasoning process.

Use Case B: Collective repurposing of cases and division of discussion into subgroups focusing on local variances in healthcare. Even though the foundations of medical knowledge ought to be globally the same, the diagnostic and treatment process undergoes variations following cultural, legal and financial differences. The narrative of the VPs story introduces a context that could be discussed by the mass audience in separated discussion boards to address the optimal proceeding e.g., at the national or regional level. Repurposing of the context of VPs, but not on a massive scale, has been already tested in the eViP project leading to interesting insights [19]. Transfer of this activity on a massive scale will deepen discussion and enable addressing learner's individual healthcare context.

Use Case C: Division of content into short cases for flexible selection and adaptive learning with VPs. We propose to design VPs for MOOCs by building short cases focusing just on the most important step in the decision making process (as in key-feature VPs [20]), rather than presenting long and complex patient stories. This enables building large VP collections from which learners can select those which meet their individual objectives. When expanding this idea, the next step is to integrate those cases with computational models allowing experimenting with the content ("what-if-nodes") or generating populations of similar VPs ("multiple-case-packages") [21].

2.2. Technical requirements

Fig. 1 depicts our approach to identify the technical requirements for implementing the proposed use cases. This focused our discussion on the tools ("T" in Fig. 1) needed to enable interactions between the elements of the information system.

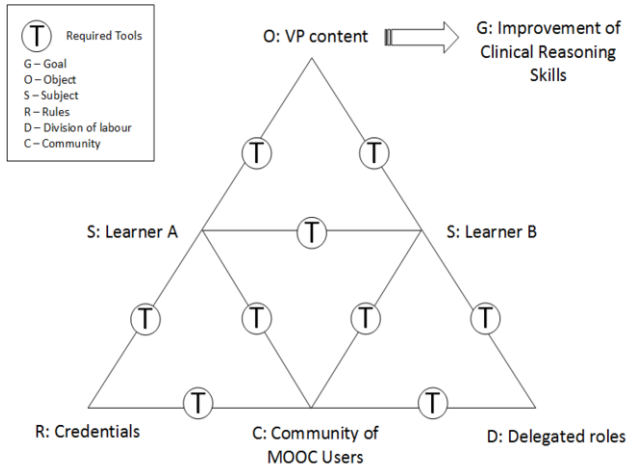


Figure 1: Identification of tools required for introduction of VPs in MOOCs using the activity theory [13].

The relationships between the learners, type of access to VP content depending on the role of the MOOC participant, and rules for acquiring credentials, require an identity management mechanism to be shared between the MOOC platform and VP system. We envision this being implemented by sharing authenticated sessions using the IMS LTI standard [22]. The personalized access to content is to be achieved by a systematic indexation of the VPs with metadata, preferably using Healthcare LOM standard [23], as demonstrated by projects as eViP [11]. Filtration and prioritization require also the implementation of competency assessment tool executed on enrolling users in the MOOC [24]. We plan to enable a self-formation of a hierarchy in the MOOC user community using a karma point mechanism [10]. This would enable assigning more teaching roles to the learners (e.g., in moderation of discussion or influence on SCT grading). Distributed discussion of the VP content addressing cultural adaptation requires a wiki-like mechanism enabling forking of the case into local in parallel-edited adaptations, managing different versions and provenance of the changes. Finally, documentation of achievement of the planned learning objectives in VPs requires a technical infrastructure for digital badges [7]. We expect its implementation to be simplified and standardized by the application of MedBiquitous' specifications for reporting learning competences and activities [23].

3. Discussion

In this paper we investigated the possibility of extending MOOCs by VPs, aiming at improving clinical reasoning skills. We signaled in three use cases how features known from VPs: SCT questions; cultural repurposing; short "key-feature" cases and integration with computational models, may leverage the mass customization and distributed intelligence. The practical usefulness of the solutions and the exact roles of the stakeholders are to be addressed and evaluated in planned future studies.

Technical requisites for these scenarios, but also opportunities arising from existing standards and collected experience were discussed; the proposed solutions are currently in early stages of implementation in Open Labyrinth and edX platform, but we envision they generalize well to different MOOC platforms and VP systems.

Even though there is still a long way to go for a full implementation, our results point out new ideas for extensions of MOOC platforms in the healthcare context. This leads from the passive presentation of videos, common in contemporary MOOCs, to more discipline-specific solutions, taking advantage of the audience's distributed intelligence and enabling mass customization.

References

[1] Yuan L, Powell S. MOOCs and open education: implications for higher education. JISC CETIS White Paper: The University of Bolton; 2013.
[2] Sonwalkar N. The first adaptive MOOC: a case study on pedagogy framework and scalable cloud architecture – Part I, MOOCs Forum. 2013;1(P):22–9.
[3] Harder B. Are MOOCs the future of medical education?. BMJ. 2013;346:f2666.
[4] Grünewald F, Meinel C, Totschnig M, Willems C. Designing MOOCs for the support of multiple learning styles. LNCS. 2013;8095:371–82.
[5] Online learning and distance education resources [Internet]. What's right and what's wrong about Coursera-style MOOCs; [updated 2012 Aug 5; cited 2014 Jan 27]. Available from: http://www.tonybates.ca/2012/08/05/whats-right-and-whats-wrong-about-coursera-style-moocs/
[6] The education group [Internet]. Seminar archive: Professor Chris Dede; [updated 2012 Sep 12; cited 2014 Jan 27]. Available from: http://educationgroup.mit.edu/HHMIEducationGroup/?p=3560
[7] Mehta NB, Hull AL, Young JB, Stoller JK. Just imagine: new paradigms for medical education. Acad Med. 2013;88:1418–23.
[8] Cook D, Triola M. Virtual patients: A critical review and proposed next steps. Med Educ. 2009;43:303–11.
[9] Ellaway R, Candler C, Greene P, Smothers V. An architectural model for MedBiquitous virtual patients, technical report. Baltimore: MedBiquitous; 2006.
[10] Grover S, Franz P, Schneider E, Pea R. The MOOC as distributed intelligence: dimensions of a framework & evaluation of MOOCs, Proceedings CSCL 2013, vol. 2; Madison, USA, 2011, 42–45.
[11] Zary N, Hege I, Heid J, Woodham L, Donkers J, Kononowicz AA. Enabling interoperability, accessibility and reusability of virtual patients across Europe-design and implementation. Stud Health Technol Inform. 2009;150:826–30.
[12] Ellaway RH, Davies D. Design for learning: deconstructing virtual patient activities. Med Teach. 2011;33(4):303–10.
[13] Wilson TD, A re-examination of information seeking behaviour in the context of activity theory. Information Research 2006;11(4):paper 260.
[14] edX [Internet] [cited 2014 Jan 27]. Available from: https://www.edx.org/
[15] Openlabyrinth.ca [Internet] [cited 2014 Jan 27]. Available from: http://openlabyrinth.ca/
[16] Kononowicz AA, Hege I, Adler M, de Leng B, Donkers J, Roterman I. Integration scenarios of virtual learning environments with virtual patients systems, E-mentor. 2010;5(37):52–4.
[17] Charlin B, Vleuten C. Standardized assessment of reasoning in contexts of uncertainty: the script concordance approach, Eval Health Prof. 2004;27(3):304-19.
[18] Casus [Internet] [cited 2013 Jan 27]. Available from: http://casus.eu/
[19] Kononowicz AA, Stachoń A, Guratowska M. To start from scratch or to repurpose: that is the question. BAMS. 2010;6(11):57–63.
[20] Fischer MR, Kopp V, Holzer M, Ruderich F, Jünger J. A modified electronic key feature examination for undergraduate medical students: validation threats and opportunities, Med Teach 2005;27(5):450–5.
[21] Kononowicz AA, Narracott AJ, Manini S, Bayley M, Lawford PV, McCormack K, et al. A framework for different levels of integration of computational models into web - based virtual patients, J Med Internet Res. 2014;16(1):e23.
[22] IMS GLOBAL Learning Consortium [Internet]. Learning Tools interoperability [updated 2014 Jan 5; cited 2014 Jan 27]. Available from: http://www.imsglobal.org/toolsinteroperability2.cfm
[23] MedBiquitous [Internet]. Standards [cited 2014 Jan 27] Available from: http://www.medbiq.org/std_specs/standards/index.html
[24] Clayton J, Elliott R. The CAT amongst the pigeons: A reflective framework approach to personalised professional development in open, flexible and networked learning. In: G. Williams, P. Statham, N. Brown, B. Cleland (Eds.) Changing demands, changing directions. Proceedings ascilite, Hobart: Australia. 2011;244–9.

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New Bachelors Degree Program in Health Informatics in Ethiopia: Curriculum Content and Development Approaches

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Abstract: With a widespread use of information technology in healthcare organizations, there is a pressing need for professionals who are both skilled in the use and management of information systems and knowledgeable in the field of healthcare. To fill this need, the department of health informatics at the University of Gondar started a new bachelor's degree in the health informatics program commencing in 2012. The curriculum was developed by a thorough needs assessment and considering the recommendations of the international medical informatics association. The program has duration of 4 years with a total of 249 ECTS. Currently there are 57 students enrolled in the program and 15 full time academic staffs are involved in the teaching and research activity of the department. To share our experience for other countries, in this paper we explain the curriculum development process and its content to the health informatics community.

Keywords. Health informatics education, Curriculum, Ethiopia, University of Gondar

Introduction

Healthcare organizations, not only in Ethiopia but also in most developing countries, are becoming increasingly reliant upon information and communication technology to support the daily clinical routine. Training knowledgeable, motivated and capable healthcare information technology (HIT) staff is essential for overcoming the bottlenecks to achieve national and global goals in quality of health care services and health data [1]. In the health information system strategic plan of Ethiopia, enhancing health management information systems through computer based information systems is kept as a priority task in the health sector policy until 2020 [2]. With this firm interest and ambitious plan, it is evident that the country needs HIT professionals who are aware of the complex health care processes and who can manage, plan, develop and provide expert consultations to the health care sector.

To fill this gap, the University of Gondar - one of the oldest research, teaching and community service oriented higher education institution in Ethiopia - through its health informatics department designed a health informatics bachelor's degree program. The

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department of health informatics was established as an independent health informatics teaching and research centre in 2004. The aim of this program is to train students who can handle the current pressing needs of health information technicians. This bachelor program is the first of its kind in Ethiopia and East Africa.

In Ethiopia, two masters programs in health informatics already exist, one in Gondar University and the other in Addis Ababa University. The programs were started in 2007 with the support of Norad's program for master studies (NOMA). Additionally, there is another HIT diploma program running in several health science colleges, which was started through the collaboration of the ministry of health of Ethiopia and the Tulane University technical assistant project for Ethiopia (TUTAPE). The assessment made by TUTAPE in 2008 specified that the country would need more than 7700 HIT technicians by 2015 to meet the HIT professionals requirement of the health sector [3]. To satisfy this need, the HIT training program was started in 2009 and currently runs in more than 15 colleges throughout the country and more than 1000 students already graduated. Until 2012, there were only masters and diploma (certificate study being one level below bachelors in the Ethiopian education system) program which gives those diploma graduates no option to upgrade their study which in turn leads to the migration of those professionals to other fields. Our bachelor program is therefore believed to give an opportunity to promising HIT diploma graduates to continue their education to the bachelor and masters level with a potential of climbing the professional ladder accordingly.

The purpose of this paper is therefore, to introduce the curriculum development, content and its current progress to the international health informatics community and make it available to other countries wanting to introduce health informatics bachelor programs.

1. Methods

The curriculum development process took two years (2010-2012). The approach used for the development was through assessment of Ethiopian health sector needs and review of the current health informatics education in the world. The needs assessment for the curriculum was conducted in 2010. In the assessment national and regional health offices and health science colleges were included. Data were collected through interviews and observations within those offices and the colleges that already run the diploma program. We assessed their way of work in health data management and the extent of health informatics professionals needs. In addition we reviewed the curriculum of different African and International bachelors level health informatics programs [4][5]. Moreover, the IMIA recommendation [6] was used as a basic reference for course allocation.

Internal and external evaluators analysed the draft curriculum in two different workshops conducted in 2012. Internal evaluators were medical, public health, and computer science staffs of the university. The evaluators worked on the integration of health care and computer science courses. External evaluators were experts from the ministry of health, regional health offices and delegates from other non-governmental organizations working in the health informatics sector. These groups analysed the needed graduate competencies in the work places of their respective organizations. After including the comments, the final version was approved by the University senate in July 2012.

2. Results

We developed a 4 years comprehensive health informatics bachelor's program curriculum by taking the local context and stakeholder needs as primary priority. We commenced the program in October 2012 by enrolling 26 students, and currently we have 26 students at the second year and 31 first-year students. The contents of the curriculum and the (planned) practical and lecture lessons are explained below year by year and listed with the specific course titles and corresponding credit hours in the respective tables 1-4.

2.1. First year of study

The first year of study aims to introduce the science of health informatics and provision of solid theoretical basis required for the next four years of study. Most of the courses are common courses in the area of both health and informatics so that the students acquire the necessary background knowledge. The first year courses result in 70 ECTS.

Table 1. Courses in the first year of study with the respective ECTS points

Year/Semester	Course Title	ECTS
1/I	Communicative English	5
	Civics and Ethical Education	5
	Fundamental of ICT to health informatics	5
	Fundamental of Health Informatics	5
	Anatomy	5
	Physiology	5
	Applied mathematics for health informatics	5
1/II	Pathology	5
	Communicable disease	5
	First aid	2
	Pharmacology	3
	Environmental and occupational health	5
	Epidemiology for health informatics	5
	Biostatistics for health informatics	5
	GIS & disease mapping	5

2.2. Second year of study

The second year of study is aimed to give more detailed knowledge about the organization of health institutions and of the overall health system, inter-organizational aspects, health administration, health economics, and health quality management. The second semester focuses on health care system development and computer programing languages. In those courses, the students are expected to understand the system development process and start to develop own systems in practice lessons using basic computer programing languages. The second year courses result in 64 ECTS.

Table 2. Courses in the second year of study with the respective ECTS points

Year/Semester	Course Title	ECTS
2/I	Health service management	5
	Health economics	3
	Monitoring and evaluation	5
	Disease coding and classification	6
	Health management information system	6

	General psychology	4
	Introduction to sociology	4
2/II	Health information project management	4
	Object oriented system analysis & design	7
	Discrete mathematics	5
	Fundamentals of programming (C++)	5
	Data structures and algorithms	5
	Object oriented programming (Java)	5

2.3. Third year of study

The third year of study is aimed at giving advanced knowledge and practice in health informatics. The students will continue to learn programming languages followed by modules such as health care database management, trouble shooting and maintenance as well as computer networking and communication services. For this 61 ECTS are planned.

Table 3. Courses in the third year of study with the respective ECTS points

Year/Semester	Course Title	ECTS
3/I	Internet programming	7
	Fundamentals of database systems	5
	Information storage and retrieval	5
	Medical knowledge based systems	6
	Biomedical instruments	5
	Computer maintenance & troubleshooting	6
3/II	Health informatics practical attachment I	6
	Computer networking and security	6
	Telemedicine	5
	Mobile health information systems	5
	Basic writing skill	5

2.4. Fourth Year of Study

The fourth year of study, with a total of 54 ECTS, is exclusively planned for practical work of the students. The students will learn advanced level courses and they will be assigned for internships in different health care organizations. There the students are expected to develop, maintain and manage different information systems in their organizational placement with close supervision of their advisers.

Table 4. Courses of the fourth year of study with the respective ECTS points

Year/Semester	Course Title	ECTS
4/I	Hospital operation systems	3
	Outpatient and inpatient systems	5
	Health record systems	6
	Practical attachment II	8
	Teaching skill for Health informatics	4
	Entrepreneurship	4
4/II	Health informatics project I	8
	Team training program	8
	Health informatics project II	8

3. Discussion and conclusion

The curriculum was designed by benchmarking different international programs [5][7] and the recommendations of IMIA in health informatics education [6]. The credit points for informatics and health courses are higher in our curriculum than those benchmarked programs given that our expectation is to graduate students with a solid understanding of the country's health system as well with advanced project management and technical skills. Those bachelor graduates are expected to play a key role in technical and management position at referral hospitals and regional health offices given the need of the complex data and infrastructure management in those offices.

The availability of other related disciplines such as- public health, computer science and informatics department in our university is an ample opportunity to effectively run the departments academic and research activity. However, lack of senior staffs (with PhD degree) in the area of health informatics is still the biggest challenge for the department. The emphasis given by the government by creating a career ladder in the health sector for future graduates of the department is an indicator of the emphasis given by the ministry to the program. But yet, the department need to interact and work more with the ministry and regional offices so that the various academic and research activities are in line with the E-health policy of the country.

The graduates of this multidisciplinary health informatics curriculum expected to be well prepared informaticians for management and technical positions, being able to meet the increasing demand of health informatics in the country. As the program is just starting, we will continuously evaluate it against the changing need of the country and the student's graduate profile. Additionally, we will work with the IMIA and HELINA health informatics education working group to share international experiences for our program.

References

[1] S. Girma, A. Yohannes, Y. Kitaw, Y. Ye-Ebiyo, a Seyoum, H. Desta, and a Teklehaimanot, "Human Resource Development for Health in Ethiopia: Challenges of Achieving the Millennium development Goals," *Ethiop. J. Heal. Dev.*, vol. 21, no. 3, Apr. 2008.

[2] Ministry of Health, "Final draft HIS Road Map Ethiopia October4,2012-Updated following NAC meeting (3)," Minstry of health of Ethiopia.

[3] L. W. B. O. ;Azene G. B. A. B, "Establishing a New Cadre of Workers for HIS: Health Information Technicians:," *Abstr. Accept. Keys to Heal. Inf. Syst. Integr. Sustain. Ctry. Ownersh. USG PEPFAR—2010 Captown, SA Conf.*, 2009.

[4] P. J. Murray, H. J. Betts, and G. Wright, "Health Informatics Education and Capacity Building in Eastern Cape Province , South Africa Background - The Need for Development of Health Informatics in South Africa The Course Model and Delivery in Mthatha," pp. 158–163, 2009.

[5] F. J. Leven and R. Haux, "Twenty five years of medical informatics education at Heidelberg/Heilbronn: discussion of a specialized curriculum for medical informatics.," *Int. J. Med. Inform.*, vol. 50, no. 1–3, pp. 31–42, Jun. 1998.

[6] I. Medical, I. Association, J. Mantas, E. Ammenwerth, G. Demiris, A. Hasman, R. Haux, E. Hovenga, K. C. Lun, H. Marin, F. Martin-sanchez, and G. Wright, "Recommendations of the International Medical Informatics Association (IMIA) on Education in Biomedical and Health Informatics - 1 st Revision," *J. Med. informatics Assoc.*

[7] D. J. Severtson, L. Pape, C. D. Page, J. W. Shavlik, G. N. Phillips, and P. Flatley Brennan, "Biomedical informatics training at the University of Wisconsin-Madison.," *Yearb. Med. Inform.*, pp. 149–56, Jan. 2007.

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eduCRATE- A *Virtual Hospital* Architecture

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Abstract. *eduCRATE* is a complex project proposal which aims to develop a virtual learning environment offering interactive digital content through original and integrated solutions using cloud computing, complex multimedia systems in virtual space and personalized design with avatars. Compared to existing similar products the project brings the novelty of using languages for medical guides in order to ensure a maximum of flexibility. The *Virtual Hospital* simulations will create interactive clinical scenarios for which students will find solutions for positive diagnosis and therapeutic management. The solution based on cloud computing and immersive multimedia is an attractive option in education because is economical and it matches the current working style of the young generation to whom it addresses.

Keywords. Virtual Hospital, eLearning, cloud computing, medical guidelines.

Introduction

Simulation is a technique for practice and learning that can emulate and amplify real experiences with guided ones, often "immersive", that evoke or replicate substantial aspects of the real world in a fully interactive fashion. Simulation-based learning can be the way to develop health professionals' knowledge, skills, and attitudes, whilst protecting patients from unnecessary risks [1, 2]. Simulation-based medical education (SBME) is becoming a powerful force in addressing the need to increase patient safety through quality-care training. Recognizing the benefits of SBME, increasing numbers of bodies involved in medical and health care education and training are establishing simulation centres worldwide [1, 3]. In classical medical education many students feel the difference between the class versus clinical environment, considering that they are inadequately trained in management of physical examination, and diagnosis. Medical simulation is proposed as a technique to bridge this educational gap [4], allowing the enhancement of several skills: technical and functional expertise training, problem-solving and decision-making skills, interpersonal and communications skills or team-based competencies, but applying the "*primum non nocere*" principle, as well.

Recent advances in educational technology are offering an increasing number of innovative learning tools, as the use of virtual 3D worlds, also known as *Virtual Immersive Environments* (VIEs). The advantages of using VIEs for learning include: (i)

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Practicing real world skills with rich feedback in a safe environment that does not impact real processes or persons; (ii) Mastering a technique, behaviour or method through guided rehearsals again and again as many times as is needed; (iii) Ability to practice in the virtual environment not accounting location or time, only having access to a computer [5]. There are several approaches regarding implementing and using the virtual hospitals. The most frequently used solutions are online virtual worlds like *Second Life* and *OpenSim*. Using an *avatar* one can visit places in virtual worlds and socialize with others (see Figure 1). *Second Life* allows developers to personalize the virtual worlds and add some interactivity by using *Linden Scripting Language*.



Figure 1. Example of *Virtual Hospital* in Second Life

Another popular way to develop Virtual Reality (VR) applications is the use of game engine platforms like Unity3d [6] or Unreal Engine [7], where virtual environments are created together with their own interaction models between users and virtual elements. Several of the most popular virtual hospitals worldwide are: *Virtual Hospital* from the *Imperial College of London* [8], *Virtual Hospital* from *University of Brighton* [9], simulators from *Keele University* [10] and *Inmedea Simulator* [11].

Currently in Romania there are no advanced VR software solutions applied in medical education. The *eduCRATE* project (*edu*cation + Hippo*CRATE*s) proposes a *Virtual Hospital* representing a virtual learning environment providing medical students the opportunity to simulate situations encountered in the medical practice. This project suggests several technological novelties, as presented in the followings.

1. Method: requirements, roles

The *eduCRATE* project will issue a complex information system for management and development of interactive multimedia content that supports modern and qualitative medical education for cardiology and urology disciplines, based on scenarios using *avatars*, helping students to train on a casuistry extracted from the real world. 3D models will be provided for patients, students, consulting rooms, tools, devices, medical equipment etc. that will provide a virtual space for simulation of medical activity. Interaction in terms of medical information will be based on guidelines and medical scenarios and on the *Electronic Health Records* (EHR) of patients. The solution based on cloud computing and multimedia is an attractive option in education because it matches the current working style of the young generation whom it is addressed. The solution is economical, too: the infrastructure is provided scalable, depending on the actual needs and thus relieving the institutions from the burden of purchasing and maintaining it.

The *eduCRATE* project suggests an absolute novelty for this kind of applications: the use of medical protocols and guidelines, by using a standard representation language. Compared with previously presented solutions, which run fixed scenarios, *eduCRATE* proposes to perform simulations following a set of scenarios defined in an external database, according to medical protocols and guidelines. Such scenarios may be added or modified anytime, giving to the project more flexibility compared with previous solutions, and can easily be adapted to any clinical scenario.

Medical students are the end users of the system: they will interact with virtual patients, will collect the medical history and will review clinical symptoms, laboratory tests and imaging investigations, and will receive suggestions for possible diagnostics (differential diagnoses) in a complex VR environment. The students should consider these suggestions, choose the best option and interpret it (i.e. positive diagnosis).

Information is needed to define scenarios implementation and to manage their associations with the students. Thus the system is "fed" with the necessary information, interacting with four different types of users, these actors playing different roles:

- The medical guidelines developers that implement, using standardized representation and specific software environments, the medical scenarios.
- Representations editors of VR - the multimedia specialists that define/design/edit these representations which form the VR in which the medical students will be immersed for training and/or examination.
- Administrators of patients' medical data are medical academics that will introduce in the system medical records of the patients, fictitious or specially designed for this purpose, to build casuistry designed for educational purposes.
- Administrators of didactical activity - academics that assign various scenarios to the students: customize the training, implementing complex interaction scenarios (where in cyberspace "meet" and interact more students and possibly professors, around a virtual patient), define tests, allocate them to the students and assess the results reports.

The system will offer functions like:

- Creating and managing flow representations of the clinical process (medical guidelines) using dedicated representations and environments, like *Clinical Decision Support Systems* (CDSS).
- Creating and managing patient medical information according to different medical cases, necessary for training and evaluation processes, using an EHR system, also including importing data facilities.
- Building VR models needed to accurately and completely represent the proper interaction of the clinical process.
- Providing an integrated service to individually access the virtual space enabling the simulation of the patient-student interaction.
- System administration, including generating specific reports.

2. Results: a new System Architecture

The system is built in a modular manner to facilitate reconfigurations and updates. The proposed system architecture for this project is presented in Figure 2.

The interaction with students is done through their immersion in a VR environment in which themselves, represented by *avatars*, examine virtual patients, accessing

the EHR containing demographic data, medical history, previous visits, laboratory tests, imagistic investigations, ECG, treatments, with the possibility to react on the available

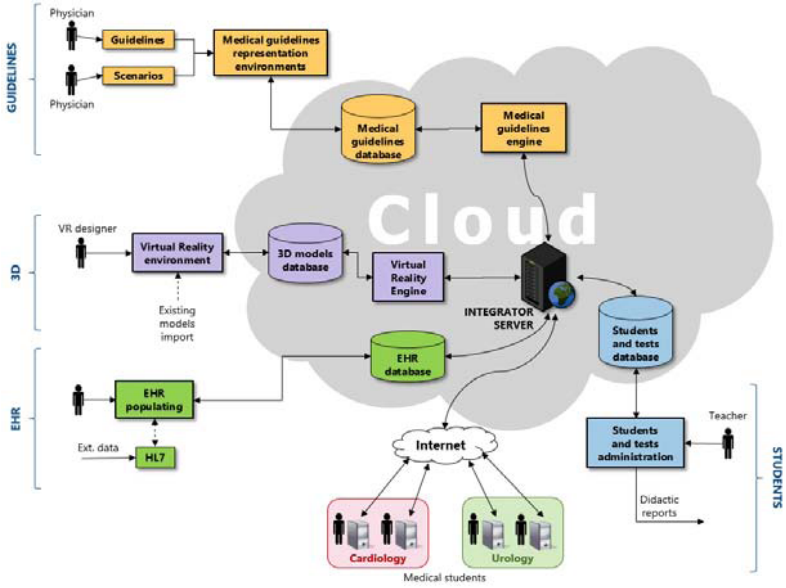


Figure 2. The *eduCRATE* Virtual Hospital System Architecture

information through decisions, additional requests, different virtual treatments applied like being a real doctor.

The representations will respect the frame of well-known standards or templates:

- The VR environment was selected to be one well-known and spread, which can be easily used to allow importing 3D models from other similar environments. For the project we are considering several development platforms for VR environments, of which *Unity 3d* distinguishes for its features.
- EHR will have a similar specific structure met in common hospital information systems, but importing data from any source of medical data will be considered, using the interoperability standard HL7-CDA [12].
- The decision scenarios for the medical act will be represented internally by specialized languages standards [13, 14, 15, 16]; ARDEN syntax was selected.

The Integrator itself will be developed in C#. The synchronization between components is done by messages. Infrastructure issues are solved using the economic solution of cloud services; this simplifies the role of the professors in the medical universities; thus they do not have to buy/build/manage IT infrastructures, because these concerns are transferred to the cloud provider. Thus, the solution becomes very easy to extend, any new entity can be virtually connected to services, with the consent of the owners of the solution.

2.1. Conclusions

This paper presents a new learning method and environment, with original features, that uses technology, for a real need to train future doctors, to stimulate associative thinking and decision-making. As a result, a new Software System Architecture, based

on cloud computing technologies, medical guidelines representation, 3D immersive virtual reality, and electronic health records, is described. This system is not replacing a medical professor, but provides support required by the younger generation, constituting itself as an innovative way of education in medicine. Evaluation of learning outcomes compared to conventional methods will provide reasons for widespread introduction of this type of training, by curriculum restructuring and student-centred learning. Using this *Virtual Hospital* application, the "*primum non nocere*" ethical imperative will provide the framework for medical training at the highest standards, for patient safety and error management. The novelty of the approach is given by the flexibility offered by integrating the medical guidelines and the EHR, in contrast with the current relatively inflexible solutions.

From the educational point of view the project will provide a new and modern learning environment, in a realistic approach, engaging and dynamic, that includes a wide range of medical cases. From the medical point of view the new *Virtual Hospital* application will facilitate clinical practice training without exposing the patients to any risk. Exercising various clinical scenarios, the students can improve their timing and skills. This can prepare them for future real clinical situations.

References

[1] Lateef F. Simulation-based learning: Just like the real thing. Journal of Emergencies, Trauma, and Shock. 2010; 3(4): 348-352.
[2] Ziv A, Erez D, Munz Y, Vardi A, Barsuk D, Levine I, et al. The Israel Center for Medical Simulation: a paradigm for cultural change in medical education. Academic Medicine. 2006; 81(12): 1091-1097.
[3] Ziv A, Wolpe PR, Small SD, Glick S. Simulation-based medical education: an ethical imperative. Simulation in healthcare. 2006; 1(4): 252-256.
[4] Okuda Y, Bryson EO, DeMaria S Jr, Jacobson L, Quinones J, Shen B, et al. The utility of simulation in medical education: what is the evidence? The Mt. Sinai Journal of medicine. 2009; 76(4): 330-343.
[5] Karl Kapp [Internet]. Immersive Learning Environments. Training Industry; [updated 2009 Sep 23; cited 2014 Jan 24]. Available from: http://www.trainingindustry.com/blog/blog-entries/immersive-learning-environments.aspx.
[6] Kuang Y, Jiang J. The Designing of Training Simulation System Based on Unity 3D. International Conference on Intelligent Computation Technology and Automation; 2011 Mar 28-29; Shenzen: China.
[7] Lewis J, Brown D, Cranton W, Mason R. Simulating visual impairments using the Unreal Engine 3 game engine. 1st International Conference on Serious Games and Applications for Health; 2011 Nov 16-18; Braga: Portugal.
[8] Imperial College London [Internet]. Game-based Learning for Virtual Patients in Second Life; [updated 2013; cited 2014 Jan 24]. Available from: https://www1.imperial.ac.uk/medicine/elearning/secondlife/gamebasedlearning.
[9] University of Brighton [Internet]. The Virtual Hospital; [updated 2011 Nov 11; cited 2014 Jan 24]. Available from: http://about.brighton.ac.uk/snm/news/2011/111129-virtual-hospital.php.
[10] Keele University [Internet]. Virtual Patient - Keele University; [updated 2013; cited 2014 Jan 24]. Available from: http://www.keele.ac.uk/pharmacy/vp.
[11] INMEDEA [Internet]. The INMEDEA Simulator; [updated 2012; cited 2014 Jan 24]. Available from: http://www.inmedea.com/en/products_simulator.html.
[12] Corepoint Health [Internet]. HL7 CDA–Clinical Document Architecture; [updated 2013; cited 2013 May 10]. Available from: http://www.corepointhealth.com/resource-center/HL7-resources/HL7-cda.
[13] Anselma L, Montani S. Planning: Supporting and Optimizing Clinical Guidelines Execution. Computer-based Medical Guidelines and Protocols: A Primer and Current Trends. 2008; 139: 100-120.
[14] ANSI/HL7 Arden V2.8-2008, The Health Level Seven Arden Syntax Version 2.8, 2012.
[15] The ASGAARD Project [Internet]. Asbru; [cited 2012 Jul 16]. Available from: http://www.asgaard.tuwien.ac.at/plan_representation/Asbru_doc.html.
[16] Clercq P, Kaiser K, Hasman A. Computer-Interpretable Guideline Formalisms. Computer-based Medical Guidelines and Protocols: A Primer and Current Trend. 2008; 139: 22-43.

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Matching Study to Registry data: Maintaining Data Privacy in a Study on Family based Colorectal Cancer

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Abstract. Confidentiality of patient data in the field of medical informatics is an important task. Leaked sensitive information within this data can be adverse to and being abused against a patient. Therefore, when working with medical data, appropriate and secure models which serve as guidelines for different applications are needed. Consequently, this work presents a model for performing a privacy preserving record linkage between study and registry data. The model takes into account seven requirements related to data privacy. Furthermore, this model is exemplified with a study on family based colorectal cancer in Germany. The model is very strict and excludes possible violations towards data privacy protection to a reasonable degree. It should be applicable to similar use cases which are in need of a mapping between medical data of a study and a registry database.

Keywords. Confidentiality, record linkage, colonic neoplasms, genealogy

Introduction

Handling personal data is not only a matter of trust. In the worst case, leaked information can be adverse to and abused against an individual and cause severe damage. Therefore, in different fields of application, it is important to supply methods and models that provide a strong security environment. Especially when working with medical data, in particular, patient data, which often contain sensitive information, a high standard concerning obligation of secrecy needs to be maintained. One field of application in this domain is the task of medical record linkage where medical data of different datasets has to be mapped to each other. This is not a trivial task especially if patients' anonymity has to be assured at any stage of the process. In this case, the record linkage is called privacy preserving [1].

In 2013, in Germany, an ongoing study concerning family based colorectal cancer (CRC) has to face this task [2]. There are multiple risk factors contributing to the development of CRC like smoking, lack of exercise, wrong eating habits and predominantly high age [3]. Aside from known genetic dispositions [4] there has been the observation of accumulations of cases of CRC within families. This means, having a family member with CRC is a risk factor in itself and is referred to as family based CRC [5].

Genealogical links are not documented in cancer registries and are not available within the Munich Cancer Registry (MCR) itself (cf. www.tumorregister-muenchen.de). Therefore, the study design aims at gathering family information from newly diagnosed patients who accept to participate in the study. Information needed are identifying data, in specific, first name, last name, date of birth, address and gender of all close relatives of the patient. This data is matched to the MCR by using a probabilistic record linkage approach in order to identify study patients and relatives within the cancer registry who have been diagnosed with CRC or associated kinds of cancer in the past. Their medical data as well as their genealogical information has then to be passed to the analysis center for further research. Information about family members not registered in the MCR contributes to the study's finding as well.

The study design demands a highly complex safety infrastructure including multiple parties in order to fulfill the obligations based on the strict laws of privacy protection in Germany. In this work's section of methods we give a detailed overview about these obligations and requirements and a description of the model itself. In the section of results we present how we fitted the model to the study of family based CRC.

1. Methods

As postulated in guidelines regarding data privacy protection in a medical environment [6] one of the requirements for a model of data protection is the conceptual and institutional division of all participating parties. In case of performing a data matching, this should result in four different parties as illustrated in figure 1. These are typically the two institutions managing the study as well as the registry datasets which are supposed to be mapped together, the location of an independent data trustee whose main task is to perform the matching process as well as the center which will perform the final analysis. The standard procedure used for matching data is referred to as record linkage [7].

In the case of patient data, attributes like first name, last name or date of birth within the identifying data (IDAT) are used to match the patients within the different datasets. However, the IDAT should not be readable for any other participating institution. Consequently, a variant of a standard probabilistic record linkage, so called, anonymous or privacy preserving record linkage is needed that operates on one way encrypted attributes instead of attributes written in plain text. One way encryption can be achieved by applying hash functions to a string of text [8] or alternatively representing the string as a bloom filter filled with different hash values [1]. This task has to be performed by the data trustee. Before sent to the data trustee, the IDAT are marked with an institution specific ID which is a unique identifier as well as a reference to the corresponding medical data (MDAT) labelled with the same ID.

To expand the model, the third stipulation would be that MDAT should in general, aside from its originating institution, only be readable by the center of analysis. As discussed later, at the location of the data trustee a conversion of the study ID within the IDAT and consequently also within the study MDAT is required. Thus, the study's MDAT are sent to the data trustee as well. Due to the fact that it should not be readable by any other institution but the center of analysis the contents of the study MDAT have to be symmetrically encrypted before. Following, the result of the record linkage process is a list of pairs of IDs, referred to as links [9], describing which patients of the

different datasets relate to the same entity. The objective of these links is to request the MDAT of the registry according to the registry's ID within the links.

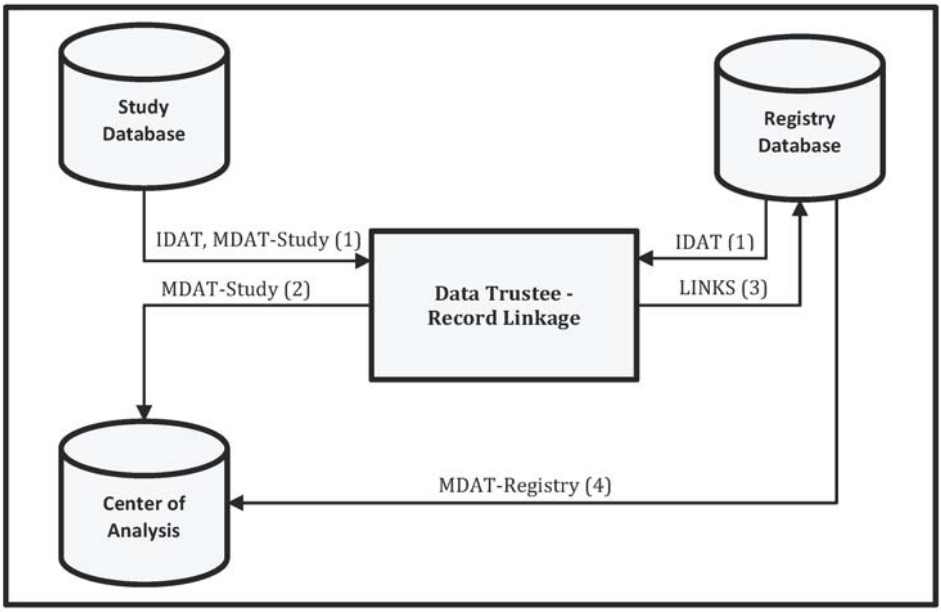


Figure 1. (1) IDAT and MDAT of the study database as well as IDAT of the registry database are sent to the data trustee. (2) After replacing the ID within IDAT and MDAT of the study database with a new random ID, the MDAT of the study database is redirected to the center of analysis. (3) After the record linkage process, the links (pairs of IDs) are sent to the registry database. (4) The requested MDAT of the registry are sent to the center of analysis. Based on the new random ID, the MDAT of the study as well as the registry database can be mapped to each other.

In order to prevent a possible identification based on the information within the MDAT, another requirement should be the realization of *k*-anonymity on the quasi identifiers within this data [10].

As a fifth request, the model demands that study and registry IDs may only be known by the original institutions as well as the data trustee. Thus, the IDs have to be replaced by a new random ID through the data trustee. This new random ID is the only ID transferred to the center of analysis.

Premise six requires that the new random ID may only be shared by the data trustee and the center responsible for analysis. Therefore this ID has to be symmetrically encrypted within the links before shared with the registry. According to the registry's ID within the links, the registry can now extract the needed MDAT, map it to the encrypted new random ID, remove the registry's ID and send the MDAT along with the encrypted new random ID to the center of analysis. In parallel, the center of analysis receives the encrypted MDAT of the study labeled with the same new random ID from the data trustee. At this point, both the MDAT of the registry as well as the study can be mapped together based on the new random ID.

To offer an additional layer of security, all transported data handled between institutions should be asymmetrically encrypted throughout the whole process. All used methods should be considerably save and up to date according to national laws, in this

case according to the recommendations of the BSI which is the bureau for security in IT technology in Germany [11].

2. Results

Within the study of family based CRC an institutional as well as conceptual division is given for both the MCR as well as the study database. The role of the data trustee is performed by an independent person which is the data protection commissioner of the University Hospitals of the Ludwig-Maximilians-Universität (LMU) while the center of analysis is represented by a statistical workgroup of the Institute of Medical Information Processing, Biometry and Epidemiology of the LMU.

The used record linkage system is a probabilistic record linkage system based on the widely used algorithm of Felligi and Sunther [12] as well as on technical guidelines formulated by Martin Meyer [13]. The system has been implemented in java 1.7 and uses some custom technologies to better adapt to the scenario. Some of these customizations have been described in a previous publication [14]. Precedent to the record linkage, the IDAT of both the MCR as well as the study database are first standardized according to UNICON guidelines [15] and one way encrypted by using a hash function of the SHA-2 family [16].

The study's MDAT consist of simple questions as well as the genealogical relations (family structure) of the patients and their relatives. To render this information unreadable when passed to the data trustee it is symmetrically encrypted by using the AES algorithm with a block length of 128bit [17]. The method has been implemented and adapted to the scenario in java by using the packages java.security.* as well as javax.crypto.*. The key to decrypt the MDAT is only shared by the study database and the center of analysis. *K*-anonymity for both the study and registry MDAT has not been done since there were no quasi-identifiers being strong enough to violate the concept of anonymity to a disconcerting degree. At the location of the data trustee and according to the model, a new random ID replaces the old ID within the study's IDAT, MDAT and consequently within the generated links. To accommodate to the sixth requirement the ID within the links is symmetrically encrypted using the same technology as previously explained before sent to the MCR. Once again the key is only given to the center of analysis.

For most transported data, a hybrid encryption system, which is a variant of asymmetrical encryption, has been implemented using the RSA/AES algorithm [18]. The used key length is 2048 bits. The technology has been adapted to the scenario and written in java.

3. Discussion

The presented model can be used as a template for studies which base their analysis on matching study data to data of medical registries. It is very strict in its requirements and therefore eliminates possible violations endangering the privacy of the patients' data. A positive approval in regard of law and ethics by the LMU's ethical review committee has been given in December 2012.

Due to the strictness of the model, comprehensive logistic and organizational efforts are needed. Therefore this model should be best suited for studies of larger scale.

As presented in the results section of this work, the requirements could be successfully applied to the study of family based CRC in Germany. One major task was maintaining the family structure throughout the whole process which could be achieved by modeling the family structure as medical data. Based on the family structure, the center of analysis is capable of rebuilding all genealogical relations between MDAT of patients and their relatives.

Because of the replacement of IDs during the whole process, it is important to note that this model is not applicable to cumulative record linkage. This means if new patients are recruited, the record linkage has to be performed on the whole dataset and not only on the new fraction of patients.

References

[1] Schnell R, Bachteler T, Reiher J. Privacy-preserving record linkage using Bloom filters. *BMC Medical Informatics and Decision Making*. 2009; 9:41

[2] Mansmann U, Stausberg J, Engel J, Heussner P, Birkner B, Maar C. Familien schützen und stärken – Umgang mit familiärem Darmkrebs. *Gastroenterologe*. 2012; 161-162.

[3] Watson AJ, Collins PD. Colon cancer: a civilization disorder. *Digestive diseases*. 2011;29(2):222-8.

[4] Half E, Bercovich D, Rozen P. Familial adenomatous polyposis. *Orphanet journal of rare diseases*. 2009 Oct 12;4:22.

[5] Slattery ML, Levin TR, Ma K, Goldgar D, Holubkov R, Edwards S. Family history and colorectal cancer: predictors of risk. *Cancer Causes Control*. 2003 Nov;14(9):879-87.

[6] Pommerening K, Drepper J, Ganslandt T, Helbing K, Müller T, Sax U, Semler S, Speer R. Das TMF-Datenschutzkonzept für medizinische Daten-sammlungen und Biobanken. Paper presented at: Proceeding of: Informatik 2009: Im Focus das Leben, Beiträge der 39. Jahrestagung der Gesellschaft für Informatik e.V. (GI). 2009;

[7] Christen P. *Data Matching – Concepts and Techniques for Record Linkage, Entity Resolution, and Duplicate Detection*. Heidelberg: Springer; 2012.

[8] Kijsanayotin B, Speedie SM, Connelly DP. Linking patients' records across organizations while maintaining anonymity. *AMIA Annu Symp Proc.* 2007; 1008.

[9] Blakely T, Salmond C. Probabilistic record linkage and a method to calculate the positive predictive value. *International Journal of Epidemiology*. 2002 Dec; 31(6):1246-52.

[10] L Sweeney. K-anonymity: A model for protecting privacy. *International journal of uncertainity, fuzziness and knowledge-based systems*. 2002; 10(5).

[11] BSI - Technische Richtlinie, Kryptographische Verfahren: Empfehlungen und Schlüssellängen, BSI TR-02102. 2013;

[12] Felligi I, Sunter A. A theory of Record Linkage. *American Statistical Association Journal*. 1969; 64:1183-1220.

[13] Meyer M. Kontrollnummern und Record Linkage. *Das Manual der epidemiologischen Krebsregistrierung.* Hentschel S, Katalinie A, editor. Zuckschwerdt. 2011;57-68.

[14] Nasseh D, Stausberg J. Impact of variations in Anonymous Record Linkage on Weight Distribution and Classification. Poster presented at: 14th World Congress on Medical and Health Informatics, Kopenhagen. 2013;

[15] Hinrichs H. Bundesweite Einführung eines einheitlichen Record Linkage Verfahrens in den Krebsregistern der Bundesländer nach dem KRG, Abschlussbericht, Projekt Deutsche Krebshilfe. Antragsnummer 70-2043-Ap I. OFFIS. Oldenburg; 1999

[16] Gilbert H, Handschuh H. Security Analysis of SHA-256 and Sisters. *Selected Areas in Cryptography*. 2003; 175–193

[17] Daemen J, Rijmen V. AES Proposal: Rijndael. 1999;

[18] Palanisamy V, Jeneba M. Hybrid cryptography by the implementation of RSA and AES. *International Journal of Current Research.* April 2011;33(4): 241-44.

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The Everyday Ethics of Field Work Research with Vulnerable Patients

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Abstract. Patients are increasingly involved in health informatics research. Researchers are always aware of the ethical dimensions of their research, but studies in the field with patients – especially among the frail, elderly, cognitively impaired - present specific additional 'everyday moral dilemmas'. Reflecting on experiences of a hospital study of patients with dementia, this paper draws attention on the type and constant presence of this situated ethics, the immediacy of decision-making, and the importance of everyday ethics for health informatics.

Keywords. Health informatics, research methods, ethics, patients

Introduction

There is an increasing interest in health informatics research involving patients. For example, health IT implementations are evaluated in terms of patient outcomes, or research is carried out to design or evaluate patient-facing technology intended to assist patient decision-making, or for self-management, self-care, or assistive purposes (e.g. [1, 2]). Health informatics research thus calls for an increased "focus on patients' perspectives" [3] and direct involvement of patients as end-users [4].

Ethical issues[1] permeate research with patients, especially among the frail and elderly, or cognitively impaired population. Yet it could be argued that these vulnerable people[2] would gain the most from technological innovation, for example to help them maintain a degree of independence and autonomy. Furthermore, being involved in research would give them a voice often otherwise silenced [7].

"Ethics is an ever present concern for all researchers" [8:567]. The health informatics literature has explored issues of ethics pertaining to research on patient data (e.g. [9, 10]), but few are the studies exploring the ethical issues related to directly involving patients (e.g. [2, 11]). In this paper, I draw attention to some of the everyday ethics dilemmas faced by a researcher in this field, using examples from an on-going study in hospital wards in England (UK). While this study is not specifically aimed at implementing patient-facing technology, the research experience resonates with, and is relevant to, studies in this area.

[1] In this paper I am interested in ethics with a small e, "the moral what-to-do questions […] that require […] to evaluate and choose between alternatives" [5:48] on an everyday basis, while in the field. This is also known as 'everyday ethics', 'ethics in practice' or 'microethics' [6]. It is not the Ethics with a capital E of Ethics Committees or Ethics Councils.

[2] Some of the situations discussed in this paper are specific to research with vulnerable people. But it could be argued, all patients are vulnerable.

1. Methods

This paper is based on research in the field I am currently conducting for a study aimed at the design and implementation of a decision support tool for the assessment and management of pain in patients with dementia[3]. At the time of writing, the study is taking place in 4 NHS hospital organisations in England and Scotland. Inpatients of 2 hospital wards per site – and the care they receive - are our unit of analysis. Qualitative data are being collected with a mix of methods including observations, documentary analysis of patient hospital records, and interviews with clinical staff, managers and carers. This paper is based on personal experiences of collecting data in one of the 4 hospitals – in an elderly medicine ward and a vascular ward. This included the recruitment and observation of 8 patients and audit of their hospital records, 71 hours of observations at the patient's bedside (over 22 days, in the period from May to November 2013), and about 124 hours of observation of the ward context. Observations of patients and any interactions they may have had, were carried out at the bedside for up to 3 days. Thus, relations with the patients in this study did not benefit from familiarity built over long periods of time [12], but over relatively brief research encounters.

The patients included in the study were elderly and had a diagnosis of dementia. Their consent to participate was subject to capacity assessment to consent, consultation with staff and assent of carers [13]. The process was agreed with NHS Ethics Committees in England and Scotland and informed by the Mental Capacity Act 2005 and the Mental Health (Care and Treatment) (Scotland) Act 2003 [4]. Ethics Committees approval and oversight provide some assurance about the ethics of these research activities, but they do not free the researcher from judgments and decisions of ethical nature while in the field. As it has been said, "It is at the level of 'ethics in practice' that researchers must do the real ethical work" [6:273].

2. Results

2.1. Consenting, then leaving them

The first encounter with the patient was fraught with moral dilemmas. Both the situation of being hospitalised, and their cognitive impairment, influenced their ability to consent freely. The same conditions also influenced relatives or carers' assent. More than once, relatives/carers expressed hopes or wishes for the researcher to provide their elderly relative with some company and opportunities for interaction while in the hospital. Thus they qualified their assent for study participation and by doing so created expectations that were outside of the remit and role of being a researcher.

Observations at the bedside were limited to three days for each patient. I was 'company' for three days, and then I left; and I may have left them to boredom or distress, posing a further dilemma. And so, on occasions, I stayed, for a few more hours.

[3] "The detection and management of pain in patients with dementia in acute care settings: development of a decision tool" (HS&DR - 11/2000/05) http://www.nets.nihr.ac.uk/projects/hsdr/11200005

[4] http://www.legislation.gov.uk/ukpga/2005/9/contents, http://www.legislation.gov.uk/asp/2003/13/contents

I find the nurse with [the patient], she is putting his boots on and he seems angry and in distress. He wants to go home. As the nurse leaves I talk with him, as I realise he has seen me. He wants to leave the hospital …. We end up chatting until 4pm.

These points of initial contact (informed consent) and points of departure (leaving the participant) highlight some of the ethical challenges of doing research with patients. Patients and relatives had different and varied reasons for accepting to participate in the study [14] and through their reasons they gave my work a different dimension. While I was conducting research, I was also fulfilling other functions, such as providing company and interaction; this potentially created situations of 'dual agency' – potentially "conflicting duties or loyalties" [15].

2.2. Observations and Interventions

On repeated occasions during observation sessions patients or staff asked me to intervene. This raised another dilemma; *Was it right to say yes? Was it right to say no?* Small acts of 'participation' (intervention) could be associated with harm. But the opposite was also true, and harm could have been associated with non-intervention.

He kept falling asleep on the chair. And when awake, tried to get out of the chair. I told him to wait and went looking for somebody to help him. At the nurses' station the clerk said there is a risk of falling, not to let him get out of the chair. When I explained that I was not authorised to intervene she said she isn't either but that better to intervene than to have a fall. So I went back to the patient and thought that if I engaged him in conversation he would stop trying to get up …

Another patient […] returning to the chair from a visit to the toilet, asked me if I could help her. I offered her my arm. […] Though I did wonder what would be the consequences if she fell while I helped her.

On other occasions it was the situation that demanded action.

A patient all of a sudden starts breathing deeply and crying out – ah! Ah! Ah! and rocking on her chair. I and another patient ask if she is okay. She says "I got this sudden spasm. Very frightening." She is still breathing heavily. I call the healthcare assistant outside the room for help, she gives her an inhaler and calls a nurse…

The meal lady asks [the patient] for tea or coffee and cake. [The patient] answers coffee […] the cup seems too heavy for her. Is she going to spill hot coffee on herself? I intervene: I take the cup off her hands. But if not helped, she won't have it.

Acute and explicit health and safety situations such as the patient's sudden lack of breath, were rare. Instead small scale everyday 'calls for assistance' were frequent and were those that created greater ambiguity in terms of ethical response. Additionally, they posed a methodological dilemma: intervening meant changing patient experience or the dynamic of the patient interaction with healthcare staff subject of study.

3. Discussion

As technology is increasingly ubiquitous, health informatics systems are designed for a variety of contexts; research is expanding its boundaries to settings involving directly patients – from hospital rooms, to people's homes – with different patient populations. The experience of carrying out data collection with this frail, vulnerable group of elderly patients has highlighted the complexity and potential ethical dilemmas researchers may face in these contexts. In my role as a researcher I intended to minimize the impact of my presence on the ward, conducting the field study in line with a non-participant research design. However, I found that there is no such a thing as *non-participant observation* in this kind of research. Just by being at bedside, my presence affected the patients' experience of their hospital stay and illness, and their interaction with the environment. Furthermore, either I found myself needing to intervene, or I was explicitly asked to. Thus I 'helped out' much more than I had anticipated - I called for help on behalf of patients, opened a door for a claustrophobic one, passed a glass of water to a blind lady, adjusted settings of TV sets, even caught a bee that entered the room on a summer day. Because of the hospital context and the patients' frailty, many of these interventions bore an element of risk for the patient, and therefore implied an ethical choice. In terms of patient recruitment, the choice has a 'hard' character of either/or - the patient either participates or not (though being then sensitive to cues of the wish of participants to withdraw from the study [14]). A more nuanced 'soft' range of choices is possible for questions of intervention, as intervention can take many forms. Thus, for example, in the case of the patient at risk of falling from his chair, my intervention took the form of engaging in conversation instead of actively stopping him from standing up. Although the study can be considered low-risk, bearing minimal risk for the patient, I was still at risk of invading their privacy and personal space, or contributing to (while trying to prevent) physical harm (e.g. from a fall). Choices were made on the basis of ethical principles of 'doing no-harm', respect for the person's dignity and recognizing the person's "inherent rights to privacy, respect and self-determination" [16:796]. I was aware that "participants can be wronged even if they are not harmed" [16:796]. Decisions were also informed by my understanding of the situation, empathy with the participants, and the relationship established with the patient in the brief time of our encounter. In everyday ethics, choice and outcomes are situated and contingent; dilemmas are resolved "situationally" – i.e. "considering the individual circumstances each dilemma encompasses" [8:568]. Furthermore, these situations are "integral to the entire research process and not just frustrating asides" [8:575]. These decisions are taken in a very brief time frame; they are many a "snap decision" [8:572]. "I began hastily to calculate my position" writes Goodwin recounting an ethic dilemma in the field [8:572]. But often there is no time to contemplate or calculate alternatives. There is no time to think beforehand, engage in reflexivity about the specific situation [6], or being fully conscious of the rationales for different options or the choice being made. This is a reason why researchers need to develop "ethical competence" and skills [6:269] – i.e. develop means of addressing and responding to ethical concerns if and when they arise in research [6:276]. It may be inevitable that the right – or the best - decision cannot always be made 'on the spur of the moment'. If in the field there is no time to think, reflecting on events and thinking about ethics whilst outside of the field can better prepare the researcher for the next ethical 'snap decision' to be faced. It can help the researcher gain 'a way of thinking', an 'alertness' to situated moral dilemmas [6].

Health informatics aims to use technology 'to make a better world' [17] improving healthcare and people's well being; we need ethical means for ethical ends, starting perhaps from small scale everyday ethics and field research.

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References

[1] T. Greenhalgh, J. Wherton, P. Sugarhood, S. Hinder, R. Procter, R. Stones, What matters to older people with assisted living needs? A phenomenological analysis of the use and non-use of telehealth and telecare, *Social Science & Medicine* **93** (2013), 86-94.

[2] A. Das, D. Svanæs, Human-centred methods in the design of an e-health solution for patients undergoing weight loss treatment, *International Journal of Medical Informatics* **82** (2013), 1075-1091.

[3] A.G. Ekeland, A. Bowes, S. Flottorp, Effectiveness of telemedicine: A systematic review of reviews, *International Journal of Medical Informatics* **79** (2010), 736-771.

[4] E. Bélanger, G. Bartlett, M. Dawes, C. Rodríguez, I. Hasson-Gidoni, Examining the evidence of the impact of health information technology in primary care: An argument for participatory research with health professionals and patients, *International Journal of Medical Informatics* **81** (2012), 654-661.

[5] Nuffield Council on Bioethics, Medical profiling and online medicine: The ethics of 'personalised healthcare' in a consumer age, Nuffield Council on Bioethics, London, 2010.

[6] M. Guillemin, L. Gillam, Ethics, reflexivity, and "ethically important moments" in Research, *Qualitative Inquiry* **10** (2004), 261-280.

[7] P. Fisher, Ethics in qualitative research: 'vulnerability', citizenship and human rights, *Ethics and Social Welfar*e **6** (2011), 2-17.

[8] D. Goodwin, C. Pope, M. Mort, A. Smith, Ethics and ethnography: an experiential account, *Qualitative Health Research* **13** (2003), 567-577.

[9] S.T. Rosenbloom, J.L. Madison, K.B. Brothers, E.A. Bowton, E.W. Clayton, B.A. Malin, D.M. Roden, J. Pulley, Ethical and practical challenges to studying patients who opt out of large-scale biorepository research, *JAMIA - Journal of the American Medical Informatics Association* **20** (2013), e221-e225.

[10] H.W. Samuel, O.R. Zaïane, D. Sobsey, *Towards a definition of health informatics ethics,* Proceedings of the 1st ACM International Health Informatics Symposium, Arlington, Virginia, USA, 2010, pp. 257-264.

[11] J. Galliers, S. Wilson, A. Roper, N. Cocks, J. Marshall, S. Muscroft, T. Pring, *Words are not enough: empowering people with aphasia in the design process* Proceedings of the 12th Participatory Design Conference: Research Papers - Volume 1, ACM, Roskilde, Denmark, 2012, pp. 51-60.

[12] C. Ellis, Telling Secrets, Revealing lives: relational ethics in research with intimate others, *Qualitative Inquiry* **13** (2007), 3-29.

[13] T.B. Monroe, K.A. Herr, L.C. Mion, R.L. Cowan, Ethical and legal issues in pain research in cognitively impaired older adults, *International Journal of Nursing Studies* **50** (2013), 1283-1287.

[14] M. Gysels, C. Shipman, I.J. Higginson, "I will do it if it will help others:" Motivations among patients taking part in qualitative studies in palliative care, *Journal of Pain and Symptom Management* **35** (2008), 347-355.

[15] K.W. Goodman, S. Adams, E.S. Berner, P.J. Embi, R. Hsiung, J. Hurdle, D.A. Jones, C.U. Lehmann, S. Maulden, C. Petersen, E. Terrazas, P. Winkelstein, AMIA's Code of Professional and Ethical Conduct, *JAMIA - Journal of the American Medical Informatics Association* **20** (2013), 141-143.

[16] Z. Ludin, *On ethical problem solving in user-centered research: an analysis*, CHI '11 Extended Abstracts on Human Factors in Computing Systems, ACM, Vancouver, BC, Canada, 2011, pp. 791-798.

[17] G. Walsham, Are we making a better world with ICTs? Reflections on a future agenda for the IS field, *Journal of Information Technology* **27** (2012), 87-93.

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Determinants of Eligibility and Use of Ehealth for Cardiac Rehabilitation Patients: Preliminary Results

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Abstract. To foster implementation of eHealth in care practice, it is important to gain insight into the factors that influence acceptance. The aim of this study was to identify determinants of eligibility and use for completing an electronic needs assessment for cardiac rehabilitation. We analysed the influence of age, gender, diagnosis, health literacy, quality of life scores, and depression and anxiety scores. Among 240 patients entering CR in two clinics, 101 patients were deemed eligible to use the system by their CR professional, of which 75 (74.2%) actually used it. Only 50% of the patients who had an acute coronary syndrome and 20% of the patients with chronic heart failure were deemed eligible. Furthermore, there was a decreasing trend towards usage in female patients, patients with symptoms of anxiety, and patients with a better quality of life. In the future we will continue to explore barriers and success factors as experienced by the patients and the participating clinics to optimize the system.

Keywords. Cardiac rehabilitation, eHealth, technology acceptance, uptake

Introduction

Chronic diseases are increasing in prevalence and becoming a key challenge for modern health care systems [1]. eHealth is generally viewed as an effective means to manage the care for chronically ill patients. Patients may see an opportunity in using eHealth to participate in information sharing and decision making, to be in more control of their disease and of the quality of care delivered to them [2]. However, eHealth technologies are not always accepted by patients [2], and this has led to eHealth implementation failures [3]. This is a serious concern for both patients and healthcare organizations as foreseen benefits and returns on investments are not attained. Therefore, research into patient characteristics predicting use of eHealth systems is required. Identifying these characteristics can help in creating systems that fulfill patients' needs and increase the chances of eHealth implementation success. To

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this end, the current study aimed to analyze patient characteristics affecting use and eligibility of an electronic needs assessment system for cardiac rehabilitation patients.

1. Methods

1.1. Background

To support coronary heart disease patients in their recovery from a cardiac incident or intervention, they receive cardiac rehabilitation (CR). CR is a multidisciplinary therapy that aims to improve the physical and psychological condition of patients [4]. In the Netherlands, a needs assessment procedure concerning medical, physical, psychological, and social condition, and lifestyle parameters is performed by CR professionals prior to the rehabilitation. This is in line with international standards and the Dutch Guidelines for CR [5]. Based on this needs assessment an individualized rehabilitation programme consisting of four possible group based therapies (exercise training, education, lifestyle change therapy, and relaxation and stress management training) and individual counselling is offered.

To improve the efficiency of the data gathering process, we developed the electronic needs assessment system MyCARDSS which can be used by patients at their homes. The current version of the system implements the questionnaires recommended by the Dutch guidelines comprising about 85 data items concerning quality of life, depression and anxiety, social functioning, work resumption, stress, and lifestyle behaviour. MyCARDSS is linked to the CARDSS system, a clinical electronic patient record (EPR) system that offers decision support facilities to CR professionals [6].

MyCARDSS was implemented in three Dutch hospitals during a pilot implementation from August 2013 to January 2014. The preliminary results of this pilot are presented in this paper. CR professionals decided which patients were eligible to use MyCARDSS based on two factors: mastery of the Dutch language and internet access at home. Patients should be able to read Dutch to understand the needs assessment questions.

Eligible patients were invited by their CR professional to use MyCARDSS. They received a web address and personal access code. All patients that used MyCARDSS and submitted their answers via MyCARDSS were considered to be users of MyCARDSS.

1.2. Data Collection and Statistical Analysis

Data on each patient's age, cardiac diagnosis and intervention, MacNew Quality of Life score [7], Patient Health Questionnaire-9 (PHQ) depression score and Generalized Anxiety Disorder Assessment-7 (GAD) score were obtained from the EPR system CARDSS. The Quality of Life score ranges from 1 to 7, where higher scores indicate a better quality of life. The PHQ-9 score ranges from 0 to 27, and the GAD-7 score ranges from 0 to 21, where in both cases higher scores indicate more symptoms.

An additional paper questionnaire was given to patients to collect data on their health literacy. The Dutch version of the Set of Brief Screening Questions (SBSQ), consisting of three questions was used [8]. The resulting score ranges from 0 to 4, where higher scores indicate more adequate health literacy. The paper questionnaire was given to patients when they visited the hospital to discuss their rehabilitation needs.

Logistic regression analysis was performed to assess the influence of patients' age, gender, quality of life-, anxiety- and depression scores on eligibility and use of MyCARDSS.

2. Results

During the study period, 240 patients entered CR in the two clinics. Mean age of the patients was 64.9 ± 10.6 years, and 171 (71.3%) were male. One hundred and thirteen patients (47%) were diagnosed with an acute coronary syndrome (ACS), of which 78 (33%) underwent coronary revascularisation (CABG or PCI). Sixteen patients (7%) had a chronic cardiovascular disease (stable angina pectoris or heart failure). Seventy-three patients (30%) underwent an elective revascularisation intervention (PCI or CABG). Diagnostic data of 27 patients (11%) were not available, 11 patients (5%) had another diagnosis like transplantation or arrhythmia. The mean quality of life score was 5.1 ± 1.0. The median GAD-7 score was 2.0 with an interquartile interval (IQI) of 0.0 to 6.0. The median PHQ-9 score was 3.0 with an IQI of 1.0 to 7.0.

Table 1. Patient characteristics and use

Determinants	Eligibility Odds ratio (95% CI)	Use Odds ratio (95% CI)
Gender (female)	**1.59 (0.79-3.22)**	**0.22(0.04-1.13)**
Age (per 10 years)	**1.02 (0.99-1.05)**	**0.98 (0.91- 1.04)**
ACS with intervention	**0.73 (2.11-2.54)**	**0.67 (0.13-3.01)**
ACS without intervention	**0.47 (0.12-1.83)**	**1.51 (0.25-9.08)**
Chronic diagnosis	**4.18 (0.63-27.79)**	**0.30 (0.02-4.11)**
Elective PCI	**2.78 (0.64-12.01)**	**0.96 (0.07-13.29)**
Elective CABG	**2.83 (0.68-11.73)**	**4.65 (0.24-92.06)**
Other diagnosis	**1.89 (0.32-11.12)**	**0.00 (0.00-0.00)**
Unknown diagnosis	**Reference category**	**Reference category**
Quality of life score	**1.15 (0.71-1.87)**	**0.27 (0.67- 1.04)**
Depression PHQ-9 score	**1.01 (0.90-1.13)**	**0.87 (0.66-1.16)**
Anxiety GAD-7 score	**1.04 (0.94-1.16)**	**0.83 (0.66-1.02)**
Health literacy (n=55)	**n/a**	**0.94 (0.31-2.79)**

n/a= not measured

In total, 101 patients (42.1%) were found eligible to use MyCARDSS. Mean age of the eligible patients was 63.6 ± 9.8. Of the 16 patients with a chronic disease, CR professionals considered only 3 (19%) eligible for using MyCARDSS, 40 of the 78 (51%) ACS patients who did undergo an intervention were considered eligible and 20 of the 35 (57%) ACS patients who did not undergo an intervention were considered to be eligible to use MyCARDSS. None of the factors were associated with eligibility.

Seventy-five (74.2%) eligible patients actually used MyCARDSS, 56 (75%) of them were male. 2 of the 3 (67%) eligible patients with a chronic diagnosis, 17 of the 20 (85%) eligible patients diagnosed with ACS who did not undergo an intervention and 29 of the 40 (73%) eligible patients diagnosed with ACS who underwent an intervention accepted to use the system. Gender, age, diagnosis, and anxiety score, depression score and quality of life score were not associated with system use. There is

a trend towards less system use in females, more anxious patients, and patients with a better quality of life.

Only 55 patients filled in the health literacy questionnaire, of whom 35 used MyCARDSS. Health literacy was not significantly associated with the use of MyCARDSS (Table 1).

3. Discussion

In this study we explored patient characteristics that affected eligibility and use of MyCARDSS, an electronic needs assessment system for cardiac rehabilitation patients. We found no strong associations between the factors studied and eligibility or use. However, there was a decreasing trend towards system use in females, more anxious patients, and patients with a better quality of life.

To our knowledge, no previous studies have investigated patient characteristics determining eligibility for using eHealth applications. CR professionals considered only 40% of patients eligible for using the electronic needs assessment system, which is less than expected. In the Netherlands, over 90% of all households have a broadband internet connection. We have planned to conduct in-depth interviews with CR professionals of the participating CR clinics to study these results related to eligibility.

We found no relation between age, gender and use of MyCARDSS. Among 39 studies analyzing the impact of age and gender on acceptance of eHealth, only one one showed that patients of a higher age were more likely to accept eHealth applications, whereas 19 found that a higher age was negatively associated with acceptance [3,9]. In 26 (84%) out of 31 studies exploring the impact of patient gender on eHealth acceptance, no effect was found [9,10]. Our patient population does not vary much in age but represents a group of a relatively old age. Likewise, most patients are male. This might explain why we did not find an association between age and gender and use of MyCARDSS. However, the majority of patients who were found eligible also actually used the system, apparently not deterred by their age. In a follow-up study we will investigate the reasons for non-usage of eligible patients by interviewing these patients.

Our results show a trend towards less system usage both among patients with a better quality of life and among patients with higher anxiety levels. Patients with a better quality of life may feel healthier and may thus be less motivated to follow CR and use MyCARDSS. To our knowledge, no previous studies have investigated the influence of quality of life on patient use of eHealth. Also, as far as we know, no other studies have investigated the relation between patients' anxiety and use of eHealth. It is however known that more anxious patients have a need for more regular contact with their caregivers [11]. It is conceivable that the more anxious patients in our study likewise felt dependent upon their caregiver and preferred to await the consultation with the CR professional before they would start using the system. We did not find an association of depression with use of MyCARDSS, whereas higher levels of depressive symptoms have been shown to have a negative influence on use of a personal health record [9]. A possible explanation for this difference in results could be that our patients had to use MyCARDSS only once and merely for providing data on their health, whereas patients in described in Lober et al. had to use the personal health record on a continuous basis for educational purposes [9]. It is known that patients with depressive symptoms are less interested in these types of programs [12].

Our study showed no association between health literacy levels and use of the eHealth system, while in general patients with lower health literacy are less likely to accept eHealth because they experience difficulties in recognizing the benefits of eHealth without being explicitly informed on those merits [9]. Due to the small number of patients (n=55) that filled in the health literacy questionnaire, our study may have been underpowered. After full implementation of MyCARDSS, we will not only study the association between health literacy and use of MyCARDSS more thoroughly but likewise whether differences in patients' health literacy levels have an impact on the completeness and quality of the data collected.

A limitation of this study is the small number of patients included in the pilot phase of the implementation of MyCARDSS, which has lasted only a few months. Most of the effects described will be explored further when we have included a larger patient population. In the future we will expand MyCARDSS with functionality by which patients will be supported in monitoring their own disease and health conditions and encouraged to manage their own disease. We will continue to explore barriers and success factors as experienced by the patients and the participating Dutch clinics to optimize the MyCARDSS system.

References

[1] Jackson AM, McKinstry B, Gregory S, Amos A. A qualitative study exploring why people do not participate in cardiac rehabilitation and coronary heart disease self-help groups, and their rehabilitation experience without these resources. *Prim Health Care Res Dev* **13** (2012), 30–41.
[2] Or CKL, Karsh BT, Severtson DJ, et al. Factors affecting home care patients' acceptance of a web-based interactive self-management technology. *J Am Med Inform Assoc* **18** (2011), 51-9.
[3] Hardiker NR, Grant MJ. Factors that influence public engagement with eHealth: a literature review. *Int J Med Infom* **80 (**2011), 1-12.
[4] Piepoli MF, Corra U, Benzer W, et al. Secondary prevention through cardiac rehabilitation: from knowledge to implementation. *Eur J Cardiovasc Prev Rehabil.* **17** (2010), 1-17.
[5] Rehabilitation Committee: Netherlands Society for Cardiology (NVVC) and Netherlands Heart Foundation (NHS) and Working Group PAAHR. *Multidisciplinary Guidelines for Cardiac Rehabilitation* (in Dutch). Utrecht: Netherlands Society for Cardiology (NVVC), 2012.
[6] Goud R, de Keizer NF, ter Riet G, et al. Effect of guideline based computerised decision support on decision making of multidisciplinary teams: cluster randomised trial in cardiac rehabilitation. *BMJ* **338** (2009) b1440.
[7] Dixon T, Lim LL, Oldridge NB. The MacNew heart disease health-related quality of life instrument:
[8] reference data for users. *Qual Life Res* **11 (**2002) 173-83.
[9] Fransen MP, Schaik van TM, Twickler MB, Essink-Bot ML. Applicability of Internationally Available Health Literacy Measures in the Netherlands. *J Health Commun* **16** (2011) 134-149
[10] Lober WB, Zieler B, Herbaugh A, et al. Barriers to use of a personal health record by an elderly population. AMIA Annu Symp Proc. 2006:514-8.
[11] Or CKL, Karsh BR. A systematic review of patients acceptance of consumer health information technology. *J Am Med Inform Assoc*. **16** (2009), 550 –560
[12] Dowson CA, Kuijer RG, Mulder RT. Anxiety and self-management behavior in chronic obstructive pulmonary disease: what has been learned? *Chron Respir Dis* **1** (2004) 213-220
[13] Rotgé JY, Tignol J, Aouizerate B. Improving the management of depression in primary care. *Encephale* **33** (2007) :552-60.

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Supporting Patient Screening to Identify Suitable Clinical Trials

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Abstract. To support the efficient execution of post-genomic multi-centric clinical trials in breast cancer we propose a solution that streamlines the assessment of the eligibility of patients for available trials. The assessment of the eligibility of a patient for a trial requires evaluating whether each eligibility criterion is satisfied and is often a time consuming and manual task. The main focus in the literature has been on proposing different methods for modelling and formalizing the eligibility criteria. However the current adoption of these approaches in clinical care is limited. Less effort has been dedicated to the automatic matching of criteria to the patient data managed in clinical care. We address both aspects and propose a scalable, efficient and pragmatic patient screening solution enabling automatic evaluation of eligibility of patients for a relevant set of trials. This covers the flexible formalization of criteria and of other relevant trial metadata and the efficient management of these representations.

Keywords. Clinical trials, trial metadata, eligibility criteria matching, semantic interoperability, healthcare standards, HL7 RIM, BRIDG, SNOMED-CT

Introduction

Clinical trials are key instruments in clinical research that enable the validation of research hypotheses, turning them into evidence that can be applied in standard clinical care. The population to be enrolled in a trial is usually described by a set of free-text eligibility criteria that are both syntactically and semantically complex, which makes their automatic evaluation on the patient data in order to assess the eligibility of that patient for a set of trials a challenging task.

To automate the evaluation of eligibility of patients for trials it is necessary to (1) extract and represent the semantics of the eligibility criteria in a machine-processable way and (2) automatically match each criterion with the relevant data elements available for each patient. The main focus in the literature has been on the first aspect and on proposing different methods for modelling and formalizing the eligibility criteria [1]. However the current adoption of these approaches in clinical care is limited and there is little evidence of the use of relevant healthcare standards or of evaluations

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in real clinical settings. Due to the semantic complexity of criteria, these formalisms are either too complex and their modelling and implementation requires significant effort, or do not sufficiently capture the semantics of each criterion to enable its automatic evaluation. Less effort has been dedicated to the second issue, the automatic matching of eligibility criteria to the patient data managed in clinical care.

We address both aspects and propose a scalable, efficient and pragmatic Patient Screening solution enabling automatic evaluation of eligibility of patients for a relevant set of clinical trials. This covers the flexible formalization of criteria and of other relevant trial metadata and the efficient management of these representations. Additionally, we rely on our standards-based semantic interoperability solution to provide shared semantics between formalized trial information and care data, and to facilitate automatic linkage and matching of trial criteria to patient data. The solution has been built and evaluated with clinical trials of the Breast International Group (BIG)[2] and with anonymized patient datasets collected in the context of care[3].

1. Methods

In this section we describe our approach to formalization and representation of the trial criteria and introduce the key components of the Patient Screening solution. We also briefly describe the approach that is at the basis of our semantic solution as this provides key benefits leveraged by the application.

1.1. The formalization and standard representation of trial metadata

We have previously investigated the structure of the criteria in terms of re-occurring context patterns and of the core semantics encapsulated in each criterion, i.e. concepts that we have subsequently identified in standard terminologies [2]. Despite their syntactic semantic complexity, criteria have similarities in their structure and include one or more context patterns (e.g. expressing restrictions, conditions, etc.) and one or more concepts that express the core meaning of the criterion and give an indication of the patient data that is necessary for the evaluation of that particular criterion. Figure 1 gives examples of both types of entities co-occurring in criteria.

The concepts present in the criteria (e.g. cancer, Tamoxifen, radiotherapy) are linked in our solution to one of several standard terminologies/ontologies and become part of the core dataset used by the semantic solution. The context patterns such as “No concurrent()” or “No prior()”/”No history()” express what needs to be evaluated in the patient data in relation to the concept. We associate the patterns to templates that express the execution logic of the criteria. Complex criteria can include several patterns and therefore they will be represented by combining several templates.

Different context expressions with the same meaning are associated to the same template. E.g. “No prior()” and “No history()” require the same execution logic so they correspond to the same template. Templates can be linked to several formalisms and representations stored in our Trial Metadata Repository (described in Section 1.2).

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[2] www.breastinternationalgroup.org.

[3] This work has been partially funded by the European Commission through the INTEGRATE project (FP7-ICT-2009-6-270253). www.fp7-integrate.eu.

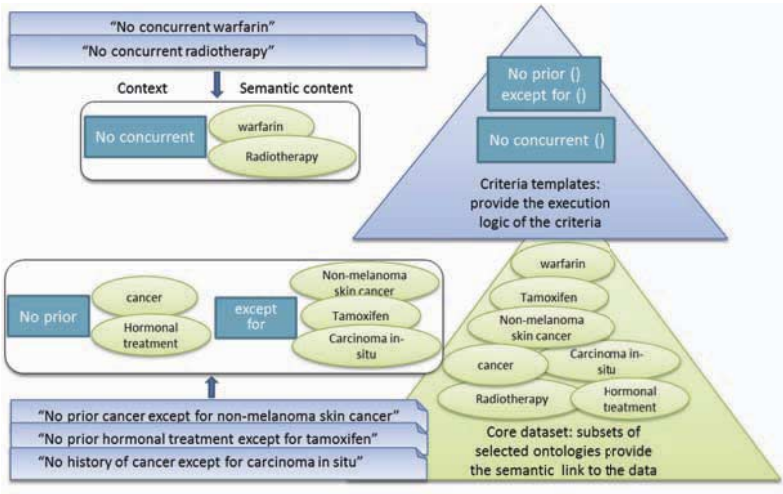


Figure 1. The structure of the eligibility criteria: elements describing context and core meaning

The placeholders in the patterns/templates, depicted above with "()", are filled in by concepts as Figure 2 shows. In the template these will be input parameters for an instantiation of that template. The formalisms and representations (and their chosen instantiations) can be specific to an application, a deployment, etc.

1.2. The Trial Metadata Repository

An important component in our solution is the Trial Metadata Repository (TMR) that manages all the metadata regarding clinical trials. This component flexibly addresses the needs of all applications in the environment that need access to trial metadata. For instance, for Patient Screening the TMR registers the following: (1) the trial acronym, (2) the trial description, (3) the target accrual range, (4) the number of enrolled subjects, (5) the start and (expected) end date of the trial, (6) the status of the trial (e.g. recruiting, closed, etc.) and (7) the eligibility criteria (text, executable logic, etc.). The TMR leverages the Biomedical Research Integrated Domain Group (BRIDG) model [3] to improve future interoperability of the repository and to gain the knowledge of the different perspectives ultimately encoded in the domain model. The BRIDG model is scoped and extended to address the needs of our solution. The TMR allows to store for each criterion several representations/formalisms and versions of execution logic.

1.3. The Core Dataset and the Semantic Interoperability Solution

At the centre of our semantic solution that links trial descriptions to the information model representing the patient data is the core dataset as in [4]: Soundly defined and agreed-upon clinical structures consisting of standard-based concepts, their relationships, quantification etc., that together sufficiently describe the clinical domain. To maximize reuse we chose to capture the semantics of the clinical terms by standard terminology systems such as SNOMED-CT[4] and LOINC[5], which are widely used in

[4] http://www.ihtsdo.org/SNOMED CT/

the clinical domain. Our data model leverages the HL7-RIM and the HL7 implementation guidelines[6]. The underlying semantic solution is described in [5]. In [6] we estimated the effort required for implementing mappings to the patient information model, the scalability of our solution with the number of trials and its extensibility to other clinical domains.

2. Results

For matching trial criteria to available patient information we developed an application which retrieves from the TMR the relevant template-instantiations of the criteria and applies them on the patient data retrieved from the patient data source. In the current implementation each template is instantiated to a representation that is a Groovy [7] script including SPARQL [8] queries to retrieve the necessary patient data (an example is provided in Figure 2). This solution is both efficient and flexible. It exploits the structure of the criteria enabling a high degree of reuse of templates across trials and criteria as the same patterns often re-occur across trials, and enables automatic matching to patient data leveraging the semantic solution.

We do not attempt full formalization of criteria as we believe that this is not necessary for efficient patient recruitment. The high overlap in templates across trials enables us to efficiently reuse the execution logic to address the real issue of automatic eligibility assessment: matching criteria of trials to the data elements of a large number of patients. Taking into account that the number of very complex criteria is rather small, we do not expect that further effort in formal representation of criteria and in pattern extraction yields high impact in real life scenarios for eligibility assessment.

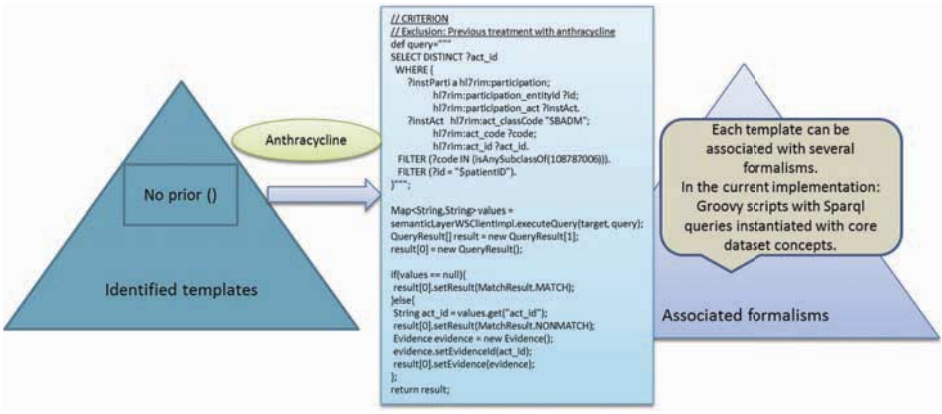


Figure 2. From templates to instantiated templates and their associated formalism

Based on the requirements of our clinical users we selected the relevant parts of the BRIDG model. We extended the subset of classes and class attributes of BRIDG with application-specific constructs, resulting in the information model underlying the trial metadata repository. The information model is subsequently exposed by web-services. It contains constructs to express inclusion and exclusion criteria and their

[5] http://loinc.org/

[6] https://www.hl7.org/implement/standards/

relation to trials, including specific content to allow the actual matching/verification of a trial criterion with a patient's data. When a new trial begins, its metadata is added to the TMR. In this step, criteria are linked to existing templates and corresponding formalisms, and the context variables (i.e. initial concepts) are specified. New templates can be added for criteria that are (partially) not covered by existing templates and in that case the corresponding execution logic is defined. As a trial has on average no more than 15-20 eligibility criteria and as our previous analysis showed that many of the patterns and concepts in criteria frequently repeat across trials, this step is not effort intensive. Once the trial metadata is uploaded to the TMR, it can be reused by the application in any other healthcare organization connected to the environment by updating the queries to the local information model.

3. Discussion

The approach described in this paper aims to automate certain tasks of the patient screening procedure to enhance modern clinical trial recruitment. Our novel solution automatically identifies the clinical trials for which a patient is potentially eligible by matching the trial criteria to the available patient information. Our approach is generic and flexible, integrating loosely coupled components with well-defined standard interfaces and making use of prominent standards in the healthcare domain, such as BRIDG for the Trial Metadata Repository and SNOMED-CT and LOINC to model semantics. We combine the use of formal representations of eligibility criteria with a pragmatic and efficient implementation in which templates are linked to execution logic and extensively reused. The semantics in our environment leverage standard ontologies and terminologies which supports efficient deployment in real healthcare environments.

The solution has been developed to suit the needs of a large clinical research network in the breast cancer domain. Extension to other clinical domains and deployment in new environments is straightforward due to the generic loosely-coupled architecture and the extensive use of standards. The solution can make use of different formalisms and data representations, and any of the components can be independently extended or replaced to fit the needs of new environments.

References

[1] Weng C, Tu SW, Sim I, Richesson R. Formal representation of eligibility criteria: A literature review. Journal of Biomedical Informatics. 2010; 43(3): pp. 451-67.
[2] Milian K, Bucur A, ten Teije A. formalization of clinical trial eligibility criteria: Evaluation of a pattern-based approach. Proc. of the BIBM. 2012; pp. 1-4.
[3] http://bridgmodel.nci.nih.gov/
[4] Vdovjak R, Claerhout B, Bucur A. Bridging the gap between clinical research and care - Approaches to semantic interoperability, security & privacy. Proc. of HEALTHINF. 2012; pp. 281-286.
[5] Paraiso-Medina S, et al. Semantic interoperability solution for multicentric breast cancer trials at the Integrate EU project, Proc. of HEALTHINF. 2013; pp. 34–42.
[6] Bucur A, et al. Identifying the semantics of eligibility criteria of clinical trials based on relevant medical ontologies. Proc. of the BIBE. 2012; pp. 413-421.
[7] http://groovy.codehaus.org/
[8] http://www.w3.org/TR/rdf-sparql-query/

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Teaching Bioinformatics to Engineers

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Abstract. The paper refers to our methodology and experience in establishing the content of the course in bioinformatics introduced to the school of "Information Systems in Healthcare" (SIIS), master level. The syllabi of both lectures and laboratory works are presented and discussed.

Keywords: medical informatics; bioinformatics; molecular databases, education

Introduction

The discussion around the curriculum for healthcare information professionals (HIPs) is an old topic in medical informatics. The doctoral level was introduced in Romania in 1992 [1], but it took almost two decades to begin a solid program for preparation of "health information professionals". Such a program has been initiated at University Politehnica in Timisoara [2]. "Information Systems in Healthcare" (SIIS) graduates have the abilities to use IT and information management to achieve increased quality in healthcare. The pool for this master degree of four semesters consists mainly in engineers, informaticians, physicians and economists. The first semester includes basic courses: Electronic Healthcare Record, Databases, Medical informatics fundamentals, and **Bioinformatic**s. The second semester is dedicated to application of technology in medicine, based on large projects that reunite 3 disciplines: Management of healthcare IT projects, Development of software applications for healthcare, and e-Health applications and also a course on Computer aided diagnosis. For the 3rd semester the courses are Human Computer Interaction, Medical equipments/Management of resources in healthcare, Medical Imaging, and Methods and communication in medical informatics. The course of bioinformatics is presented in the first semester, having 28 hours of lectures and 14 hours of laboratory classes. Our first printed course was published in 2011 [3] and all power point presentations are available on our website [4].

1. Course Structure

Our initial approach followed similar curricula in bioinformatics, published and available on the net. However, in most cases, one could rely on a solid background in various disciplines, asked as prerequisite, which was not our case where, due to various

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specific conditions, some students lack some basic knowledge. The solution was to determine what knowledge is missing and supply it in a set of supplementary or introductory courses; our experience in this line is presented here.

1.1. Methodology for establishing basic general knowledge structure

We started with a theoretical approach by defining a global interdisciplinarity index (IDI) of a course, with domain quotas (DQ), both between 0-100 [5]. They were applied to our course by analyzing the "subject index" of a very popular handbook of bioinformatics [6], classifying manually the terms according to their "native" discipline.

To summarize the results - a number of 703 terms were classified, from which 549 were imported (from other disciplines), yielding IDI = 78.1, with:

- DQ(molecular biology) = 15.9,
- DQ(biochemistry) = 14.7,
- DQ(general biology & genetics) = 13.4,
- DQ(biophysics & physiology) = 8.3,
- DQ(general medicine & pharmacology) = 8.1,
- DQ(mathematics & computer science) = 17.8.

Second step: we considered the structure of our audience: 85% from engineering (70%) or mathematics/informatics (15%), about 10% graduated medicine and 5% from other profiles. Neither graduates of engineering profiles nor those from mathematics or informatics had classes of biochemistry, molecular biology or genetics. The need of basic knowledge in these disciplines became obvious.

Finally, we estimated a need of about 10 out of the 28 hours of lectures [3,4] to be allocated to general knowledge and the rest for specialty (bioinformatics) knowledge.

1.2. Structure of general basic knowledge lectures

Starting from the results presented above, we developed the following lectures:

introduction: fundamentals of information theory (properties of information, informational entropy, redundancy) and system theory; notion of medical information, classification on structural levels, informational view on medical and healthcare activities, chapters of medical informatics, place and role of healthcare informatics professionals and of bioinformaticians;

basic knowledge of biophysics and physiology: composition of living matter, intermolecular forces, stability of molecular structures, solutions: hydrophobicity, pH, biological thermodynamics: catabolic and anabolic processes, bioelectrogenesis: active and passive membrane transport, signal transduction, bioenergetics: mitochondrial processes, regulatory processes, physical methods in biomedical laboratory: spectroscopy, X-ray diffraction, mass spectrometry, electrophoresis, flowcytometry;

biochemistry of proteins and nucleic acids: amino acids: structure and properties, primary structure of proteins, secondary structure (alpha helix and beta sheets), tertiary and quaternary structure of proteins, nucleic acids: nucleotides, primary structure of DNA and RNA, double helix structure of DNA, sequencing methods;

molecular biology: cell structure, description of major components (membrane, nucleus, ribosomes, and mitochondria), cellular division: mitosis and meiosis, DNA

replication, protein synthesis processes: transcription, splicing, RNA types, translation; genetic code, protein synthesis control;

biology and genetics: hierarchical classification terms, evolution theories, phylogeny, genetics: mendelian genetics (terminology, Mendel's laws), chromosomal theory (chromosomes, linkage, crossing-over, mutations), genetic maps, genes, molecular genetics, physical maps, genome, human genome.

1.3. Structure of specialty lectures

For the second part, which actually represents the core of the bioinformatics course we followed the classical structure, common in most similar courses from other universities (University of Pennsylvania, Johns Hopkins and Cambridge University) [6,7,8]. The structure of the second part of our course is summarized below:

- individual sequence analysis: graphical and parametric methods, 3D structures, coiled-coil proteins;
- pairwise alignment: dot plots, distances, dynamic programming: global alignment (Needlman-Wunsch algorithm), local alignment (Smith-Waterman), complex models (repeated matches, overlapping, and hybrid match), affine gaps;
- substitution matrices: PAM matrix, BLOSSUM, matrices for nucleic acids (Jukes-Cantor, Kimura), testing alignment significance;
- multiple sequence alignment (MSA): scores for MSA (pair sum, minimal entropy), graphical representations, algorithms, ordering models (star, tree);
- Markov chains: Laplace probabilities, modeling sequences by Markov chains, open reading frames ORF), gene finding; hidden Markov models (HMM): CpG islands, distinction symbol/state; HMM algorithms (forward, Viterbi, Baum-Welch), HMM for discrimination, log-odd scores;
- phylogenetic analysis: terminology, rooted and unrooted trees, distances, algorithms: UPMGA (unweighted pair group), ultrametric distances, neighbor joining, methods based on parsimony (Fitch, Sankoff), testing trees – "bootstrap"
- overview of applications: clinical diagnosis, disease risk, identification of drug targets – drug design, gene therapy, personalized healthcare.

2. Structure of Practical Laboratory

The practical laboratory classes were condensed in the second part of the semester, being in close link to the lectures of the second part. The syllabus for practical works was covered in five meetings of three hours each. The structure followed a classical scheme [4,9], comprising both individual work following procedural protocols and problem solving.

Practical classes start with "NCBI integrated databases (DB) search" using keywords, learning DB interrogation, medical articles search by various criteria using GQUERY [10]. "Entrez" enables molecular biology data reconstitution and visualization of references from integrated DB's. Among the included modules we can cite here: PubMed (articles and citations from DB Medline), GenBank (nucleotide sequence DB), PDB (protein sequences and macromolecular 3D structures).

In the second practical work the students have to search the DB's to retrieve certain nucleotide sequences, to find the chromosome locating them, to determine sequences or genes responsible for a disease, to search the DB's for certain amino acid

sequence, determine the matching degree (similarity, homology) with sequences from DB's, using BLAST (Basic Local Alignment Search Tool) [11].

Next practical work is a detailed study of protein structures – secondary, tertiary and quaternary, explored with PDB (Protein Data Bank) [12]. 3D structures are visualized by Cn3D and RasMol programs (Raster display of Molecules) [13]. Raster is used for displaying solid surfaces, able to open .pdb files, very useful in molecular graphics. Animation is also playing an essential role in visualizing molecular dynamics simulations; various techniques are taught: zooming, clipping (movement in Z-plane of the display, for depth perception), rotation-translation, atomic superposition, torsional space visualization (Ramachandran diagram). Conventional representation of secondary structures is also presented (cylinder for alpha helix and ribbon for beta sheet). Among the problems to solve we can cite: determination of C-terminal or N-terminal end of a protein, number of polypeptide chains, determination of alpha helixes and beta sheets, building secondary, tertiary and quaternary structures of proteins etc.

In another laboratory work DNA and protein sequences are compared using Align X, a subprogram of Vector NTI [14], for general description of a protein: number of amino acids, its function, molecular weight, electrical charge, protein alignment and its display using score matrices from Needleman-Wunsch or Smith-Waterman algorithms. In problem solving the students have to create by Vector NTI a nucleotide sequence, to visualize its DotMatrix plot, to compare two or more proteins by Vector AlignX, to build the graph of alignment quality, to visualize the phylogenetic tree using various substitution matrices (PAM, BLOSSUM) etc.

The last laboratory work is dedicated to MSA (Multiple Sequence Alignment) by Crustal [15], visualization of phylogenetic tree with the same program, setting up the alignment parameters as a Postscript file. Advanced phylogenetic analysis is made with Phylip package [16], starting from an alignment of peptidic sequences of a protein, read it with ClustalX, creating a .ph file and estimation by bootstrap procedure of the degree of congeniality between branches of the tree, using Njplot and Treeview modules.

3. Discussions and Conclusions

The contents presented above refer one the courses from the curriculum of students in "Information Systems in Healthcare", and "Biomedical Engineering", master level, not as major specialization in Bioinformatics. However, it has been considered as a potential future specialization of our graduates.

The preliminary study, for estimating the domains feeding the pool of prerequisite knowledge showed the real complexity of bioinformatics, which integrates knowledge of a quite large variety. It brings in very useful data for tailoring the introductory lectures, according to background preparation of the audience. In our case, when most students graduated computer science or informatics, we were oriented towards emphasizing basic knowledge from biomedical disciplines, starting with biophysics and physiology, biochemistry, molecular biology, general biology and genetics.

Even the proportion of terms from pharmacology and general medicine was similar to biophysics and physiology, we have not designed a special lecture for that part, since the terms referred mainly to names of some diseases or drugs.

The basic knowledge from information theory was summarized in the introductory lecture and the parts of mathematics needed for a good understanding were resumed in the specialty courses, just before using them.

The very process of classifying the terms has several weak points. In this phase we have only counted the terms, disregarding their importance for the didactic process, where some notions are essential for further understanding, while others (like drug names) have little importance. Weighted DQs and IDI would improve the overall image about the interdisciplinarity of a domain [5]. One should also consider the granularity used in building the "subject index"; quite often there are subdivisions for more general notions. But, despite all these shortcomings, the indices introduced by us offer a good "first approximation" of interdisciplinarity, with practical applicability. We would recommend that the disciplines with DQs > 10 to become "prerequisite".

For the small group of graduates of biomedical profiles, the "missing" knowledge resided in exact sciences domain; we have introduced one supplementary course, trying to cover some basic knowledge, but this direction has still to be more careful considered for the future.

We also paid a special attention to have a good correlation between contents presented in the lectures and practical works and the contents presented above show this close link. We consider that searching medical databases, both the literature and molecular structures should be taught to all students in medicine and biology. Bioinformatics has a high rate of progress, new sequences are added every day, new data processing tools are developed, allowing prediction of function of molecules and detection of molecular causes of diseases – all these knowledge becoming the base of molecular medicine, a major step towards personalized healthcare.

The feedback from our students, were encouraging. The quality of understanding seemed to show a marked increase for the last two generations for whom the new structure of the course has been introduced. This course was considered very important, quite comprehensive and “more interesting than Discovery Channel”.

References

[1] Mihalas GI, Lungeanu D. Strategy for Medical Informatics Evolution of Trends in European Medical Informatics Education at the University of Medicine and Pharmacy in Timisoara. Yearbook of Medical Informatics, Stuttgart: Schattauer, 1997: 113-119.
[2] http://siis.aut.upt.ro/.
[3] Mihalas GI, Paralescu S, Tudor A. Bioinformatica (in Romanian). Timisoara: Victor Babes, 2011.
[4] www.medinfo.umft.ro/dim/bioinformatica.htm.
[5] Andor M, Tudor A, Paralescu S, Mihalas GI. Interdisciplinarity Index - Application for Bioinformatics. Proceedings RoMedInf 2014, Bucharest: Carol Davila Univ. (in press).
[6] Lesk A M. Introduction to Bioinformatics. New York: Oxford Univ. Press, 2008.
[7] Pevsner J. Bioinformatics and Functional Genomics. Hoboken NJ: Wiley, 2009.
[8] Durbin R, Eddy S, Krogh A, Mithchison G. Biological Sequence Analysis. Cambridge UK: Cambridge Univ. Press, 1998.
[9] Claverie JM, Notredame C. Bioinformatics for Dummies. Hoboken NJ: Wiley, 2006.
[10] www.ncbi.nlm.nih.gov/gquery , www.ncbi.nlm.nih.gov/Database/tut1.html.
[11] blast.ncbi.nlm.nih.gov/Blast.cgi
[12] www.rcsb.org/pdb/home/home.do
[13] rasmol.org/
[14] www.bioinformatics.uthscsa.edu/www/genomics/windows.html
[15] www.clustal.org
[16] bioweb.pasteur.fr/seqanal/phylogeny/phylip-uk.html.

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Requirements for Prototyping an Educational Electronic Health Record: Experiences and Future Directions

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Abstract. Electronic health records and related technologies are being increasingly deployed throughout the world. It is expected that upon graduation health professionals will be able to use these technologies in effective and efficient ways. However, educating health professional students about such technologies has lagged behind. There is a need for software that will allow medical, nursing and health informatics students access to this important software to learn how it works and how to use it effectively. Furthermore, electronic health record educational software that is accessed should provide a range of functions including allowing instructors to build patient cases. Such software should also allow for simulation of a course of a patient's stay and the ability to allow instructors to monitor student use of electronic health records. In this paper we describe our work in developing the requirements for an educational electronic health record to support education about this important technology. We also describe a prototype system being developed based on the requirements gathered.

Keywords: Electronic health records; educational systems; health education.

Introduction

The adoption of health information is rapidly increasing. In particular, electronic health record (EHR) adoption is rising globally. Health professionals are expected to interact effectively with these technologies and understand both their benefits and limitations. However, it has been repeatedly reported that education about these technologies in health professional programs may not be keeping up with their increasing deployment in the real world [1,2]. To address this issue, researchers at the School of Health Information Science at the University of Victoria have created a Web-based platform for deploying a variety of EHRs and related technologies for educational purposes [3]. This Web portal has allowed various health professional students, including medical, nursing and health informatics students to remotely access and interact with a range of systems that are being made available using the WWW. In a number of projects, these technologies have been integrated into course and class work. For example, in one pilot project we focused on integrating EHRs into problem based learning for medical

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students. In doing so, the curriculum was enhanced by requiring medical students to obtain the "patient problem case of the week" using an EHR (instead of using paper records) which was remotely accessible through the educational electronic health record portal. In addition, during class time students were introduced to key features associated with EHRs, such as standardized coding and integration with clinical decision support. In this work it was found that by bringing information technology directly into education about patient problems, students could learn about both biomedical issues in the context of exploring patient cases within an electronic health record [3]. In addition, this research led to modification of open source electronic health records used in education by nursing students and health informatics students. The intent of this work was to provide students with hands-on exposure to EHRs.

Introducing health professional students to EHRs will be essential in order to help them cope with their practice upon graduation. Although this need has led to new ways of integrating health information technology in health professional learning, including EHRs, there are often aspects of electronic health records that the educators involved want to modify, change or enhance in order to better support educational processes and student learning [4]. For example, course instructors indicated that they wanted the ability to easily enter dummy patient case data into electronic health records used by students for learning. [5]. In this paper we describe our current work in developing the requirements for such systems and for creating an initial prototype based on our requirements analyses. The initial target group for the prototype described in this paper is health informatics students, but the same EHR is also targeted to be employed for educating medical and nursing students about health information technology. The learning objectives are to facilitate students in gaining hands-on experience with EHR technology, in the case of health informatics students to learn more about the technological aspects of system use. For health professional students the approach can be integrated into other methods such as problem-based learning [3].

1. Requirements for an Educational EHR

Based on our earlier work [5,6] in developing EHRs for educational use, a number of features and functions were identified as being potential features of an "ideal" educational EHR. For example, from our work in integrating EHRs into a course designed to teach medical students how to take patient histories, it was found that introduction of the full range of commercial EHR features was neither wanted nor desirable for this type of educational application, as having the full set of features enabled detracted from learning about note taking. This work was based partly on results from conducting interviews with both students and faculty who used a prototype educational EHR, as well as from review of the literature. As a result, one of our identified requirements was to design a system where certain features (e.g. use of decision support capabilities) could be "turned off" until needed in the curriculum [6]. One of the most desired features from all of our pilot projects was the need to have an authoring tool that would allow instructors of courses to pre-populate the student's EHR data space with dummy patient health data. This has been problematic with commercial EHR systems not designed to allow for this, as well as for open source systems, where even this type of feature is not always easy to program in [6]. In addition, the capability to freely add new features as "overlays" to the underlying EHR being used for education is highly desirable. From the instructor's perspective, the

instructor's "view" should be able to allow course instructors using EHRs to do the following: (1) enter dummy patient case data that students can access, (2) set up logging of student activities (i.e. using a log file that would for example track student access to system features and functions), (3) allow for summary of student activities and quiz results, (4) allow for setting up quizzes and tutorials, both to access students' health knowledge and ability to use the EHR technology itself. Additionally, the ability to set up a bank of patient cases that can be drawn from for creating student exercises and simulations is desirable. From our prior work, a desired feature was to provide a way for instructors to release key pieces of health data (e.g. consult reports, lab results etc.) over time to create a more realistic experience and simulate a patient's course for the student [5]. From the students' perspective, the EHR should be able to allow students to receive educational material and advice that is integrated directly into the educational record, and that allows for student quizzes and feedback (both about health information contained in the record and about using the EHR features themselves) [6]. Students should also be able to select from different patient cases to explore using the EHR and there should be built in tutorial features to illustrate use of different parts of the EHR.

From a technical point of view, ideal features include ability to run the educational EHR without instructors having to deal with complex system installations. To deal with this, as described above, we have created a Web portal that hosts varying EHRs that are accessible over the WWW. To do this we have leveraged our technical work and have allowed not only University of Victoria students to access the EHRs but have also provided the link to other educational programs. Other ideal capabilities included: (1) the ability to work on different platforms – mobile, tablets, laptops, desktops etc., (2) the ability to be easily customizable, (3) the ability to illustrate different user interface styles, (4) the ability to integrate with decision support tools and other applications, (5) automated logging capabilities. From a technical point of view, we are also working on moving our portal-based approach running on servers that are maintained at our university's data center to a more general cloud-based solution, where the EHRs will be available remotely on the "cloud". In addition, from a design perspective, we have concluded that new features that are added should become part of a toolset, that are general enough that they could be integrated with a variety of different underlying EHRs, in which these features could be easily added (rather than tightly embedding them within a specific system).

2. Design of an Educational EHR Prototype Based on the Requirements Analyses

Based on the requirements of an ideal educational EHR described above and on our prior experiences in developing and working with educational EHRs we have developed a prototype educational EHR that embodies a number of the key requirements as described above. The underlying EHR was programmed using Oracle APEX ® and uses and Oracle ® database and has all the features of a working clinical EHR, including all the basic functionality for entry and retrieval of patient medications, procedures, diagnoses, images and treatments. Figure 1 shows an example of the user interface of the prototype where an instructor has logged into the EHR to enter a patient case (using a case entry form) that will be automatically uploaded into the profiles of all students who will be interacting with that case. The interface allows for entry of patient information that will populate the students' EHRs when they log in.

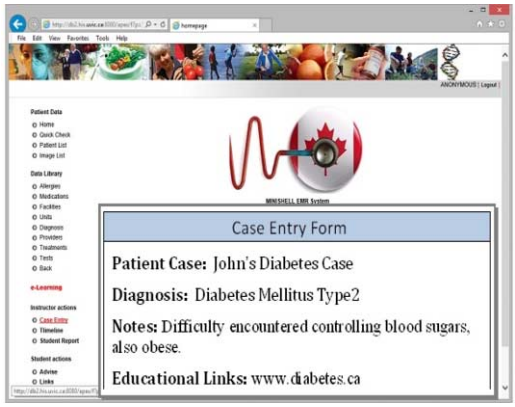


Figure 1. Instructor view: patient data entry

Figure 2 shows an example of the user interface (as seen in the instructor view) where the user (e.g. a professor) has logged in and is creating a time-line that will control the deployment of information to students about the case they are studying (i.e. "John's case of diabetes") over a three day period. This timed release of information to students allows instructors to create realistic simulated patient cases over time.

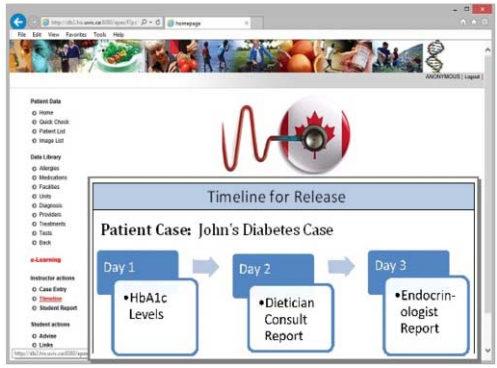


Figure 2. Instructor view: timeline for data release

Figure 3 shows an example of the user interface as seen by a student who has been using the EHR. In the figure, a pop-up window has been triggered that presents the

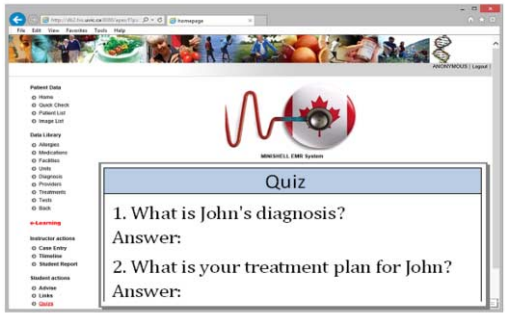


Figure 3. Student view: quiz

student with a quiz about the patient case they are studying. It should be noted that such tutorials can be embedded into the educational EHR, making the tutorials more realistic as they are presented in the context of interacting with a real EHR and its associated patient data (instead of interacting with "stand-alone" tutorials).

3. Discussion and Future Directions

The work described in this paper describes our efforts in moving from requirements for an educational EHR to development of a prototype system designed to embody the ideal features from the requirements. This work is on-going and we are currently extending the prototype design to include features such as the ability of instructors to block EHR functions to allow for a "training wheels" approach to presenting the EHR to students. Our current work also includes plans for conducting usability testing of the prototype system with students and instructors. From our prior work we have learned that a number of features and functions are needed in order to create software that is both realistic and that also contains features that facilitates use by students and instructors. In addition, we are exploring integrating tools and services associated with learning management systems (LMSs) within the EHR, including scheduling, learning boards, learning portfolios, blogs and web 2.0 [7]. This will include access to educational resources such as case studies and training videos accessible from within the EHR. We are also working on moving the system from a local server to a cloud-based solution, where the EHR and its associated learning resources will be made available through the cloud. This is expected to facilitate ease of system deployment .

References

[1] J. Mantas, E. Ammenwerth, G. Demiris, A. Hasman, R Haux, W Hersh, E Hovenga, K.C. Lun, H. Marin, F. Martin-Sanchez, G. Wright, Recommendations of the International Medical Informatics Association (IMIA) on Education in Biomedical and Health Informatics, Methods Inf Med 2010; **49** (2): 105 –120.

[2] M. Storck, F. Uckert, Virtual ward round, *Stud Health Technol Inform* **169** (2011), 213-217.

[3] E. Borycki, A. Kushniruk, R. Joe, B. Armstrong, T. Otto, K. Ho, H. Silverman, J. Moreau, N. Frisch, The University of Victoria Interdisciplinary Electronic Health Record Educational Portal, *Stud Health Technol Inform* **143** (2009), 49-54.

[4] T. Otto, A. Kushniruk, Incorporation of medical informatics and information technology as core components of undergraduate medical education, *Stud Health Technol Inform* **143** (2009), 62-67.

[5] R. Joe, A. Kushniruk, E. Borycki, B. Armstrong, T. Otto, K. Ho, Bringing electronic patient records into health professional education, *Stud Health Technol Inform* **150** (2009), 888-892.

[6] E. Borycki**,** A. Kushniruk, B. Armstrong, R. Joe, T. Otto, Integrating electronic health records into health professional and health informatics education, *Acta Informatica Medica* **18**(1) (2010), 20-24.

[7] C. Dalsgaard, Social software: E-learning beyond learning management systems, *European Journal of Open Distance and E-Learning* **2** (2006).

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Do Electronic Health Records Help Undergraduate Students Develop Health Informatics Competencies?

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Abstract. In this paper we describe the effects of hands-on exposure to an educational electronic health record (EHR) system upon undergraduate health informatics (HI) student competency development. We undertook a quasi-experimental study (i.e. pre-test, post-test design), where students were given the opportunity to do hands-on work with an educational EHR over a 10 week period. HI student competencies were measured pre and post educational EHR exposure. Several HI student competencies improved significantly following hands-on work with the EHR. As well, students provided more in-depth and higher quality case study answers after working with the educational EHR.

Keywords. health informatics, biomedical informatics, undergraduate, education, electronic health record

Introduction

Worldwide there has been a significant rise in the number of electronic health records (EHRs) that are being implemented in regional health authorities, hospitals, clinics, long term care facilities, and physician offices as national and regional governments invest in modernizing health care. With these investments in the EHR, there has emerged a significant demand for an educated workforce that understands not only the processes that are involved in delivering health care, but the technologies that are used to support health professionals. In this paper we describe our research to date investigating the effects of providing HI students with hands-on exposure to EHRs in the classroom upon competency development [1-2]. This work represents a contribution to the HI literature as it is one of the few studies that focus upon the effects of student exposure to an EHR upon HI professional competency development.

1. Literature Review

Over the past several years, several publications have highlighted the barriers to introducing educational EHRs into health professional classrooms. These barriers

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include a lack of: (a) access to differing types of educational EHRs, (b) trained HI professionals to manage educational EHR systems, (c) faculty developed training materials to be used in the classroom along with the EHR, (d) curriculum integration with the EHR, and (e) faculty who are versed in the subject of health informatics [3-9]. Although there have been a number of efforts aimed at creating and disseminating HI competencies internationally, less work has been conducted in developing methods for instilling those competencies in HI students [6].

2. Methods

2.1. Participants

Students enrolled in a mandatory third year course in the undergraduate HI program were invited to participate in the study by a research assistant who made in-person presentations to students, and an invitation letter was also distributed to students via a class list serve.

2.2. Materials

The researchers developed an EHR educational portal that allows HI students to directly access and work with several industry representative educational EHRs remotely over the WWW in the classroom and at home [3]. As an extension of this work, an educational EHR was integrated into the laboratory component of the course to provide students with hands-on opportunities to learn about the technology. The course has both a lecture and a laboratory component, and consists of two 1.5 hour lectures and one 2 hour lab each week for a full semester (12 weeks in length).

2.3. Procedure

During the laboratory component of the course, students were provided with an opportunity to gain experience with use of the EHR. Students were introduced to the EHR and provided with opportunities to directly work with the EHR (i.e. hands-on use) in the early part of the course (i.e. week 2 of the course). At the beginning of the course, students who decided to participate in the study were asked to complete several questionnaires: (a) a demographic questionnaire, (b) a learning styles questionnaire and (c) a HI competency questionnaire. Demographic data were collected to describe the characteristics of the students. Learning styles data were collected to describe the learning styles of the participants [9]. Competency questionnaire data were collected in order to assess the student's current HI competencies. The HI competency instrument collects data about four differing types of HI competences (i.e. information management, clinical/health sciences, the Canadian health care system, and the management sciences). The instrument is based on Canada's Health Informatics Association (COACH's) core competencies. Students were asked to self-evaluate their HI competency development on a 5-point Likert scale (1=lowest and 5= highest).

Students were also asked to complete a case study prior to working with the EHR (and then 10 weeks after using the EHR). The case studies consisted of a description of a scenario where an EHR was used along with questions. Students were

asked to read a short scenario about how a regional health authority is implementing an EHR. The case study exercise involved asking students to provide a list of statements describing how technology affects and improves regional health authority services. Cases were developed by one HI instructor and were independently evaluated and judged to be equivalent by another instructor. HI instructors were used to judge the quality and equivalence of both cases. After week two of the course, students were provided with opportunities to work with an EHR (i.e. "hands-on work"). "Hands-on work" involved learning about and using differing EHR features and functions in a laboratory setting. This "hands-on" laboratory work was a new feature added to the course. At the end of the course students were asked to complete an HI competency questionnaire and a second case study - ten weeks after working with the EHR in the laboratory setting. The competency questionnaire and case study answers were collected by the research assistant.

3. Results

The results of the analysis of the demographic data, learning styles inventory data, HI competency instrument data, and case study data are presented in this section of the paper. 54% (n= 17/32) students agreed to participate in the study – a high response rate.

3.1. Demographic, Learning Styles and HI Competency Data

Student participants completed a short demographic questionnaire. The majority of participants were female (13/23; 57%), and between the age 20-24 (16/22; 73%). Most participants were in their third year of the HI program (20/22; 91%) and had completed two cooperative education work-terms (14/23; 61%). Following this, students were given a Learning Styles Inventory questionnaire to assess the dominant learning mode preferences in the class (Brown and Cooper, n.d). Brown and Cooper (n.d.) divide learning styles into three categories: cognitive (auditory language, visual language, auditory numerical, visual numerical and tactile/concrete), social (individual learning, and group learning), and expressive (oral expressiveness and written expressiveness). Using the Learning Styles Inventory, students answered a series of 45 questions on a Likert scale of 4 ("most like me") to 1 ("least like me"). Questions were divided into the learning styles subcategories (listed above) and tallied [10].

As outlined earlier, participants were asked to complete a HI Competency Instrument both before and after receiving hands-on exposure to the educational EHR (i.e. 10 weeks of using and working with the EHR in the laboratory component of the course). The competency instrument was used to collect data about four competency areas based on Canada's Health Informatics Association (COACH's) core competencies: information management, clinical/health sciences, the Canadian health care system, and management sciences. Participants self-rated their HI competencies higher after 10 weeks of hands-on exposure to the EHR on 10 out of the 18 (56%) competencies at the 0.05 level. Specifically, participants rated significantly higher on 3 of the 6 (50%) questions pertaining to information management, 3 of the 6 (50%) questions related to clinical and health sciences, and 1 of the 2 (50%) questions about management related HI competencies. Meanwhile, participants scored significantly higher on 3 out of the 4 (75%) measures relating to the Canadian health care system. In summary, participants had significantly higher ratings ($p<0.05$) on 10

out of the 18 (56%) HI competency measures after having hands-on exposure to the EHR.

3.2 Case Study Data

Anonymized student solutions to the case studies were judged for their quality by two HI researchers who have industry experience. As well, case study data was provided in random order to our experts who judged the quality of the EHR design solutions. In HI, experts from the field are often used to develop and validate the representativeness of study materials to ensure the ecological validity or real-world representativeness of tasks participants are asked to perform [5].

The quality of the solutions to the case studies were scored on a five point Likert Scale (where 1 = poor and 5 = excellent) by two graduate level HI experts. As part of this process, the experts commented on the strengths and weaknesses of each of the solutions. The experts were blind to the students who solved the case studies and whether the case study was completed before or after receiving the lectures only or "hands-on work" with the EHRs (to prevent bias in reviewing the student solutions). The evaluators are familiar with the professional competencies, and evaluating the quality of EHR solutions. The first case study (prior to hands-on use of the EHR) was completed by 17 participants. Meanwhile, the second case study (after EHR use) was completed by 22 participants. Student participants' scores remained the same (i.e. a 0.23 difference on a 5 point Likert scale). Both the case study given before the EHR intervention (Case Study 1) and the case study given after (Case Study 2) had a median of 4; however, the mode in Case Study 1 (i.e. 5) was higher than that of Case Study 2 (i.e. 4). Tests for differences were conducted for the case study scores. No statistically significant differences were found for the quality of the case scores.

The researchers also determined the number of unique data elements (i.e. number of points brought up by students) that were present in the responses to both cases (pre and post implementation). The mean number of data elements per participant was higher in Case Study 1 (6.35) compared to Case Study 2 (5.5). However, both the median and mode are higher in Case Study 2 (median = 6; mode = 6) compared to Case Study 1 (median = 5; mode = 5). Overall, the mean number of data elements was higher in Case Study 1, meanwhile the mode and median were higher in Case Study 2.

Student answers to the cases were also qualitatively analyzed for key themes related to the COACH core competencies. 17 themes emerged from the data. All of the themes were common across both case study solutions (i.e. they appeared in both). However, the frequency of the majority of key themes increased by 53% from Case Study 1 to Case Study 2. For example, more students for Case Study 2 identified how EHRs reduce medical errors and redundancy, and increase efficiency as important themes. As well, the frequency of themes surrounding record availability and patient management also increased from Case Study 1 to Case Study 2. Other important themes that were more prevalent after hands-on exposure to the EHR included DSS, public health, privacy, and better interface designs.

Alternatively, there was a decrease in the frequencies for the following six (6/17; 35%) themes: interoperability, records being available, information exchange, storage, patients having access to information, and information organization/data management. Meanwhile, participants noted cost savings, and comprehensive medical data equally in both case studies (2/17; 12%). Overall, the majority of themes that emerged in this

study increased from the baseline administration of Case Study 1, to the administration of Case Study 2 (after gaining hands-on experience using an EHR).

4. Discussion and Conclusion

This research is one of the few studies that specifically focuses on how HI undergraduate students (rather than nursing or medical students) acquire health IT competencies in a four year baccalaureate program. The study also shows that hands-on exposure to an EHR as a new addition to a course can lead to statistically significant improvements in student competency development in 10 health professional competency areas (as described by COACH). With the introduction of hands-on exposure to the EHR, students now have the opportunity to use an EHR in a laboratory setting, experience its features, functions and workflows as well as observe how data is inputted and retrieved. This EHR also allows students to see how the technology acts as a data collection tool for healthcare administrators so that the data can be extracted and used in quality improvement (thereby improving the healthcare system overall). Lastly, students became more sensitive to the ability of the EHRs to reduce medical errors and redundancy of information while improving healthcare organizational efficiency (as evidenced by the answers to the case studies). A limitation of this study is its pre/post test design. We were unable to randomize the students to an intervention or control group due to the limited number of students in the class. Future research needs to explore the effects of introducing hands-on usage of educational EHRs upon undergraduate and graduate (i.e. Masters, Doctoral) student basic and advanced HI competencies throughout a typical HI curriculum. As well, there is potential to use clinical simulations in conjunction with EHRs as a method for teaching students about technology. Such research would help academics with tracking of student competency development and lead to studies where differing types of teaching techniques and course content could be studied to identify those teaching strategies and approaches that best support student competency development.

5. References

[1] COACH. HI and health information management and human resources report, 2009.
[2] S. B Issenberg W.C. McGaghie, E. R. Petrusa, D. L. Gordon, R. J. Scalese. Features and uses of high-fidelity medical simulations that lead to effective learning. *Med Teach* 2005: **27**(1): 10-28.
[3] E. M. Borycki, R. Joe, B. Armstrong, P. Bellwood, R. Campbell. Educating health professionals about the electronic health record. Know Manage E-Learning: *An Int J* 2011: **3**(1): 51-62.
[4] M. Triola, E. Friedman, C. Cimino, E. Geyer, J. Wiederhorn, C. Mainiero. Health information technology and the medical school curriculum. *Amer J Manag Care*. 2010 Dec;**16**: SP54-SP56.
[5] E. M. Borycki, A. W. Kushniruk, R. Joe, B. Armstrong, T. Otto, K. Ho, H. Silverman, J. Moreau, N. Frisch N. The University of Victoria Interdisciplinary Electronic Health Record educational portal. *Stud Health Tech Inform* 2009: **143**: 49-54.
[6] D. Gloe. Selecting an academic electronic health record. *Nurs Educ*. 2010 Jul; **35**(4): 156-161.
[7] A. Bowers, J. Kavanagh, T. Gregorich, J. Shumway, Y. Campbell, S. Stafford. Student nurses and the electronic medical record. *CIN*. 2011 Dec; **29**(12): 692-697.
[8] J. Brown, R Cooper. Learning styles inventory. Freeport, NY: Educational Activities; 1990.
[9] A. Otto, A. Kushniruk. Incorporation of medical informatics and information technology as core components of undergraduate medical education. *Stud Health Tech Inform*. 2009: **143**: 62-67
[10] COACH. HI Professional Core Competencies: v3. 2012. [Internet]
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e-Literacy in health care

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Abstract. This paper explores notions of e-Literacy (otherwise IT literacy or digital literacy) in health care. It proposes a multi-dimensional definition of e-Literacy in health care and provides suggestions for policy makers and managers as to how e-Literacy might be accounted for in their decisions.

Keywords. Health care, e-Literacy, IT literacy, information systems, electronic prescription, electronic patient record, information systems implementations

Introduction

The digitalisation of health care today involves core clinical functions, requiring health care professionals (HCPs) to use a multiplicity of information systems (IS) and digital devices. To make effective use of them HCPs need a variety of skills, which we refer to as e-Literacy. This term, partly replacing the earlier term of IT literacy, signifies a useful shift from a narrow focus on technology and its direct use (e.g. being able to use a keyboard or a word processor), to a focus on purposeful use (e.g. using IS to make an appointment for a patient, to code a diagnosis or treatment, or to send an electronic note to another HCP). The literature on e-Literacy (or digital literacy as it is also called) is substantial [1] but most studies related to health care are concerned with patients or citizens using web-based health sites [2, 3]. Similarly many studies on implementation of IS in health care emphasise the importance of IT skills for HCPs but seldom elaborate on the nature of those skills.

This paper draws on studies of implementations of electronic patient records in secondary care and of the routing of electronic prescriptions in primary care in England's National Health Service (NHS) to explore notions of e-Literacy in health care. It proposes a multi-dimensional definition of e-Literacy in health care and provides suggestions for policy makers and managers as to how e-Literacy might be accounted for in their decisions.

1. Methods

We draw on our research experience in the field of IS in health care spanning more than a decade. In particular, reference is made to findings from two research projects for the evaluation of two English NHS National Programme for IT initiatives – the NHS Care Records Service (CRS) in hospital settings (project 1), and the Electronic Prescription

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Service (EPS) in primary care (project 2)[2]. These evaluations began in 2008, and were completed respectively in February 2011 and January 2012.

These were large longitudinal studies of a national scale. A team of researchers were involved from four Universities in England and Scotland. A mix of research methods were applied, including observations of work practices and doctors' clinics, interviews with stakeholders, survey and documentary analysis. Across the two studies, empirical research was conducted in a variety of settings, including 17 NHS Hospital Trusts, 7 general practice surgeries and associated high street pharmacies. Among our research participants were hospital doctors and general practitioners, nurses, hospital and community pharmacists, allied health professionals, receptionists and clerks, administrators and managers, IT implementers and trainers, all involved in different ways in the implementation and adoption into use of new health IT. The studies were reviewed by NHS Ethics Committees and classified as service evaluations; informed consent was obtained from participants; all data – transcripts of interview recordings and field notes - were anonymised so that either individuals and/or their organisations would not be identifiable.

Further details on the methods for each of the two studies can be found in the project publications (e.g. [4, 5]).

2. Results

This section highlights key findings from the two studies described above in relation to the systems use and e-Literacy.

2.1. Project 1 - the NHS Care Records Service: implementation of Electronic Patient Records in secondary care

Attitudes towards IT / Self efficacy

HCPs revealed a variety of attitudes towards IT. Some HCPs in principle welcomed IT but had reservations about the particular systems in use. Others feared how IT would impact their working lives. Confidence in being able to use the systems (to follow the screens, to input data) varied between professionals.

Nurses, in particular, were perceived (by other professional groups and at times by themselves) as having poor knowledge of IT. But this view was not supported by all: "*Everybody is at a different level with computers aren't they, but it's not a particular issue, because it's easy to use. … We've all been trained in it and nobody has ever said that they can't use it any more. It's a practical thing, the more you use it then the more familiar you get with it."* (Nurse 1, Site C)

Experience of training

Opinions regarding the experience of training varied from very negative to decisively positive. In all the sites users felt that support from trained individuals within their own team was most valuable. A common complaint was that the training

[2] "An Evaluation of the Implementation and Adoption of the NHS Care Records Service (NHS CRS) in Secondary Care in England" (CfHEP005) - http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CFHEP/reports/projects/005.aspx, and the "Evaluation of the Electronic Prescription Service in primary care" (CfHEP004) - . http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/PHEB/CFHEP/reports/projects/004.aspx. Two of the authors (TC and VL) have been involved in both projects, one author (EK) was involved in CfHEP005.

was too early and the material was forgotten by the time it was needed to be put to use. Other criticisms included concerns that training was *'"not sufficient"* and *"rushed"*. In some Trusts, users felt that the training *"was way too broad based and too generic and it missed a point"* (HCP, Site D) and that it *"didn't focus precisely on the bits of the system that we had to use and was not about the actual workflow that we would be doing"* (HCP, Site D). Thus HCPs perceived that the training was on the direct use of the system (buttons and interfaces) rather than on its purposeful use (e.g. to get jobs done and problems solved).

Dimensions of e-literacy

e-Literacy as a set of basic computer skills

Some HCPs (those with little exposure to IT) were predominantly concerned with their ability to 'use computers' and in particular to type fast. IT staff also defined skills needed by HCPs to use the system in very narrow, often technical terms: "*It's not hard—it's not something that's really technical hard; it's just about inputting information. […] I think a lot of them don't feel confident and they are frightened."* (Configuration Architect, Site C).

e-Literacy as a purposeful use

Yet, HCPs' attitudes to the new systems were not simply shaped by their level of IT skills but also by concerns about the fit of the system with work practices. Their comments about the training indicate that they saw 'being able to use the system' as ability to perform their work, not as a set of abstract or isolated skills.

e-Literacy as sense making

Others sought even deeper understanding of the system they were asked to use*: "I think that the understanding of [the IS] by us, clinicians is not good. I think we need to understand. [..] I think perhaps what we should have had is education about what it meant. What the outcome might be and how we might understand how the system actually works, that would have been useful.* (HCP, Site C)

At the time of the research it was too early for the new practices to be fully institutionalised and new innovative ways of working to emerge, taking full advantage of functionalities offered by the new IS being implemented (the NHS CRS systems). Our research does however indicate that as time passed the HCPs learned new IT skills, become more familiar with computers in general and specifically with the new IS. They developed their understanding of what such system might mean for their work at present and perhaps in the future.

2.2. Project 2 - the Electronic Prescription Service in primary care

Dimensions of e-literacy

e-Literacy as practical knowledge of IS

In this study most of the users had already gained some familiarity with the new IS introduced in their primary care clinic. They often had developed an understanding of the idiosyncrasies of the system and the work context of its use, as the following observation notes indicate: "*The receptionist receives the request for a prescription and processes it; she explains that 'if she presses Request, then it goes in a box [inbox/workflow] and the doctor never sees it, it gets lost'. So instead she tells me if she re-authorises it (and produces a new one) then the doctor sees it*."

"*with [the new IS] you have to be careful because the last patient record you have accessed gets automatically reselected. Any action you are doing can get recorded under that record*"

e-Literacy as practical knowledge of IS in work context

Knowing how to use the system effectively also means being familiar with the context (understanding IS through understanding the work context), rather than having an abstract knowledge of the technology. This may call for pre-empting problems, knowing the next step before it happens and knowing that something should happen. For example, one of the authors observed that when a member of staff could not find prescription requests which should have arrived by email she checked the previous system (the webmail). She returned with a few requests printed out and commented: "*I thought it was funny, even if it was only one, we would have had something"*.

e-Literacy as whole system understanding

This requires users to understand why in certain cases the system's output might not be as expected and be able to predict the system's behaviour, e.g. to see why items prescribed might not make an electronic prescription. Some of the existing software provided limited feedback on why this was the case, but not all system messages (e.g. error messages) were informative. More complex cases may involve understanding the effect data entered in one field might have on other fields, as relationships between fields/areas of the system may not be immediately perceivable.

"*[The software] generates automatic warnings for patients under/over use of medications. But the system only generates automatic warnings if the GP enters correct data in the field 'Duration' and GPs do not understand the meaning of this field and do not use it correctly. Also, warnings are set too low, generating too many false alarms and therefore GPs prefer to switch them off.*" (GP and ex-member of software supplier User Group).

3. Discussion

3.1. Conceptualising e-Literacy

Table 1 depicts different dimensions of e-Literacy that underpin effective use of IS in health care, as illustrated by our research.

Table 1. Dimension of e-Literacy in health care

Dimensions e-Literacy as:	**Description**
Self-efficacy, Motivations and Attitudes to IT	Attitudes to using IT. Beliefs regarding having (or not) the appropriate skills / abilities.
Computer skills	Set of (abstract) skills that an individual needs to acquire to use the system, such as typing, navigating sites, etc.; ability to 'input data'.
Purposeful use /Practical knowledge of IS in work context	Ability to use the system to perform health care related work. Higher level: understanding system's idiosyncrasies, anticipating problems, knowing what to look for and where.
Whole-system understanding	Understanding interdependencies of the socio-technical system. This may include understanding how the data will be used by other parts of the system, and by other HCPs, managers, researchers, etc.
Sense making	Sense making or working out meanings and implications of ITs for individuals, groups, or organizations (e.g. for professional identity).
Innovating and transformation processes	Understandings and beliefs regarding IT potential to transform health care. Ability to innovate with IT.

Medical work is usually done in groups or teams and in co-operation with others and IT has to be integrated in this context [6]. A higher level e-Literacy implies an

ability to understand how *others* work might be mediated through use of IT, how different parts of a system connect and how different systems are interconnected. This includes seeing relationships between fields and the consequences of data manipulation beyond its first intended purpose. In the case of health information exchanges such as the routing of prescriptions between organisations, connecting prescribing software with a range of dispensing software, central repositories, and different data dictionaries, require a relatively higher level of e-Literacy.

e-Literacy is certainly not acquired once for a lifetime but is dynamic and changing. Innovative ways of delivering health care utilising new technologies, from texting to health related Web 2.0 applications, demand new set of skills from health care professionals, and may also requires some old skills to be set aside.

We thus propose the following definition of e-Literacy in health care:

> *a dynamic and context-specific ensemble of the skills, attitudes and understandings necessary and appropriate for working with digital tools and systems (including computers, smart phones and other devices) in order to perform health care related tasks both individually and as part of a team, and to participate in processes of (technology-led) change within institutional settings*.

3.2. Implications for practice

Our conceptualization of e-Literacy in health care has implications for the way IS implementation and post-implementation activities are organized. For example, managers need to support 'sense making' activities, i.e. to assist individual and groups in 'working out' what the new system means for them and their work. There is a need for more focus on 'what you are communicating and to whom' instead of 'what data needs to be entered and where'. Although some formal training before a system is implemented (i.e. before it goes 'live') is needed, on-going support and 'learning-by-doing', including collaborative learning should be emphasised. Perhaps it also means that organizations are never fully 'ready' for the implementation of a new system. They need to prepare themselves but also to allocate significant resources towards on-going support and learning. Indeed it is as people develop their e-literacies that they might find ways for innovative uses of IS.

References

[1] Knobel, M, Lankshear, C, editors. A New Literacies Sampler. Peter Lang, New York; 2007.
[2] Klecun, E. Digital Literacy for Health: The Promise of Health 2.0. IJDLDC. 2010; 1(3): 48-57.
[3] Neter, E. eHealth literacy: extending the digital divide to the realm of health information, J Med Internet Res. 2012; 14(1): 1439-4456.
[4] Sheikh A, Cornford T, Barber N, Avery A, Takian A, Lichtner V, et al. Implementation and adoption of nationwide electronic health records in secondary care in England: Final qualitative results from prospective national evaluation in "early adopter" hospitals. BMJ. 2011; 343:d6054.
[5] Lichtner V; Venters W; Hibberd R; Cornford T; Barber N. The fungibility of time in claims of efficiency: The case of making transmission of prescriptions electronic in English general practice. Int J Med Inform. 2013; 82(12): 1152-1170.
[6] Berg, M. Health Information Management: Integrating Information Technology in Health Care Work. Routledge, London; 2004.

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Concept for Linking De-identified Biomedical Research Data Using a Study Participant Management System

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Abstract. Biomedical research projects show an increasing demand of large numbers of participants from different recruiting centers to achieve statistically significant results. The collected types of data are stored in distributed databases and are linked to the participant by different non-resolvable identifiers (layered pseudonyms) for de-identification. To ensure the quality of the gathered data, regular quality assurance analyses are required at each local center. Because of the distributed databases and layered pseudonyms the analyses can only be achieved manually. Therefore, the process is error-prone and laborious. The objective of this paper is to propose a solution concept to automate the manual process by using a local study participant management system. It orchestrates the process and enables the quality assurance analyses within a clinical data warehouse.

Keywords. data privacy, study participant management, biomedical research, quality assurance analysis, research IT infrastructure, ETL

Introduction

Biomedical research projects have an increasing demand for longitudinal studies. Some of these studies require a large number of participants or study patients to achieve significant scientific results. Large numbers of participants matching the inclusion criteria of the projects can only be achieved through collaborations between different biomedical research institutions. [1–3]

Furthermore, it is necessary for biomedical research projects to collect several types of data for each participant; e.g. phenotypic, image, or biomaterial data [3]. To reduce the risk of re-identification, collaborative biomedical research projects implement a central project IT infrastructure which is based on two well-established patterns: data separation and layered pseudonyms [4–7]. The data separation pattern requires distributed databases for the participants' data. Layered pseudonyms, different non-resolvable identifiers per participant for each database, are used to further reduce the participants' risk of re-identification. The layered pseudonyms are not linked directly to the protected health information (PHI) data of the participants. It is advised to maintain this data in a central project identity management system (IDMS), which should be provided by a trusted third party [5,6].

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The implementation of both patterns improves the data security but also presents an obstacle to researchers of a local center trying to link their gathered data. The data linkage requires knowledge about the correlation of the layered pseudonyms per participant in the databases. The information can only be found in the IDMS and the paper-based documentation of the local branch. To combine the data the local center has to implement a manual process using paper-based documentation of the layered pseudonyms per participant and manually acquiring exports from the databases. The manual linkage process is very laborious and error-prone. For reasons of data protection the IDMS does not provide an interface for data querying.

A real-world example for a collaborative biomedical research project is the Clinical Research Group 241 (KFO 241). The local center of KFO 241 in Göttingen has to perform weekly quality assurance (QA) analysis on their gathered data. At present they employ the described manual linkage process. As a first step to replace the paper-based documentation a study participant management system (SPMS) was deployed. The SPMS enables researchers to manage the PHI data and the associated layered pseudonyms for participants maintained by the local project center. In contrast to the central IDMS, the SPMS offers functionalities; e.g. for querying and retrieving participants. [8]

The objective of this paper is to provide a concept for reducing the workload and preventing errors when linking the data from the different databases using a SPMS.

1. Methods

To develop a concept for linking data an analysis was performed to elicit the requirements for QA. Subsequently, a proposal for the fulfillment of the elicited requirements was conceptualized.

1.1. Requirements Analysis

Previously [8], the staff at the local center of the KFO 241 in Göttingen were interviewed as stakeholders. The results of the interviews were re-evaluated for this work. Furthermore, relevant documentation of the IT infrastructure and the data protection concept [9] were analyzed. The primary goal of the requirements analysis was to elicit the requirements for QA.

1.2. Solution Concept

The proposed solution is: (a) build on the SPMS, which offers researchers functionalities for the management of their participant; e.g. maintenance of PHI data, appointment planning, consent management, and a link to the central IDMS for the retrieval of layered pseudonyms [8]. (b) i2b2 as a clinical research data warehouse [10] offers an interface for research analyses; e.g. employing R [11]. To process the exported data from the databases, (c) an extract, transform, and load (ETL) tool is used. UML activity and sequence diagrams [12] were used to model the concept.

2. Results

2.1. Requirements Analysis

The interviewed stakeholders specified the following questions, which need to be addressed during the weekly QA analysis:

- How many participants are enrolled in the project?
- How much biomaterial of which quality was collected?
- Which phenotypic data has corresponding biomaterial (or not)?
- How many participants completed the study and how much phenotypic data and biomaterials were collected?

It was pointed out by the stakeholders that the manual process needs to be improved immediately as increasing numbers of enrolled participants prolong the process.

The IT infrastructure of the KFO 241 consists of a phenotype database, a biomaterial database, and an IDMS. In addition, the local center employs a SPMS to maintain their participants. The full IT infrastructure is described in [8] and builds on the data separation and layered pseudonyms patterns [4–7].

2.2. Solution Concept

The proposed solution concept could simplify and automate the manual, laborious, and error-prone data linkage process.

In the center of the concept the SPMS as a broker orchestrates the workflow involving researchers, phenotypic and biomaterial database, ETL, and i2b2 (see **Figure 1**).

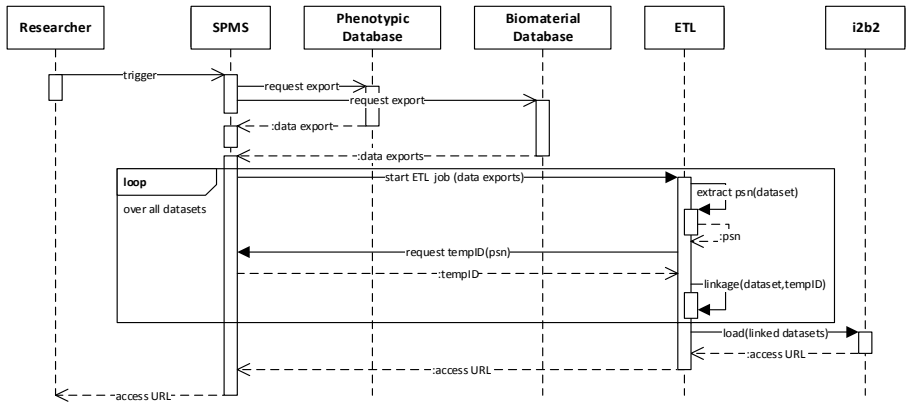


Figure 1: After researchers trigger the workflow, the SPMS orchestrates the needed communication between databases, ETL, and i2b2. Exports are requested from the IT operators of the databases. After receiving the exports the SPMS starts an ETL job with the exports. During the job (see loop) the layered pseudonyms (psn) are extracted from the exports and sent to the SPMS. The SPMS returns a temporary identifier (tempID) which is unique for each participant (see **Figure 2**). Afterwards, the ETL job replaces the pseudonyms by the corresponding tempID and combines the datasets. The combined dataset is then loaded into the i2b2. Researchers can now access the datasets via the access URL which is returned by i2b2.

To match the pseudonyms with a temporary identifier an algorithm was designed that handles the replacement as well as the case of layered pseudonyms which are not connected to any maintained participants in the SPMS (see **Figure 2**).

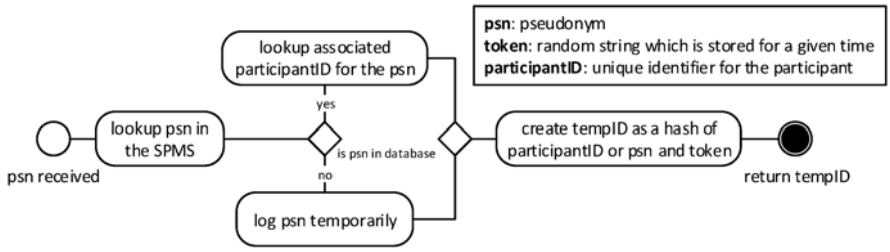


Figure 2: shows the tempID generation algorithm with the SPMS: After receiving the pseudonym the algorithm checks for its existence. Once it is found the corresponding participantID is looked up and then the hash of the participantID combined with the session token is returned as the tempID. In case the pseudonym is nonexistent it is temporarily logged and a combination of pseudonym and token is hashed and returned as the tempID.

3. Discussion

The performed requirements analysis was a continuation of the analysis described and reuses the previous elicited requirements. Additionally common questions for QA analysis were identified with the described stakeholders of the KFO 241. [8]

Conducting QA analysis on data collected within research projects is covered by the data protection regulations whereas research analyses often require an approval of the projects' ethics research board. To ensure the participants' privacy during the QA analyses the proposed algorithm within the SPMS further de-identifies the data by the usage of tokens with limited period of validity. Each participant's data is linked with a unique tempID only during the lifetime of the used token. The validity period of the tokens is adjusted to the duration of the ETL jobs.

Because of the SPMS's new broker role the proposed solution could only be established for recruiting centers which employ a SPMS with the described feature set. One alternative solution for institutions without a SPMS is the implementation of the algorithm (see **Figure 2**) within the IDMS and the introduction of a central clinical research data warehouse; e.g. i2b2. However, the described solution requires functionalities for querying pseudonyms, which is a contradiction to the current functionalities of the IDMS as it only provides functionalities for data input but not for querying data due to data protection reasons [6,7]. A complex access control would have to be established within the IDMS in order to ensure that only pseudonyms of participants maintained by the local center can be requested. The implementation within the IDMS would require a high developmental effort to ensure data security and concerns all centers of the project because it is a central component of the IT infrastructure. In contrast, the proposed extensions of the SPMS are minor changes because mandatory functionalities, like role-based access control, are already implemented and only the participants' PHI data of one center are maintained per SPMS installation.

Next step would be the implementation of the concept as a prototype to evaluate its feasibility. This would involve the following extensions of the current SPMS: (1) A service to send data export requests to the IT operators of the phenotype and biomaterial database; e.g. email. (2) Integration of the ETL job for combining the datasets provided by the IT operators. (3) The implementation of an interface, which offers functionalities of the algorithm described in **Figure 2**. Finally, the ETL job is linked to the i2b2 for uploading and analyzing the combined data.

The presented solution concept provides ways for researchers to run basic QA analysis via i2b2. It could also be used to allow scientific analyses on data collected of participants of the local center. Therefore, the already implemented consent manager of the SPMS should be linked with the data linkage process to only include the participants who allowed scientific analysis on their data.

According to [4], the described patterns are also used in international biomedical research projects. Therefore, it should be evaluated to which extend the solution concept could be considered in international projects as well.

Acknowledgments

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References

[1] Anderson-Schmidt H., Adler L., Aly C., Anghelescu I.-G., Bauer M., Baumgärtner J., Becker J., Bianco R., Becker T., Bitter C. *et al.*, The "DGPPN-Cohort": a national collaboration initiative by the German Association for Psychiatry and Psychotherapy (DGPPN) for establishing a large-scale cohort of psychiatric patients. *Eur Arch Psychiatry Clin Neurosci* (2013).

[2] Demiroglu S.Y., Skrowny D., Quade M., Schwanke J., Budde M., Gullatz V., Reich-Erkelenz D., Jakob J.J., Falkai P., Rienhoff O. *et al.*, Managing sensitive phenotypic data and biomaterial in large-scale collaborative psychiatric genetic research projects: practical considerations. *Mol Psychiatry* (2012), **17**:1180-1185.

[3] Sullivan P.F., The psychiatric GWAS consortium: big science comes to psychiatry. *Neuron* (2010), **68**:182-186.

[4] Helbing K., Demiroglu S.Y., Rakebrandt F., Pommerening K., Rienhoff O., Sax U., A Data Protection Scheme for Medical Research Networks. *Methods Inf Med* (2010), **49**:601-607.

[5] Pommerening K., Sax U., Müller T., Speer R., Ganslandt T., Drepper J., Semler S.C., Integrating eHealth and medical research: The TMF data protection scheme. In *E-health. Combining health telematics, telemedicine, biomedical engineering and bioinformatics to the edge: global experts summit textbook*. Edited by Blobel B, Pharow P, Nerlich M. Amsterdam: IOS Press, 2008:5-10.

[6] Faldum A., Pommerening K., An optimal code for patient identifiers. *Comput Methods Programs Biomed* (2005), **79**:81-88.

[7] Pommerening K., Das Datenschutzkonzept der TMF für Biomaterialbanken (The TMF Data Protection Scheme for Biobanks). *it* (2007), **49**:352-359.

[8] Schwanke J., Rienhoff O., Schulze T.G., Nussbeck S.Y., Suitability of customer relationship management systems for the management of study participants in biomedical research. *Methods Inf Med* (2013), **52**:340-350.

[9] S.Y. Demiroglu, M. Quade, J. Schwanke, L. Gusky, D. Skrowny, T.G. Schulze, Datenschutzkonzept für die Klinische Forschergruppe 241, 2012 (cited Jan 26, 2014). Available from: http://www.kfo241.de/materials/20120718_datenschutzkonzept.pdf.

[10] Murphy S.N., Weber G., Mendis M., Gainer V., Chueh H.C., Churchill S., Kohane I., Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2). *J Am Med InformAssoc* (2010), **17**:124-130.

[11] Bellazzi R., Diomidous M., Sarkar I.N., Takabayashi K., Ziegler A., McCray A.T., Data analysis and data mining: current issues in biomedical informatics. *Methods Inf Med* (2011), **50**:536-544.

[12] Pilone D., Pitman N.: *UML 2.0 in a nutshell*, O'Reilly, Sebastopol, California, 2005.

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Analysis of eligibility criteria from ClinicalTrials.gov

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Abstract. Electronic health care records are being used more and more for patient documentation. This electronic data can be used for secondary purposes, for example through systems that support clinical research. Eligibility criteria have to be processable for such systems to work, but criteria published on ClinicalTrials.gov have been shown to be complex, making them challenging to re-use. We analysed the eligibility criteria on ClinicalTrials.gov using automatic methods to determine whether the criteria definition and number changed over time. From 1998 to 2012 the average number of words used to describe eligibility criteria per year increased by 46%, while the average number of lines used per year only slightly increases until 2000 and stabilizes afterwards. Whether the increase of words resulted in increased criteria complexity or whether more data elements are used to describe eligibility needs further investigation.

Keywords. Eligibility criteria, clinical trials, secondary use

Introduction

Nowadays routine documentation of patients in hospitals is done in electronic health records (EHR) in increasing numbers. The electronic availability makes it easier to re-use data for other purposes, for example EHR data has the potential to support clinical research [1] as existing systems already show [2; 3]. For such systems to work, eligibility criteria of clinical trials have to be represented in a processable format, but criteria, taken from ClinicalTrials.gov (CT.gov) in 2003, showed to have significant semantic complexity [4]. Since 2003 the number of studies published on CT.gov has increased exponentially, but whether the definition and number of eligibility criteria changed over time has not been investigated. An increase in complexity could result in increased documentation work and at the same time a lower possibilities for re-using EHR data. In this study we analyse eligibility criteria taken from CT.gov in 2013 using automatic methods with respect to number of words used to formulate eligibility criteria as a first step to determine whether the characteristics of the criteria changed over time.

1. Methods

In August 2013 we downloaded 149.825 studies from CT.gov in the XML format. From the 21 available fields we loaded the start_date, end_date, eligibility criteria,

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mesh_terms, NCT-ID and phase into a PostgreSQL database for further analysis. We disregarded those studies without eligibility criteria available ("Please contact site", "No eligibility criteria" or empty field).

The start_date field was used to determine the year of the study. Counting the number of studies from CT.gov for each year and phase showed that before 1998 the numbers are small and we decided that each year and phase should have 50 studies as a minimum. Therefore we investigated years 1998-2012 and phases 1-4. Studies with "phase 1/2", "phase 2/3" and "phase 0" were not analysed.

We used SQL queries to determine the number of words and lines for each study, assuming that a line in the criteria is similar to a bulleted list. Special characters like bullet points or blank lines were not counted. Using those numbers we computed the averages for each year and phase. Box-and-whisker plots and diagrams were created to represent the numbers.

2. Results

From initial 149.825 studies downloaded 90.709 remained (60.5%) with useful information about eligibility criteria. 81.296 (54.3%) started between 1998 and 2012, of which 72.308 studies (48.3%) are phase 1-4 and were used for the analysis. Figure 1 shows the number of studies for each year and phase.

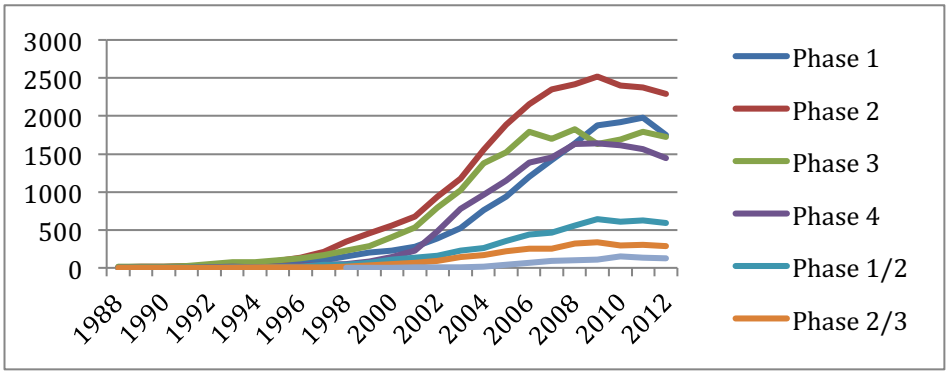


Figure 1 - Number of studies per year and phase

The average number of words per year and phase increased from 1998 to 2012 as can be seen in figure 2, while the media remains constant (figure 3). For phase 1 studies the number of average words per year increased from 236 in 1998 to 342 in 2012 for example.

The average number of lines used per year and phase remains fairly constant (figure 4), with an exception for phase 1 & 2 studies, which peak out in the year 2001 and afterwards stabilized at around 20 lines for both phases. The median of lines used is likewise constant (figure 5).

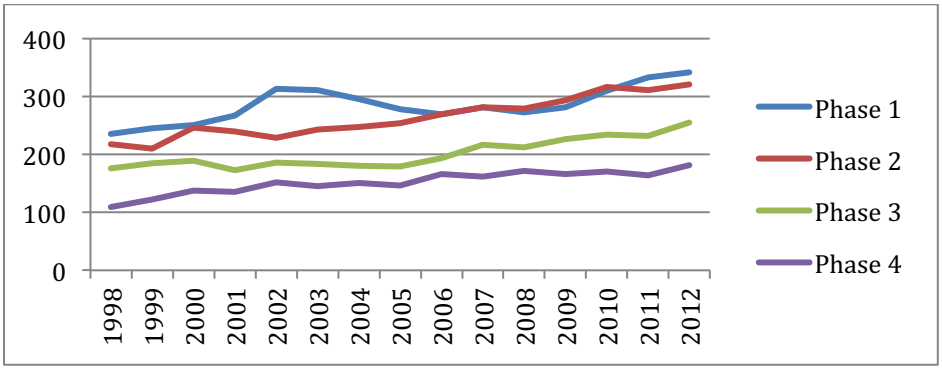


Figure 2 - Avg. number of words used in the eligibility criteria per year and phase

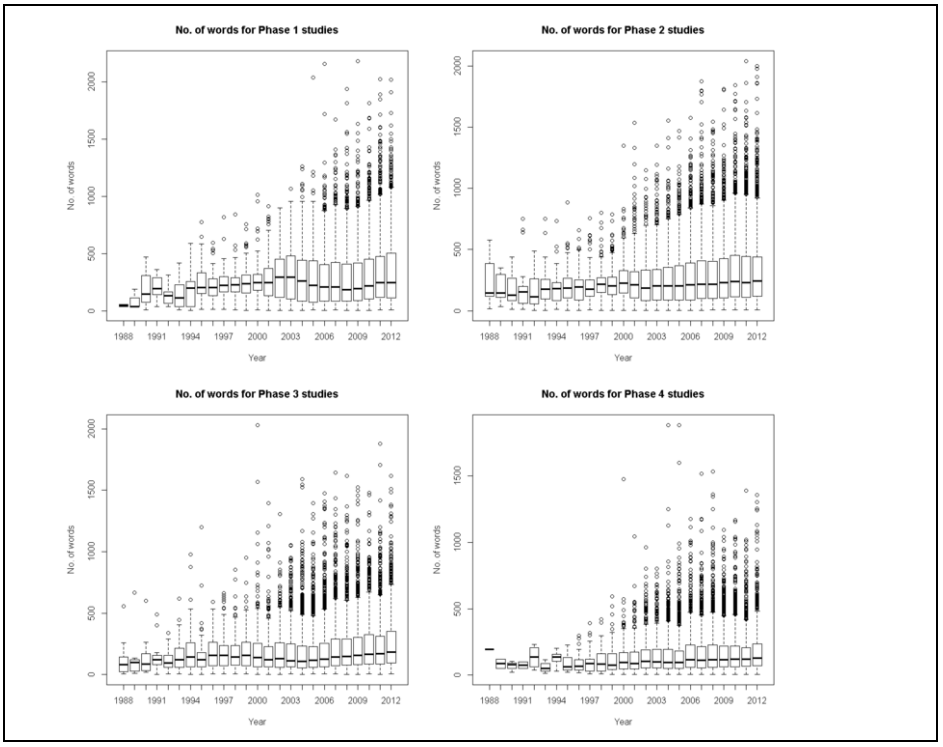


Figure 3 – Box plots showing the number of words per year and phase

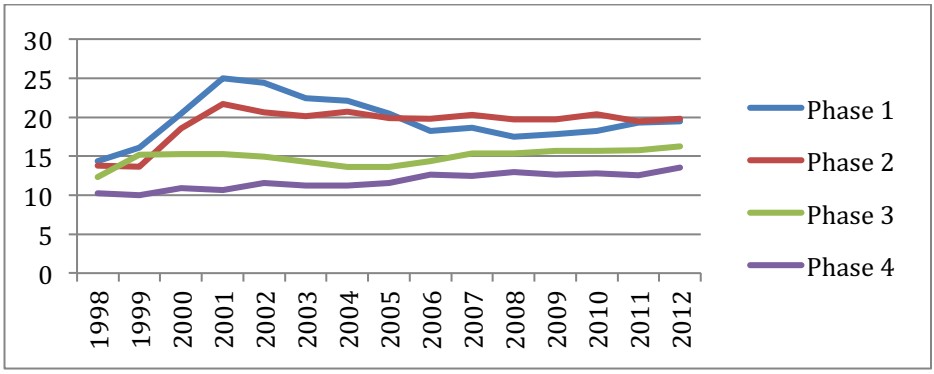


Figure 4 - Average number of lines used to describe eligibility criteria per year and phase

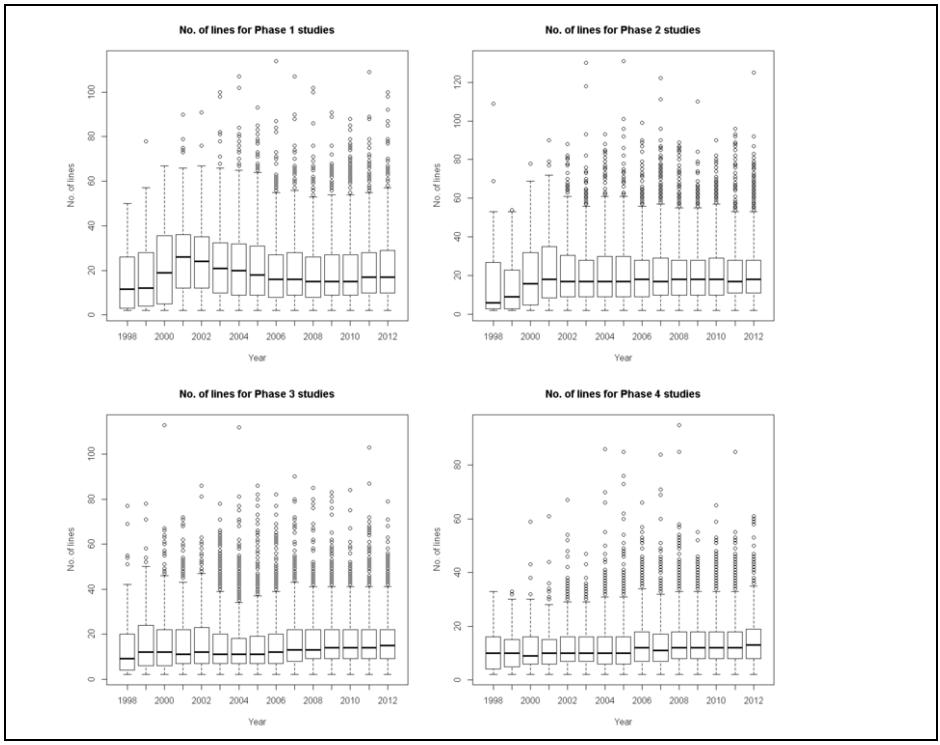


Figure 5 – Box plots showing the number of lines used to describe eligibility criteria per year and phase

3. Discussion

Our analysis shows that almost 40% of the studies available on CT.gov do not have any information regarding the eligibility criteria available. A drastic increase of published studies on CT.gov is noticeable from 1988 to 2005 (average increase 27% per year) which levels off afterwards and even decreases from 2011 to 2012 by -7% in figure 1.

While there was a general tendency to describe eligibility criteria with more words – average number of words increased by 40% from 201 words in 1998 to 281 words in 2012 over all phases - this was not reflected in the lines used. This could mean that (1) the criteria are described in more detail now than they were in the past or (2) more data elements are used in one line to describe eligibility (e.g. "Healthy male or female aged 18-55 years old (inclusive) without significant physical or clinical laboratory abnormalities."). In our work we used automatic methods without analysing the free text criteria manually. The analysis of word counts and lines is a first step to quantify the change over time for a large set of studies, but further research is needed to identify whether the first or the second possibility occurred.

There are still many challenges for secondary use of EHR data for clinical research. If the complexity of eligibility criteria increases, existing methods and representations [5] might have to be extended and if studies use more data elements the challenge of data completeness [6] for systems supporting clinical research increases as well. Tools or representations that support the mapping of EHR data and eligibility criteria would become more important to bridge the gap between those two domains.

References

[1] Coorevits P, Sundgren M, Klein GO, Bahr a, Claerhout B, Daniel C, et. al. Electronic health records: new opportunities for clinical research. J. Intern. Med. 2013 Aug;1–14.

[2] Ferranti JM, Gilbert W, McCall J, Shang H, Barros T, Horvath MM. The design and implementation of an open-source, data-driven cohort recruitment system: the Duke Integrated Subject Cohort and Enrollment Research Network (DISCERN). J. Am. Med. Inform. Assoc. 2011 Sep;

[3] Dugas M, Lange M, Müller-Tidow C, Kirchhof P, Prokosch H-U. Routine data from hospital information systems can support patient recruitment for clinical studies. Clin. Trials 2010 Apr;7 (2):183–9.

[4] Ross J, Tu S, Carini S, Sim I. Analysis of eligibility criteria complexity in clinical trials. AMIA Summits Transl. … 2010;46–50.

[5] Weng C, Tu SW, Sim I, Richesson R. Formal representation of eligibility criteria: a literature review. J. Biomed. Inform. 2010 Jun;43 (3):451–67..

[6] Weiskopf NG, Hripcsak G, Swaminathan S, Weng C. Defining and measuring completeness of electronic health records for secondary use. J. Biomed. Inform. 2013 Oct;46 (5):830–6.

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Towards an automatic harmonization of the representation of medical reports to assess their similarities

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Abstract. Numerous hospitals contain unexploited knowledge deposits. These often take the form of unstructured records with heterogeneous content, which, at various levels of those organizations, register past cases. Those records are for instance patient medical records. Accessing the knowledge and experience they gather would help us to handle present cases. We present here a method to normalize textual reports in foetopathology in order to constitute a proper case base that will be the target of case-based reasoning techniques. Statistics of noise and silence generated by this method on 10 cases are presented.

Keywords. Information extraction, information representation normalization, natural language processing, domain ontologies

Introduction

Analysis of textual medical data often requires several preliminary steps to reach a state in which the data is algorithmically tractable. Common typos put aside, we often have to deal with imprecise contexts, misplacements of information and the variability of expression inherent to each health practitioner. This happens even if a report template has been defined beforehand. The major task of the French project Accordys (Aggregation of content and knowledge to perform case-based reasoning on fetal dysmorphologies) [1] is to address those difficulties in the domain of foetopathology. Medical reports used in this project are paper or electronic documents that have been written throughout more than 10 years of medical practise by several foetopathologists. Those reports can in addition be deteriorated: parts may have been lost or clean extraction from proprietary software may not be possible, leading to some incomplete reports. In order to empower both current and future practitioners to reuse that memory to better future diagnoses, the goal of the Accordys project is to develop a software tool which can (i) harmonize the representation of cases to authorize their comparison (i.e. measurement of similarities), (ii) qualify the usability of each case in the context of a case-based reasoning system and (iii) construct a case base using Semantic Web technologies and domain ontologies for interoperability and extensibility purposes. The long-term goal is to automate the time-consuming cognitive process of narrowing down

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diagnoses of present cases by finding past cases with similar malformations. We present in this paper an adaptable method for medical reports harmonization that addresses previous points (i) and (ii). It is based on a tree matching methodology and can be combined with regular natural language processing techniques.

1. Methods

Our objective is to construct the hierarchical context of the observations found in a foetopathology report, by placing them in a tree, and then match this tree against a model so that (i) we have a common representation to compare two reports and (ii) we may disambiguate sentences (e.g. in order to know which organ is concerned in observations like "small detachment of the membrane seen at ultrasound"). Being often composed of sections, sub-sections and items, we argue that medical reports and templates (models) of those reports provide a tree-like structure that can be followed to support their structuring, thus giving the possibility to make the software independent of the model in use and then extensible to other kinds of reports, medical or not. Then, once the case is transformed into a tree, each observation requiring further language processing appears in leaf position in that tree, its ancestor nodes providing information about its context. In our application, we match the tree associated to the case (the medical report) to the tree corresponding to the model (validated by practitioners).

After describing the precise nature of the material that we use, we expose a review of relevant existing approaches, then we propose the adaptation of a general flexible tree matching algorithm and finally show the interest of the approach in our context.

1.1. Material

For the purpose of this specific work, we used a corpus of about 12,000 words, spread over 20 reports. The medical reports are bare Unicode text with some hierarchical structure guiding the reading. They are obtained in the context of Accordys from the scan, optical character recognition and anonymization of the paper reports of the Trousseau hospital (Paris, France). Those reports contain at most nine major sections (clinical summary of the case, external macroscopic examination of the foetus, autopsy, radiographies, histopathological examination of viscera, macroscopic and histological examination of the placenta, cytogenetics and a conclusion). Most of the reports contain only a fraction of those sections (e.g. cytogenetics is often absent and autopsy may have been refused by the parents), not always under the same names and not exactly in the same order.

Each section can contain subsections or directly information laid out most of the time as full sentences or bullet lists (plain enumerations or colon-separated site/observation pairs). Paragraphs and titles may be truncated or missing, leading to incomplete data and to the impossibility to directly know the context of some observations.

1.2. State of the art

Extracting the meaning of each sentence contained in medical reports is often achieved through the use of natural language processing methods. Those methods [2, 3]

aim at providing syntactic and semantic types to the words appearing in a sentence and links between them, thus producing a graph for each line or sentence.

To construct the context, automatic structuring methods exist [3], but they often try to fit the reports in a semantic model that is predefined and hard-coded into the software. Tree matching allows more genericity. It has been studied for a while [4], notably in the context of Web development and mining [6]. Depending on the constraints several methods exist that can provide an optimal mapping or an approximation of it. An optimal mapping can be produced in polynomial time if it is constrained by:

- the ancestry (if a node N1 in tree 1 is mapped to a node N2 in tree 2, then children of N1 can only be mapped to children of N2, and conversely);
- the ordering (if N1 is mapped to N2, then next sibling of N1 can only be mapped to one of the next siblings of N2).

We saw that those constraints are unacceptable in our context: titles may be missing and we do not know the order in which the sections will appear in our reports and the same goes for the items (observations for instance) in each section.

Flexible tree matching [5], as the name suggests, can alleviate those constraints. It uses a stochastic method to sample approximations of the best mapping. Mappings, bipartite graphs, are valued by computing a cost for each of their edges. The cost of each edge between some pair of nodes (N1, N2) is the sum of three terms: (i) the distance between the labels of N1 and N2 (a function chosen by the user), (ii) the number of children of one of N1 or N2 not mapped to children of the other node and (iii) the number of siblings of one of N1 or N2 not mapped to siblings of the other node. Terms (ii) and (iii), *ancestry* and *siblings* terms, covers the structural cost of the mapping, they assess the respect it makes of the global shapes of the trees. A cost is also induced by every node that is left unmapped (this is symbolized by a mapping to a *void* node). Each one of those terms is multiplied by a weight, which allows the user to tune the importance of each term depending on the domain of application. See [5] for the detailed computations.

1.3. Methodology

The first step of the proposed methodology is to construct the *model tree.* It is obtained through a collaboration with the foetopathologists at the Trousseau hospital involved in the Accordys project. The resulting tree has been manually derived from the original document template they established for foetopathology reports, yet further information has been added to it, notably in the leaves. Types are inserted as annotations when the node is to contain information whose type is known in advance (e.g. numeric values or values chosen from a defined set of symbols) and nodes corresponding to observed weights or measurements are annotated with units. The result is a hierarchical case model that has been validated by the foetopathologists.

The next step is to turn the text of the reports into intermediary trees which we call *case trees*. All trees produced are formatted in JSON and stored in a document database. A simple rule-based approach is adopted to turn each line of the report into a node of the case tree: for instance if we determine from the shape of a given line that it should be a title, then the node produced from it should be the ancestor of the nodes produced from the subsequent lines. If we see that a given line is a colon-separated site/observation pair, then the site forms a node and the observation a sub-node of it.

Once those two previous steps are complete, we aim at determining for each case tree how many of its nodes can find a corresponding node in the model tree, thus computing a mapping between both. We use flexible tree matching [5] to do so. The task here is to find the parameters for the mapping computation process that give the best results in our context of foetopathology reports. As exposed in the state of the art, flexible tree matching targets the lowest-cost mapping. We compute the whole cost by summing the cost of each edge (node-to-node mapping) and dividing it by the sum of the sizes of both trees. The function computing the cost between two labels is a lexical distance. We use the Levenshtein distance divided by the length of the shortest label and multiplied by 2 if the nodes have different types (e.g. if one is a title and the other one an observation). Each structural cost term (*ancestry* and *siblings* terms) is weighted, and we have to choose those weights as well as the *void*-mapping cost.

The evaluation step consists in computing mappings for 10 different reports using the same set of parameters and assessing the average noise (percentage of nodes of the case tree mapped to an incorrect node in the model, thus creating false information) and silence (percentage of nodes that were not mapped when a correct mapping was possible) given by the system on those 10 reports.

2. Results

Our experiments showed that tuning the parameters of the algorithm is not easy. Our model tree contains no less than 576 nodes and since the algorithm (1) initially evaluates all the possible mappings between all nodes of the case tree and all nodes of the model tree and (2) repeatedly re-evaluates some of those possible mappings, then the process of fully mapping one case can take up to an hour on a 4-core computer. This slows the parameter tuning process.

The parameter set we found interesting in our experiments was the following:

- ancestry cost weight of 0.21
- siblings cost weight of 0.25
- void-mapping cost of 1.2

These values are completely dependent on the function we chose to compute distances between labels. The other parameters were left as suggested in [5]. On a test base of 10 reports (randomly selected from our corpus), theses parameters gave us on average a noise of 23.7% and a silence of 8.6%, giving an average accuracy of 67.7%.

Noise could be reduced by decreasing the void-mapping cost, but siblings cost should be also lowered then, as we noticed that even slight decreasing of the void-mapping cost can lead to a whole block of siblings being no longer mapped.

We noticed a recurrent behaviour of the FTM algorithm: it tends to start by mapping the leaves of both trees. Since leaves cannot induce any ancestry cost they tend to look like the best available mappings at the beginning. The problem is that in our case trees the leaves are the least relevant nodes to map. They usually are the observations that are specific to each case and not always resemble a node in the model tree. This makes us think that removing the case leaves or detailing the case of leaves when computing the distance between labels could be of use, to increase the cost of label differences between leaves and then avoid misleading the algorithm, since if leaves are mapped incorrectly then the mapping of their parents will be perturbed.

3. Discussion and conclusion

Turning reports into trees could benefit from having the original documents in a format containing their lay-out (like DocBook) instead of bare text. If stuck with free text, statistical methods can be used to recognize patterns and give types to text chunks [7].

Finding the right parameters for the mapping process could also be done thanks to machine learning techniques, as proposed in [5], by giving the system hand-made mappings it could use to learn a set of parameters.

The next evolution of the approach we present here is to experiment with other metrics for label comparison, namely a distance based on the semantics of the labels [8, 9]: one goal of Accordys is to develop a domain ontology, which can be used to further normalize the case trees and establish semantic links between nodes of the trees.

Conversely, the method we present here can also be useful for the task of *building* this domain ontology: by repeatedly computing mappings to a common model, one may (i) identify new commonalities in reports, thus new levels of detail to be included in such an ontology or at least (ii) inventory new alternate labels for existing concepts.

We said our method was orthogonal to regular natural language processing techniques. [10] presents those applied in Accordys, and we still need to assess the value brought by our method when it comes to processing the corpus of the project.

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References

[1] J. Charlet, Agrégation de contenus et de connaissances pour raisonner à partir de cas de dysmorphologie foetale, *Proceedings of the 1st SIG IMIA French Workshop* (2013).
[2] Ö. Uzuner, 2010 i2b2/VA challenge on concepts, assertions, and relations in clinical text, *Jounal of Medical Informatics Association* **18 (**2011), 552–556.
[3] R.K. Taira, Automatic Structuring of Radiology Free-Text Reports, *RadioGraphics* **21** (2001), 237–245.
[4] C.M. Hoffman, Pattern Matching in Trees, *Journal of the Association for Computing Machinery* **29** (1982), 68–95.
[5] R. Kumar, Flexible Tree Matching, Proceedings of the International Joint Conference on Artificial Intelligence **22** (2011), 2674–2679.
[6] N. Jindal, A Generalized Tree Matching Algorithm Considering Nested Lists for Web Data Extraction, *Proceedings of the SIAM International Conference on Data Mining* (2010).
[7] J. Lafferty, Conditional Random Fields: Probabilistic Models for Segmenting and Labeling Sequence Data, *Proceedings of the 18th International Conference on Machine Learning* (2001), 282–289.
[8] S. Harispe, A framework for unifying ontology-based semantic similarity measures : A study in the biomedical domain. *Journal of biomedical informatics* (2013).
[9] A. A. Sánchez-Ruiz, Measuring similarity in description logics using refinement operators, *Case-Based Reasoning Research and Development* (2011), p. 289–303.
[10] L. Déleger, Annotation of specialized corpora using a comprehensive entity and relation scheme, *Proceedings of the Ninth International Conference on Language Resources and Evaluation* (2014).

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Crucial Issues in Think Aloud Techniques for Cross Cultural Studies

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Abstract. Implementing user-centered design (UCD) principles and conducting usability testing is especially critical in projects where developers do not originate from the deployed environment. However, traditional usability testing techniques in cross-cultural settings can be problematic and may produce unexpected results. Measures should be taken to identify and mitigate any cultural factors that may influence UCD testing and deployment . In this paper, we focus on the think-aloud method. We use a current mHealth development and research project in Tanzania as a case study to highlight issues in UCD in cross-cultural settings. We offer recommendations for UCD methods and cultural considerations for low to middle income countries.

Keywords. mHealth, Think-aloud technique, Usability, User-Centered Design, LMICs

Introduction

Providing basic health services in low to middle income countries (LMICs) can be challenging due to constrained resources, differences in cultural norms, and lower health literacy levels. Increased interest from various agencies has resulted in information and communications technology development (ICT) for mHealth (mobile health) interventions in LMICs [1] as these can offer vital support for strategic, health-related goals [2].

Cross-cultural partnerships have surged for product development, although software developers frequently originate outside the deployed environments. The World Health Organization (WHO) recommends usability processes as part of any mHealth strategic plan to help ensure the success of product implementations [3]. Implementing user-centered design (UCD) principles, including usability testing, is especially critical in projects where developers do not originate from the deployment environment.

Traditional usability testing techniques in cross-cultural settings can be problematic and may produce unexpected or spurious results. For this study, we use a

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recent mHealth project in Tanzania as a case study to highlight issues with UCD. We outline methods, describe experiences, identify reasons for testing breakdown, and offer recommendations.

UCD is an approach to systems development focused specifically and intentionally on usability [4] by placing users at the center of the design process [5]. The user context, environment, and requirements are closely examined during all stages of product design and evaluation [6-8]. A spectrum of methods may be used, from very early product testing using tools such as storyboards, to active and detailed participatory design during coding. We focus on one kind of UCD method: the think-aloud protocol.

1. Methods

The product was a prototype for a new decision support protocol on a mobile health platform, based on the WHO Integrated Management of Childhood Illness (IMCI) protocol [9, 10]. Called eIMCI, it was designed to support isolated, first-time clinical encounters in the treatment of children suffering from general, acute illnesses. The targeted users were mid-level health workers in rural and urban areas of Tanzania. This research project was a subset of a larger randomized controlled trial and included WHO recommendations.

The think-aloud protocol asks users to verbalize a running explanation of their thoughts, actions, perceptions, and expectations of the software as they perform representative tasks. Our goal was to evaluate: user satisfaction and usefulness of the product, learnability, ease of learning navigation, perceived efficiency, effectiveness, and accessibility/fit with clinical workflow.

Early formative usability testing often employs smaller samples [11]. We had three participants selected by convenience sampling. Inclusion criteria were: consent to participate, ability to speak and read English, and being a clinical provider. All participants were familiar with the protocol; none had prior experience using mobile phones as in a clinical setting, all participants were previously trained in using the original paper version of the IMCI protocol, spoke fluent English as a second language, and completed clinical training in English, reflecting the current standard health practices in Tanzania.

To guide the evaluation, the developers created eIMCI clinical test case scenarios. Each participant first received a training session of about 30 minutes. Participants were instructed to begin the think-aloud assessment and to navigate through the test case scenario by stating out-loud what they were doing, how they were doing it, and where they were in the application The researcher also encouraged participants to comment on their usability impressions and asked for suggestions for improvement. The researcher recorded comments and actions of the participants in typed notes in real time.

2. Results

Challenges were evident with the think aloud testing. Each participant used the eIMIC to successfully complete the tasks in the test case scenarios; however, inducing comments was not successful. Providers' comments were non-specific despite strong encouragement to describe confusing or challenging experiences. Difficulties with the

application were obvious to the researcher (SP), e.g., actions for logging in, saving and sending data required considerably more time to learn and resulted in frequent errors. The researcher witnessed obvious user errors and frustration based on facial expressions and body language at specific, consistent points in the application, but no participants acknowledged them. The application crashed several times during one test. Amazingly, the participants verbalized no dissatisfaction, although the participant's body language indicated confusion.

All participants verbalized positive perceptions and with only praise and offered no suggestions,. When asked to provide specific feedback on how the content, workflow, and interface might be improved or to state what was difficult about using the application, participants gave only general praise about eIMCI.

A final challenge concerned verbalizing eIMCI navigation. All three participants gave only general perceptions instead of the actual steps used for navigation. The researcher made multiple attempts to clarify the instructions with no success. Therefore, the only useful data from the entire think-aloud protocol were the observed errors captured during training. These allowed for training to be redesigned to increase allotted time for learning trickier tasks. The researchers chose to abandon the method.

3. Discussion

The reasons for the failures are not completely clear but may be methodological, cultural and/or linked to a demand characteristics bias. Participants were able to use eIMCI to complete tasks and the training was obviously successful. Unfortunately, the research team could not determine users' full understanding of screen headings or the context of eIMIC usage using the think-aloud protocol method.

A potential methodological issue was that the usability method was unfamiliar to the users or perhaps the instructions were not clear enough to withstand language barriers despite participants being generally fluent in English. More likely, a cultural issue prevailed. The UCD process could have been interpreted as a test with participants wanting to avoid making a mistake. This may have occurred despite the researcher's emphasis that the product, not the user, was being evaluated. Another reason may be that the navigation was straightforward enough that the exercise seemed meaningless to the participants. However, this last reason is less likely because the researcher observed obvious usability issues during every user's interaction.

The overwhelmingly positive responses may reflect a demand characteristics bias, a phenomenon in which participants alter their behavior or feedback to accommodate what they believe are expectations of the researchers [12]. Dell et al. indicated this can occur in international research because foreign researchers may be perceived as having a greater social status than research subjects [13]. Dell and colleagues determined that demand characteristics biases significantly influenced their participant responses in a human-computer interaction assessment of a product in a developing world setting.

The eIMCI researchers did not anticipate or fully appreciate the extent this phenomenon might affect the current study. The main lesson learned is that demand characteristic biases are critical to consider any cross-cultural setting but particularly in LMICs and cultures where participants might perceive discrepancies in social status. Completing eliminating this bias may not be possible, so investigators must consider its

potential effect during initial planning and mitigate major effects as much as possible [13].

The think-aloud method may not be appropriate for some cultures. Rubin and Chisnell advise usability testers to abandon the method if it appears to yield unproductive or inauthentic results [5]. This could be the case for other researchers. Yet, mitigation may include other less drastic modifications than abandoning the method as discussed below.

3.1. Modifications

Several modifications to the traditional think-aloud testing method are suggested for cross-cultural settings. First, find a key informant. In this study, the research team hired a provider who unexpectedly emerged later as a key informant. Using the application for about four months, the provider had daily interactions with research team to help develop trust and open communication. The informant gave comments and proposed many changes. These included text/dialogue categories, match to clinical flow, formatting, and other usability issues. These suggestions were evaluated for feasibility, approved by developers, and iteratively implemented and re-tested.

The application was also refined by observing typical clinical workflow, using customary healthcare frameworks, and using the flow of the paper IMCI protocol. In the end, the team made successful, iterative improvements for application fit to workflow.

Other steps to mitigate risk in future projects might also include employing a native speaker who is in a trusted position related to the participant. Allowing extra time to complete each component may also help the exercise not feel like a test. Alternatively, providing participants with choices of designs to compare or using ranking exercises may be more successful for evaluating satisfaction. Last, the use of other metrics may prove more helpful than eliciting open-ended, qualitative feedback.

3.2. Conclusion

The failure of the method to yield a deeper understanding of user perspectives was a valuable lesson in cross-cultural usability testing methods. The think-aloud method typically works well across a variety of settings to attain deeper understanding of users' cognitive processes, to elicit feedback about the user experience, and to gather suggestions for product improvement [14, 15]. However, the technique relies on a participant's ability to perform as they would in the absence of observation. Perceived differences in social status and response expectations may have limited the usefulness of the think-aloud protocol for health providers in Tanzania. We recommend planning for demand characteristics bias, using a key informant or native speaker during UCD testing, or choosing alternate strategies such as ranking exercises, for health software development in low to middle income countries.

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4. References

[1] J.A. Blaya, H.S.F. Fraser, & B. Holt, E-Health technologies show promise in developing countries, *Health Affairs,* ***29*** (2) (2009), 244-251.

[2] H. Masanja, D. de Savigny, P. Smithson, J. Schellenberg, J. Theopista, C. Mbuya, G. Upunda, C.V. Boerma, T. Smith, & H. Mshinda, Child survival gains in Tanzania: Analysis of data from demographic and health surveys, *The Lancet* **371** *(*2008), 1276-1283.

[3] T. McCurdie, T. Svetlana, M. Casselman, M. Yeung, C. McDaniel, W. Ho, & J. Cafazzo, MHealth consumer apps: The case for user-centered design, *Horizons*, **fall** (2012) [cited April 11, 2013], 49-56, Available from http://www.aami-bit.org/doi/pdf/10.2345/0899-8205-46.s2.49

[4] C. Smith, J. Thorp, & S.L. Henry, Notes on user centered design process (UCD). *W3C web accessibility initiative* (2004) [cited April 10, 2013], Available from http://www.w3.org/WAI/EO/2003/ucd

[5] J. Rubin, D. Chisnell, *Handbook of Usability Testing: How to Plan, Design, and Conduct Effective Tests*, Wiley, Indianapolis, Indiana, 2008.

[6] Resources: About Usability, *UXPA Resources: About Usability* (2010), [cited November 2, 2012], Available from http://www.upassoc.org/usability_resources/about_usability/index.html

[7] B. Schneiderman, C. Plaisant, *Designing the User Interface* (5th ed.), Pearson Higher Education, Boston, 2010.

[8] N. Evan, International standards for HCI and usability, *UsabilityNet: International Standards* (May 2006) [cited April 2, 2012] Available from http://www.usabilitynet.org/tools/r_international.htm

[9] S. Perri, B. Hedt, T. Routen, N. Lesh, A. Shao, C. Rambaud-Althaus, N. Swai, & M. Mitchell, Using eIMCI to Enhance Provider-Caretaker Communication for Treatment of Children Under Five in Tanzania, *mHealth Summit Conference*, Washington DC. December 5-8, 2011.

[10] A. Shao, C. Rambaud-Althaus, S. Perri, N. Swai, M. Mitchell, J. Kahama-Maro, V. D'Acremont, & B. Genton, Safety of a new Algorithm for the Management of Childhood illness (ALMANACH) to improve quality of care and rational use of drugs. *7th European Congress on Tropical Medicine and International Health*, Barcelona, Spain, November 5-6, 2011.

[11] J. Neilsen, International Use: Serving a Global Audience, *Designing Web Usability: The Practice of Simplicity* (pp. 312-344), New Riders Publishing, Indianapolis, 2009.

[12] R. Rosenthal, R.L. Rosnow, *Artifacts in behavioral research: Robert Rosenthal and Ralph L. Rosnow's classic books: A re-issue of Artifact in behavioral research, Experimenter effects in behavioral research and the volunteer subject* (p. 111), Oxford University Press, New York, 2009.

[13] N. Dell, V. Vaidyanathan, I. Medhi, E. Cutrell, & W. Thies, Yours is better!: participant response bias in HCI, *Proceedings of the 2012 ACM Annual Conference on Human Factors in Computing Systems* (pp. 1321-1330) (May 2012), ACM.

[14] C. Anderson, A. Gifford, A. Avery, H. Fortnum, E. Murphy, J. Krska, & C. Bond, Assessing the usability of methods of public reporting of adverse drug reactions to the UK Yellow Card Scheme, *Health Expectations* **15**(4) (2012), 433-440, doi:10.1111/j.1369-7625.2011.00686.x

[15] H.L. Munger, Testing the Database of International Rehabilitation Research: Using rehabilitation researchers to determine the usability of a bibliographic database. *Journal of the Medical Library Association* **91**(4) (2003), 478.

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Interconnection of Electronic Medical Record with Clinical Data Management System by CDISC ODM

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Abstract. EDC system has been used in the field of clinical research. The current EDC system does not connect with electronic medical record system (EMR), thus a medical staff has to transcribe the data in EMR to EDC system manually. This redundant process causes not only inefficiency but also human error. We developed an EDC system cooperating with EMR, in which the data required for a clinical research form (CRF) is transcribed automatically from EMR to electronic CRF (eCRF) and is sent via network. We call this system as "eCRF reporter". The interface module of eCRF reporter can retrieves the data in EMR database including patient biography data, laboratory test data, prescription data and data entered by template in progress notes. The eCRF reporter also enables users to enter data directly to eCRF. The eCRF reporter generates CDISC ODM file and PDF which is a translated form of Clinical data in ODM. After storing eCRF in EMR, it is transferred via VPN to a clinical data management system (CDMS) which can receive the eCRF files and parse ODM. We started some clinical research by using this system. This system is expected to promote clinical research efficiency and strictness.

Keywords. Medical Records Systems, Computerized Clinical Research, CDISC, ODM, eCRF

Introduction

With the growth of importance of evidence based medicine, efficient clinical data collection method is desired for clinical research. These days, EDC has been used in the data collection process for clinical research, where a CRC transcribes data in a medical record to an EDC terminal. EDC has a merit of making instant remote monitoring possible. In addition, it improves data accuracy by checking system on the timing of data entry and streamlines data management process.

In Japan, more than 50% of hospitals with more than 400 beds implement EMR system. Despite this, a CRC transcribes data shown on an EMR terminal screen to an EDC terminal manually. It is desired that necessary data for CRF which is recorded in EMR can be transcribed to electronic CRF (eCRF) automatically. This vision was already proposed by Clinical Data Interchange Standards Consortium (CDISC). CDISC developed Operational Data Model (ODM) as standard eCRF[1)]. However,

prepopulating of CRF by the data in EMR has not yet been in practical use in actual clinical research. We developed a system, which transcribes some data required for a CRF from EMR automatically and sends completed CRF via network. We call this system as "eCRF reporter". In this paper, we describe the outline of this system.

1. Methods

1.1. Data flow of the system

The purpose of eCRF Reporter is to generate an electronic CRF file in EMR system and send it to a clinical data management system (CDMS) in a datacenter. The interface module of eCRF reporter can retrieves the data in EMR database including patient biography data, laboratory test data, prescription data and data entered by templates in progress notes. The eCRF Reporter also enables users to enter data directly to eCRF. The eCRF Reporter generates a CDISC ODM file and a PDF document which is a readable form of Clinical data in ODM. After storing eCRF in EMR, it is transferred via VPN to the CDMS which can receive the eCRF files. When a data manager accepts the eCRF, the data in the ODM is stored into a database. The data flow concerning the eCRF Reporter is depicted in Figure 1.

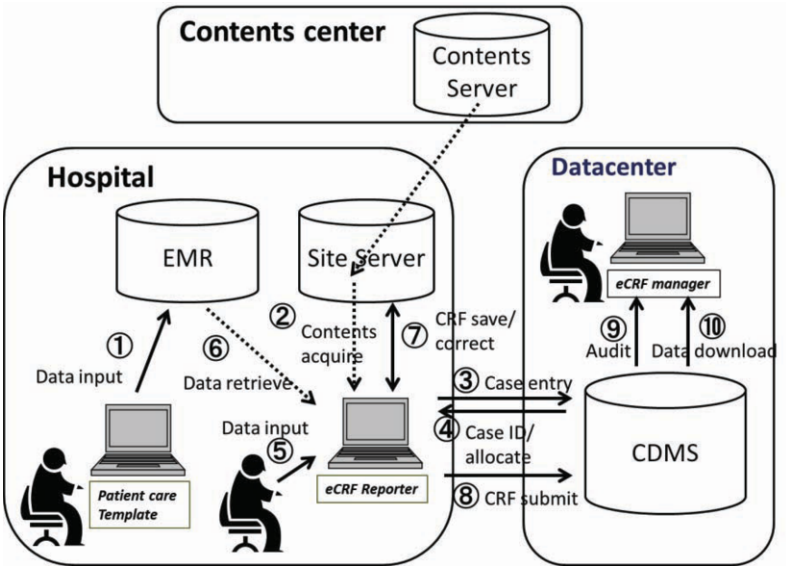


Figure 1. Data flow of the system

1) When doctors intend to write progress note, they use patient care templates to generate structured data[2]. It outputs both narrative text for progress note field by using natural language generation technique and data XML for data processing. The data XML is essentially a set of key values. Each key item whose value is supposed to be retrieved from eCRF Reporter is put a reference code.

2) eCRF Reporter also uses the template module as user interface. Its task is to generate ODM file. Master data and program are completely separated in eCRF Reporter, so any

CRF can be made by letting eCRF Reporter program read master data. Adding to template master XML file, project configuration file and ODM file are also necessary for eCRF Reporter. These contents are delivered from a contents center to eCRF Reporter systems located in hospitals. By this mechanism, the hospitals which participate in a clinical research can generate the same CRF for each project.

3) When a new study case is found, a reporter creates study case with necessary information. At this time, the eCRF Reporter sends case information but personally-identifying information.

4) When the CDMS in the datacenter receives study case information, it sends back study case ID number. If the study is clinical trial and needs random allocation, the CDMS allocates the case into the prepared groups. The eCRF Reporter receives study case ID number and stores it in a local database.

5) A doctor or CRC inputs data by using CRF template for each study case.

6) The CRF template can retrieve data in the EMR database. The CRF Reporter program passes keywords to the interface module which is made by EMR vendor. Then the interface module retrieves patient's biography data, laboratory test data, prescription data, or data entered by the template in progress note from the corresponding database in EMR according to the keywords and returns retrieved data to the template engine.

7) Incomplete CRF can be saved in the local server and can be added or corrected afterward. After completing the CRF, the eCRF Reporter generates ODM file using data binding technique. It also generates a readable form of Clinical data in ODM as a PDF document. The ODM and the PDF are stored in EMR just before submission.

8) eCRF Reporter submits a completed eCRF (ODM and PDF) to CDMS in a datacenter via network.

9) eCRF Manager is client software of CDMS. Data manager can check the received eCRF using eCRF Manager. If the CRF contains some errors, the data manager refuses it and asks the CRC or the doctor in charge to correct it. If the data manager accepts it, the ODM is parsed and the containing data are saved into the CDMS database.

10) The data manager can download the data stored in the database of the CDMS to make an analysis of them.

1.2. System configuration and network

There are two types of installation configuration of the eCRF Reporter. One is server client type. The site server in a hospital keeps the contents of eCRF Reporter. When a user selects a study from a PC in the EMR system, the contents files corresponding to the study are delivered to the PC. The site server also has a database that stores the data XML, the ODM file and a PDF document generated by the eCRF Reporter. It also has a function of a proxy server to relay a completed eCRF sent from the PC to the CDMS. This type system needs always-connected network. We adopted On-Demand VPN provided by NTT data for it.

Another type is software that runs on a single PC. It has local database in the PC disk or USB memory. This type can be used anywhere without set up. Because the eCRF Reporter in this configuration is separated from EMR system, it cannot retrieve data from EMR database. Users connect with the network when they request the

contents files corresponding to the study and when they send entry information to the CDMS to get case ID. When users enter data to fulfill the eCRF, it can be used in offline mode. After finishing data entry, users again connect with the network to send eCRF files to the CDMS. For this type system, we adopted SSL-VPN provided by Cisco.

2. Results

The datacenter was set up in Osaka University Hospital, which deals with clinical studies conducted by Osaka University Medical School and its related facilities. By using this proposed system, 5 studies already started and 4 studies is now preparing. The outline of the 5 started studies is as follows: 1) Observation study with follow-up of acute coronary insufficiency. Its CRF includes 4 event forms. 2) Observation study with follow-up of mammary gland cancer. Its CRF includes 12 event forms, some of which are repeatable. 3) Clinical trial concerning preventive effect of clipping on breeding after colon polypectomy. This study uses stratified random allocation function of the CDMS. Its CRF includes 5 event forms. 4) Ovarian cancer registry. Its CRF includes 1 event. 5) Melanoma registry. Its CRF includes 1 event.

Just before starting this service, the system has been evaluated in detail and is regarded with high esteem by all of CRCs and doctors in charge

3. Discussion

When paper based medical record is used in daily practices, EDC system is the best way to promote efficiency in clinical research activities. However, in the clinic where EMR is used, the current EDC system has several shortages. Firstly, double data entry is required for daily care and clinical research. It is not only cumbersome but also mistakable. Secondary, the data entered for a clinical research into an EDC does not exist in the institutional database. Thus if a patient is enrolled into another research which requires the same data entered for the first study, even though, they have to be reentered into another EDC. The purpose of our project is realizing single data entry for care and clinical researches through EMR-CDMS data integration.

Our near-term target is multicenter academic clinical researches. Because contrary to sponsor initiated clinical trial, the budget of an academic clinical research is limited, they sometimes have to be conducted without employing CRC. In this case, double data entry for care and clinical research becomes a significant barrier for its execution. Our method can solve this problem. Academic research often includes observational study whose collecting items in CRF are more diverse than those of clinical trials; however, the items collected for observational study are almost same with those recorded in progress note in daily practice. Thus our method is more suitable for observational study than clinical trial.

The concept of our system has been already discussed well. CDISC Electronic Source Data Interchange (eSDI) Group proposed 5 scenarios for electronic source data (eSource) interchange[3]. Our method corresponds to the 4th scenario; “eSource extraction and investigator verification (using electronic health records)”.

The implementation scheme of our project is similar with that of Retrieve Form for Data-capture (RFD) integration profile[4]. "Form Manager" is compatible with the contents center in our system, which deliver ODM, template master and project configuration file to each site server. "Form Filler" corresponds to the template program with the interface module that creates eCRF. "Form Archiver" is one of the functions of EMR. "Form Receiver" is compatible with CDMS in the datacenter. However, the adopted concrete technique in our system especially for "Form Filler" is different from those in RFD.

The method we took is quite similar with the RE-USE project to the EHR4CR platform[5]. In the RE-USE project, patient care centric templates were made independently to clinical researches. Thus a standardized terminology is necessary for re-using data. They used SNOMED for it, however, only 13.4% of the data elements in CRF were found in EMR templates. In our project, patient care centric templates are made simultaneously with templates for a clinical research. Thus we can set the common items with the same options in both templates and put reference codes beforehand. Thus standardized terminology is not indispensable for our system. In care templates, some items can be added if they are needed for daily practice. We assume that if a patient is enrolled to a clinical research, the doctor in charge uses special templates during research execution. Even though, the doctor can input any information not related to the research into the progress note.

Although our method can prepopulate CRFs without fault, the current system has a shortage especially when it will use in sponsored initiated clinical trials. It needs a lot of time to set up patient care centric templates in each hospital. Thus it may not be practical when many hospitals and clinics simultaneously participate in a clinical research. We are now planning to develop next version system in which master of patient care centric templates can also be delivered from a contents center. The doctors participating clinical research use the same template for patient care during clinical research execution period. We think this method will become more practical for re-use of data entered for daily practice for a clinical research.

References

[1] Clinical Data Interchange Standards Consortium (CDISC) (Internet]). 15907 Two Rivers Cove, Austin, Texas, USA; ©2008. Standard available from: http://www.cdisc.org/models/odm/v1.3/index.html (cited Apr 20, 2009).

[2] Matsumura Y, Kuwata S, Yamamoto Y, Izumi K, Okada Y, Hazumi M, Yoshimoto S, Mineno T, Nagahama M, Fujii A, Takeda H. Template-based data entry for general description in medical records and data transfer to data warehouse for analysis. Stud Health Technol Inform 2007; 129 (Pt 1): 412-6

[3] CDISC Electronic Source Data Interchange (eSDI) Group. Leveraging the CDISC standards to facilitate the use of electronic source data within clinical trials version, November 20, 2008. < http://www.cdisc.org/stuff/contentmgr/files/0/2f6eca8f0df7caac5bbd4fadfd76d575/miscdocs/esdi.pdf >

[4] IT Technical Committee. Retrieve Form for IHE Data Capture (RDF) Trial Implementation IHE IT Infrastructure Technical Framework Supplement 、 August 10, 2010 , http://www.ihe.net/Technical_Framework/upload/IHE_ITI_Suppl_RFD_Rev2-1_TI_2010-08-10.pdf

[5] El Fadly A, Rance B, Lucas N, Mead C, Chatellier G, Lastic PY, Jaulent MC, Daniel C. Integrating clinical research with the Healthcare Enterprise: from the RE-USE project to the EHR4CR platform. J Biomed Inform. 2011 Dec 44; Suppl 1: S94-102

10. Technology and System Evaluation

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Barriers to Implementing eHealth: A Multi-dimensional Perspective

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Abstract. This paper strives to identify barriers that hamper eHealth implementation from different perspectives. The benefits offered by eHealth and the need for eHealth preparedness is first discussed. This is followed by a discussion on the integral components of a robust eHealth infrastructure. Then, the barriers to eHealth such as technical interoperability issues, lack of holistic approach and technology disconnect are explained in detail. Finally, solutions to promote better adoption of eHealth through government policies, standardisation and training are also discussed.

Keywords. eHealth, implementation barrier, technical interoperability, eHealth preparedness

Introduction

eHealth refers to the use of health information systems and communication tools to improve management and delivery of healthcare, by making electronic medical records remotely accessible and facilitating proactive patient participation [1]. eHealth can deliver healthcare to geographically remote locations, by facilitating remote access to critical medical data. eHealth has the potential to reduce overall costs by eliminating redundancy of diagnostic testing, travel expenses accumulated by rural patients travelling to urban hospitals, and reducing emergency cases by promoting regular check-ups [2]. eHealth, once adopted on a large scale, will also accumulate useful data for medical research and contribute towards financial planning for healthcare. *Thus, eHealth aims to help patients, physicians, hospitals and governments* optimally utilis*e the healthcare system.*

In developed countries, healthcare costs are increasing and making healthcare unaffordable. More than forty million people in the USA are uninsured and cannot afford medical treatment [3]. Even in countries where universal healthcare is in place, fiscal pressure has called for changes to make healthcare more efficient [2]. An efficient healthcare system would reduce patient exclusion based on social inequalities, by increasing stakeholder participation. eHealth would contribute to these objectives as its self-service model would promote stakeholder participation by being more accessible.

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Information technology has been successful in optimising performance and reducing costs in sectors such as banking and engineering [4]. Implementation of health information systems improves organisational efficiency by optimising business processes and improving decision making by generation of accurate and reliable data. Furthermore, various studies have found that eHealth systems have enhanced treatment outcomes, reduced clinical visits and increased hospital efficiencies [5-7]. Hospitals that maintain electronic health records have also been successful in reducing medical error rates [8-9].

eHealth not only holds a lot of potential to relieve the overburdened healthcare system, but can also contribute to health-related behaviour modification and long-term management of chronic illnesses [10]. It can make healthcare accessible to populations that previously did not have financial means or geographical access to modern medicine. Implementation of eHealth will require a dedicated information system tailor-made for the medical field, due to increased privacy concerns surrounding medical data, time-critical nature of treatment and varying skill levels of stakeholders. Thus, an electronic health information system needs to integrate the following:

a) *Comprehensive planning, regulatory, and legislative framework* to identify resources necessary to operate a fully-functional, medical information system.
b) *Indicators* to represent targets such as inputs, outcomes, and health status in health information systems, which is critical to develop a strategy [11].
c) *Data sources* such as health records based on census and surveys; institution-based data recorded by medical organisations such as patient records.
d) *Data management* framework to securely handle the data storage, sources, analysis, flow, and quality assurance.
e) *Information processing tool* to transform raw data into information that will influence evidence-based decision making.
f) *Information dissemination* to enable health-related information to be easily available and accessible to decision makers, facilitators and other stakeholders.

The implementation of eHealth faces several barriers such as aversion to change, legal complications, privacy concerns, technology disconnect, security issues and technical barriers [12]. As proper implementation of eHealth can deliver affordable yet better quality healthcare, it is critical to address these issues. As eHealth is a relatively nascent field, implementation issues are expected like any newly surfacing technology[12]. This study seeks to understand such implementation issues in eHealth.

1. Methods

A literature review was conducted by analysing peer-reviewed journal articles published in academic journals in the period 2000-2014. ***Google Scholar*** was used for this research, as it is capable of finding relevant articles published in various journals. Keywords such as ‘eHealth’, ‘eHealth implementation barriers’ and ‘eHealth technical issues’ were used to identify relevant articles. Out of hundreds of search results, thirteen full text publications were selected for further analysis based on keyword relevance; another eleven resources were used to gather background information.

2. Barriers in implementing eHealth

eHealth can improve quality of healthcare, reduce medical errors, and lower healthcare costs [13-14]. This section discusses barriers that affect smooth implementation of eHealth.

2.1. Technical interoperability

Technical interoperability is a critical issue, as older electronic medical record systems were not designed to work in a network environment [15]. Software developers have not found an affordable way to bridge these technological gaps [16]. Moreover, regulations pertaining to health information systems are stringent, due to the sensitive nature of medical data [17]. Data in a medical information system comes different sources including administrative data, health statistics and medical records. As data from different streams will have to be correlated, analysed and processed to generate relevant reports, the data will have to be standardised to make it relevant and useable. Following are the issues involved in integrating various data sources in a single system:

Administrative data: This includes data generated by patient interaction with healthcare facilities such as hospitals and pharmacies [18]. This data is used by administrators and policymakers to track resource utilisation, treatment outcomes and cost. To integrate this data into an eHealth system, the data will have to contain a consistent set of identifiers. By having standardised identifiers, the data can be utilised in different activities such as reimbursement, policy making and developing strategy.

Clinical Data: This includes data generated from patient medical records maintained by hospitals, which includes medical history and diagnostic test results [19]. Clinical data is used to determine procedure appropriateness, clinical outcomes and assess quality of care. As different medical cases have varying degrees of diagnosis validity, reliability and procedure codes, it is practically complex to categorise all relevant cases within a particular diagnosis code. While categorising responses to a certain treatment, diagnosis codes may not be able to indicate the broad range of disease severity or exact response to the illness treatment [20].

Enrolment data: Enrolment data, generated by hospitals, is used by health insurance providers or governments to determine eligibility criteria and coverage costs[12]. Enrolment data can also help determine the rate at which diseases occur and are treated, thereby determining performance of healthcare plans and organisations.

2.2. Lack of Holistic Approach

While designing and implementing a health information system, developers and stakeholders need to pursue a holistic approach. The data stored and generated by an eHealth system will be used by stakeholders from various health-allied sectors such as insurance and pharmaceuticals. As most of these health-allied sectors lack systemic thinking and shared visions, they operate in isolation and thus the delivery of their services is not standardised. Lack of standardisation among hospitals also makes it harder to develop a uniform health information system that can standardise treatments, medical processes and operations. As the cost benefits of eHealth have not been fully

understood by senior management in the healthcare industry, it has led to inadequate resource allocation for designing and implementing a health information system [20].

2.3. Technology Disconnect

Recent developments in medicine have led to rapid changes in diagnostic tests, treatments and medications. So, developers of health information systems have to develop a system that would evolve dynamically with such changes, which complicates the design process. During the design and implementation of an eHealth system, the potential users and other stakeholders should be involved in defining system functional requirements and testing the system. However, as medical staff and physicians are overworked, they lack time and motivation to get involved in the eHealth software development process [21]. Furthermore, failure to effectively communicate the potential benefits of eHealth is also a reason for lack of motivation [22]. Thus, developers find it hard to understand exact functional requirements of eHealth, which reduces efficiency of system [21].

3. Overcoming implementation barriers

Different countries have varying internet adoption rates, healthcare budgets and healthcare policies. Thus, every country will have to analyse its macro-level issues, unique strengths and limitations to develop country-specific strategies [23]. However, having a framework to assess a country's eHealth preparedness is a common necessity [24]. Governments, hospitals and developers will have to implement various initiatives and incentives to overcome the aforementioned barriers. Failure to follow a gradual approach may affect every day functioning, which is unacceptable.

Hospitals have to implement standard operating procedures in their day-to-day operations, which will simplify computerisation of medical data. Non-profit organisations and academic research institutions should work with hospitals to certify eHealth applications, to ensure that they securely and efficiently manage medical data. Governments that have difficulty enforcing eHealth will have to weed out legal hassles, which will inspire confidence among physicians as well as consumers. Hospital support staff has to be trained to use eHealth applications and also assist physicians in eHealth adoption.

4. Conclusion

Various aspects of eHealth were briefly discussed to understand the significance of successful eHealth implementation. It was found that technical interoperability factors like data incompatibility are one of the most important barriers to eHealth implementation. Furthermore, it was found that the failure of governments and hospital managements to adopt a holistic approach, coupled with lack of technology awareness makes eHealth implementation even more complicated. Various solutions to improve interaction between physicians, support staff and software developers were discussed to overcome implementation barriers pertaining to technology disconnect. The importance

of training and standardisation of hospital procedures were also found to be critical to improve eHealth implementation.

References

[1] Detmer D, Bloomrosen M, Raymond B, Tang P. Integrated personal health records: transformative tools for consumer-centric care. BMC Med Inform Decis Mak. 2008; 8(1):45.
[2] Alvarez RC. The promise of e-health: a Canadian perspective. eHealth Int. 2002; 1(1):4.
[3] Garson A. The US Healthcare System: problems, principles and potential solutions. Circulation 2010; 101(16):2015-2016.
[4] Kramer WJ, Jenkins B, Katz RS. The Role of the Information and Communications Technology Sector in Expanding Economic Opportunity. MA: Harvard University; 2007.
[5] Pollak VE, Lorch JA. Effect of electronic patient record use on mortality in end stage renal disease, a model chronic disease: retrospective analysis of nine years of prospectively collected data. BMC Med Inform Decis Mak. 2007; 7(1): 38.
[6] Garrido T, Jamieson L, Zhou Y, Wiesenthal A, Liang L. Effect of electronic health records in ambulatory care: retrospective, serial, cross sectional study. BMJ. 2005; 330(7491):581.
[7] Wang SJ, Middleton B, Prosser LA, Bardon CG, Spurr CD, Carchidi PJ. A cost-benefit analysis of electronic medical records in primary care. Am J Med. 2003; 114(5):397-403.
[8] Koppel R, Metlay JP, Cohen A, Abaluck B, Localio AR, Kimmel SE. Role of computerized physician order entry systems in facilitating medication errors. Jama. 2005; 293(10):1197-1203.
[9] Blaya JA, Fraser HS, Holt B. E-health technologies show promise in developing countries. Health Affairs 2010; 29(2).
[10] Ghatak A, Hazlewood JG, Lee TM. How private health care can help Africa. The McKinsey Quarterly 2008.
[11] National eHealth Collaborative Initiative [Internet]. Challenges and Barriers to Successful HIE Implementation. Available from http://www.nationalehealth.org/challenges-and-barriers-successful-hie-implementation
[12] Wickramasinghe N, Schaffer JL. Realizing value driven e-health solutions. US: IBM Center for the Business of Government; 2010.
[13] Lang M, Melia A. The Implementation of Electronic Healthcare Records within the Irish Health Service: An Analysis of User Attitudes. Paper presented at the Irish Social Science Platform Annual Conference; 2009; Galway: Ireland.
[14] Vesely A, Zvarova J, Peleska J, Buchtela D, Anger Z. Medical guidelines presentation and comparing with Electronic Health Record. Int J Med Inform. 2006; 75(3):240-245.
[15] McGinn CA, Grenier S, Duplantie J, Shaw N, Sicotte C, Mathieu L, Leduc Y, Légaré F, Gagnon MP. Comparison of user groups' perspectives of barriers and facilitators to implementing electronic health records: a systematic review. BMC Medicine. 2011; 9(1):46.
[16] Greenhalgh T, Stramer K, Bratan T, Bryne E, Mohammad Y, Russell J. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory. BMJ. 2008; 337.
[17] Heinonen TA. Risk management system for medical standalone software. Tampere University of Technology; 2011.
[18] McGlynn AE, Damberg LC, Kerr AE, Brook HR. Health Information System: Design Issues and Analytic Applications. Rand Publishers; 2000.
[19] Marshall NM. Dying to know: public release of information about quality of health care. Rand publishers; 2000.
[20] Anderson J. Social, ethical and legal barriers to e-health. Int J Med Inform 2007; 76(5).
[21] Dennis A, Wixom BH, Roth RM. System Analysis and Design. New Jersey: John Wiley & Sons; 2009.
[22] Mair FS, May C, O'Donnell C, Finch T, Sullivan F, Murray E. Factors that promote or inhibit the implementation of e-health systems: an explanatory systematic review, Bull World Health Organ 2012; 90(5):357-364.
[23] Kummervold PE, Chronaki CE, Lausen B, Prokosch HU, Rasmussen J, Santana S, et al. eHealth Trends in Europe 2005-2007: a population-based Survey, J Med Internet Res. 2008; 10(4).
[24] Li J, Seale H, Ray P, Rawlinson W, Lewis L, MacIntyre R. Issues Regarding the Implementation of eHealth: preparing for future influenza pandemics. Interact J Med Res. 2012; 1(2).

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Perceived usefulness of a usability issues reporting form to help understand "usability-induced use-errors": a preliminary study

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Abstract. The Medical Device regulation requires manufacturers to anticipate and prevent risks of use errors of their medical device. However, manufacturers experience difficulties to understand the concept of "usability-induced use-errors". Based on a "usability framework" aiming at describing the relationship between usability design principles, usability flaws, usage problems, and outcomes, a usability evaluation reporting form had been designed to support understanding the use-error concept. This paper reports the preliminary evaluation of the perceived usefulness of this form. Results show that manufacturers found helpful the presentation of the results of a usability evaluation through this form for it supports the understanding of the usability origins and the consequences of use-errors. Even if the use of this reporting form should be made easier as usability experts experience difficulties to fill it, it seems a promising way to clearly present "usability-induced use-errors" to manufacturers.

Keywords. Human engineering; heuristic inspection; usability; pain monitor; use error;

Introduction

Manufacturers are asked by medical devices' (MD) regulatory authorities to anticipate and manage risks of use-errors related to poor design decision made during the design process [1]. Yet, manufacturers experience difficulties to understand what use-errors concretely refer to and how to prevent them. One reason for those difficulties may be found in a misunderstanding of the impact of their design choices on potential use-errors [2].

A use-error is an "act or omission of an act that results in a different medical device response than intended by the manufacturer or expected by the user" [3]. They are part of the "technology-induced errors", i.e. errors induced by the introduction of health information technology [4]. Amongst use-errors, a subset origins in the poor design of the device in terms of usability, namely "usability-induced use-errors".

Providing manufacturers with usability evaluation reporting forms that structure the description of potential use-errors may help them understand use-errors and their

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origin in usability. This paper proposes a preliminary evaluation of the perceived usefulness of such a usability study reporting form. We took the opportunity of a formative heuristic inspection of a medical device to gather perceptions of manufacturers and usability experts' on this form.

1. Background

The reporting form has been developed from a "usability framework" [5] aiming at describing the relationship between usability design principles, usability flaws, usage problems, and outcomes (cf. figure 1).

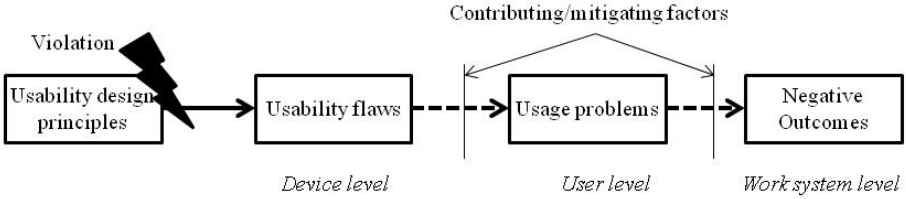


Figure 1. Schematic representation of the origin of usability flaws and of the propagation of their consequences towards the user and the work system in which it is implemented (adapted from [5])

Usability design principles (also usability heuristics/criteria) are recommendations for good practice in usability (e.g. [6]). When those principles are not applied during the design of a product, usability flaws appear. Those flaws are noticed from the device perspective. When the device is put in use, flaws may negatively impact users' experience. Those negative experiences are usage problems. Finally, usability flaws may also have consequences on the work system in terms of performance, workarounds and patient-safety (i.e. negative outcomes). The propagation of the infraction of the usability principles up to the work system is rather probabilistic than causal: mitigating factors independent from the device characteristics (e.g. high training, regular workload or adapted resilience) may prevent this propagation; au contraire, contributing factors (e.g. lack of training or high workload) may facilitate this propagation. In the framework, "usability-induced use-errors" are a specific type of usage problems which consequences are noticeable at the outcomes level.

2. Study context

NIPE® is a comfort monitor displaying graphically the result of an algorithmic transformation of the cardiac frequency retrieved from patient's monitoring [7]. It supports monitoring the well-being of newborns especially for babies born with delivery complications and preterm/ill babies. Usability experts have been solicited to ensure the device be compliant with usability requirements, i.e. safety use, to go to CE marking. Their intervention included applying the usability engineering process. The results of the present study were recorded during the first formative evaluation of this prototype through a heuristic evaluation.

3. Methods

3.1. Heuristic evaluation

Three usability experts independently performed a heuristic inspection of the NIPE® using Scapin and Bastien's list of usability principles [6]. They followed frequent and reasonably foreseeable worst use case scenarios based on the analysis of the intended context of use analysis (details in [8]). To stick to risk management requirements, for each usability flaw, the risk associated to their consequences was estimated (low, medium or high) as a function of their severity and frequency. Two involved experts (RM and CB) already took part in the intended context of use analysis; the third one (NL) read the detailed report of the analysis.

In contrast with usual heuristic inspections, this one was supported by a structured reporting form adapted by RM from the "usability framework" (table 1).

Table 1. Instances of reports of usability flaws through the proposed reporting form.

Usability principle	Violation (usability flaw)	Potential usage problem	Potential outcome	Probability x Severity = Risk
Significance of codes	There is no information about the meaning of the curve and the smiley (Figure 2, right)	Difficult to interpret, wasting time and inability to understand	Decision based on a wrongly understood information	Moderate x Moderate = Medium
Consistency	"Instantaneous" NIPE® index corresponds to the "averaged index" curve not to the "instantaneous index" one (Figure 2, left)	Inability to understand, wrong representation of the patient status, doubt about the reliability of the device decreasing confidence	Decision based on a wrongly understood information	Moderate x Minimal = Low

3.2. Perceived usefulness evaluation

Data on perceived usefulness of the reporting form has been recorded opportunistically via handwritten notes by RM. They were collected from four representatives of the manufacturers (chief executive, designer, engineer and quality control officer). To see the benefice-risk ratio of the structured reporting form, it was necessary to evaluate its perceived usefulness but also if difficulties were encountered filling it in. Therefore, comments from two usability experts (CB & NL) were also collected to get their perception on filling in the form.

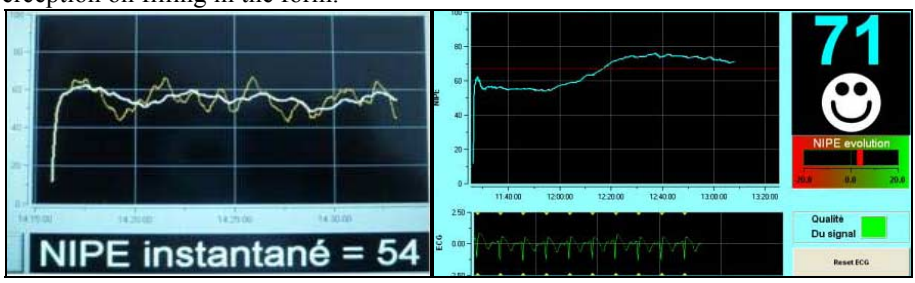


Figure 2. Screenshots of the "instantaneous" NIPE® screen (left) and of the main NIPE® screen (right)

Recorded comments were classified by RM as advantages and drawbacks either for filling in the form or for interpreting its content.

4. Results

A total of 46 usability flaws are uncovered. A huge majority (40) are assigned with a low risk: they mostly deal with non prompting icons and graphical elements along with the handling of the setting features. Six usability flaws are considered with a medium risk: they are related to the difficulty to interpret the NIPE index. For instance, there is a potential risk of use-error (usage problem) related to the misinterpretation of the valence of the NIPE index which could lead to a wrongly based therapeutic decision.

As for the perception of the usefulness of the reporting form, users' main comments are synthesized in Table 2. Manufacturers' representatives consider this way to present the results is useful to understand the origins and consequences of use-errors. As for usability experts, they think it can be useful to help readers to understand the origin of the use-errors because it presents more clearly and in a more structured way the results of the inspection. However, they reported also difficulties to fill in the form, e.g. it is sometimes difficult to anticipate the usage problems and outcomes. Nonetheless, they think this form could improve the consistency of their reports. In sum, whatever the profile of the user, no perceived drawback was reported about interpreting usability results through the form.

Concerning the filling in of the report, an important insight is that the usability expert who did not analyze the context of use (NL) was unable to anticipate potential usage problems and outcomes along with their related risks.

Table 2. Synthesis of the main comments from manufacturers' representatives and usability experts on the usefulness of the reporting form. Comments are sorted as perceived advantages or drawbacks and according to the potential function of the reporting form (support to report vs. support to interpretation).

		Usability experts	Manufacturers' representatives
Data reporting	Advantages	Compels to have the mind clear about the description of the usability flaw, the potential usage problems and outcomes.	Non applicable
	Drawbacks	Difficult to make easy-to-distinguish descriptions of usage problems and outcomes (hard "exercise in style"). Difficult to anticipate some usage problems/outcomes along with the risk level even more when the expert did not perform the context of use analysis. Not obvious whether the estimated risk is related to usage problem, outcome or both. It makes harder its estimation.	Non applicable
Data interpretation	Advantages	More precise description of the usability flaws: straight to the point. Clarify the consequences of the usability problems. Outcomes related to patient safety risks are clearly identifiable.	It is important distinguishing how the usability flaws can affect the users from the use-errors they can induced. Faster identification of the origins of potential use-errors.
	Drawbacks	/	/

5. Discussion

This paper presents a first attempt to clarify the concept of "usability-induced use-errors" during usability evaluation by turning a "usability framework" into a reporting form. This preliminary study focuses on the perceived usefulness of this form. Overall,

manufacturers and usability experts consider this form can be useful to understand "usability-induced use-errors"; however, usability experts reported difficulties to fill in it. Those difficulties could be fixed by explaining more clearly how to evaluate the severity of the consequences of a usability flaw. In sum, basing the usability evaluation reporting form on a framework linking usability principles, usability flaws, usage problems and negatives outcomes seems a promising way to help manufacturers understand "usability-induced use-errors". Another important result that could have been expected is the impossibility for a usability expert to anticipate usability flaws' consequences without having performed first an analysis of the intended context of use.

There is an increasing need for standardized descriptions of usability flaws related to use-errors [9] (a) to capitalize on them and build databases allowing comparisons across systems and (b) to use those databases to design in an informed way similar medical devices. Yet, databases of structured descriptions of "usability-induced use-errors" are currently often confidential or hardly accessible. Reporting forms can structure them: e.g. Peute *et al.* [10] developed an efficient scheme to capitalize unambiguously usability facts; however, this scheme is research-oriented and not adapted to manufacturers' needs. An important added-value of the present reporting form is that, besides providing a detailed report of potential use-errors, their underlying usability causes and their potential impact, manufacturers understand it.

References

[1] European Parliament and Council. Council Directive 2007/47/EC (2007), Official Journal L247/21.
[2] S Pelayo, S Bras Da Costa, N Leroy, S Loiseau, MC Beuscart-Zephir. Software as a medical device: regulatory critical issues. *Stud Health Technol Inform* **183** (2013), 337-42.
[3] International Electrotechnical Commission. *Medical Devices - Application of usability engineering to medical devices (Rep. No. ISO 62366)*. International Electrotechnical Commission, Geneva, 2008.
[4] AW Kushniruk, MM Triola, EM Borycki, B Stein, JL Kannry. Technology induced error and usability: the relationship between usability problems and prescription errors when using a handheld application. *Int J Med Inform* **74** (2005), 519-26.
[5] R Marcilly, MC Beuscart-Zephir, E Ammenwerth, S Pelayo. Seeking evidence to support usability principles for medication-related clinical decision support (CDS) functions. *Stud Health Technol Inform* **192** (2013), 427-31.
[6] DL Scapin, JMC Bastien. Ergonomic criteria for evaluating the ergonomic quality of interactive systems. *Behaviour and Information Technology* **6** (1997), 220-31.
[7] J De Jonckheere, D Rommel, J Nandrino, M Jeanne, R Logier. Heart rate variability analysis as an index of emotion regulation processes: Interest of the Analgesia Nociception Index (ANI). *Conf Proc IEEE Eng Med Biol Soc* (2012), 3432-5.
[8] R Marcilly, S Bras Da Costa, C Boog, MC Beuscart-Zephir, J De Jonckheere, S Pelayo. Impact of the context of use analysis for the extension of an existing medical device: an analgesia monitor case study. *Stud Health Technol Inform* **194** (2013), 139-44.
[9] LW Peute, KF Driest, R Marcilly, S Bras Da Costa, MC Beuscart-Zephir, MW Jaspers. A framework for reporting on human factor/usability studies of health information technologies. *Stud Health Technol Inform* **194** (2013), 54-60.
[10] LW Peute, R Khajouei, A Hassman, MW Jaspers. Classification and priorization of usability problems using an augmented classification scheme. *J Biomed Inform* **44** (2011), 948-57.

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Methods uncovering usability issues in medication-related alerting functions: results from a systematic review

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Abstract. This paper aims at listing the methods used to evaluate the usability of medication-related alerting functions and at knowing what type of usability issues those methods allow to detect. A sub-analysis of data from this systematic review has been performed. Methods applied in the included papers were collected. Then, included papers were sorted in four types of evaluation: "expert evaluation", "user-testing/simulation", "on site observation" and "impact studies". The types of usability issues (usability flaws, usage problems and negative outcomes) uncovered by those evaluations were analyzed. Results show that a large set of methods are used. The largest proportion of papers uses "on site observation" evaluation. This is the only evaluation type for which every kind of usability flaws, usage problems and outcomes are detected. It is somehow surprising that, in a usability systematic review, most of the papers included use a method that is not often presented as a usability method. Results are discussed about the opportunity to provide usability information collected after the implementation of the technology during their design process, *i.e.* before their implementation.

Keywords. Human engineering; usability; systematic review; decision support, clinical; method

Introduction

Usability studies are now mandatory to ensure an optimal and secure use of health technologies [1]. Usability is "the extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specific context of use" [2]. It deals with the features of the graphical user interface along with the fitting between the system behavior and its users' needs. Numerous usability methods are listed in books, standards and papers (e.g. [2;3]). Yet, each method applies at a different step of the product lifecycle [2] and they do not allow uncover the same kinds of usability issues [4]. Moreover, as far as we know, for health

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technologies, there is no precise inventory of the methods used and of the usability issues they allow to retrieve.

Medication-related alerting functions are health technologies for which usability issues are recurrently highlighted (e.g. [5]). We performed a systematic review identifying clear facts about the types of usability flaws reported for this technology [6;7]. Usability flaws are concrete descriptions of the characteristics of the system that do not match usability design principles. When the system is put in use, usability flaws may cause usage problems, *i.e.* bothering of and even impairing user's experience with the technology. Finally, they may also generate negative outcomes in the work system, including patient safety issues. Results from this systematic review are presented in [6]. The present paper deals with original data and results not published elsewhere. It reports a sub-analysis aiming at answering the following questions: "what are the methods used that detect facts on usability flaws in medication-related alerting systems? What type of usability issues those methods allow to detect?"

1. Method

This review targeted original evaluation studies of medication-related alerting functions supporting the management of e-prescription by physicians, pharmacists and nurses and used in general hospital or in primary care general practice. Papers were searched in references databases (PubMed, Scopus and Ergonomics Abstract; last update on June 2013) and this search was completed by searching references lists of included papers. To be included, papers must report facts (not hypotheses) on usability flaws identified voluntarily or incidentally and the method used must be sufficiently well-described. Papers reporting evaluation of the perceived usability (e.g. through questionnaires) were excluded. For each paper included in the analysis process, two authors (RM, MCBZ) extracted together the used methods and the uncovered usability flaws, usage problems and negative outcomes. Usability flaws were categorized by both reviewers using first an existing usability heuristics [8] and then developing sub-categories through an inductive process.

The same experts used an extraction grid to list all methods used in the included papers. Then, based on the methods applied and on their aim, papers were sorted by both reviewers independently in four categories:

- "Expert evaluations": usability audits performed in-lab by several experts and involving any actual user
- "User-testing/simulation": observation of intended users using the technology following usage scenarios and while thinking-aloud in lab
- "On site observation": observation of the actual usage of the technology by actual users in the work system
- "Impact analyses": retrospective analyses of the results of the activities with the system or of the experience of actual users

While "expert evaluation" and "user-testing/simulation" are used during the design process of the product, "on-site observations" and "impact studies" are per se related to the evaluation of the product once implemented in a work system, e.g. in "post market surveillance".

Then, for each kind of evaluation, the number of papers reporting usability flaws, usage problems and negative outcomes was counted. For usability flaws, results were sorted according to their category.

2. Results

Out of the 6380 papers identified, a total of 26 papers matched the inclusion criteria and were analyzed in detail. Included papers propose a great variety of types of methods (cf. Table 1). The agreement score between both experts on the categorization of the papers aaccording to the type of evaluation is almost perfect good (Cohen's κ = 0.94). The only disagreement was solved during a meeting. "Expert evaluation" is reported in 4 papers, "user-testing/simulation" in 6, "on site observation" in 11, and "impact studies" in 7. One paper reports both "expert evaluation" and "user-testing/simulation" and another "user-testing/simulation" and "on-site observation".

Table 1. Number of papers for the four types of evaluation. Sum is over 26 because two papers use two types of evaluation (one both "expert evaluation" and "user-testing/simulation" evaluations and the other both "on site observation" and "user-testing/simulation").

Type of evaluation	Instance of typical methods applied	Number of papers
"Expert evaluation"	Cognitive walkthrough, heuristic inspection	4
"User-testing/simulation"	User-testing, simulation	6
"On site observation"	Observation of the actual use (shadowing)	11
"Impact studies"	Focus groups/interviews on the usage of implemented systems, retrospective analysis with expert review	7

Both papers that used two types of evaluations did not allow distinguishing unambiguously the type of usability issues uncovered by each type of evaluation. Therefore, they were not included in the subsequent analysis. Table 2 presents the number of papers reporting usability flaws, usage problems and negative outcomes according to the type of evaluation used.

Table 2. Number of papers reporting usability flaws, usage problems and negative outcomes according to the type of evaluation. Additionally, usability flaws are sorted according to their category.

Usability issues			"Expert evaluations"	"User-testing"	"On site observations"	"Impact studies"
Usability flaws	General	Guidance	1	3	1	4
		Workload	1	3	6	3
		Significance of codes	0	2	1	2
		Consistency	1	0	1	0
		Explicit control	0	0	2	0
		Adaptability	0	0	1	0
		Error management	0	0	1	0
	Specific	Low signal-to-noise ratio	0	2	9	5
		Alert content	1	2	4	1
		Transparency	2	0	5	2
		Alert appearance	1	0	5	2
		Tasks and control distribution	0	1	3	2
		Alert features	1	1	3	0
Usage problems			0	4	10	5
Negative outcomes			0	3	7	4

Only papers using "on site observations" report every category of usability flaws along with usage problems and outcomes. This exhaustive coverage is mainly due to one paper [9] that used on-line appendices to provide the complete list of uncovered usability flaws. Without this paper, adaptability and error management categories of flaws would not have been represented. "Impact studies" report 3 out of 7 general

categories of flaws and all but one category of specific flaws. They report also both usage problems and outcomes. As for "user-testing/simulations", they report all categories of specific flaws along with usage problems and outcomes but only 3 out of 7 categories of general flaws. Finally, "expert evaluations" report 3 out of 7 categories of general flaws and 4 out of 6 categories of specific flaws; this type of evaluation does not report any usage problem or outcome.

3. Discussion

This paper aimed at answering two questions: "what are the methods used that detect facts on usability flaws in medication-related alerting systems? What type of usability issues those methods allow to detect?" Results show that a wide range of methods is applied (from heuristics inspection to shadowing). Once the methods categorized in four types of evaluations, results confirmed that those types do not report similar usability flaws, as it has already been noticed in the literature for other types of technologies (e.g. [4]), and that not all of them report usage problems and outcomes.

Since this systematic review focused on usability, it was somehow logical to think that included papers would be usability studies. However, we took as main inclusion criteria for the papers the report of facts on usability flaws and not a specific type of method. Results surprisingly show that usual usability methods such as "expert evaluations" and "user-testing/simulation" do not constitute the larger proportion of the papers included in the review; those evaluations do not provide the best coverage of types of flaws, usage problems and negative outcomes. As expected, "impact studies" provide insight on usage problems and outcomes but do not cover all types of usability flaws. On the contrary, "on site observations", that are not promoted as usual usability evaluation methods, are the most numerous studies included and provide a complete coverage of flaws, usage and outcomes. This type of evaluation allows an evaluation in the context of use after the technology is implemented. The flaws it highlights emerge from the integration into the clinical context; they are not specific to the characteristics of a given context. In sum, the evaluation of the technology while interacting with the work organization, different users' profiles and other technologies uncovers flaws that could have not been detected out of the work system (*i.e.* in-lab).

Even if there may be reporting and publication biases, it is not deniable that "on site observations" provide a valuable insight on the question of the usability of medication-related alerting functions and more generally on health technologies. This result questions the coverage power of usual usability methods used during the design process (*i.e.* "expert evaluation" and "user-testing/simulation"). More specifically, just like other papers do (e.g. [4]) they question the power of detection of "user-testing/simulation" and their coverage in term usability flaws. Currently, the question of the power of "user-testing/simulation" is handled through calculating the optimal size of the sample of participants to observe in order to uncover all significant usability flaws (e.g. [10]). Results from the present study show that the coverage is not only a matter of sampling but also a matter of learning from the actual use of the technology.

Yet, for medical devices such as medication-related alerting functions, it is not allowed to implement a technology that has not been formerly CE marked [1]. Therefore, "on site observations" of the usage of such technologies are not possible.

An approach to bypass this issue is to capitalize the usability facts that have already been reported in the literature to elaborate a kind of "usability checklist". This

checklist should be supported by empiric evidence: it must rest on reliable and exhaustive databases of usability facts reported (usability flaws and related usage problems and negative outcomes). For this purpose, it is necessary that all usability facts be precisely reported in on-line appendices of published papers [11]. Ultimately, such a grid specific to a given technology (e.g. alerting functions or infusion pumps) could be used during the design process of this technology, before it be CE marked and used in a work system. It would allow providing Human Factors experts and designers during the design process with the usability knowledge coming from the actual usage of similar systems. Therefore, it would be possible to anticipate issues that are uncovered generally only after the implementation of the system. This type of tool would increase the power of pre-implementation usability evaluations.

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References

[1] European Parliament and Council. Council Directive 2007/47/EC (2007), Official Journal L247/21.
[2] International Standardization Organization. Ergonomics of human-system interaction -- Usability methods supporting human-centred design (ISO/TR 16982:2002). Geneva, International Standardization Organization, 2002.
[3] MC Beuscart-Zephir, P Elkin, S Pelayo, R Beuscart. The human factors engineering approach to biomedical informatics projects: state of the art, results, benefits and challenges. Yearb Med Inform (2007): 109-27.
[4] MW Jaspers. A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. Int J Med Inform 78 (2009): 340-53.
[5] JS Ash, DF Sittig, EM Campbell, KP Guappone, RH Dykstra. Some unintended consequences of clinical decision support systems. AMIA Annu Symp Proc (2007): 26-30.
[6] R Marcilly, E Ammenwerth, F Vasseur, E Roehrer, MC Beuscart-Zephir. Usability flaws of medication-related alerting functions: a systematic review. Int J Med Inform. Submitted.
[7] R Marcilly, MC Beuscart-Zephir, E Ammenwerth, S Pelayo. Seeking evidence to support usability principles for medication-related clinical decision support (CDS) functions. Stud Health Technol Inform 192 (2013), 427-31.
[8] DL Scapin, JMC Bastien. Ergonomic criteria for evaluating the ergonomic quality of interactive systems. Behaviour and Information Technology 6 (1997), 220-31.
[9] AL Russ, AJ Zillich, MS McManus, BN Doebbeling, JJ Saleem. Prescribers' interactions with medication alerts at the point of prescribing: A multi-method, in situ investigation of the human-computer interaction. Int J Med Inform 81 (2012), 232-43.
[10] M Schmettow, W Vos, JM Schraagen. With how many users should you test a medical infusion pump? Sampling strategies for usability tests on high-risk systems. Journal of biomedical informatics 46 (2013), 626-41.
[11] LW Peute, KF Driest, R Marcilly, S Bras Da Costa, MC Beuscart-Zephir, MW Jaspers. A framework for reporting on human factor/usability studies of health information technologies. Stud Health Technol Inform 194 (2013), 54-60.

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Designing and Conducting Low-Cost In-Situ Clinical Simulations: A Methodological Approach

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Abstract. The need to develop more effective and usable systems in healthcare has led to increasing adoption of usability engineering methods. Primary among these methods has been usability testing, which involves observing representative users while they carry out representative tasks using health information systems. However, such testing may not capture the cognitive and social contexts of use of systems in real settings, necessitating the use of clinical simulations. Such simulations involve testing representative users carrying out representative tasks, systems in realistic and representative environments. In this paper we describe our work in both reducing the cost of simulation testing while at the same time increasing the fidelity of the simulations. We describe an approach which involves conducting simulations within real work environments and contexts as a way to achieve a high level of ecological validity. The stages involved in setting up such low-cost in-situ clinical simulations are detailed in this paper.

Keywords: Clinical simulations; usability testing; system evaluation

Introduction

It has become increasingly clear that the usability of health information systems is a major issue and that usability engineering methods need to be applied widely in the design, implementation and evaluation of health information systems. Usability testing typically involves observing representative users (e.g. health professionals) while they interact with an information system under study (e.g. a medication administration system) to carry out representative tasks using the system (e.g. medication order entry) [1]. While recommendations based on usability testing have led to improvements in the usability of many health information systems, there are still many reports of systems being released that are not usable, do not match user information needs and that do not fit into the complex workflows of healthcare situations in which they are deployed [2]. In this paper we describe an approach that extends usability testing to clinical simulations, whereby testing not only involves representative users doing representative tasks, but also involves testing systems in representative contexts and settings typical of real-world use of the technology. In the past, simulation testing has typically involved testing systems in fixed simulation laboratories that attempt to capture the environment of real use [3]. In this paper we describe our work towards extending the fidelity of such clinical simulations further by taking such simulations

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into the actual real settings of use – i.e. by conducting the clinical simulations "in-situ" in real hospital and clinical settings using portable recording methods and approaches.

1. Background: Clinical Simulations

In order to increase the ecological validity of studies that focus on evaluating the impact of health information systems, in recent years traditional usability testing methods have been augmented by studies that more closely match real-life conditions of system use in healthcare. Among these methods are clinical simulations, where the fidelity of user interactions during testing approximates real-life situations [4-5]. This has typically involved conducting user studies in simulation laboratories which include one-way mirrors and observation rooms, where users are studied while they carry out tasks. An alternative approach has involved conducting the simulations in the actual hospital and healthcare environments where the systems will be ultimately deployed [5]. This approach argues for testing systems "in-situ" rather than testing in a site that may not be representative of the actual system use. The in-situ approach does require access to real healthcare settings, for example, access to hospital rooms or operating rooms after hours for testing, but has a number of distinct advantages. For one, the cost of setting up a simulation environment is reduced, as an "artificial" fixed laboratory environment does not need to be developed. Secondly, the fidelity of the simulation is higher when studies are conducted in a real environment. Thirdly, testing of information systems in the real setting allows for trying out systems with all interfacing technologies that would be available once the system is released there (e.g. data monitoring devices, bar-coding etc.). In addition, for some studies involving patients, it may be difficult to bring them to a fixed usability or simulation laboratory, so bringing the testing to the patients is more feasible.

2. Methodological Approach

An approach to carrying out in-situ clinical simulations is described in this section of the paper. The steps involved are based on a range of studies we have conducted and although there may be variation in the exact steps, the overall approach typically involves consideration of each of the below steps.

Step 1. Development of Test Plan: This step involves identification of the overall objectives of the evaluation, including the need for conducting the testing as a clinical simulation and the degree of fidelity (i.e. realism) required in the simulation.

Step 2. Selection of Representative Users: In this step the main characteristics of representative users (e.g. physicians or nurses etc.) of the system are identified. In the case of simulations, this typically involves not only selection of individual users, but selection of the group or team of users that will use the system to collaborate and therefore may need to be represented.

Step 3. Selection of Representative Tasks: Similar to usability testing, a set of representative tasks need to be identified that will drive the clinical simulations. However, unlike usability testing which might focus on individual tasks, for clinical simulations of real life clinical situations, tasks may focus on the

individual but they may also include tasks involving the interaction among multiple individuals (of differing types of backgrounds) working collaboratively.

Step 4. Selection of Representative In-Situ Testing Environments: This step clearly differentiates in-situ clinical simulations from usability testing as real settings and environments must be identified. Furthermore, unlike fixed laboratory simulations (which take place in a centralized simulation facility) setting up in-situ clinical simulations typically involves discussing contexts of real system use with collaborators at sites where the system will actually be deployed. In these discussions, issues related to selecting particular recording technologies and constraints such as physical space as well as specific local ethics review board requirements need to be considered. This may also require permission and support from the institution's IT staff as screen recording software may need to be deployed on the computers in a clinic where the simulation will take place, and arrangements may also need to be made for having ceiling mounted cameras put into place to record group activity during the simulation. From our experience this has typically involved one or more members of our team traveling to potential test locations and settings. Here, the team member works with local collaborators to set up a testing environment prior to data collection. This may involve setting up testing in environments like clinics in partitioned off areas or side rooms, or even in operating rooms, for conducting simulations during off hours.

Step 5. Carrying out the Clinical Simulations: The actual procedure for carrying out the simulations will depend on the constraints imposed by conducting studies in real settings (e.g. physical space, ethics requirements etc.). For example, in some settings full access to an electronic health record system and all accompanying technologies (e.g. bar coding, medication administration systems etc.) may be available for testing in the live setting. In this case the realism of the simulations involving the electronic health record can be maximized and the scenarios tested can test not only the system under study but how well it integrates with other technologies in the live setting. In other cases, the testing may be restricted to having subjects interact with a training version of an electronic health record in isolation.

Step 6. Analysis of Data: The analysis of data from clinical simulations conducted in-situ is typically similar to the analysis of video and audio that results from usability testing and is reported elsewhere [5,6]. However, the ability to test health information systems in real settings and under more realistic conditions typically leads to a richer data stream, including potentially recording screens from multiple computers, along with audio and video recording of interactions in a room setting. The analysis and coding of this data may be facilitated by using a number of computer-supported video coding tools (see [6]).

Step 7. Input into Re-design and Customization: The ultimate objective of conducting in-situ clinical simulations is to obtain detailed feedback that can be used to improve the selection, design or customization of health information systems. The results from step 6 data analysis should be summarized and presented to the relevant implementation and management teams (e.g. summary of types and frequency of coded usability or workflow problems and issues encountered under different contexts of use).

3. Experiences to Date

Our initial work in conducting clinical simulations in-situ involved a project where a medication administration system was to be tested in real clinical settings in a hospital in Japan [6]. The researchers from Canada initially planned to travel to the hospital to set up the study, but due to travel constraints, the instructions for selecting a representative hospital room and system set up were emailed to a team of collaborators at the hospital site in Japan. The recording equipment including installing Hypercam ® screen recording software on computers running the new medication administration software in a typical hospital room. In addition, the researchers in Canada worked collaboratively with their Japanese colleagues to create a list of medication entry tasks to be tried out during the simulations. In addition, to add to the realism of the simulation, a mannequin patient (with a bar coded identification bracelet) was set up in the room, so that time to do tasks such as setting up intravenous medication bags could be monitored in addition to recording interactions with the system itself. Eleven doctors and five nurses participated in the study at the Japanese site and were video recorded (computer screens as well as a recording of physical activities in the room using a camcorder on a tripod) as they carried out the medication administration tasks. After the simulations were completed participants (i.e. nurses and doctors) were interviewed about their experience using the system. The data (recordings stored on a secure hard drive) were couriered to the Canadian researchers who identified key issues from the recordings and made recommendations to the system implementation team in Japan. The recommendations included the need for implementing an emergency override function when urgency did not permit users of the system to complete the tasks.

In a recent study involving collaboration with the authors and a large American health institute, we employed the methodological approach described in this paper to test the deployment of a set of clinical guidelines [7]. These guidelines were designed to be triggered from within a major commercially available electronic health record system deployed in the New York hospital site. To assess the requirements for conducting in-situ simulation testing the first author of this paper initially travelled to the physical site in New York and worked with staff there to locate office and clinical settings where video recordings would be made. This also included working with the local IT staff at the healthcare organization to set up screen recording software on local computers. The initial simulation tasks involved having eight physician participants follow scripts that forced them through key functions of the system in order to detect basic usability problems. In a second round of simulation testing, the impact of the system on workflow was simulated by introducing a "digital patient", which consisted of a recording of a patient. This allowed the researchers to observe participants' (eight physicians) interaction with the system where they drove the interaction and where the guidelines were triggered by the participants' interactions (rather than by a fixed script). Finally, in a third condition, the recording approach was extended beyond clinical simulations to recording live interactions of physicians with the clinical guidelines (where the screen recording was triggered when guidelines were invoked). The transcripts of the audio and video from this in-situ data collection were transcribed and coded to identify ways in which the implementation of the guidelines could be optimized. This data analysis was conducted collaboratively and from a distance using skype® to share coding documentation and support collaboration between the Canadian and American researchers. From this work it was found that addressing a number of simple usability issues (such as making messages on alerts clearer and using

local medical terminology in the alerts) greatly increased the uptake of the guidelines in subsequent clinical trials. In addition, the in-situ simulation allowed for identifying issues in the local workflow involved in using the guidelines. In particular it was found some guidelines did not trigger when expected and others were automatically invoked too early or late to affect decision making. In terms of the cost-effectiveness of the approach, from this type of experience the cost of conducting such studies is reduced as compared to testing in a fixed laboratory, but the approach does typically include costs for initial travel of the investigators to the site to set up the recordings. The cost of recordings is reduced as free software can be used for that purpose, and analysis cost has been reduced by using free coding software and well-developed coding tools.

4. Discussion

To improve usability of healthcare information systems there is a need for both centralized usability testing of systems and localized testing. Centralized conformance testing and evaluation of systems is important. There is also a move towards greater application of usability engineering methods involving fixed laboratories where systems can be tested using traditional usability engineering approaches (i.e. usability testing) as well as testing involving more realistic clinical simulations. Although this is important, ensuring a system conforms to usability requirements at a centralized facility does not guarantee that when the system is released to a specific institution that the system will indeed be usable or safe. In this paper we have argued for greater use of in-situ usability testing. From our experience such in-situ testing is both cost-effective and is necessary in order to understand how an information system will fit into the complexities of real healthcare environments [7]. Furthermore, this type of testing brings the important issue of context to the fore by arguing for conducting testing not only at centralized testing facilities or in fixed laboratories, but also testing those systems within real settings where systems will be released. This supports assessing how well systems fit into local workflows and how well the systems integrate with other technologies in a real life setting [8]. We are also extending the approach for use in the selection and procurement of health information systems.

References

[1] J. Nielsen, *Usability engineering*, Elsevier, New York, 1994.
[2] M. Beuscart-Zephir, S. Pelayo, F. Anceaux, J. Meaux., M. Degroisse, P. Degoulet, Impadt of CPOE on doctor-nurse cooperation for the medication ordering and adminstrative process, *Int J Med Inform* **74**(7) (2005), 629-641.
[3] K. Lawton, K. Binzer, P. Skjoet, S. Jensen, Lessons learnt from conducting a high simulation test in health IT, *Stud Health Technol Inform* **166** (2011), 217.
[4] A. Kushniruk, E. Borycki, J. Anderson, J. Nicoll, J. Kannry, Using clinical and ocmputer simulations to reason about the impact of context on system safety and technology-induced error, *Stud Health Technol Inform* **194** (2013), 154-159.
[5] E. Borycki, A. Kushniruk, Identifying and preventing technology-induced error using simulations: application of usability engineering technologies, *HealthcQ* **8** (2005), 99-105.
[6] A. Kushniruk, E. Borycki, S. Kuwata, J. Kannry, Predicting changes in workflow resulting from healthcare information systems, *Healthc Q* **9** (2006), 114-118.
[7] A. Li, A. Kushniruk, J. Kannry, D. Chrimes, T. McGinn, D. Edonyabo, D. Mann. Integrating usability testing and think-aloud protocol analysis with "near-live" clinical simulations in evaluating clinical decision support, *Int J Med Inform* **81** (2012), 761-772.
[8] J. Patrick, A. Ryan, R. Herkes, Introduction of enhancement technologies into the intensive care service, Royal Prince Alfred Hospital, Sydney, *Health Inform Management* **37**(1) (2008), 40.

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Web-site Evaluation Tools: A Case Study in Reproductive Health Information

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Abstract. Background and Objective: Internet forms an opportunity to inform, teach, and connect professionals and patients. However, much information on Internet is incomplete, inaccurate, or misleading, and not only in the medical domain. Because of the potential for damage from misleading and inaccurate health information, many organizations and individuals have published or implemented scoring tools for evaluating the appropriateness or quality of these resources. The objective of this study is to identify and summarize scoring tools that have evaluated web-sites providing reproductive health information in order to compare them and recommend an overarching evaluation tool. **Methods:** We searched Ovid MEDLINE(R) (1946 to July 2013) and OVID Embase (1980to July 2013); and included English language studies that have evaluated the quality of websites providing reproductive health information. Studies only assessing the content of websites were excluded. **Results:** We identified 5 scoring tools: 1-The HON (health on the net) Code of Conduct for medical and health Web sites, 2-Silberg scores, 3-Hogne Sandvik scale, 4- Jim Kapoun's Criteria for Evaluating Web Pages, and 5-The Health Information Technology Institute (HITI) criteria. We have compared these scales and identified 14 criteria: authorship, ownership, currency, objectivity/content, transparency/source, interactivity, privacy/ethics, financial disclosure, navigability/links, complementarity, advertising policy, design, quantity, and accessibility. We integrated these criteria and introduced a new tool with 10 criteria. **Conclusion:** Website evaluation tools differ in their evaluation criteria and there is a lack of consensus about which to use; therefore, an integrated easy to use set of criteria is needed.

Keywords: Internet, pregnancy, reproductive health, evaluation, quality measurement

Introduction

The number of health information resources and online services are constantly increasing, but it is difficult for health information consumers, such as the patients and the general public, to assess the quality of the information provided. More than one-third of Internet users are health information consumers (World Internet usage statistics and population statistics, 2004).

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The number of people accessing the Internet has also grown. According to Internet World Stats the number of Internet users increased by 528 % between 2000-2011, and there were more than 346 million websites in 2011 [1]. In 2011, more than 80 percent of adults reported using the Internet as a resource for healthcare decisions [2].

Health information on Internet may be from a leading expert with an excellent documentation and a complete bibliography, or it may be in the form of emotional support from a friendly support group. Unfortunately, the Internet can also deliver sales propaganda, the latest medical complaints, or even the most sophisticated, pseudo-scientific scams. The user finds it difficult to determine which information is usable and reliable; how it can be evaluated, critiqued, or verified; when it should be ignored, rejected, debunked, or erased [3].

Because of the potential damage from misleading and inaccurate health information, many organizations and individuals have published or implemented some criteria for evaluating the appropriateness or quality of these resources [4]. The Web is potentially a valuable resource for women with many health problems such as postnatal mental illnesses and reproductive health in terms of providing them with information, support and occasionally online interventions [5, 6]. Evaluations of information on the Internet have shown that in issues like abortion, the quality of information is low [5].

The objective of this study is to identify and summarize scoring tools that have evaluated web-sites providing reproductive health information in order to compare them and to recommend an improved integral one.

1. Methods

We searched all relevant studies in English but regardless of their peer-review/ publication status, in Ovid MEDLINE(R) (1946 to July 2013) and Embase (1980 to July 2013) databases. Studies were included when their authors: (1) searched the World Wide Web systematically for reproductive health information (2) evaluated the quality of health information against certain criteria, for example; by judging the authority of source, assessing the accuracy of information, readability, or comprehensiveness. Studies were excluded if they only assessed the content of web sites or newsgroups.

2. Results

We screened 1777 citations and retrieved 25 potentially eligible full articles, finally 10 studies met our inclusion criteria. We identified five scoring tools. HONcode is the oldest and the most used ethical and trustworthy code for medical and health related information available on Internet. The HONcode is designed for three target audiences: the general public, the health professionals and the web publishers, actively involving the site owner in the process of certification. All the tools' criteria are shown and contrasted in Table 1.

We identified five scoring tools and extracted 34 criteria from them, then mapped these criteria and identified 14 general ones (Figure 1): authorship, ownership, currency, objectivity/content, transparency/source, interactivity, privacy/ethics, financial disclosure, navigability links, complementarity, advertising policy, design, quantitative report, and accessibility.

2.1. The new scoring tool

We integrated fourteen criteria in 10 categories and constructed our recommended tool for evaluating web-sites providing reproductive health information. This tool contains 3 "Who"'s: Who is the author of the webpage, person or institution that has been published in the website and who are the sponsors of the website; 2 "What"'s about the purpose of the website and the evidence or resources; 4 "How"'s for clarifying the appropriate design, easy to use, regard to privacy and ways of interaction; and finally when was the site updated. (Table2).

3. Discussion

The identified evaluation scoring tools differed in their evaluation criteria. We found 34 criteria and summarized them in 14 general one and created a tool with 10 easily applicable criteria for evaluating web-sites providing reproductive health information. Limiting the number of criteria enhances the tool's routine use [11].

Kim et al (1999) reviewed published criteria for specifically evaluating health related information on Internet. They found 29 published rating tools and extracted 165 criteria from those tools. 132 (80%) criteria out of them were grouped under one of 12 specific categories. They reported that the most frequently cited criteria were those dealing with content, design and aesthetics of the site, disclosure of authors, sponsors, or developers, currency of information (including frequency of update, freshness, maintenance of site), authority of source, ease of use, and accessibility and availability [4]. In the current study, all of the frequently mentioned criteria in Kim et al's study have been identified. Finally they concluded the next step is to identify and assess a clear, simple set of consensus criteria that the general public can understand and use [4].

There are two ways to reduce the individual's risk of encountering an inadequate site on the Web. Increasing the ability of the individual to filter inadequate sites or reducing the proportion of inadequate information on the Web [12]. Since continuous review of thousands of websites offering health information is difficult and expensive, a better approach would be empowering patients to evaluate online content for themselves. But there is a lack of consensus about the best tools to use for web-site evaluation and instruments have many and differing criteria. Therefore, an effective and easy set of criteria is needed.

We have proposed a tool, which contains all key criteria for evaluating web-sites providing reproductive health information; further study is required to complete it by using in other heath area. This tool has 10 easily understandable and applied criteria. Future research is needed to compare the effectiveness of our and other evaluation tools on satisfaction of users and rely to content of reproductive health information websites.

Our study was limited to reproductive health websites. However the criteria that were identified are similar to those reported in Eysenbach et al's systematic review [12] suggesting the wider applicability of our findings.

Table 1. The five studied scoring tools

The HON (Health On the Net)	Silberg scores	Hogne Sandvik scale	Jim Kapoun Criteria	HITI criteria
Authoritative: It indicates the	Author's name,	**Authorship**: Author's	**Accuracy**: Page lists the author and institution	**Credibility**: Source, context, currency,

qualifications of the authors.	credentials and affiliations	name and qualification	that published the page and provides a way of contacting him/her.	relevance/utility, editorial review process
Complementarily: Information should support, not replace, the doctor-patient relationship.	Statement of site ownership	**Ownership**: Name and type of provider	**Authority:** Page lists the author credentials and its domain is preferred (.edu, .gov, .org, or .net)	**Content:** Accuracy, hierarchy of evidence, original sources stated, disclaimer, omissions noted
Privacy: Confidentiality of data relating to individual patients and visitors to a Web site	References	**Source**: References given to scientific literature	**Objectivity**. Page provides accurate information with limited advertising and it is objective in presenting the information.	**Disclosure:** Purpose of site, profiling
Attribution: It cites the source(s) of published information, date, medical and health pages.	Date first posted	**Currency**: Date of publication or update	**Currency**. Page is current and updated regularly (as stated on the page) and the links (if any) are also up-to-date.	**Links:** Selection, architecture, content, back linkages and descriptions
Justifiability: Sites must back up claims relating to benefits and performance.	Date last up dated	**Interactivity**: Clear invitation to comment or ask questions by an email address or link to a form	**Coverage.** It can view the information properly--not limited to fees, browser technology, or software requirement.	**Design**: Accessibility, logical organization, internal search engine
Transparency: Sites must provide information in the clearest possible manner and provide contact addresses for visitors that seek further information or support	Statement of site sponsorship	**Navigability**: Information easily found by following links from home page		**Interactivity:** Mechanism for feedback, chat rooms, tailoring
Financial disclosure: It identifies funding sources	Statement of a lack of conflict of interest	**Balance**: Balanced information, without bias in favor of own products or services		**Caveats:** Alerts
Advertising policy: Clearly distinguishes advertising from editorial content				

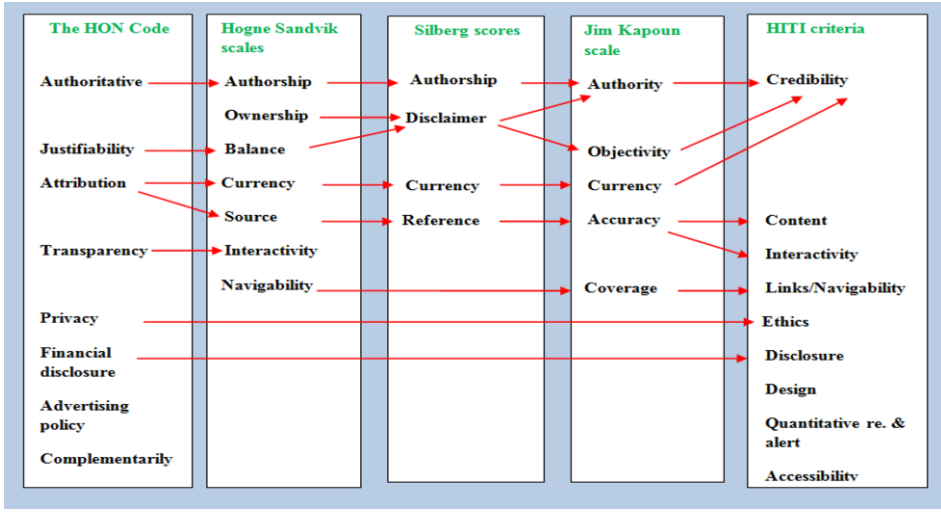


Figure 1- mapping of the five scoring tools

Table 2. Our recommanded scoring tool for evaluation web-sites providing reproductive health information

Criteria	Description
Who writes/editorial board	Identifying who wrote the material**,** who are responsible for the professional and scientific edition and review of the web site materials
Who Runs	Clarifying who is responsible for the site and its information
Who Pays	Funding source of website and advertising policy
What Purpose	Presenting a clear statement of the purpose
What Evidence/sources	Clearly stating the original source of information if it is collected from other web sites or sources
How _ Design	Readability of text, use of image, graph, video and so on
How _ Ease of Use	Easily finding the information on the site or other sites by search engine or links
How _ Regard to Privacy	Describing web site liability and privacy statement
How _ Contact	Ways to contact the site owner, such as email, chat etc.
When	Date of update or review

References

[1] INTERNET USAGE STATISTICS December 31, 2011. Available from: http://www.internetworldstats.com/stats.htm.

[2] Ford EW, Huerta TR, Schilhavy R, Menachemi N. Effective US health system websites: establishing benchmarks and standards for effective consumer engagement. Journal of healthcare management/American College of Healthcare Executives. 2012;57(1):47.

[3] Ambre J, Guard R. Criteria for Assessing the Quality of Health Information on the Internet 1977. Available from: http://www.mitretek.org/hiti/showcase/documents/criteria.html.

[4] Kim P, Eng TR, Deering MJ, Maxfield A. Published criteria for evaluating health related web sites: review. BMJ. 1999;318(7184):647-9.

[5] Moore D, Ayers S. A review of postnatal mental health websites: help for healthcare professionals and patients. Archives of women's mental health. 2011:1-10.

[6] Carrillo-Larco RM, Pérez-Lu JE, Alvarado-Vásquez E, Curioso WH. Evaluation of the quality of information about pregnancy found in webpages according to the Peruvian guidelines. Revista peruana de medicina experimental y salud publica. 2012;29(1):76-81.

[7] Health on the Net Foundation 2011 [updated 2011]. Available from: http://www.healthonnet.org/HONcode/Conduct.html.

[8] Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet. JAMA: the journal of the American Medical Association. 1997;277(15):1244-5.

[9] Sandvik H. Health information and interaction on the internet: a survey of female urinary incontinence. BMJ. 1999;319(7201):29-32.

[10] Kapoun J. Teaching undergrads WEB evaluation: A guide for library instruction. 1988 [updated 10 May 2010]. Available from: Source URL: http://olinuris.library.cornell.edu/ref/research/webcrit.html.

[11] Bernstam EV, Shelton DM, Walji M, Meric-Bernstam F. Instruments to assess the quality of health information on the World Wide Web: what can our patients actually use? International Journal of Medical Informatics. 2005;74(1):13-20.

[12] Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA : the journal of the American Medical Association. 2002 May 22-29;287(20):2691-700. PubMed PMID: 12020305. Epub 2002/05/22. eng.

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User Satisfaction and Experience with a Telehealth System for the Danish TeleCare North Trial: A Think-Aloud Study

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Abstract. The aim was to evaluate a redesigned version of Telekit – a telehealth system developed for the Danish TeleCare North Trial. Telekit is used in the management of care in patients diagnosed with chronic obstructive pulmonary disease (COPD). This paper summarises the experience and the feedback received from six COPD-participants in terms of usability and satisfaction. Participants were asked to think-aloud while performing some system specific tasks. After each session, participants completed a post-test questionnaire. The think-aloud test was recorded, and notes from the tests were categorised and analysed. All tasks were completed by participants. Difficulties were observed concerning monitoring of measurements and use of the touchscreen. User feedback was mainly positive, and nearly all participants perceived Telekit as very easy to use. The study provides important insight regarding use of Telekit by patients suffering from a chronic illness and increased understanding about, how similar systems can more effectively be used in such home health initiatives.

Keywords. Handheld computer, user-computer interface, usability, chronic obstructive pulmonary disease, telemedicine

Introduction

Chronic obstructive pulmonary disease (COPD) is an important cause of morbidity and mortality worldwide. The disease has a significant impact on patients' quality of life and imposes a significant burden on healthcare resources. Consequently, there is need for new COPD management to meet factors influencing the disease [1].

Telehealth technologies are used in home and community settings to enable monitoring of chronic patients' well-being (for example, by measuring vital signs) and communication with health care providers using synchronous or asynchronous communication platforms [2]. Given that the patients are going to operate these tools, their experiences of and satisfaction with these devices must be evaluated. Furthermore, there seems to be a need for usability evaluation in older adults with chronic diseases using telehealth solutions, as the technology is expected to pose considerable challenges [3,4]. Elderly's physical and cognitive capabilities are limited compared to

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younger adults and this may interfere with the elderly's use of telehealth technologies [5].

A large-scale Danish project, TeleCare North, has developed a telehealth system (Telekit) to all COPD patients in the North Denmark Region. All eleven North Jutland municipalities, the North Denmark Region, general practitioners and Aalborg University are taking part in the project. The project attempts to develop a technology and educational environment, which will empower patients to retake responsibility for their own lives. Approximately 600 of the 1,225 patients are in possession of the Telekit system at home, and use it as support in monitoring and treatment of their disease [6,7].

A heuristic evaluation, performed by usability experts, has been used to evaluate an early version of the Telekit system in order to refine the usability and elucidate the factors that affect the implementation to operation. Findings from the evaluation indicated that Telekit needed improvements. The most serious problems included the inability of the system to inform users of how to perform measurements correctly and to "speak the users' language". The usability problems found in the heuristic evaluation have led to several significant changes in the telehealth system, and the system is ready for a user test planned to involve COPD patients [8].

In this present study, we used a simple think-aloud test to determine user's experience and satisfaction with the revised version of the Telekit system. Such research is needed to address potential gaps in the use of technology by chronic-care patients.

1. Methods

1.1. Participants

Test participants were recruited through the list of 17 pilot patients from the project TeleCare North. Six (three women, three men) participants were randomly selected to participate in the think-aloud test. The average age was 69 (min 65, max 73). They constituted different stages of disease severity (one mild, one moderate, four severe). Those in the severe stage were in the need of oxygen therapy [9]. The participants had various technology experiences; three novices, two users with some knowledge, one expert (daily user). The participants had received the Telekit system and an introduction six months earlier.

1.2. Telekit

The Telekit system consists of a tablet (Samsung Galaxy TAB 2, 10.1, Samsung Electronics, Seoul, South Korea), a fingertip pulse oximeter (Nonin, Onyx II % SpO_2, A&D Medical, Tokyo, Japan), a blood pressure monitor (Model UA-767, plus BT-C, Nonin Medical, Minnesota, USA), and a Precision Health Scale (UC-321PBT-C, A&D Medical, Tokyo, Japan). The scale is not included in the test. The Telekit system version 1.11.3 was tested.

The COPD patients perform measurements and ask questions related to their disease. The measurements and questions are transferred wirelessly to health care providers. Health care providers respond if data show deviations from expected values [10].

1.3. Study design and data collection

The participants performed the think-aloud test in their own homes, because they usually use Telekit in that environment. They were handed six tasks, representing typical user goals. This included; 1) login, 2-3) perform measurements (blood pressure, oxygen saturation), 4) find graphical images of their measurements 5) write a message to health care providers and 6) logout. The observer wrote notes about what was being verbalised and observed, including aspects in need of clarification (see Table 1). Additionally, demographic data was collected to provide descriptive information about the test participants. The test was audiotaped to create a set of audio recordings for back up, and each task was timed during the test. Each think-aloud session took approximately 40 minutes including introduction, tasks and debriefing.

Participant satisfaction with Telekit was assessed using a satisfaction and usability questionnaire, which we developed to determine the underlying facilitators or barriers to adoption. The questionnaire was in two parts; 1) nine questions about satisfaction and 2) ten Likert Scale usability questions from a modified translated version of the System Usability Scale (SUS) [11]. The questionnaire and observations were categorised and analysed.

Table 1. Test procedure.

Pre-test arrangements	System specific tasks	Post de-briefing
Written consent	Login on tablet	Follow up questions
Participant information	Measure oxygen saturation	Satisfaction and usability questionnaire
Background questionnaire	Measure blood pressure	
Introduction to think-aloud test	View measurements	
	Write a message	
	Logout on tablet	

2. Results

2.1. Satisfaction and usability questionnaire

The majority of participants considered Telekit easy to use. Five out of the six participants used it on a weekly basis. All agreed that most people could learn to use the system, and they felt quite confident using Telekit.

Differences in how much time they spent on the system were found. Four participants used up to half an hour on Telekit weekly, and the rest spent more time. Five participants used the system for more than measuring blood pressure, pulse and oxygen saturation, e.g. for weight measurements. Three participants had involved other relatives in the use of Telekit. Two participants had never contacted health care providers in the use of Telekit, while the rest had contacted health care providers for assistance between 1-3 times (n=2), 3-6 times (n=1), or more than 9 times (n=1).

There were different answers to the question about the need for technical assistance. Just one participant needed support. The other five participants were neutral or refused the question with “strongly disagree”. The functions in the user interface of the Telekit were perceived as well-integrated, and three participants agreed that there was not any kind of inconsistencies. The other half answered neutral.

2.2. Think-aloud test and observations

All six tasks were completed. The women had difficulties obtaining a reaction from the touchscreen because of long fingernails or perhaps cold fingers. This often required several attempts, before the tablet responded. If there was no reaction to commands, the participants reacted by pressing the touch screen multiple times. This could result in incorrect answers to questions being selected.

Some keys were difficult to identify on the keyboard, which prevented them to move on in the system. Several of the participants did not press the key [next] before they took measurements, even though, this was evident to the user. This resulted in incomplete measurements. Additionally, one participant made mistakes in the sequence of actions so that the measurements were taken too early or too late because of the location and naming of buttons.

Half of the participants could not remember their user name and password enabling them to login. Due to the lack of memory, the codes were written on paper, or the tablet was constantly on stand-by mode. One participant had to call the health care providers to get a new code, and they responded by calling a technician, who could solve the problem. One participant had mistyped username and password leading to password locking.

Two of the participants could not send their oxygen saturation, and even though they knew the problem in advance, they had not reacted. The problem was that the battery condition of the fingertip pulse oximeter was not sufficient to send the measurements.

Some comments, concerning the design and application of the system were obtained from the participants. One commented that there was too much writing in the application. The size and readability of the screen was considered appropriate but some keys caused difficulties.

3. Discussion

This study has gathered some important insight of, whether the Telekit system is user-friendly and satisfying from the patient's point of view. Usability testing on telehealth systems like Telekit needs to be tested in COPD patients, who are suffering from exacerbations. The technology experience differed between the participants. This provided a comprehensive picture of the overall use of the system. The overall feedback was positive and they were satisfied with the functionality of Telekit. However, it should be considered, whether the textual material can be shortened in order to obtain a more flexible system for experienced users.

Different issues indicate a need for a call center, so that the users can easily call for technical assistance or ask questions, if they experience problems using the system. For instance, there were problems using the login-function, as more of the participants had forgotten their password. In these situations, they doubted which person to call.

The previous heuristic evaluation of Telekit uncovered user interface design problems, and was used to improve the usability of Telekit before planning a potential user test [8]. The findings of this user test turned out to be different compared to the problems identified in the heuristic evaluation. The experts had focus on the design of the system. Participants in the think-aloud were more interested in whether Telekit could help them manage measurements and disease. This indicates the importance of

using both user testing and inspection methods - an aspect, which is also recommended by Nielsen [12].

It is a challenge to test technologies in older adults with COPD, as it is likely a new situation. This is caused by lack of formal education, and the situation can be confusing, if they do not know what is going to happen [13]. To eliminate confusion and uncertainty, we focused on explaining participants the plan beforehand. We timed each task during the test but we did not use these measures, because in most cases the recording contained stories unrelated to the test. There was in turn created a pleasant atmosphere by listening to the participants' historical narratives. It created an environment of trust and security that enabled the expression of feelings.

The think-aloud test was tested on participants that had received education a half year before. Therefore, they were all familiar with Telekit and more experienced in the use of the system compared to new users. These users may have overlooked basic problems and acquired habits in the use of the equipment. The results from the think-aloud test will probably be different, if we test it on new users. Also, this test was fairly small sized, which may limit external validity. A larger size would be required to assess COPD patients' opinions. Though, it is common knowledge that five test subjects are enough in the use of usability methods, as it is expected that five persons will detect approximately 75-80% failures, problems and shortcomings [14].

In conclusion, this article has provided information about how COPD-patients use Telekit by assessing the overall usefulness of and satisfaction with the system. The patients' satisfaction and experiences of new technologies is important information in the improvement of the design of current and future systems, and it help predict the level of their success. The results confirm that Telekit is a useful tool that fits COPD patients' needs. Though, there is still need for improvements, and Telekit will still be updated to new versions.

References

[1] Epidemeology and Statistics Unit ALA. Trends in COPD (Chronic Bronchitis and Emphysema): Morbidity and Mortality. 2013.
[2] Ho K, Cordeiro J, Hoggan B, N. Lauscher H, Grajales F, Oliveira L, et al. Telemedicine: Opportunities and developments in Member States: Report on the second global survey on eHealth. 2010.
[3] Horton K. The use of telecare for people with chronic obstructive pulmonary disease: implications for management. J Nurs Manag 2008;16:173–80.
[4] Vermeulen J, Neyens JC, Spreeuwenberg MD, van Rossum E, Sipers W, Habets H, et al. User-centered development and testing of a monitoring system that provides feedback regarding physical functioning to elderly people. Patient Prefer Adherence 2013;7:843–54.
[5] Chun YJ, Patterson PE. A usability gap between older adults and younger adults on interface design of an Internet-based telemedicine system. vol. 41, 2012, p. 349–52.
[6] TeleCare Nord. Business case TeleCare Nord. Aalborg: 2012.
[7] TeleCare Nord. Forskningsdesign i TeleCare Nord. Aalborg: 2013.
[8] Heyckendorff P, Hasselstrøm M, Kristian O. A Heuristic Evaluation of a Telehealth Solution from the Danish TeleCare North Large- Scale Randomized Trial 2013:1.
[9] Roisen, RR, Vestbo J. Global Initiative for Chronic Obstructive Lung Disease. 2013.
[10] Dinesen M. TeleCare Nord - FAQ 2013;2013.
[11] Brooke J. SUS : A Retrospective 2013;8:29–40.
[12] Nielsen J. Characteristics of Usability Problems Found by Heuristic Evaluation 1995.
[13] Silva PA, Nunes F. 3 x 7 Usability Testing Guidelines for Older Adults 2010:1–8.
[14] Virzi RA. Refining the Test Phase of Usability Evaluation : How Many Subjects Is Enough ? Hum Factors 1992;34:457–68.

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Context Mediated Usability Testing

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Abstract. Usability testing is an important part of health information technology HIT design. However, usability issues will vary by the contexts where a system is used. To date there are few studies that have described contextual factors of usability testing. This paper uses a case study of a surgical information system to develop a model of four contextual categories that impact usability testing. We discuss each of the contexts in detail and then suggest how they can be used to develop a general framework to enable better understanding of the role of context in usability testing and evaluation of HIT.

Keywords. Usability testing, context, evaluation, health information technology

Introduction

Usability testing is an important part of health information technology (HIT) design. The importance of usability testing has been well documented in the literature for helping to develop safe HIT that also is usable from an end user perspective. However, despite increased usability testing of research and commercial HIT applications, there are still reports of safety and usability issues emerging from HIT implementations [1].

Recent approaches to usability testing have seen the development of approaches that evaluate usability in different contexts. While classic usability methods such as think aloud are good for capturing user interactions with HIT they fail to account for the surrounding contexts that may impact usability. The International Organization for Standardization (ISO) definition of usability testing is *"the effectiveness, efficiency, and satisfaction with which the users can accomplish their tasks in the intended context of product use"* [2]. That definition emphasizes the need to understand the user, technology and contexts of use.

Several different usability approaches exist including heuristics, cognitive walkthrough and think aloud [3]. Recent studies have combined usability approaches and clinical simulation to attempt to emulate actual clinical workflow [4]. However, with the array of usability approaches it can be difficult to understand what approach to use in which setting. There are few studies that have looked at how to position different usability approaches with the situational contexts where HIT is used.

Regardless of how well we design HIT there is frequently a chasm between the ostensive dimension (abstract systems design representation such as flowcharts) and performance dimension (actual measureable circumstances of HIT usage) [5]. Failure to account for the chasm leads to unintended consequences post implementation. If we

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can identify specific performance contexts we could better position usability testing to account for these contexts as part of HIT design and evaluation.

Overall, while flow charts or use cases may represent the typical or ideal way that a task is done, the context where the technology is used will impact how the task is conducted in real settings. While general guidelines exist for identifying contexts of use (i.e. user types, attributes, tasks, environment) [1], there is a lack of systematic approaches for developing context specific approaches to usability testing. This paper addressees that shortcoming and develops a model to guide the development of context mediated usability testing. We use a case study of the evaluation of a surgical information system to model different contexts of use and suggest evaluation strategies for the contexts. We then suggest how our work can lead to a general framework for better understanding the role of context in usability testing and evaluation of HIT.

1. Methods

In April 2009 a multi-campus hospital in an urban Canadian City implemented a Surgical Information Management system (SIMS). The goal of SIMs was to bring common data and connectivity across the perioperative spectrum. After implementation the hospital sought to evaluate how the system was being used in the different areas and across the different campuses. From April 2012 to June 2013 we conducted over 130 hours of non-participant observations across all the clinical areas and campuses. We also conducted 8 interviews and 3 focus groups with different categories of users including anaesthetists, nurses and managers.

The observational notes were transcribed into written notes that documented users, activities and processes. The interviews and focus groups were transcribed verbatim. The transcribed notes were then analyzed using content analysis. Our analysis focused on usability issues with SIMS across the different perioperative areas.

2. Results

There are two parts to our results. First, we describe the perioperative patient flow and describe the four contextual categories that influence how users interacted with SIMS. Second, we discuss how the categories can be used to develop a general framework to support usability testing.

2.1. Perioperative Patient Flow and Contextual Categories

The perioperative process starts with a visit to the Pre-Admission Unit (PAU) approximately two to six weeks prior to surgery. Patients are either assessed by a nurse alone, or, depending on their clinical condition, a nurse and an anesthesiologist. Any necessary tests (i.e. lab tests, diagnostic imaging, electrocardiogram) are coordinated during the PAU visit. On the day of the patient's surgery he is admitted to the Same Day Admission (SDA), or Surgical Day Care Unit (SDCU), where their preoperative care takes place prior to going into the Operating Room (OR). Following surgery patients are taken to the Post Anesthetic Care Unit (PACU) for immediate care following their surgery. Patients who are returning home on the same day as their

surgery are returned to the SDCU for continuing care until they meet the discharge criteria. Patients who are being admitted return to SDA to be transferred to a care unit.

Fig. 1 shows the patient flow through the perioperative areas described above. After analyzing our data described in section 1 we identified four overarching contextual categories: task workflow, organizational processes, information entry/retrieval, and temporal factors. Figure 1 also shows how these categories vary across the perioperative areas. Below we discuss each of the contextual categories from the perspective of usability issues.

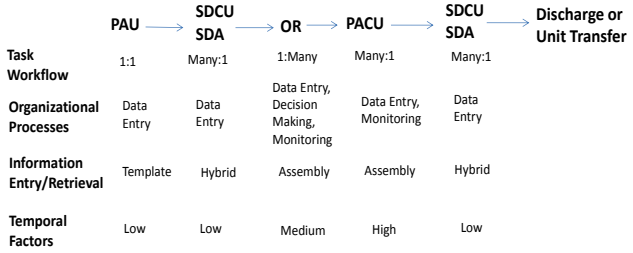


Figure 1. Perioperative areas and contextual category variation by area

2.1.1. Task Workflow

While usability testing typically focuses on a user with an individual system the workflow of the user may also impact usability when carrying out work tasks. PAU is a direct one-to-one relationship as a nurse enters data into SIMS while assessing an individual patient. In comparison, the workflow in the OR involves data entry into SIMS, as well as monitoring of IV pumps, anaesthetic gas machines, blood pressure and heart rate machines, as well as administrating medications to the patient. OR data entry is one-to-many with as many as three systems needing to be looked at. PACU and SDCU also have unique workflows as each nurse is responsible for several patients in SIMs making these areas many-to-one.

2.1.2. Organizational Processes

The processes in which users interacted with SIMS also varied across each area in the healthcare organization. PAU and SDCU/SDA are primarily data entry areas whereas the OR has a more varied set of processes that include data entry, monitoring, and decision making. For example, patients in the OR often receive complex cocktails of anesthesia medication that may have several drugs and percentages. Anesthetists described how a benefit of the previous paper based system is that writing down the complex drug data was part of the decision making process. In SIMS the cognitive aspect is replaced by selection from a drop down list, which anesthetists said did not have the same impact as writing it down. The relationship between collaborative and individual processes also was problematic. For example, a process like handover between the perioperative areas (particular OR-PACU) is a collaborative process. However, individual usability issues with SIMS had impacts on collaborative processes. Nurses and anaesthetists in the OR would at times have trouble finding the specific field they needed for data entry. A solution was to put the data into a generic memo field. A consequence of that is that nurses in PACU may miss seeing the data because they do not routinely look in memo fields.

2.1.3. Information Entry/Retrieval

Information entry and retrieval are common tasks in any HIT. SIMS changed how entry was done and at times it was a substantial change depending on the perioperative area. PAU uses a generic data entry template for all patients organized by body systems (e.g. respiratory, neurologic, cardiology). The usability considerations in PAU are the time and effort it takes to move from field to field or how to enter data not found in the template. Once the patient has surgery it determines the data entry that is done post-surgery. The impact of that is data entry in PACU becomes 'assembly' where the fields (i.e. wounds, drains) are assembled for each patient's context. Usability considerations for assembly data entry include: the time that it takes an RN to first find the data field (i.e. wound), add it to the patient's chart, and then enter in the data values. Information retrieval was also impacted by SIMS. Because of a lack of integration between the different SIMS modules (i.e. between PAU and SDA) some of the patient data is put into the hospital EMR program. Therefore on the day of surgery if a nurse or physician wants to see PAU data they need to open the EMR system, which at times meant toggling two screens to the view current data in SIMS and historical data in the EMR.

2.1.4. Temporal Factors

The length of time that a patient has been in the perioperative spectrum can also cause usability issues. One issue is the amount of data on a patient is proportionate to how long the patient has been in the perioperative spectrum. This issue was particularly significant in the OR and PACU as anesthetists and nurses commented that a patient's blood pressure or presence of pain or other symptoms gets much of its significance from how it compares to previous data points. However, it was not easy to scroll back to find the relevant data points. Another usability issue that grew over time was a 'resolution' problem. Resolution refers to the granularity of data points and was a significant problem in the OR and PACU where patients data included vital signs and medication data. Vitals are done more frequently and to prevent them from looking too condensed on the screen a user would increase the resolution to one hour. The issue with that is if a patient's medication dose is fentanyl 25mcg every 15 minutes and the resolution is set to 1 hour then a nurse sees the 100 mcg total for the hour but not the individual doses. The resolution must be scaled down to see the individual doses. Vitals and medication data have different scales but only one scale can be viewed at a time. Nurses described having a hard time understanding the resolution issue and it does present the potential for patient safety errors because of misreading of medication doses.

2.2. Contexts to Support Usability Testing: Towards a General Framework

The contexts identified above define the complexity of clinical tasks. Furthermore, this complexity varied across different clinical areas, such as the OR, where it requires more complex data entry as the clinical nature of the processes are more complex (where nurses had to use memo boxes to supplement their assessments). We are currently using the four contextual categories described in the case study to develop a framework for modelling contexts and their impact on usability testing. The framework will help explore the relationship of usability to the evaluation of a range of HIT. Although we have found that traditional usability testing can provide insight into task

workflows, it is also necessary to consider the impact of usability at the level of organizational processes in order to fully understand impact of systems (as illustrated in the case study in this paper). In addition, studies focusing on entry and retrieval are central to gaining a full picture of the impact of systems at the contextual level. Finally, usability issues must be considered along a temporal continuum, where usability issues may change, grow or wane over time, making temporal factors an important component of complete usability evaluations.

3. Discussion

The contexts in which HIT is situated and used are complex and we need to incorporate context into the evaluation of HIT. This paper provided insight on contextual considerations of HIT evaluation. We identified four overarching categories of contextual categories and the usability implications of the categories. For example, we identified different variation of tasks such as data entry and retrieval and showed that assembly data entry has more steps and is much more time consuming than template data entry. These differences need to inform usability testing and evaluation of data entry tasks.

We also described the relationship between individual and group usability issues. An individual inability to find a data entry field can resonate into group issues because individual workarounds such as putting data into a memo field can prevent other care team members from finding the data. That issue is a precursor for medical errors.

It is not that one method for evaluating usability is better than another, but rather methods need to be informed by context. Further, multi-method approaches may be required in contextually complex situations. Multi-tasking environments such as in the OR require multi-dimensional usability evaluation such as think aloud, cognitive task analysis and simulation. Collaborative activities such as handover need to be evaluated using collaborative approaches that achieve common ground between individual and group activities. Temporal factors must also be taken into account as usability issues may become more complex with time. Formal development and testing of the general framework we discussed in section 2.2 is the next phase of our research..

References

[1] A. Kushniruk, C. Nohr, S. Jensen, E.M. Borycki, From Usability Testing to Clinical Simulations: Bringing Context into the Design and Evaluation of Usable and Safe Health Information Technologies. *Yearb Med Inform,* (2013), 78-85.

[2] ISO 9241-11: Ergonomic requirements for office work with visual display terminals (VDTs) – Guidance on usability. 1998. www.it.uu.se/edu/course/ homepage/acsd/vt09/ISO9241part11.pdf. last Accessed Jan 7, 2014.

[3] M.A. Jaspers, A comparison of usability methods for testing interactive health technologies: Methodological aspects and empirical evidence, *Int J Med Inform* **78** (2009), 340-53.

[4] A.C. Li, J.L. Kannry, A. Kushniruk, D. Chrimes, T.G. McGinn, D. Edonyabo, et al., Integrating usability testing and think-aloud protocol analysis with "near-live" clinical simulations in evaluating clinical decision support, *Int. J.Med. Inform*. **81** (2012) 761–772.

[5] L. Novak, J. Brooks, C. Gadd, S. Anders, N. Lorenzi. Mediating the intersections of organizational routines during the introduction of a health IT system, *European Journal of Information Systems,* **21** (2012), 552-569.

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Participatory Heuristic Evaluation of a Tablet Computer System for Clinical Microbiology

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Abstract. MultiplexBCT is a molecular-based diagnostic test for rapid identification of microorganisms in positive blood cultures. A MultiplexBCT Android tablet computer application is being developed as an accessory to the diagnostic test. The aim of the application is to facility the end user's workflow by supporting data entry and communication of the MultiplexBCT test results in a hospital environment. This paper reports the results and benefit of a participatory heuristic evaluation conducted on the MultiplexBCT application. The design is an extension of heuristic evaluation that includes end users as work-domain experts to complement usability experts for inspection of a user interface. The user interface assessment identified 86 heuristic violations, which consisted of both product- and domain-related issues. These results will be used to guide further development of the MultiplexBCT application to ensure that the system will fully support the workflow of the end users when using the MultiplexBCT diagnostic test.

Keywords. Usability, Heuristic evaluation, Handheld computer, Clinical microbiology, Bloodstream infection, Sepsis

Introduction

Bloodstream infections are a prominent cause of sepsis, which is associated with high mortality and annually affects millions of people globally [1]. For treating patients with sepsis, quick initiation of effective antimicrobial treatment is essential. An instantaneous diagnosis of the causative microorganisms is not possible with current technologies, and the goal today is therefore to obtain and communicate a diagnosis as soon as possible in order to adjust empirical antibiotic therapy. Diagnostic tests based on molecular microbiology are being developed, and shows promise of shortening the time span for identifying causative microorganisms compared to regular blood culture analysis, which is considered the gold standard today [2].

MultiplexBCT is a molecular-based diagnostic test, which is under development for direct identification of microorganisms from positive blood cultures within one hour. The MultiplexBCT test will use an accessory tablet computer application to assist medical laboratory technicians by supporting analysis and data entry of test results, and

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for facilitating rapid communication of test results, which may lead to an earlier optimized antimicrobial treatment. The MultiplexBCT application exists as a functional prototype, and its design has been based on supporting the existing workflow of medical laboratory technicians conducting blood culture analysis [3][4].

During the development of clinical information systems (CIS), usability inspection methods are often applied to reveal and correct user interface design flaws to improve usability. Poor system usability can lead to a risk of clinical errors or failure in clinical adoption of CIS [5–7]. Usability inspection methods are based on having evaluators inspect user interfaces to identify usability problems [8]. Heuristic Evaluation (HE) is a widely used usability inspection method, where usability experts evaluate a systems user interface against a list of heuristics [8]. However, the heuristics used in HE have been described as product-oriented with little consideration of the workflow in which the system is used [9,10]. This can be problematic when evaluating user interfaces of CIS, because they are implemented in complex domains, and domain-related user interface issues may go unnoticed or be inaccurately interpreted.

Participatory Heuristic Evaluation (PHE) is an extension to HE. To ensure an understanding of the context for which the system is being developed, PHE includes end users as work-domain experts in addition to usability experts [9]. Additionally, PHE extends the original list of heuristics to include a focus on task and work support of the system. A study has shown that work-domain experts provide equally valid results for usability inspections, although they are less thorough than usability experts [11]. We conducted a PHE of the MultiplexBCT application as part of its development phase to identify design flaws in the user interface. The scope of this paper is to report the results and benefit of the PHE conducted on the MultiplexBCT tablet computer application.

1. Materials and Methods

1.1. MultiplexBCT

The MultiplexBCT application is being developed for the Android operating system (Google Inc., Mountain View, California, USA). For the PHE the application was installed on a 10.1-inch Asus Transformer Pad TF300T (ASUSTeK Computer Inc., Taipei, Taiwan) Android tablet. When fully developed the MultiplexBCT system will be connected with a laboratory information system, however the prototype used for the PHE simulated this link. A CHS 7DiRx Bluetooth barcode scanner (Socket Mobile, Newark, California, USA) was used as an accessory for the MultiplexBCT application to support data entry through barcode scanning.

1.2. Participatory Heuristic Evaluation

The PHE consisted of two evaluator groups with four evaluators each: usability experts and work-domain experts. Three of the usability experts had a Master of Science degree in Biomedical Engineering and Informatics, and the fourth evaluator had a Master in Clinical Science and Technology degree. All usability experts had a general knowledge of the healthcare sector, but limited knowledge of clinical microbiology. All the usability experts had previous experience with HE. The work-domain experts group represented the end users of the MultiplexBCT application, and had knowledge of the

clinical laboratory context, in which the MultiplexBCT application will be used. The work-domain experts were four medical laboratory technicians. None of the work-domain experts had any previous experience with evaluating usability. All study participants were daily users of smartphones and/or tablet computers.

Before each inspection, the evaluators received both a written and verbal description of the study's purpose and method. Furthermore, each evaluator was briefed in the expected use of the MultiplexBCT application and diagnostic test. The evaluators were asked to inspect the MultiplexBCT application against a list of 15 heuristics, as defined by Muller et al. [9]: 1 – *System status*, 2 – *Task sequencing*, 3 – *Emergency exits*, 4 – *Flexibility and efficiency of use,* 5 – *Match between system and the real world*, 6 – *Consistency and standards*, 7 – *Recognition rather than recall*, 8 – *Aesthetic and minimalist design*, 9 – *Help and documentation*, 10 – *Help users recognize, diagnose, and recover from errors*, 11 – *Error prevention*, 12 – *Skills*, 13 – *Pleasurable and respectful interaction with the user*, 14 – *Quality work*, 15 – *Privacy*.

The work-domain experts group were given a more thorough explanation of heuristics than the usability experts group, due to their lack of experience with usability testing. The evaluators inspected the MultiplexBCT application individually and were asked to think aloud during the inspection.

The inspection was guided by a test leader, who gave the evaluator a series of tasks to complete, which ensured that all parts of the MultiplexBCT application was inspected. The test leader took notes and answered domain-related questions. When heuristics violations were found, they were evaluated on a severity scale defined by Nielsen ranging from 0-4 (no problem to catastrophe) [8]. A single component of the user interface could violate several different heuristics, in which case the relevant heuristics would be noted individually and each attributed a severity rating.

After the PHE had been conducted, the notes on violated heuristics from each evaluator were compiled into a single list of heuristic violations, where duplicate problems were merged.

2. Results

The usability inspection identified 132 heuristic violations, of which 42 (32%) were identified by the work-domain experts group, and 90 (68%) were identified by the usability experts group. 86 unique heuristic violations remained after duplicates were merged. 13 (15%) heuristic violations were identified by both evaluator groups, 17 (20%) were only identified by the work-domain experts group, and 56 (65%) were only identified by the usability experts group. The evaluators from the work-domain experts group identified between 6-15 (mean 10.5) of the merged heuristic violations, while the members of the usability experts group each identified 16-35 (mean 22.5). The frequency of merged heuristic violations identified is shown in Figure 1 both separately, and as combined findings.

In average, the heuristic violations were given a severity rating of 2.05 (2.14 for work-domain experts, and 2.01 for usability experts). The severity score of 0 was not used by any evaluators. The severity score of 4 corresponding to catastrophe was used four times by the usability experts and once by a work-domain expert. The catastrophe rating was used for the following heuristic categories: *Emergency exits* (1), *Consistency and standards* (1), *Help and documentation* (1), and *Quality work* (2).

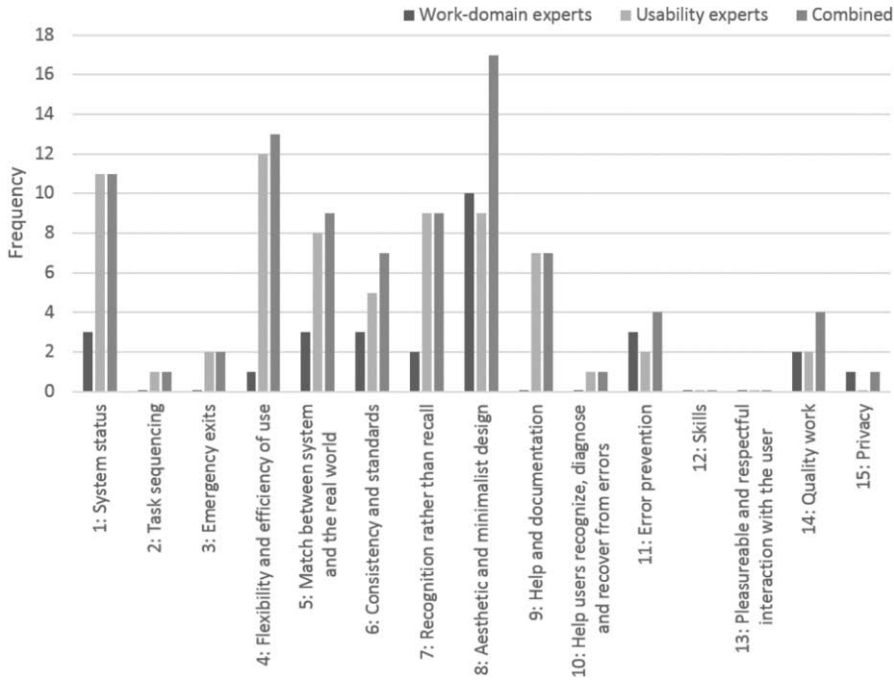


Figure 1. Frequency of merged heuristic violations identified for each of the 15 heuristics found by evaluators of the work-domain experts group, the usability experts group, and their combined result.

3. Discussion

The PHE conducted in this study revealed 86 different heuristic violations in the MultiplexBCT application prototype. Each of these heuristic violations was assigned a severity score, which allowed for prioritization of improvements for the user interface of the MultiplexBCT application. Five heuristic violations were given a catastrophe usability rating, and two of these were related to quality control, which may not have been identified without the extended heuristic list of the PHE.

The two most frequently violated heuristics were for *Aesthetic and minimalist design* and *Flexibility and efficiency of use* with 17 (20%) and 13 (15%) heuristic violations, respectively. For the heuristic violations identified for *Flexibility and efficiency of use*, the usability experts identified 12 out of 13 (92%) problems alone. The work-domain experts identified most violated heuristics for the *Aesthetic and minimalist design* heuristic with 10 out of 17 (59%). The work-domain experts could utilise their domain knowledge to recognize irrelevant information. Optimization of the user interface based on this feedback should make it easier for end users to focus on relevant information. Additionally, the work-domain experts group identified more heuristic violations for the *Error prevention* heuristic than the usability experts group, and were the only group to identify a heuristic violation related to *Privacy*. These results suggest that some heuristic categories benefit more than others may by involving end users as a complementary group to usability experts in HE when developing CIS.

The usability experts group identified 65% of the heuristic violations, which is likely a result of their usability experience. A more extensive training in heuristic evaluations of the clinical laboratory staff may have resulted in the identification of additional heuristic violations [12]. However, this may also have resulted in heuristic violations already identified by the usability experts to be found again, instead of identifying additional domain specific heuristic violations. A limitation of the study is, that some of the 17 violated heuristics identified only by the work-domain experts may also have been identified if four additional usability experts had participated in the HE, as more evaluators increase the proportion of heuristic violations found [8].

In conclusion, the PHE conducted on the MultiplexBCT Android application has been beneficial as it revealed both product- and domain-related user interface issues. Further development of the MultiplexBCT application will focus on improving the interface issues, so that the application fully supports the end user's workflow. This should lower the risk of clinical errors, and increase the chance of a successful adoption of the system in the clinical environment.

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References

[1] Slade E, Tamber PS, Vincent J. The Surviving Sepsis Campaign : raising awareness to reduce mortality. Crit Care 2003;7:1–2.
[2] Stefani S. Diagnostic techniques in bloodstream infections : where are we going ? Int J Antimicrob Agents 2009;34S:S9–S12.
[3] Samson LL, Pape-Haugaard LB, Søgaard M, Schønheyder HC, Hejlesen OK. Exploring End Users' System Requirements for a Handheld Computer Supporting Both Sepsis Test Workflow and Current IT Solutions. Stud Health Technol Inform 2013;192:524–8.
[4] Samson LL, Pape-Haugaard LB, Hejlesen OK. Eliciting requirements for a tablet-based data entry and reporting system for use in clinical microbiology laboratories to facilitate blood culture analysis: a case study. Scandinavian Conference on Health Informatics 2013:79–82.
[5] Jaspers MWM. A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. Int J Med Inform 2009;78:340–53.
[6] Ash JS, Berg M, Coiera E. Some Unintended Consequences of Information Technology in Health Care : The Nature of Patient Care Information System-related Errors. J Am Med Informatics Assoc 2004;11:104–13.
[7] Horsky J, McColgan K, Pang JE, Melnikas AJ, Linder J a, Schnipper JL, et al. Complementary methods of system usability evaluation: surveys and observations during software design and development cycles. J Biomed Inform 2010;43:782–90.
[8] Nielsen J. Usability Inspection Methods. New York: John Wiley & Sons, Inc.; 1994.
[9] Muller MJ, Matheson L, Page C, Gallup R. Methods & tools: Participatory Heuristic Evaluation. Interactions 1998:13–8.
[10] Po S, Howard S, Vetere F, Skov MB. Heuristic evaluation and mobile usability: Bridging the realism gap. Mob Human-Computer Interact 2004:49–60.
[11] Følstad A, Anda BCD, Sjøberg DIK. The usability inspection performance of work-domain experts: An empirical study. Interact Comput 2010;22:75–87.
[12] Scandurra I, Hägglund M, Engström M, Koch S. Heuristic evaluation performed by usability-educated clinicians: education and attitudes. Inf Technol Heal Care 2007;130:205–16.

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eHealth-as-a-Service (eHaaS): A data-driven decision making approach in Australian context

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Abstract. A commitment in 2010 by the Australian Federal Government to spend $466.7 million dollars on the implementation of personally controlled electronic health records (PCEHR) heralded a shift to a more effective and safer patient centric eHealth system. However, deployment of the PCEHR has met with much criticism, emphasised by poor adoption rates over the first 12 months of operation. An indifferent response by the public and healthcare providers largely sceptical of its utility and safety speaks to the complex sociotechnical drivers and obstacles inherent in the embedding of large (national) scale eHealth projects. With government efforts to inflate consumer and practitioner engagement numbers giving rise to further consumer disillusionment, broader utilitarian opportunities available with the PCEHR are at risk. This paper discusses the implications of establishing the PCEHR as the cornerstone of a holistic eHealth strategy for the aggregation of longitudinal patient information. A viewpoint is offered that the real value in patient data lies not just in the collection of data but in the integration of this information into clinical processes within the framework of a commoditised data-driven approach. Consideration is given to the eHealth-as-a-Service (eHaaS) construct as a disruptive next step for co-ordinated individualised healthcare in the Australian context.

Keywords. PCEHR, eHealth, data-driven, cloud computing, SOA, eHaaS

Introduction

The Australian national e-health strategy paints the Australian healthcare landscape as a complex network of public and private sector healthcare providers with multi-government funding and oversight [12]. Thus it is perceived by policy makers that the introduction of a national eHealth infrastructure and the personally controlled electronic health record (PCEHR) will deliver a nationally consistent approach for the implementation of interoperable information systems. However, the PCEHR has received criticism from consumers and practitioners regarding the lack of inclusive stakeholder governance and useful health information content. Moreover, resistance by practitioners and unrealised consumer expectations bring into question the functionality of the current model.

The roadmap presented by the National E-Health Transition Authority (NEHTA) clearly articulates project milestones and objectives successfully achieved over the life of the project nevertheless, sociotechnical factors inherent in projects of this scale appear to have been underestimated. As a catalyst for healthcare reform, it is suggested

that the PCEHR program be expanded as part of a larger data-driven framework. Individualised patient care is achievable with the PCEHR by facilitating large scale data scalability, analytics and visualization to augment clinical decision making. Technology trends point to emerging data capture, management and dissemination technologies driving the democratisation of data resulting in an increasingly sophisticated digital healthcare consumer. The expectation of a new generation will be to access records containing longitudinal health information online aggregating information from all data sources [5].

Establishing the PCEHR as the keystone of a holistic eHealth 'as a service' strategy unifying longitudinal patient information must take priority on the healthcare reform agenda. Moreover, the real value in patient data lies not just in the collection of data but in the integration of human-centred information into clinical processes within the framework of a commoditised data-driven approach to the delivery of care. As a preliminary work, this paper explores the proposition of developing eHealth-as-a-Service (eHaaS) as a data-driven extension to an integrated health record bank construct. The aim is to establish contextually relevant decision support modalities that will encourage universal stakeholder engagement. This will be achievable through the delivery of actionable insight extracted from vast data clouds defining the quantified digital consumer of the 21st century. Thus, the focus of this paper is an examination of where research may contribute to the development of a data-driven approach for clinical decision support and co-ordinated care management.

1. Method

The proposition encourages a top-down approach for the synthesis of current theory to establish an understanding of a multi-disciplinary coherence between technology, environment and healthcare stakeholders. As a means to develop and contextualise a theoretical framework underpinning the adoption of the eHaaS construct it is useful to conduct a preliminary literature review. The intent is to distil key concepts and identify common themes in order to consolidate an understanding of the socio-technical aspects of knowledge sharing, data unification and value creation in a complex ecosystem. Developing an informed perspective of how the eHaaS construct might be established as an appropriate data-driven platform was underpinned by searches of Web of Science, PubMed, SpringerLink, ProQuest, JAMA, IEEE Xplore, Google Scholar. Search terms relating to 'health record', 'health record bank', 'personal health record', 'PHR', 'EHR', 'PCEHR', 'health information bank', 'health information exchange', 'HIE', 'ehealth', 'health IT', 'health information technology', 'HIT', data-driven', 'decision support', 'DSS', 'CDS' 'cloud', 'big data', 'SOA' were used. This review draws on the literature published in the period between 1995 and 2013.

2. Results and Discussion

With over 150 articles accessed the review does not offer an exhaustive overview of all references due to limited time and limited space to detail. However, it does provide conceptual perspectives on future directions for sharing and adding value to health information and establishes potential research streams within the complex technology and social frameworks inherent in healthcare. Moreover, it highlights that a new

generation of consumer increasingly immersed in a personalised online ecosystem is disseminating vast amounts of data both human and machine generated. With the emergence of Big Data technologies these disparate data sets are being mined to build detailed profiles of the quantified digital consumer for actionable insights by business, government and increasingly by the life sciences. In all areas, the life sciences have evolved in the digital age into a data-enabled science [8]. Using terms like big data, data-intensive or data-driven, this type of approach to healthcare is characterised by those technologies located in the domain of data analytics, data mining, business intelligence and decision support [9].

The challenge faced by practitioners using contemporary care models is the reliance on population based statistical averages, fragmented health records, selective laboratory testing and diagnosis based on the skill and tacit knowledge of individual practitioners [3]. A data-driven approach will facilitate the analysis of large volumes of time-series data useful for pattern discovery and predictive modelling [2]. However, emphasis must be placed on reliable data and the aggregation of data from large and diverse populations to produce reliable and replicable findings [1]. The Institute of Medicine (IOM) envision future clinical decision making that leverage "personal health knowledge bases" to support practitioners in the aggregation, integration and transformation of information into actionable decisions [14]. Therefore it is suggested that the new wave in clinical decision support systems adopt a data-driven approach drawing on a multitude of relevant data repositories and sources to create "personal health knowledge bases". In conjunction with the PCEHR these systems will intelligently integrate personal information with an individualised form of evidence for collaborative decision making by the practitioner and patient [14]. To achieve this potential however requires a platform that will facilitate efficient and trusted unification of all health information available in real-time across the continuum of care. As the building blocks of an eHealth system, personal health records (PHR), electronic medical records (EMR) and Electronic Health Records (EHR) are encapsulated in the eHaaS framework with the interconnections comprising human behaviour and information flow a key design consideration [16].

2.1. Value of healthcare information

An effective interoperable health information community must establish strong partnerships between all stakeholders in a complex interdisciplinary ecosystem. Providing the "glue" for this partnership is the patient controlled integrated personal health record containing complete longitudinal patient information. While the theoretical benefits of patient controlled health records point to a reduction in costs and medical errors, improved coordination, quality of care and better stakeholder communications, the practical benefits have not yet emerged [17]. The PHR model like many emerging Internet-based health-related services, tend to exhibit limited functionality, and lack permanence [6]. Intrinsically, a unified functioning system for the exchange of comprehensive health information does not exist [5] and this can also be said for the Australian context.

While a connection to national and international health policy is drawn through the recognition that consumer engagement is critical to quality improvement and cost containment, a study based on interviews with healthcare professionals in the U.S. provide valuable insight into the importance of practitioner engagement and endorsement for successful stakeholder adoption of PHR systems [13]. When coupled

with privacy and security concerns, patient confidence and trust, practitioner liability and risk concerns, the digital divide, information ownership, transparency and policy implications, financial sustainability and information quality [18] it becomes clear that the development of an appropriate data-driven model meeting the expectations of all stakeholders is a complex undertaking.

2.2. Defining eHealth-as-a-Service

The rise of the internet as an enabling technology has resulted in the emergence of cloud computing. Best characterised by its just in time, scalable and elastic nature utilising internet technologies for the provision of IT capabilities 'as a service' [4] cloud technologies are maturing. The traditional economic drivers for its adoption is giving way to a more user and solution driven focus on innovation. According to IDC, the growing interdependence on 3rd Platform technologies - mobile, social and Big Data, signals a new phase of growth for cloud computing [7]. With forecast growth of 25.3% between 2013 and 2017, cloud services are a key enabler for organisations in the way they consume information technology [7].

Drawing a connection to the varied definitions of eHealth that encompass a broad range of medical informatics applications there is a common theme that emphasize the communicative functions of eHealth utilising the internet [15]. When surveying the literature there is an abundance of novel enabling technologies and research studies delivering improvements in the quality, safety and efficiency of healthcare. However, there remains a significant disconnect between the promise and reality in the delivery of eHealth [11]. As the architectural core for eHaaS cloud computing, application programming interfaces (API) and a service oriented architecture (SOA) based platform will deliver the rich functionality required to support complex multidisciplinary workflows. Similarly, the growing commoditisation of data requires a consolidation of cloud services that provide seamless and efficient access to health information from multiple platforms at any time from any location. However, services must be aligned to operational requirements in order to create value specific to the individual needs of the stakeholders. Thus, at the operational level, eHaaS offers a framework for identifying service models that will facilitate value creation, collaboration and knowledge sharing across the continuum of care. In this context the opportunity to address diverse perspectives inherent in eHealth programs illustrate the potential for collaboration and co-creation leveraging eHaaS (Refer Figure 1).

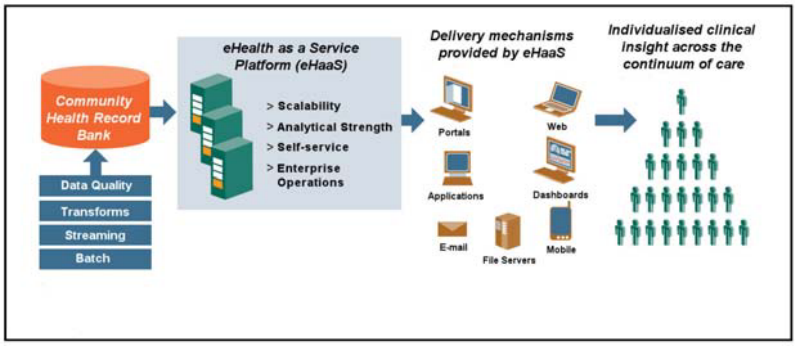


Figure 1. eHaaS conceptual model, adapted from [10]

3. Conclusion

The PCEHR represents a nascent step towards a broader more individualized approach to the delivery of care and as such requires continued support from policy makers, healthcare leaders and providers in its adoption. At the heart of a larger eHaaS initiative, an integrated PCEHR and the national eHealth infrastructure present a unique opportunity for Australian healthcare practitioners to leverage eHealth in innovative ways to improve healthcare. What is more, an eHaaS construct advances the future state perspective that truly open global healthcare systems will address the inequities in health care access and thus improve patient safety through universal stakeholder engagement.

References

[1] C. Bennett, T. Doub, and R. Selove, EHRs connect research and practice: Where predictive modeling, artificial intelligence, and clinical decision support intersect, *Health Policy and Technology* **1** (2012), 105-114.
[2] H.K. Bhargava, D.J. Power, and D. Sun, Progress in Web-based decision support technologies, *Decision Support Systems* **43** (2007), 1083-1095.
[3] N. Chawla and D. Davis, Bringing Big Data to Personalized Healthcare: A Patient-Centered Framework, *Journal of General Internal Medicine* **28** (2013), 660-665.
[4] A. Di Maio, U.S. Federal Definition of Cloud Computing: Handle With Care, in, Gartner Industry Research, Online, 2009.
[5] J.D. Gold and M.J. Ball, The Health Record Banking imperative: A conceptual model, *IBM Systems Journal* **46** (2007), 43-55.
[6] D.T. Gunter and P.N. Terry, The Emergence of National Electronic Health Record Architectures in the United States and Australia: Models, Costs, and Questions, *Journal of Medical Internet Research* **7** (2005), e3.
[7] IDC, IDC Forecasts Worldwide Public IT Cloud Services Spending to Reach Nearly $108 Billion by 2017 as Focus Shifts from Savings to Innovation, Online, 2013, p. Press Release.
[8] E. Kolker, E. Stewart, and V. Ozdemir, Opportunities and challenges for the life sciences community, *OMICS: A Journal of Integrative Biology* **16** (2012), 138-147.
[9] S. Kudyba, Healthcare informatics: improving efficiency and productivity, CRC Press, 2010.
[10] J. Markarian, S. Brobst, and J. Bedell, Critical Success Factors Deploying Pervasive BI, in: *Informatica, Teradata, Microstrategy*, 2007.
[11] C.A. Meier, M.C. Fitzgerald, and J.M. Smith, eHealth: Extending, Enhancing, and Evolving Health Care, *Annual Review of Biomedical Engineering* **15** (2013), 359-382.
[12] National E-Health and Information Principal Committee (NEHIPC), National e-Health Strategy, in: DoHA, ed., Deloitte Touche Tohmatsu., Australia, 2008.
[13] K.M. Nazi, The personal health record paradox: health care professionals' perspectives and the information ecology of personal health record systems in organizational and clinical settings, *Journal of Medical Internet Research* **15** (2013), e70.
[14] L. Olsen, D. Aisner, J.M. McGinnis, and Institute of Medicine. Roundtable on Evidence-Based Medicine, *The Learning Healthcare System: Workshop Summary*, National Academies Press, Washington, DC, 2007.
[15] C. Pagliari, D. Sloan, P. Gregor, F. Sullivan, D. Detmer, J.P. Kahan, W. Oortwijn, and S. MacGillivray, What is eHealth (4): a scoping exercise to map the field, *Journal of Medical Internet Research* **7** (2005), e9.
[16] T. Sahama, L. Simpson, and B. Lane, Security and privacy in eHealth : is it possible? A sociotechnical analysis, in: *15th International Conference on e-Health Networking, Applications and Services,* J.R. Rodrigues, ed., IEEE, Lisbon, Portugal, 2013.
[17] R. Steinbrook, Personally Controlled Online Health Data - The Next Big Thing in Medical Care?, *The New England Journal of Medicine* **358** (2008), 1653-1656.
[18] W.A. Yasnoff, L. Sweeney, and E.H. Shortliffe, Putting Health IT on the Path to Success, *The Journal of the American Medical Association* **309** (2013), 989-990.

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Heuristic evaluation and thinking aloud test of a digitized questionnaire for diabetes outpatient clinics

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Abstract. Diabetes is a chronic disease characterized by hyperglycaemia. The number of patients with diabetes is expected to exceed 592 million in 2035. The growing number of diabetics is a great burden for the Danish healthcare system. The Danish government desires a modern and efficient healthcare system with a high patient security and a coherent continuity of care. To achieve these outcomes medical record-keeping, paper questionnaires and notes must be digitized. The current system enforces that the diabetics fill out questionnaires in paper form after which the healthcare personnel enter the same information in the electronic health record. In this study, an online questionnaire was designed and the usability was evaluated using the following parameters: learnability, efficiency, memorability, errors, and satisfaction. The parameters were evaluated by using the discount usability engineering method. 5 double specialists and 6 patients diagnosed with diabetes provided the data of the study. The results indicated that simple and obvious figures were preferred in the online questionnaire, as well as error preventing in the form of validation fields. This study inspire to further development in the digitizing process.

Keywords. Usability, evaluation, thinking aloud test, diabetes, outpatient clinic, digitized questionnaire

Introduction

Diabetes is a chronic disease which typically leads to late diabetic complications, such as retinopathy, neuropathy, nephropathy, cardiovascular diseases, and problems with wound healing [1, 2]. In the USA the growing number of diabetics was estimated to cost more than $ 245 billion in 2012 [3]. The number of affected patients is expected to exceed 592 million in 2035 worldwide [4].

In order to prevent late diabetic complications, the diabetics need to attend consultations every 3rd month in diabetes outpatient clinics, where the average blood glucose level, HbA1c, is evaluated. Furthermore they are screened for late complications, and enquired about their everyday life as diabetics [5].

Each time the diabetics attend this consultation, they are required to fill out a questionnaire in paper. This questionnaire contains questions such as name, civil registration number, their current use of medicine, contact person, and their

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information etc. When the patient has filled out the questionnaire, the healthcare personnel enter the given answers in the electronic health record. This means that the healthcare personnel use unnecessary resources for documentation rather than using them to improve the consultations and empower the patients.

The use of paper questionnaires as well as the increasing number of diabetics and their consultations every 3rd month, provide challenges for the Danish healthcare system [6]. To accommodate these challenges the Danish government has, together with the Danish Regions and the National Association for the Councils, adopted The National Strategy for digitizing the Danish healthcare system. This includes the digitization of questionnaires, medical records, and miscellaneous notes [6]. The digitization process follows the new type of patient, namely patient 2.0. These patients desire a high quality and presence in consultations, as well as efficiency, technology, and patient safety [7, 8].

A systematic review by Yu et al. recommend critical assessments of web-tools consisting of efficiency, clinical usefulness, and usability, as technology can improve patient health [9, 10]. Several studies indicate that availability, interaction with healthcare professionals, and usability are important parameters regarding patient's use of technology [9, 11, 12].

The National Strategy for digitizing the Danish healthcare system and studies substantiate the need of tools with high usability. Deursen et al. find that the general user population in the USA lacks an understanding of the basics of surfing on the Internet [11]. Therefore a high usability is paramount when designing a digital questionnaire. The aim of the study was therefore to design and evaluate an online questionnaire by the discount usability engineering method.

1. Methods

To design and evaluate the online questionnaire, the discount usability engineering method was applied [13]. The method contains four elements: field work, heuristic evaluation, scenario-based study, and thinking aloud test [13].

Five paper form questionnaires, all different from one another, were acquired from five different diabetes outpatient clinics in Denmark. The five questionnaires were used as inspiration for the contents of the online questionnaire. The online questionnaire was programmed and designed in Adobe Dreamweaver CS6. When the programming was complete, two pilot studies were conducted. The pilot studies were conducted before the five heuristic evaluation sessions in order to raise the reliability of the study [13].

In order to conduct the heuristic evaluation, five double specialists were selected. Double specialists refer to persons with knowledge in the field of programming as well as health [13]. All of the double specialists had a master in Biomedical Engineering and Informatics from Aalborg University and all of them were PhD. students at Aalborg University.

Each double specialist had to identify usability issues in the digitized questionnaire. To evaluate the usability the double specialists used the usability expert Jakob Nielsen's ten heuristics [14] which can be seen in Table 1.

Table 1. Jakob Nielsen' ten heuristics and corresponding description

Heuristic number	The heuristic
1	Visibility of the system
2	Match between system and the real world
3	User control and freedom
4	Consistency and standards
5	Error preventing
6	Recognition rather than recall
7	Flexibility and efficiency of use
8	Aesthetic and minimalist design
9	Help users recognize, diagnose, and recover from errors
10	Help and documentation

[15]

Each double specialist received a brief introduction to Nielsen's heuristics, which was to be used in their evaluation. Thereafter a scenario was provided for the specialists, in order to ensure the full use of the online questionnaire [13]. The specialists were instructed to identify usability issues and rate the usability issues in the degree of severity as seen in Table 2.

Table 2. The severity rating 1 to 4 with corresponding definitions

Severity Rating	Definition
1	Cosmetic problem only: need not to be fixed unless extra time is available on project
2	Minor usability problem: fixing this should be given low priority
3	Major usability problem: important to fix, so should be given high priority
4	Usability catastrophe: imperative to fix this before product can be released

[16]

After the five heuristic evaluation sessions were completed, all the identified issues were systematized and thereafter used to redesign the online questionnaire.

Following the heuristic evaluations, the thinking aloud test was conducted. The test included six diabetics of different age, in order to test usability over a wide age spectrum. Information about the six diabetics can be seen in Table 3.

Table 3. Information regarding the six users respectively: age, diabetes type, lived years with diabetes.

User-number	Age	Diabetes type	Lived years with diabetes	Sex
User 1	64	Type 1	37	Female
User 2	67	Type 2	14	Female
User 3	69	Type 2	16	Female
User 4	17	Type 1	5	Male
User 5	18	Type 1	6	Male
User 6	50	Type 2	4	Male

Each diabetic received an introduction to the thinking aloud test. They were instructed to say out loud usability issues with the online questionnaire. This included the content, the colors, annoyances etc. [13]. After finishing the thinking aloud tests the identified usability issues were evaluated. They were then used in a second redesign of the online questionnaire.

2. Results

An online questionnaire was designed and evaluated. The five heuristic evaluations provided the following results seen in figure 1. Heuristic no. 1, *Visibility of the system* and heuristic no. 5 *Error preventing* were the most used heuristics.

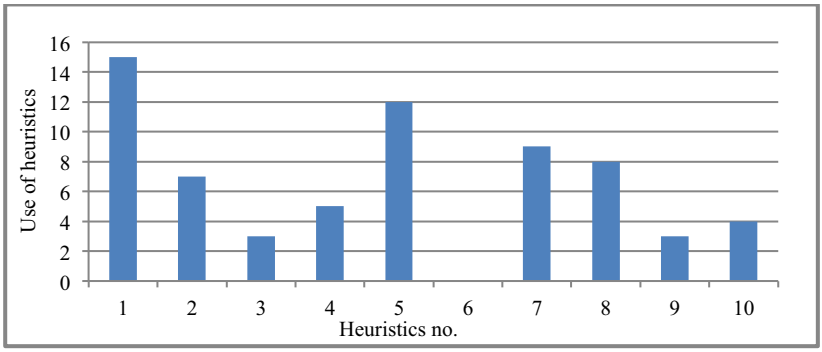


Figure 1. Use of heuristics during the heuristic evaluations

Through the six thinking aloud tests the users expressed the following wishes in regards to the online questionnaire:

- Simple figures
- Layman's terms
- Help text
- Error prevention
- Easy navigation

3. Discussion

It seems easy to digitize a paper questionnaire, but the results indicate the importance of remembering the five elements, learnability, efficiency, memorability, error, and satisfaction. Several studies confirm the importance of big font size, simple presentation in general, and a page setup that avoids scrolling [17-19]. But the big font size can conflict with the aesthetics because it does not fit the used typography on online questionnaires. Other studies show that people scan a web page instead of reading a web page [20, 21]. From that perspective easy navigation, error prevention, and simple figures are important elements to raise the efficiency, learnability, and memorability. Error prevention is easy to implement, but it comes with the risk of influencing the aesthetics negatively.

According to the usability expert Jakob Nielsen is it possible to identify 75 % of the usability issues by using only five test users - in that perspective the method is beneficial because it is easy to accomplish and it is cheap [22]. Though, there are some problems with the method. Prior to the thinking aloud tests, it was made clear to each user that their current internet skills or lack thereof, were irrelevant for the study as the evaluation of the user interface was the aim of the study [13]. It can be speculated whether they have felt the test as an examination and did not give their real opinion about the digitized questionnaire because a lack of internet skills.

An online questionnaire was designed and evaluated with the intention to provide inspiration for future digitized questionnaires in diabetes outpatient clinics. The online questionnaire paid regards to the double specialists' advises and the users wishes.

It can be assumed that the number of digitized questionnaires and other tools will increase in the future. Digitizing is also in tune with the patient 2.0, but it is important to provide help to the users that don't have the same skills as the patient 2.0 [8]. The

discount usability engineering method is systematic and holistic and pay attention to the double specialists' advises and the users wishes.

References

[1] Organization WH. Diabetes, 2013 [2.1.2014]. Available from: http://www.who.int/mediacentre/factsheets/fs312/en/index.html.

[2] Hilsted J, Borch-Johnsen K, Sandahl Christiansen J. *Diabetes*. Munksgaard Danmark, København, 2007.

[3] Association AD. Economic Costs of Diabetes in the U.S. 2012. *Diabetes Care* (2013], 1-14.

[4] Federation ID. IDF Diabetes Atlas. 6th edition. *International Diabetes Federation* (2014], 19-48

[5] Sundhedsstyrelsens Diabetesstyregruppe - Enheden for Planlægning S. Det gode patientforløb og senkomplikationer. *Sundhedsstyrelsen* (2004), 1-17.

[6] Institut SS. Digitalisering med effekt - National strategi for digitalisering af sundhedsvæsenet 2013-2017. *Statens Serum Institut* (2013), 19-48.

[7] Chinn D. Critical health literacy: A review and critical analysis. *Social Science and Medicine* (2011), 60-67.

[8] Bos et al. Patient 2.0 empowerment. *International Conference on Semantic* (2008), 164-167.

[9] Yu et al. Systematic review and evaluation of web-accessible tools for management of diabetes and related cardiovascular risk factors by patients and healthcare providers. *Journal of the American Medical Information Association* (2012);19(4), 514-522.

[10] Collins SA, et al. Health literacy screening instruments for eHealth applications: a systematic review. *Journal of biomedical informatics* (2012);45(3), 598-607.

[11] van Deursen AJ, et al. Internet skills performance tests: are people ready for eHealth? *Journal of medical Internet research* (2011);13(2), 35.

[12] Grahame M. et al. Age differences in search of web pages: the effects of link size, link number, and clutter. *Human Factors: The Journal of Human Factors and Ergonomics Society* (2004);46(3), 385-398.

[13] Nielsen J. *Usability engineering*. Morgan Kaufmann Publishers Inc. San Francisco, CA, USA, 1993.

[14] Nielsen J. Usability 101: Introduction to Usability, 2012 [3.1.2014]. Available from: http://www.nngroup.com/articles/usability-101-introduction-to-usability/.

[15] Nielsen J. 10 Usability Heuristics for User Interface Design, 1995 [3.1.2014]. Available from: http://www.nngroup.com/articles/ten-usability-heuristics/.

[16] Nielsen J. Severity Ratings for Usability Problems, 1995 [3.1.2014]. Available from: http://www.nngroup.com/articles/how-to-rate-the-severity-of-usability-problems/.

[17] Turner-Bowker DM, et al. Heuristic evaluation and usability testing of a computerized patient-reported outcomes survey for headache sufferers. *Telemedicine and e-Health* (2011); 17(1), 40-45.

[18] Kahn P, Lenk K. Principles of Typography for User Interface Design. *Magazine interactions* (1998); 5(6), 1-15.

[19] Melody IY, Megrew R. Evolution of Web Site Design Patterns. *ACM Transactions on Information System* (2005); 23(4), 463-397.

[20] Nielsen J. How Users Read on the Web NN/g Nielsen Norman Group, Evidence-Based User Experience Research, Training, and Consulting, 1997. Available from: http://www.nngroup.com/articles/how-users-read-on-the-web/.

[21] John Morkers JN. Concise, Scanable, and Objective: How to Write for the Web NN/g Nielsen Norman Group - Evidence-Based User Experience Research, Training, and Consulting, 1997. Available from: http://www.nngroup.com/articles/concise-scannable-and-objective-how-to-write-for-the-web/.

[22] Nielsen J. Why You Inly Need to Test with 5 Users, 2000 [3.1.2014]. Available from: http://www.nngroup.com/articles/why-you-only-need-to-test-with-5-users/.

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Evaluation of a Clinical Simulation-based Assessment Method for EHR-platforms

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Abstract. In a procurement process assessment of issues like human factors and interaction between technology and end-users can be challenging. In a large public procurement of an Electronic health record-platform (EHR-platform) in Denmark a clinical simulation-based method for assessing and comparing human factor issues was developed and evaluated. This paper describes the evaluation of the method, its advantages and disadvantages. Our findings showed that clinical simulation is beneficial for assessing user satisfaction, usefulness and patient safety, all though it is resource demanding. The method made it possible to assess qualitative topics during the procurement and it provides an excellent ground for user involvement.

Keywords. Clinical simulation, eHealth, Human Factor, Procurement, Assessment

Introduction

Qualitative aspects such as human factors and interaction between technology and end-users are generally challenging to assess. In a public procurement process (PPP) one further have to follow strict rules, where the assessment must be quantitative in order to equally and precisely compare the offered information systems. Typically, assessment in a PPP is done by structured assessment of the vendors' textual descriptions of the offered solutions and their written replies to the requirement specification. Assessments of textual descriptions however, are insufficient in order to fully assess human factor issues [1]. Clinical simulation is a well-known qualitative method for evaluating clinical information systems; the method is useful to illuminate the interaction between technology and human factors [2-6]. While the literature is comprehensive regarding descriptions of how clinical simulation can be used in evaluation of a single information system, literature is limited on how simulation can be used to systematically assess and compare several information systems and their support of clinical work processes in a PPP.

In connection with a large PPP of an EHR-platform in two large regions in Denmark, covering 40.000 clinicians, 20 hospitals serving 2.5 mill citizens, we have developed and evaluated a clinical simulation-based method for assessing and comparing human factor issues [7]. The method was developed to support assessment of qualitative aspects such as user experience, usability and patient safety. While the method

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draws upon existing and well documented practices of evaluation of human factor issues [4,8-10] it was necessary to make some adjustments to these practices because of the rigid nature of a PPP. The PPP implies several challenges to the use of a qualitative assessment approach: 1) assessment results must be comparable, 2) assessment of the different EHR-platforms must be done uniformly, 3) the process has to be transparent, 4) the results have to be easily collected and rapidly analyzed. The size of the actual PPP further adds a couple of challenges 1) all aspects of the EHR-platform should be covered, 2) all clinical specialties and professional needs should be dealt with, 3) all possible types of users should be considered and preferably included in the assessment.

The assessment method was developed based on our previous experience with simulations [4, 9-12] and applied in practice in the PPP process. The aim of the simulation set-up was primarily to assess the three EHR-platforms in case and secondarily to actively involve clinicians in the PPP. The aim of this paper is to describe the evaluation of the method, its advantages and disadvantages. The evaluation of the method is described according to the three aspects of human factor issues that the method was designed to cover; 1) user satisfaction, 2) usefulness and 3) patient safety.

1. Methods

The purpose of the evaluation of the assessment method was to answer the following questions: 1) what is the eligibility of the method, 2) what are the advantages/disadvantages compared with other assessment methods, and 3) reveal possible issues to be improved. The assessment covered 12 clinical scenarios and 18 health professionals from various specialties and professions. Three EHR-platforms were assessed during a period of 10 working days. The clinicians had a full day of training in each of the three platforms followed by two days of clinical simulation [7], after accomplishment of a simulation scenario the clinicians assessed how the tested platform supported the task. The testing was scheduled in three subsequent three-day periods, where the clinicians would scrutinize all the platforms.

The evaluation of the assessment method was qualitative, including observations and semi-structured interviews of key actors and participating clinicians. Observations were conducted during 10 days of assessment, and on the last day all clinicians were interviewed in three groups. Subsequently 15 interviews were conducted with project and legal managers, health informatics, vendors, patient safety experts, and observers during the clinical simulations. The qualitative approach enabled us to conduct the evaluation without interfering with the assessment process, and concurrently obtain a thorough insight in user experiences and perceived benefits and challenges of the method. All interviews were transcribed, and analyzed using a qualitative approach of content data analysis.

2. Results

There was a high level of concordance among the interviewees in the study. The results from the interviews supported the findings from the observations in the study. Generally, the use of ‘patients’ in the simulations supported fidelity of the scenarios and facilitated a smooth flow in the simulations. The clinicians however expressed that the patient cases lacked complexity; there were fewer patients than in every-day work, the

working environment was less stressful than normal. Furthermore, they found it difficult to learn a complete new EHR-platform in the short time given. The evaluation results in table 1 below reflect the three themes the method was designed to address.

Table 1 Results from evaluation of assessment method.

User satisfaction
• Subjective evaluation of user satisfaction is easily done by clinical simulation followed by questionnaires, but objective assessment of user satisfaction is difficult, due to the close correlation to work practice and clinical tasks. • It was difficult to assess minor variances in ease of use. • Clinical simulation supports user involvement, but it is difficult to assess other aspects than the end-user aspect in the assessment. • Use of all the tested EHR-platforms during the testing period made it possible to reflect on and assess each of the platforms and their differences. • There were a lot of interruptions during the simulations, which affected the fidelity and realism and made it difficult to observe the usability on the spot. • The standardized assessment questionnaires supported the clinicians in assessing each single system and their diversity.
Usefulness
• Clinical simulation was an efficient way to exhaustively examine the vendors' textual descriptions of the platforms. • The assessment method made it possible to gain deep insight in the EHR-platforms and how they provided support of work practice and needs and consideration concerning organizational implementation • Clinicians perceived clinical simulation as a good way to be involved in the PPP • Assessment across specialties and healthcare professions were made possible and differences in clinical requirements became obvious. • Structured training provided insight in other parts of the EHR-platforms, than users would have obtained if they were to explore the platforms on their own. • Scenarios covered most standard procedures and daily work practices and made it possible to gain insight in how the EHR-platforms supported patient encounters. • Functional fidelity was high even though the EHR-platforms had not been configured according to the local work practices and the clinicians were fully capable of distinguishing between clinical tasks and system functionality.
Patient safety
• Assessment of patient safety issues lies in the detail and is difficult to define in general requirements that most often are truisms of little significance. • Explicated patient safety requirements and a mention of patient safety assessment issues in the procurement material would legalize patient safety questions in questionnaires and use of patient safety experts as observers during clinical simulation. • Clinical simulation may reveal safety aspect not evident from textual descriptions. • The method could have benefitted by using patient safety experts as observers.
General
• Assessment criteria should be defined early in the PPP and clear requirements regarding human factors and patient safety should be part of the requirement specification. • Vendors found they were treated equally and fair, but would have preferred to use their own test data as implementation of scenario test data was resource exhausting.

3. Discussion

Regarding the eligibility of clinical simulation as a method to uniformly assess human factor issues in PPP's, we found that the method is indeed useful and makes it possible to assess qualitative aspects that are otherwise difficult to specify and assess [3]. Careful attention is however essential in order to develop textual requirements that can provide a solid foundation for the assessment criteria.

Clinical simulation is a sufficient method for assessing user satisfaction as it gives the users firsthand experience with the EHR-platforms in a close to real-life setting focusing on the interaction between technology, users and work practice. Although it was hard for the clinicians to obtain proficiency with the EHR-platforms within the short assessment period, they were able to state the reasons for good and bad user experiences in each of the three EHR-platforms. Training the simulation facilitator more extensively in the EHR-platforms, to enable comprehensive guidance on platform functionality during the simulations, might compensate for the lack of proficiency. Compared to other methods like heuristic inspection and low fidelity usability evaluation, clinical simulation has an advantage in taking into account the clinical context where other methods tend to focus at just one or two topics without the clinical context. Heuristic inspection focus only on the user interface and low fidelity usability test focuses on technology, and specific task for single users. These methods may however complement the clinical simulation in making a rigorous assessment of the user interface.

Regarding usefulness the clinicians found that the clinical simulation facilitated an understanding of how well the assessed EHR-platforms could support daily clinical work practices. At first there was some reluctance to work in interdisciplinary groups but this proved to be essential in facilitating a richer understanding of the functionality of the EHR-platforms in collaborative work situations. This would not have been possible in a low fidelity usability test where a single user solves a single task.

Patient safety issues proved to be especially hard to assess due to the fact that many patient safety challenges lies in the details and are triggered by unintended incidents and disturbances. It can therefore be hard, or nearly impossible, to pinpoint these challenges beforehand, instead they need to be explored along the way. Clinical simulation is however an appropriate method for assessment of patient safety aspects as it provides a comprehensive view on the IT-system taking into account the correlation between IT, work practice and unintended incidents. It is our recommendation though that in order to gain in depth views on patient safety issues this should be done in close collaboration with patient safety experts.

It is a difficult balance to make the assessment process transparent and uniform and to ensure that the scenarios are realistic and relevant for the customer and at the same time let the vendors into the decision on scenarios, test data and configurations. The assessment was not blinded, and by involving users there is a risk of mutual influence. This may be dealt with in the design of the simulation set-up. We however found that the benefits of involving users across specialties and professions were superior to these challenges.

Clinical simulation makes it possible to assess qualitative aspects that are otherwise difficult to measure, like patient safety and human factors [3]. In the requirement specification one try to specify something that is superior to what you already have, in return you get a textual description from the vendor that you try to assess by marks. Use of clinical simulation in the early phases of the procurement process may improve assessment of the offerings and make it possible to expose and assess qualitative as-

pects such as human factor, patient safety and support of work practice [4;5]. Patient safety issues are difficult to describe in sufficient detail and assess without involving clinical context and work practice either in real life or in a simulated set-up. In PPPs assessment in real life is seldom possible, whereas clinical simulation is a very suitable substitute. To set up a clinical simulation-based assessment in a PPP is a huge task, but in on our experience it should be done hence the impact of the procured platform on the healthcare organization is immense, so the value of making the procurement on a thoroughly enlightened base cannot be overestimated. The assessment may further be applied as a basis to discuss future challenges and possibilities in the implementation of the platform [12].

We can conclude that clinical simulation based assessment in a PPP is beneficial for gaining insight in user satisfaction, usefulness and patient safety. Traditional methods focus on the relation between users and user interfaces without involving the clinical context, whereas clinical simulation illuminates the relation between users, technology and work practice and hereby provides deep insight in the offered system. The applied assessment process made it possible to systematically assess each of the platforms and their differences. Clinical simulation is eligible in PPP of clinical information systems as supplement to other assessment activities. Clinical simulation is a recommendable method for assessing user satisfaction, usefulness and patient safety and provides an excellent ground for user involvement and giving voice to the users. We recommend clinical simulation to be supplemented with low fidelity usability evaluation and heuristic evaluation for assessment of minor variances in ease of use.

References

[1] Ammenwerth E, Graber S, Herrmann G, Burkle T, Konig J. Evaluation of health information systems problems and challenges . Int J Med Inform 2003 Sep;71(2-3):125-35.
[2] Borycki EM, Kushniruk AW, Kuwata S, Kannry J. Use of Simulation Approaches in the Study of Clinician Workflow. AMIA Annu Symp Proc 2006;61-5.
[3] Jensen S, Lyng KM, Nohr C. The role of simulation in clinical information systems development. Stud Health Technol Inform 2012;180:373-7.
[4] Jensen S, Vingtoft S, Nohr C. Benefits of a clinical planning and coordination module: a simulation study. Stud Health Technol Inform 2013;183:220-4.
[5] Kushniruk A, Borycki E, Kuwata S, Kannry J. Predicting changes in workflow resulting from healthcare information systems: ensuring the safety of healthcare. Healthc Q 2006 Oct;9 Spec No:114-8.
[6] Kushniruk AW, Patel VL. Cognitive evaluation of decision making processes and assessment of information technology in medicine. Int J Med Inform 1998 Aug;51(2-3):83-90.
[7] Jensen S, Rasmussen SL, Lyng KM. Use of clinical simulation for assessment in EHR-procurement: design of method. Stud Health Technol Inform 2013;192:576-80.
[8] Ammenwerth E, Hackl WO, Binzer K, Christoffersen TE, Jensen S, Lawton K, et al. Simulation Studies for the evaluation of health information technologies: experiences and results. HIM J 2012;41(2):14-21.
[9] Kushniruk A, Nohr C, et al. From Usability Testing to Clinical Simulations: Bringing Context into the Design and Evaluation of Usable and Safe Health Information Techn. Contribution of IMIA Human Factors Engineering for Healthcare Inform Working Group. Yearb Med Inform 2013;8(1):78-85.
[10] Rasmussen SL, Lyng KM, Jensen S. Achieving IT-supported standardized nursing documentation through participatory design. Stud Health Technol Inform 2012;180:1055-9.
[11] Jensen S, Nohr C, Rasmussen SL. Fidelity in clinical simulation: how low can you go? Stud Health Technol Inform 2013;194:147-53.
[12] Rasmussen SL, Jensen S, Lyng KM. Clinical simulation as a boundary object in design of health IT-systems. Stud Health Technol Inform 2013;194:173-8.

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Revisiting Heuristic Evaluation Methods to Improve the Reliability of Findings

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Abstract. The heuristic evaluation (HE) method is one of the most common in the suite of tools for usability evaluations because it is a fast, inexpensive and resource-efficient process in relation to the many usability issues it generates. The method emphasizes completely independent initial expert evaluations. Inter-rater reliability and agreement coefficients are not calculated. The variability across evaluators, even dual domain experts, can be significant as is seen in the case study here. The implications of this wide variability mean that results are unique to each HE, results are not readily reproducible and HE research on usability is not yet creating a uniform body of knowledge. We offer recommendations to improve the science by incorporating selected techniques from qualitative research: calculating inter-rater reliability and agreement scores, creating a codebook to define concepts/categories and offering crucial information about raters' backgrounds, agreement techniques and the evaluation setting.

Keywords. Heuristic Evaluation, eHealth, mHealth, Usability Research Methods

Introduction

The hallmarks of building science include the reliability and reproducibility of findings. Thus, commonly accepted research methods include techniques such as a priori definitions, initial consensus discussions among evaluators and calculations for inter-rater reliability (IRR) before independent evaluations begin. On the other hand, usability methods such as heuristic evaluation (HE) run counter to these time-honored techniques. HE emphasizes independent, individual evaluations and the generation of unique usability problems that are subsequently compiled and assigned to general heuristic categories. Expert evaluators are specifically cautioned not to cooperate during initial product assessments. While these methods allow for independent thinking and maximizing initial usability problem identification, they also make the results unique to each evaluation and are not, therefore, readily reproducible. Building science using this technique is difficult due to the large variability across evaluators and the lack of consensus on terms and definitions of usability problems. In this paper we use a current HE as a case study and offer suggestions to modify the technique to improve the reliability and reproducibility of heuristic evaluation findings. These modifications

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would result in important additions to the HE method and building a body of knowledge for usability evaluations employing heuristic evaluations.

1. Methods

The HE method is one of the most common in the suite of tools for user-centered design because it is fast, inexpensive and resource-efficient while yielding many usability issues [1, 2]. It is an informal expert usability evaluation first designed by Nielsen and Molich, [3, 4] published in 1994 [5] and is still used today [6]. The classic method has 10 heuristic categories assigned to a usability problem: H1 - Visibility of system status, H2-Match between the system and real world, H3 - User control and freedom, H4-Consistency and standards, H5 - Error prevention, H6 - Recognition rather than recall, H7 - Flexibility and efficiency of use, H8 - Aesthetic and minimalist design, H9 - Help users recognize, diagnose and recover from errors, H10 - Help and documentation [5]. Severity ratings are then determined according to impacts using this scale: 0 Not a usability problem at all, 1 Cosmetic problem only, 2 Minor usability problem, 3 Major usability problem, 4 Usability catastrophe [5].

Identified usability experts independently use typical user tasks to interact with the product's interface, determine existing usability problems and assign specific heuristic(s) violation(s) to each identified problem. Nielsen specifically indicates that communication among evaluators occurs only after the independent evaluations. Only then are the problems combined and discussed among the experts. After having reached consensus on the initial ascribed problems, any duplicates are removed, and the problems are compiled into a master list. The master list is sent out anew to each evaluator to be rated independently for severity and then averaged for each issue.

Nielsen and Molich stated their method is improved by having several evaluators because they provide collective expertise to the process [3]. Nielsen [6] recommended three to five evaluators identify usability issues and provide the associated severity ratings [1]. Three to five expert evaluators find on average between 74% and 87% of the extant usability problems [6]. Results are even higher if the expert evaluators have dual domain backgrounds such as expertise in both usability and the topic/domain at hand. As few as two to three dual domain experts typically find significantly more problems, e.g., between 81% and 90% of existing usability problems [6].

1.1. Sample Project to Illustrate HE Methodological Issues

To illustrate typical issues with the current heuristic evaluation method, we use a recent HE process as an example. The data were part of a larger project for a mHealth self-management system for diabetes patients where patients were able to monitor online parameters for their disease such as glucose levels, blood pressure, exercise and weight Three double domain experts (usability and PhD-prepared registered nurses) evaluated the diabetes mHealth application using Nielsen's HE guidelines described above [5, 6].

To begin, each evaluator viewed a short video demonstrating the application. The evaluators had a guide with common scenarios for interacting with the system and tasks representing patients' typical use such as entering and modifying values, interpreting measurements, and set goals. These preliminary steps were done to increase the consistency of the evaluation process across experts and to assure all evaluators had the same familiarity with the application. In congruence with Nielsen's guidelines, the

evaluators performed the same eight tasks during their interactions with the application and independently identified usability problems to determine their compliance with Nielsen's published heuristics.

The evaluators discussed identified usability problems after completing the evaluations. They compiled a master list of problems by consensus. The master list was then sent out to evaluators for their independent severity ratings; these were averaged to determine an overall severity rating for each usability problem.

Nielsen is silent about the need for inter-rater reliability (IRR) in the HE process. However, for the purposes here and to illustrate our points about lack of reliability across all evaluators, we used Krippendorff's α (alpha), an IRR method recommended for use with more than two raters. This method accommodates both larger and smaller sets of data as well as missing data. It is particularly recommended for fully-crossed designs (using the same set of evaluators) and ordinal data [7, 8]. We used SPSS statistical software program (version 22.0) with the KALPHA macro [8].

2. Results

Initial independent ratings resulted in 141 usability problems and 289 assigned heuristic violations. Evaluator 1 detected 86 usability problems, evaluator 2 found 33 usability problems and evaluator 3 discovered 22 usability problems. The initial problems were at various levels of conceptualization, levels of granularity and the issues overlapped in some cases. IRR on the problems and heuristic categories was not able to be calculated due to the varying conceptualizations, although the variability across evaluators was clear. Subsequently, the evaluators examined the usability problems in detail, discussed and consolidated them where feasible. Only nine initial problems were the same across all evaluators and these were consolidated into three overall usability problems. Two evaluators found 12 usability problems that were similar and these were consolidated into six issues. The remaining 120 were unique usability issues. This process resulted in a final master list of 129 usability issues.

Severity ratings had similar variability. Evaluators rated 17 of the 129 problems with the same severity score. Two of the three evaluators had the same rating for 90 problems, but for the remaining 22 usability issues, no similarities existed. At this point in the process, Nielsen recommends calculating mean severity scores, but we were curious about the extent of variability. The percentage of agreement between the three evaluators on all problems was 13.18%. When Krippendorff's α was calculated with the KALPHA macro for inter-rater reliability the result was very low - 0.0815 (Table 1).

Table 1. Krippendorff's α Reliability Estimate

A	Units	Observers	Decisions
0.0815	129	3	387

3. Discussion

The wide variability across even dual-domain evaluators is evident. For initial usability problem identification, the numbers, levels and types of usability problems varied as did the assigned heuristics. Only nine common usability problems were identified across all evaluators and 120 issues were unique. For the severity scores, the inter-rater

reliability (IRR) was a mere 13.18% (KALPHA less than α 0.10) across the three evaluators. This variability existed despite the fact that the three evaluators were prepared at the PhD level, were informatics experts and dual domain experts in both nursing and usability methods. The reasons for the differences include variation backgrounds, expertise and human judgment that is common across most domains. Another possible for the reason for this variability is that the underlying dimensions of usability are, in themselves, not valid. These differences were the genesis for this article.

This variability is not atypical of HE results. Past usability experts have not quantified the extent of the existing variability or called attention to its implications. After reviewing numerous publications, we conclude that HE evaluators have not in the past and do not currently calculate IRR. From the perspective of our ability to build science, extensive variability is a concern and additions to the HE method from qualitative research are recommended.

3.1. Recommendations for Improving Heuristic Evaluation Techniques

The scientific goals of assessing reliability of measurement in heuristic evaluation (HE) are two-fold. First, establishing reliability of judgment supports the validity of the categories. Further work should address questions of validity, e.g., two disease states may have the same signs and symptoms, but we need characteristics to distinguish between the two or we have to conclude that they are the same disease. A second perspective is to assume that the categories exist and can be measured the same by different raters (IRR). These speak to the generalizability of findings.

Improving HE techniques requires distinguishing between these two goals. Establishing the first goal requires assessing what is traditionally known as IRR (inter-rater reliability). IRR metrics vary depending on the type of data, but Kappa, Kendall coefficient of concordance and Krippendorff's α are recommended for ordinal and categorical data, e.g. HE methods, as they correct for chance agreement. Although a high IRR supports that the individual raters can reliably discriminate categories and therefore, the categories have validity, it doesn't say much about the degree of agreement between raters, which would relate to the generalizability of results. To be able to make the claim that different raters would "see" the same categories, a measure of inter-rater agreement (IRA) is also required. The simplest of these is the percent agreement. Some metrics include both, such as the Bland-Altman plots and the Intra-class correlation metric usually used for interval or ratio data [9-11].

In the field of usability, the next step in building a scientific foundation is to both report these two statistics and to conduct the necessary work to reach an acceptable level. To more fully understand what the usability problems, HE categories and severity assessments mean in terms of future research and development, information is also necessary about the background of the raters, specific procedures used to build IRA and the evaluation settings. While creating consensus on a master list is helpful, a priori IRR/IRA processes provide better reliability.

We strongly advise the creation of a codebook, an iterative process of establishing IRA/IRR. The codebook is the information needed by other researchers to establish reproducibility of results and should be provided in the appendices of published HE assessments. Establishing IRA is a rich experience that allows researchers to more fully comprehend the nature of the phenomena being investigated; science will be significantly improved as a result of adding this level of depth to the HE process [12].

The benefits for modifying HE techniques are clear. A priori definitions, common understanding of usability problems/categories derived from initial consensus discussions, and obtaining adequate IRR/IRA before independent expert evaluations would allow evaluators to create reliable and reproducible results for HE assessments in the future. A challenge is also obvious. A priori work will mean it will take more time to create the products that will improve the consistency of results across and among evaluators. This is in contrast to the published HE benefits, that HE is a discount usability technique cited as fast and resource efficient [1, 3]. However, this challenge is off-set with the knowledge that others could use these products and obtain consistent results.

4. Conclusions

Current methods in heuristic evaluation promote significant variability in usability problem generation and severity ratings even across dual domain expert evaluators. In contrast, building science requires techniques that emphasize reliability and the reproducibility of results. In this paper, we used a case study to illustrate the wide variability of findings across dual domain experts. We recommend that future usability researchers incorporate several crucial qualitative research techniques into heuristic evaluations. Specifically, we recommend developing a coding manual, calculating inter-rater reliability and inter-rater agreement among evaluators and providing information about evaluators and settings. These modifications will allow evaluators to be more consistent, results to be reproducible and a more uniform body of knowledge in usability evaluations will be available.

References

[1] Nielsen J. Usability engineering. Boston: Academic Press; 1993. xiv. p. 358.
[2] Jeffries R, et al., User interface evaluation in the real world: A comparison of four techniques, in Proceedings of the SIGCHI Conference on Human Factors in Computing System; New Orleans, Louisiana, USA; 1991. p. 119-124.
[3] Nielsen J, Molich R. Heuristic evaluation of user interfaces. In: Proceedings of the SIGCHI conference on Human factors in Computing Systems: Empowering People;Seattle, Washington, United States; 1990. p. 249-256.
[4] Molich R, Nielsen J. Improving a human-computer dialogue. Commun ACM. 1990; 33(3): 338-348.
[5] Nielsen J. Heuristic evaluation. In: Mack RL, Nielsen J, editors. Usability inspection methods. New York: John Wiley & Sons inc.; 1994. p. 25-62.
[6] Nielsen J. Ten usability heuristics. Available from: http://www.nngroup.com/articles/ten-usability-heuristics. Accessed April 23, 2014.
[7] Nielsen J. Finding usability problems through heuristic evaluation. Proceedings of the SIGCHI conference on Human factors in computing systems; Monterey, California, United States. ACM; 1992. p. 373-80.
[8] Hayes AF, Krippendorff K. Answering the Call for a Standard Reliability Measure for Coding Data. Commun Meth Meas. 2007;1(1):77-89.
[9] deVet H, Terwee CB, Knol DL, Bouter LM. When to use agreement versus reliability measures. J Clin Epidemiol. 2006;59:1033–39.
[10] Gisev N, Bell JS, Chen TF. Inter-rater agreement and inter-rater reliability: Key concepts, approaches and applications. Res Soc Admin Pharm. 2013; 9(3), 330-8.
[11] Kottner JL, Audige L, Brorson S., et al. Guidelines for reporting reliability and agreement studies (GRRAS) were proposed. J Clin Epidemiol. 2011; (64): 96–106.
[12] Streiner DL, Norman GR. Health Measurement Scales: A Practical Guide to Their Development and Use, 4th ed. New York, NY: Oxford University Press; 2008.

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Quality of life of patients with spinal cord injury in Italy: preliminary evaluation

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Abstract. Quality of life is a complex concept, entailing the person's physical health and level of independence, as well as psychological well-being, social participation and the relationship with specific and relevant aspects of the environment. The World Health Organization encourages the integration of a comprehensive definition of health when examining patient-related outcomes after injury or disease. This study aims at evaluating the quality of life of 130 Italian patients with spinal cord injury, focusing on the associations among functional status and health dimensions elicited by SF-36 questionnaire. The subscale scores that revealed a stronger impact of the lesion were those related to the physical domains, especially for the physical functioning and physical role functioning. Physical functioning scores were significantly different in the acute phase with respect to chronic phase, in inpatients with respect to outpatients and in patients with lower functional impairment versus patients with higher functional impairment. Moreover, the functional impairment influenced significantly physical role, bodily pain and vitality scales. Disease phases also showed significantly different scores for general health. No differences were highlighted between tetraplegic and paraplegic patients.

Keywords. Spinal cord injury, quality of life, SF-36

Introduction

Faced with the ever increasing demands for health services, national health systems have become interested in the effectiveness and cost-effectiveness of health care interventions. Patient-perceived health has become an important outcome of health care, and therefore a measure of effectiveness. An important consequence has been the development and promotion of generic profile measures of health status.

Health status measures are being used extensively in clinical trials, but they have a number of weaknesses for use in economic evaluations [1]. The main approach in health economics and, more in general, in medical decision making, is to value a health status in a single unit of measure known as "quality adjusted life years" (QALYs) [2,3], which reflects both life expectancy and quality of life.

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Actually, the World Health Organization's International Classification of Functioning, Disability and Health encourages the integration of a comprehensive definition of health when examining patient-related outcomes after injury or disease [4]. One of the most relevant disabilities is caused by spinal cord injury (SCI). Typical causes of spinal cord damage are trauma (such as a traffic collision, diving into shallow water, a fall, a sports injury), disease (such as transverse myelitis, multiple sclerosis or polio), or congenital disorders (such as spina bipida). Tetraplegia, also known as quadriplegia, is a paralysis caused by illness or injury that results in the partial or total loss of use of all limbs and torso; paraplegia is similar but does not affect the arms. The loss is usually sensory and motor, which means that both sensation and control are lost [5]. The rehabilitation process following a spinal cord injury typically begins in the acute care setting. Physical therapists, occupational therapists, social workers, psychologists and other healthcare professionals typically work as a team under the coordination of a physiatrist to decide on goals with the patient and develop a plan of discharge that is appropriate for the patient's condition. A primary goal of rehabilitation is to restore, to the greatest possible extent, the physical functioning of an individual after illness or injury.

The aim of this study is twofold: 1) to evaluate the quality of life (QoL) of patients with SCI, focusing on the associations among functional status and health dimensions and 2) to provide a synthetic quality of life index to be used in cost-utility analyses involving SCI patients.

1. Methods

To date, a specific, validated tool for assessing quality of life in patients with SCI is not available to our knowledge. A recent meta-analysis [6] identified the SF-36 questionnaire as the most commonly used QoL instrument in the SCI literature. It has been widely promoted by the International Quality Of Life Assessment project [7] and translations have been developed and validated for more than 60 countries. Anyway, only few studies have evaluated the quality of life of SCI patients through this questionnaire in Italy and these studies involved a limited number of patients [8, 9].

The SF-36 is a 36-item self-administered survey that measures 8 health domains: physical functioning (PF), social functioning (SF), role limitations due to physical health (RP), role limitations due to mental health (MH), general health (GH), emotional well-being (RE), vitality (VT), and bodily pain (BP) [10]. The health domains described in the SF-36 range in score from 0 to 100, with higher scores representing higher levels of functioning or better health. From these scores, two further synthetic indexes may be calculated: physical (PSI) and mental (MSI).

The SF-36 questionnaire was not originally conceived to provide a utility coefficient (U), i.e. a single value that can be directly used to calculate QALYs. However, as for other similar scales, a number of mapping functions have been developed to convert its scores into a utility value. For this study we applied the algorithm developed by Brazier and colleagues [11].

The SF-36 questionnaire has been administered to 130 SCI patients treated at the Spinal Unit of Maugeri IRCCS Foundation. Patients were recruited consecutively from January 2013 to January 2014. Spinal cord injuries were classified as complete and incomplete by the American Spinal Injury Association (ASIA) classification [12]. The ASIA scale grades patients based on their functional impairment as a result of the

injury, grading a patient from A to E where: A = Complete: no motor or sensory function is preserved in the sacral segments S4-S5; B = Incomplete: sensory but not motor function is preserved below the neurological level, including the sacral segments S4-S5; C = Incomplete: motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3; D = Incomplete: motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more; E = Normal: motor and sensory functions are normal.

A Microsoft Access database has been developed to collect patients' personal data (age, gender, disease phase – acute/chronic, ASIA grade – A or B/C or D, paralysis type – tetraplegia/paraplegia, patient status – inpatient/outpatient, cause of the lesion – traumatic/not traumatic). A user-friendly interface has been designed to input all the questionnaire responses and to implement the conversion algorithm that calculates for each questionnaire the scores of the 8 SF-36 scales plus two synthetic indexes, physical and mental (Figure 1). For the utility coefficients calculation an Excel file delivered by Brazier and colleagues was utilized.

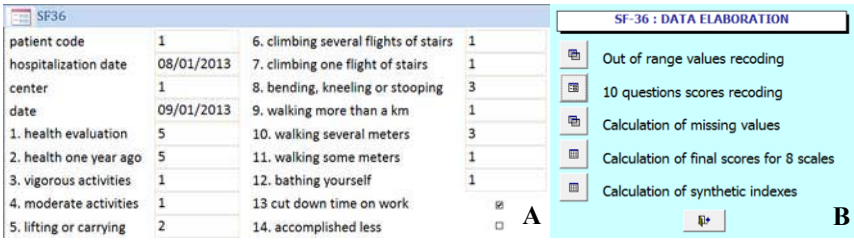


Figure 1. User-friendly interface for data input (A) and data elaboration (B)

Respondents' quality of life was evaluated comparing the distributions of all the scales in different groups of patients (Mann-Whitney test) related to gender, disease phase, ASIA grade, paralysis type and patient status.

2. Results

At the time of the questionnaire administration, 82 out of 130 patients were hospitalised while the remaining 48 were outpatients. Sixty-six patients presented a traumatic spinal cord injury and sixty-four non-traumatic injuries/illnesses. Median age was 54 years in men and 60 years in women. Patients in acute phase of disease were 36. Patients distribution between ASIA categories was well balanced (75 patients were ASIA A or B).

Values for the ten SF-36 health domains ranged from 0 to 100 except for MH that ranged from 4 to 100. Utility coefficients ranged from 0.319 to 0.965. Table 1 reports mean values and standard deviations (SD) of the health dimensions for the whole population and for the considered subgroups. The subscale scores that revealed a stronger impact of SCI were those related to the physical domains, especially for the physical functioning and physical role functioning subscales and these results are consistent with those reported in [8]. Statistically significant differences were shown for PF scores in the two disease phases ($p=0.01$) and the two patient status (inpatient or outpatient) ($p=0.005$), for GH in the two disease phases ($p=0.04$), for VT in males

versus females (p=0.048), and for PSI in the patient's status (p=0.032). PF (p=0.033), RP (p=0.008), BP (p=0.032) and VT (p=0.01) scales reported statistically significant differences between two groups with different functional impairment (ASIA A or B versus ASIA C or D). No differences were highlighted between tetraplegic and paraplegic patients as reported in [13]. No correlation was found between the values of the health dimensions and the elapsed time from the spinal cord lesion for the entire group of patients. ASIA C or D subgroup showed a significant inverse correlation between GH score and the elapsed time from the spinal cord lesion (p=0.034). This finding is likely related to the poor prognosis of motor and functional recovery and therefore of personal autonomy.

With respect to general Italian population [14] (Figure 2), SCI patients show, as expected, very low values concerning PF, RP and BP scales.

Table 1. Dimension mean values (SD) for all the patients and for the considered subgroups

Variable	All patients	Acute phase	Chronic phase	ASIA A or B	ASIA C or D	Outpatients	Inpatients
PF	19.04 (24.54)	13.06 (23.88)	21.33 (24.52)	15 (21.01)	24.55 (27.93)	27.81 (28.64)	13.9 (20.26)
RP	47.5 (44.01)	41.67 (41.4)	49.73 (44.98)	56.33 (43.71)	35.45 (41.86)	55.73 (43.83)	42.68 (43.65)
BP	50.69 (30.66)	45.39 (29.96)	52.72 (30.85)	55.81 (30.8)	43.71 (29.32)	54.9 (27.17)	48.23 (32.44)
GH	56.37 (24.46)	63.5 (21.69)	53.63 (25.01)	56.57 (24.31)	56.08 (24.89)	56.1 (26.05)	56.52 (23.65)
VT	55.85 (24.45)	53.19 (24.76)	56.86 (24.38)	60.67 (22.87)	49.27 (25.19)	56.77 (23.6)	55.3 (25.06)
SF	70.1 (30.12)	62.85 (34)	72.87 (28.2)	71.33 (29.48)	68.41 (31.17)	73.7 (29.2)	67.99 (30.62)
RE	66.15 (42.53)	64.81 (41.36)	66.67 (43.17)	71.11 (40.02)	59.39 (45.22)	70.83 (42.73)	63.41 (42.43)
MH	66.12 (23.24)	64.78 (22.58)	66.64 (23.58)	67.73 (22.85)	63.93 (23.8)	69 (22.35)	64.44 (23.72)
PSI	30.99 (9.95)	29.67 (8.44)	31.49 (10.47)	31.45 (9.41)	30.36 (10.69)	33.38 (10.82)	29.59 (9.18)
MSI	52.4 (13.59)	51.67 (12.55)	52.68 (14.02)	54.05 (13.7)	50.16 (13.23)	52.98 (13.55)	52.07 (13.68)
U	0.62 (0.14)	0.59 (0.15)	0.63 (0.14)	0.63 (0.15)	0.6 (0.13)	0.65 (0.14)	0.6 (0.14)

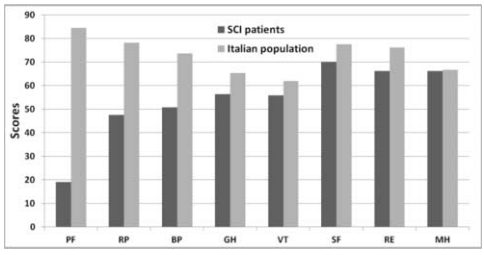


Figure 2. Scales mean scores for SCI patients and for Italian general population

3. Discussion

Achieving an adequate quality of life is considered the final goal of the rehabilitation process following a SCI and the need for outcome measures assessing health and

quality of life following rehabilitation is therefore becoming increasingly important. Since improved quality of life is indicative of the success of treatment programs, it should be routinely measured among SCI patients. The present study develops reflections on the perceived quality of life of 130 SCI Italian patients and, even if the sample size is quite small, the reported results are consistent with the ones already published.

Although in rehabilitation medicine the SF-36 questionnaire has been widely used for patients with SCI, these current measures could be insufficient to represent their serious disability because many items were developed for use in the general population. An example can be related to PF subscale which includes 3 questions referring to walking and 2 others that are related to climbing stairs. The questions posed in these terms may lead to an underestimation of the subscale scores regarding the physical functionalities. To overcome this issue, a modified version of the SF-36 questionnaire can be implemented as proposed in [15] where concepts like "climbing stairs" and "walking" are replaced with the word "going". Further researches are needed in this direction to develop valid and reliable instruments to assess the health status in people with SCI.

References

[1] Brazier J. The Short-Form 36 (SF-36) Health Survey and its use in pharmacoeconomic evaluation. Pharmacoeconomics. 1995 May;7(5):403-15.
[2] Torrance GW. Social preferences for health states: An empirical evaluation of three measurement techniques, Socioecon Plan Sci. 1976;10(3):128–136.
[3] Drummond MF, Stoddart GL, Torrance GW, Methods for the economic evaluation of health care programmes, Oxford Medical Publications, Oxford, 1987.
[4] World Health Organization, International classification of functioning, disability and health, WHO, Geneva, 2001.
[5] Kirshblum SC, Campagnolo DI, DeLisa JA, Spinal Cord Medicine, Lippincott Williams & Wilkins, Philadelphia, 2002.
[6] Wilson JR, Hashimoto RE, Dettori JR, Fehlings MG. Spinal cord injury and quality of life: a systematic review of outcome measures. Evid Based Spine Care J. 2011 Feb;2(1):37-44.
[7] Aaronson NK, Acquadro C, Alonso J, Apolone G, Bucquet D, Bullinger M et al. International Quality of Life Assessment (IQOLA) Project. Qual Life Res. 1992 Oct;1(5):349-51.
[8] Tramonti F, Gerini A, Stampacchia G. Individualised and health-related quality of life of persons with spinal cord injury. Spinal Cord. 2014 Mar;52(3):231-5.
[9] Dibenedetto M, Bovero A, Arescaldino GL, Evaluation of the disease in subjects belonging to different culture. Analysis of a research in spinal cord-injured post-traumatic patients. WCPRR. 2008, 124-131.
[10] Hays RD, Sherbourne CD, Mazel RM. The RAND 36-Item Health Survey 1.0. Health Econ. 1993 Oct;2(3):217-27.
[11] Brazier J, Roberts J, Deverill M. The estimation of a preference-based measure of health from the SF-36. J Health Econ. 2002 Mar;21(2):271-92.
[12] Kirshblum SC, Waring W, Biering-Sorensen F, Burns SP, Johansen M, Schmidt-Read M et al. Reference for the 2011 revision of the International Standards for Neurological Classification of Spinal Cord Injury. J Spinal Cord Med. 2011 Nov;34(6):547-54.
[13] Hall KM, Knudsen ST, Wright J, Charlifue SW, Graves DE, Werner P. Follow-up study of individuals with high tetraplegia (C1-C4) 14 to 24 years postinjury. Arch Phys Med Rehabil. 1999 Nov;80(11):1507-13.
[14] Apolone G, Mosconi P, Ware JE, Questionario sullo stato di salute SF-36: manuale d'uso e guida all'interpretazione dei risultati, Guerini e Associati, Milano, 2000.
[15] Unalan H, Celik B, Sahin A, Caglar N, Esen S, Karamehmetoglu SS. Quality of life after spinal cord injury: The comparison of the SF-36 health survey and its spinal cord injury-modified version in assessing the health status of people with spinal cord injury. Neurosurgery Quarterly. 2007;17(3):175-179.

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Observations and Lessons Learnt from Non Health Professionals Evaluating a Health Search Engine

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Abstract. This article presents the results of one of the stages of the user-centered evaluation conducted in a framework of the EU project Khresmoi. In a controlled environment, users were asked to perform health-related tasks using a search engine specifically developed for trustworthy online health information. Twenty seven participants from largely the Czech Republic and France took part in the evaluation. All reported overall a positive experience, while some features caused some criticism. Learning points are summed up regarding running such types of evaluations with the general public and specifically with patients.

Keywords. Internet, Search engine, User evaluations, Patients

Introduction

In the era of Dr Google, EU project Khresmoi (2010-2014, project No. 257528 (FP7/2007-2013)) aims at developing trustworthy search engines targeting three different audiences: the general public, physicians and radiologists. Khresmoi for everyone (hereinafter K4E, http://everyone.khresmoi.eu) was specifically developed for the first (and the widest) group users. This group is also known to be heterogeneous in terms of age, gender, educational and income level [1] and consequently of IT and health literacy [2,3] which is eventually linked to health status [4]. This type of user is often not aware about variability of the quality of online health information and lacks skills to judge it [5,6]. K4E aims at targeting this problem and offering an access to reliable online health resources based on 8.300 HONcode certified websites and some others manually selected by experts.

By the third year of the project the first integrated platform featuring various functionalities was developed [7] and tested in real-life settings. This article describes the results of one of the types of evaluation tests conducted in 2013 [8]. Health on the net Foundation (HON) was in charge of defining the protocols, coordinating and conducting the evaluations in collaboration with Charles University in Prague (CUNI, Czech Republic) and Evaluation and Language Resources Distribution Agency SA (ELDA, France) in different locations. The main goal of this type of evaluation was to

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understand users' acceptance and use of the prototype, specifically which tools were considered to be the most useful. Consequently, these findings were analysed and integrated in the next prototype. Although we overall followed a standard usability testing protocol, some peculiarities of health domain had to be taken into consideration while designing the study.

1. Methods

A qualitative research method was chosen in order to have in-depth understanding of the users actions and behaviour and the reasons inducing these actions. The method consisted, during an average of one hour, in observing and recording users' interaction with the prototype K4E using the Morae software by TechSmith [9] while completing three health-related online searches. The Morae software allowed capturing the screen of the computer, video (participant face), and click-through data. Set up usually included one participant, one observer - who was adding notes during the test - and one facilitator, whose aim was to assist the participant on site in case of questions or problems and to collect feedback at the end of each interview.

Several tasks covering various health topics were elaborated in English and piloted with eleven participants in two rounds in Sofia (Bulgaria) and Geneva (Switzerland). The final setup includes the same three simple tasks and several questionnaires.

The main inclusion criteria were not being a health/medical professional and at least occasionally searching for online health information. Upon agreeing to participate, all participants filled out a consent form. One page presentation of the project and a quick demonstration of the prototype were shown to the participants. Once started, participants filled in a demographic and Internet usage questionnaire. Then they had about 10 minutes to explore the search engine by themselves. Afterwards, the three tasks were given. The first task was to find a formula and calculate a Body Mass Index (BMI). The second task aimed at finding the information about treatment options for liver cancer. The third task required participants to find other patients' opinions on a drug called "Metformin". After each task, the participants had to answer two questions: whether they already had a personal experience with a problem described in the task and whether they were able to solve it (detailed in tab 1). At the end of the evaluation, an extended System Usability Scale (SUS) questionnaire was filled out. In addition to the 10 standard questions [10], we developed 15 specific to K4E questions. Participants had to grade each statement using the Likert scale from one to five, from strongly disagree to strongly agree, accordingly.

The "full user tests" were conducted during a few days from May to July of 2013 in Prague, Geneva and Paris. All the materials, originally available in English, were translated into Czech and French. However, the interface of the Morae system remained in English.

2. Results

Thirty people took part in the evaluation tests and for the final analysis 27 recordings were kept. One of the 27 participants encountered a technical problem with Morae, and his answers to the demographic questionnaire were not recorded, however some,

though not all of them were recovered by watching the video, hence in some cases a sample size is 26 (N=26).

Participants were mostly from the Czech Republic (14) and France (9), while 3 were from Switzerland (N=26). There were 14 females and 13 males of various age groups: the most prevalent were aged 30-39 (37%) and 60-69 (22%). The majority of participants hold a Master degree (41%), while all education levels were present. All participants were active online, 25 indicated they were connected to the Internet on a daily basis, and two did so several times a week. All participants also conducted online searches: 23 every day, and 4 several times a week. Everyone indicated Google as the main search engine being used (27), two Czech participants also mentioned Seznam.cz, one added Yahoo and another one added DuckDuckGo. Almost half of them (48%) said they were very confident with web search and considered themselves as expert users (N=27). 44% had problems in finding information from time to time.

As for online health search, 42% of the participants did it once a month and 16% at least once a week (N=26). All participants gave preference also to Google for looking for health content (N=27). All participants sought for information about a specific disease or medical problem. Out of 26 respondents, 9 (35%) reported having been diagnosed with various diseases, mostly (7 out of 9) for more than three years. 6 out of 9 participants reported that their Internet use to search for online health information did not change after the diagnosis, while for 2 participants it increased and for 1 it decreased.

All of the participants (after free search engine used) completed three tasks, described in Methods section, and responded to two questions per task (Tab. 1).

Table 1. Summary of experience with three tasks made by all participants (N=27).

Task	Previous experience with the issue A question asked:	Yes	Task success rate	Average time to complete the task
1	Have you already been familiar with body mass index before doing the task?	70%	100%	2.50 min
2	Have you (or someone you know) been diagnosed with liver cancer?	8%	81%	5.09 min
3	Have you previously searched for medication information on the Internet?	74%	48%	5.22 min

We wanted to understand whether the use of K4E helped with solving the tasks. In case of the first task, it was not clear as all of the participants had solved it. However, K4E did help for the second task: 80% of the participants who had no prior experience and all participants who did have prior experience with liver cancer were able to solve the task. The remaining 20% of those who did not have prior experience with liver cancer were not able to find a satisfactory answer. As for the third task, taking into account the data we had, K4E did not help. There was no significant difference in task success rate between Czech and Francophone participants.

For the analysis of the final satisfaction questionnaire we split all statements into "happy" (17) and "not happy" (8). "Happy" statements reflected positive user feedback; for such statements, the higher the grade was the more satisfied the users were with the prototype and their experience. Overall, participants agreed with the happy statements (between three and four on a five-point Likert scale). Several statements received more than four points out of five (i.e. "strongly agree") - the following system characteristics were most appreciated: (1) results classification (4.15), (2) quick learning of how to use the system (4.07), (3) feeling of confidence (4.04), (4) ease of use (4.04). On the contrary, "not happy" statements reflected disappointment

and higher grade for them meant higher dissatisfaction. All of "not happy" statements received less than 3 out of 5 which indicates that on average participants disagreed with all of them (statements like: "I thought there was too much inconsistency in this system", "I found the system unnecessarily complex" etc).

Francophone participants reported having more positive experience with the tools which would help them to understand the topic, for example, disease definition, i.e. tools targeting a health domain, while Czech users tended to appreciate more "common" search engine tools such as automatic translation and filtering.

Other feedback collected from the observation and free comments of participants can be summed up as follows. Overall, all participants were able to effectively interact with the prototype. The interface was found to be simple enough to use, but the translation, health topic cloud categorization and several other features were mentioned as needing improvement. The availability of the contents was judged as poor by most users, especially in the Czech language. Indeed, not many websites were HONcode certified in Czech and only few websites were added during the first two years of the project. While Czech participants had often turned to translated results, French-speaking participants could complete the tasks without automatic translation of results into English, though few of them used automatic translation from English. The quality of the snippet translation was deemed sufficient but requiring some improvement. A particular problem French-speaking participants encountered was with accents while typing a query. Having forums appeared to be a contradictory issue as opposite opinions exist on the matter: while some of the users considered forums and blogs a valuable source of information, others did not and would prefer to filter them.

3. Discussion

In our tests, we had Internet users of both genders, all ages, with different web search experience and skills and personal health experience. A high percentage of participants held at least a Master degree, it is nevertheless a common tendency for online health seekers to have higher education compared to the average web surfer.

The main conclusion is that the perception of the users with different profiles was overall positive and the system and its tools were helpful to solve the proposed tasks while other tools have been found in the need of further improvement.

Having analyzed users' feedback and experience we proposed the following steps to improve the prototype:

- Simplify and localize interface across the languages (including titles, filters presentation and definition of search terms),
- Improve query assistance and automatic translation,
- Expand the index, especially with Czech resources,
- Increase system speed.

Regarding the setup of the evaluation itself, users wished to have more time to explore the system on their own.

Main learning points are the following. As the main goal was to provide a roadmap for further prototype development, such evaluations are deemed to be very appropriate to truly understand user behaviour and retrieve unique and profound feedback about the system. Overall, for such kinds of evaluation, a pilot test is never superfluous, and it indeed seems appropriate to organize both pilots and tests in many small-sample steps -

for example, 2-3 persons per each step. After each step, both the setup and the prototype should evolve to allow new participants to contribute with a new input on the next step in a two-to-three month period. The last, but not the least point is directed towards patient organizations and facilities providing healthcare, to encourage them to promote such studies amongst themselves and their patients to ensure the final product meets their needs.

Follow up evaluations are being conducted in 2014 to evaluate whether the progress made in the meantime facilitates users interactions with the prototype.

HON expresses its gratitude to our partners who helped to run this evaluation: Priscille Schneller and Jérémy Leixa from ELDA and Dr. Line Kleinebreil who has contributed to the protocol development. HON thanks its team members Rafael Ruiz de Castaneda, Frederic Baroz and Samia Chahlal. We thank all the volunteers for their time and participation.

References

[1] Knapp C, Madden V, Wang H, Sloyer P, Shenkman E. Internet Use and eHealth Literacy of Low-Income Parents Whose Children Have Special Health Care Needs. J Med Internet Res, 2011, p. 13(3):e75.

[2] Sarkar U, Karter AJ, Liu JY, Adler NE, Nguyen R, Lopez A, Schillinger D. The literacy divide: health literacy and the use of an internet-based patient portal in an integrated health system-results from the diabetes study of northern California (DISTANCE). J Health Commun, 2010, pp. 15 Suppl 2:183-96.

[3] Lam K.M., Lam L.T. Health Information-seeking Behaviour on the Internet and Health Literacy among Older Australians. Electornic Journal on Health Informatics, 2012, pp. Vol 7, No 2.

[4] Fox S., Duggan M. Health Online 2013. Washington, D.C. : Pew Research Center's Internet & American Life Project, 2013.

[5] Mitsutake S, Shibata A, Ishii K, Oka K. Association of eHealth Literacy With Colorectal Cancer Knowledge and Screening Practice Among Internet Users in Japan. J Med Internet Res, 2012, p. 2012;14(6):e153.

[6] Feufel MA, Stahl SF. What do Web-Use Skill Differences Imply for Online Health Information Searches? J Med Internet Res , 2012, p. 14(3):e87.

[7] Pletneva N, Kriewel S, Kritz M. Prototype of a seconf search system based on feedback. 2013.

[8] Baroz F., Boyer C., Gschwandtner M., Goeuriot L., Hajic J., Hanbury A., Kritz M., Leixa J., Palotti J., Pletneva N., Ruiz de Castañeda R., Sachs A., Samwald M., Schneller P., Stefanov V., Uresova Z. D10.1 Report on user tests with initial search system. 2013

[9] Brooke, J. SUS: a "quick and dirty" usability scale. B. Thomas, B. A. Weerdmeester, & A. L. McClelland P. W. Jordan. Usability Evaluation in Industry. London : Taylor and Francis, 1996.

[10] Krug S. Don't Make Me Think, Revisited: A Common Sense Approach to Web Usability (3rd Edition) (Voices That Matter) . s.l. : New Riders, 2013.

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eHCM: Resources Reduction & Demand Increase, cover the gap by a managerial approach powered by an IT solutions

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Abstract. The economic and financial crisis has also had an important impact on the healthcare sector. Available resources have decreased, while at the same time costs as well as demand for healthcare services are on the rise. This coalescing negative impact on availability of healthcare resources is exacerbated even further by a widespread ignorance of management accounting matters. Little knowledge about costs is a strong source of costs augmentation. Although it is broadly recognized that cost accounting has a positive impact on healthcare organizations, it is not widespread adopted. Hospitals are essential components in providing overall healthcare. Operating rooms are critical hospital units not only in patient safety terms but also in expenditure terms. Understanding OR procedures in the hospital provides important information about how health care resources are used. There have been several scientific studies on management accounting in healthcare environments and more than ever there is a need for innovation, particularly by connecting business administration research findings to modern IT tools. IT adoption constitutes one of the most important innovation fields within the healthcare sector, with beneficial effects on the decision making processes. The e-HCM (e-Healthcare Cost Management) project consists of a cost calculation model which is applicable to Business Intelligence. The cost calculation approach comprises elements from both traditional cost accounting and activity-based costing. Direct costs for all surgical procedures can be calculated through a seven step implementation process.

Keywords. Cost Accounting, Cost Control, Information Technology, Hospital Management

Introduction

According to Harrington, 1987, "if you can measure it, you can understand it. If you can understand it, you can control it. If you can control it, you can improve it.". The implementation of management methods based on accurately and appropriately collected and analysed data would be a solution to create transparency of resource utilization. By this way today then most fundamental dimension into the healthcare sector are: resource, demand, cost and IT improvement.

'Cost is increasingly recognized as an important dimension in providing clinical care. In the current climate requiring fiscal restraint, it is becoming more important for hospital managers to assess the costs of services provided'.[15] Little knowledge about costs is a strong source of costs augmentation. Although it is broadly recognized that cost accounting has a positive impact on healthcare organizations, it is not widespread

adopted.[7] Accurate Management Accounting information have the power to introduce the following advantages to healthcare organizations: Improve pricing decisions or if reimbursement is set on basis of agreements with other organizations or institutions important negotiation advantages; better profitability assessments and resource allocation; possibility to encourage/discourage use of services; comparative analyses; income and asset management for external parties; budgeting and resource control improvements, positive changes of the decision making process, healthcare professional's education toward cost matters; department level cost determination and the introduction of responsibility accounting.[2,5,9,16]

IT provides interesting possibilities to improve healthcare services processes and overall management by the use of data to extract value. Healthcare providers had to search for new alliances and modalities to be able to cover the gap between resources and demand through a managerial approach. Especially as important tools to sustain decision making processes, IT has an fundamental role.[13] The e-HCM approach wants to combine the positive aspects of Management Accounting with modern IT by implementation of a Cost Accounting Model on Business Intelligence.

1. Methods

E-Health Cost Mamagement (e-HCM) project has the aim to calculate the overall cost of each surgical procedure performed into the operating room block (ORB). The cost accounting model is a "hybrid" cost accounting model taking elements from activity-based costing (when resource consumption is related to the process) and traditional cost accounting methodology (where source consumption is not related to the process). The seven implementation steps were closely modeled according to Upda[14] but modified in line with the research contexts' requirements.

Step 1: Building of a cross-functional steering committee

To ensure that the model with the clinical reality an interdisciplinary steering committee was build. Meetings discussed development and matters related to practical application. The participation of professionals from different disciplines (anesthesiologist, physicians, nurses, engineers) was fundamental for the creation of a successful and effective cost calculation model.

Step 2: Identification of the cost object

The team decided to choose single surgical procedures as cost objects. Direct costs referred to this will be calculated.

Step 3: Activity mapping of the surgical path

This flowchart must take into consideration all potential steps of a patient's path within the ORB. The objective is to define all activities of the surgical path as a flowchart where the whole process was broken down into its single path steps. Any surgical path mapping analysis should take into consideration at least the following four resource categories: Personnel workforce (e.g. Induction/Positioning stage:

Anesthesiologist and Anesthesia nurse); High or/and low cost materials (e.g. Induction/Positioning stage: gloves of the personnel, patient anti-thrombosis stockings, antibiotic and anesthetic, syringe and needles); Depreciation of building and devices (e.g. Induction/Positioning stage: Induction room and anesthesiological devices) and; Purchased services from other internal units or the market (e.g. Induction/Positioning stage: Induction room cleaning).

Step 4: Investigation of basic cost information

Every data received from the management accounting department or the financial accounting department or the ORB of the hospital must be thoroughly checked, verified and comprehended in terms of composition and structure.

Step 5: Surgical procedure input information

It is important to note that the hospital is not registering input for single surgical procedures (for instance, materials used for each surgical procedure). If surgical input data are not registered automatically, this type of information can be gained by a specific surgeon questionnaire. This information can be connected to cost per unit information (gathered at step 4). Following information should be asked within the questionnaire: Name of the surgical procedure; average time of surgical procedure (in minutes); DRG assigned to the procedure (Procedure Code and Description of the procedure); number of surgeons; anesthesia type (local or general); high cost materials (Description, Quantity and Number of Utilizations); number of Surgical Instrument Kits; Robot Usage (Yes or No); Open Procedure (Yes or No)

Step 6: Data processing model

Within the e-HCM model different types of cost drivers are used. Cleaning, Laundry, Sterilization and Low Cost Material resource costs constitute transaction drivers (allocation based on the number of transactions), while the allocation of Depreciation and Servicing is determined through duration cost drivers. The most important resource type, workforce, is allocated through intensity cost drivers which constitutes the most precise type of cost driver.

Step 7: Data analysis output

The basic idea of e-HCM is to integrate the cost calculation analysis on Hospitals' Business Intelligence and process data to simple and understandable performance pie charts and tables. The fundamental concept is that the first data output screen shows general information and guides the user towards more detailed data analysis. The hierarchy inside the model enables the user to have a complete insight of data regarding his/her profile'.[1] Into the model are available economic information about: Total number of procedures; Total time spitted as regular and overtime; Total number of Scheduled/Unscheduled procedures; Total costs in Millions of euro; Total costs in Millions as a pie chart as Workforce, Services, Depreciation and Materials costs; List of the 5 most expensive procedures in terms of total cost for the whole ORB (cost of surgical procedure*number of procedures performed). Also it's available a list of all

wards with their corresponding total costs, direct costs and allocated costs. There an illustrated a bar chart provides a quick comparison overview of costs of the different wards. At the end there is a cost comparison simulation section where regular time and overtime differences as well as cost variations if times, material costs and number of surgeons are varied.

2. Results

A prototype shows interesting cost accounting results. Final implementation on Business Intelligence is not already happened. The prototype shows that average cost of tonsillectomy surgical procedure in regular working time is 1.382 € with a minimum cost of 938 € and a maximum cost of 2.743 €. The standard deviation is 281 €. 91 % of resources are consumed during the surgical procedure itself and only the remaining 9% are constituted of collateral activities (transport, induction ect.). With regard to the cost type distribution workforce requires 52%, materials 37%, depreciation 10% and services 1%. If the same procedure is performed in overtime its average cost is 1.858 € with a minimum cost of 1.177 € and a maximum cost of 4.004 €. The standard deviation in overtime is of 432 € . The cost type distribution differs significantly. Workforce, because of different unit costs, consumes 65%, materials 27% and depreciation 8%.

3. Discussion

Hospital managers used those analysis to compare and illustrate processes implemented. Upon receiving OR reports, the OR managing board decide whether and/or how to improve its efficiency and organization.

The results presented above describe how a managerial approach performed by the Surgical Bord through available and reliable data has an impact in the OR workflow. By those results we are able to know and understand how the surgical workflow run in the Forlì ORB.

The surgical unit board, which is responsible for managing the work of the surgical theatres, has a monitoring tool to be able to observe the number of surgeries performed in a set period, the distribution of operations both in the emergency and in the ordinary regime (i.e. scheduled in the surgery list), the complete surgical pathway of each patient, where the patient is subsequently transported to receive surgery and where he goes after surgery. This would ensure a much fairer distribution of workloads. In fact as in the results section is show the workload of thee ORB increase its efficiency through better organization of the allocated time for each surgical units.

Research in the management of operating rooms makes it possible to reduce the costs of the services involved and to raise the efficiency standards of the service to the individuals and the community. However, this is only possible if the systems of data analysis and presentation are able to provide the correct information in the correct form. Knowledge is at the basis of improvement but it must be clearly understandable and easily accessible.

References

[1] Agnoletti V, Buccioli M, Padovani E et al. Operating room data management: Improving efficiency and safety in a surgical block. BMC Surgery 2013;13:7
[2] Baker J. Activity-based costing and activity-based management for health care. Gaithersburg: Aspen Publishers. (1998)
[3] Chan Yee-Ching L. Improving hospital cost accounting with activity-based costing. Healthcare Management Review. 1993;18, 71-78.
[4] Elixhauser A, Andrews RM. Profile of inpatient Operating Room Procedures in US Hospital in 2007. Arch Surgery. 2010;12,1201-1208.
[5] Finkler SA. et al. Essentials of Cost Accounting for Healthcare Organizazions. Sudbury: Jones & Barnett.2007
[6] Guerriero F, Guido R. Operational research in the management of the operating theatre: a survey. ealth Care Manag Sci 2011;14:89–114.
[7] Kaplan R. Porter M. The Big Idea: How to Solve the Cost Crisis in Health Care. Havard Business Review. 2011; 89: 46-64.
[8] Lievens Y, Van den Bogaert W, Kesteloot K. Activity-based costing: A practical model for cost calculation in radiotherapy. Int J Radiat Oncol Biol Phys. 2003; (2):522-535.
[9] Macario A. What does one minute of operating room time cost? Journal of Clinical Anesthesia. 2010; 233-236.
[10] Maryamaa R, Kirvela O. Who is responsible for operating room management and how do we measure how well we do it? Acta Anaesthesiol Scand. 2007; 7:809–814.
[11] Mladovsky P, et al. Health Policy Responses to Financial Crisis in Europe. Copenaghen, WHO Regional Office for Europe. 2012
[12] Oduncu FS. Priority setting, rationing and cost-effectiveness in the German Healthcare system. Med Health Care Philos. 2012
[13] Tan J. E-Health: The Next Health Care Frontier. In: E-Healthcare Information Systems. An Introduction for Students and Professionals. San Francisco: Jossey-Bass. 2005; 3-27.
[14] Udpa S. Activity-Based Costing for Hospitals. In Cost Accounting for Healthcare Organizazions. Concepts and Applications. Gaithersburg: Aspen Publishers. 1999;723-739
[15] Van Rensburg JAB, Jassat W. Acute mental health care according to recent mental health legislation Part II. Activity-based costing. Afr J Psychiatry. 2011;14, 23-29.
[16] Young DW. Management Accounting in Healthcare Organizations. San Francisco: Jossey Bass. 2008

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A semi-automatic web based tool for the selection of research projects reviewers

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Abstract. The correct evaluation of research proposals continues today to be problematic, and in many cases, grants and fellowships are subjected to this type of assessment. A web based semi-automatic tool to help in the selection of reviewers was developed. The core of the proposed system is the matching of the MeSH Descriptors of the publications submitted by the reviewers (for their accreditation) and the Descriptor linked to the research keywords, which were selected. Moreover, a citation related index was further calculated and adopted in order to discard not suitable reviewers. This tool was used as a support in a web site for the evaluation of candidates applying for a fellowship in the oncology field.

Keywords. Reviewer selection, MeSH, Citation based index, research in oncology

Introduction

Today, new postdoctoral scientists are poorly integrated into the world of research, therefore a trend inversion was deemed crucial in order to promote their research projects at an international level. Hence, a new mobility program, named Training through Research Application Italian iNitiative (TRAIN), was conceived as a part of a strategy carried out by the International Program of the Italian Cancer Network "Alleanza Contro il Cancro" to promote and develop translational mobility in the oncology field at different levels of scientists' research careers [1],[2]. This program is financed by the European Commission Seventh Framework Program (FP7) thanks to a "Cofinancing of regional, national and international programs" (COFUND) initiative which provides fellowships which depend on admission criteria verified, both manually and automatically, by the "Istitituto Nazionale per la Ricerca sul Cancro" (INRC). The project has as its main aim the call for proposals for young scientists in oncology and related fields, who should submit specific research projects to be evaluated by independent reviewers.

As many editors of scientific journals well know, the identification of appropriate reviewers for manuscripts and research projects is extremely challenging [3–5].

Consequently, a Web tool to obtain the evaluation and association of reviewers with the relative proposals was developed. One of the most important parts of this tool was an algorithm that partially automated the reviewer selection. Such tool (based on the controlled vocabulary Medical Subject Headings (MeSH) and on a citation

correlated index) attempts to measure both the productivity and impact of a scientist's publications and their correlation with the research fields relating to the presented proposals.

1. Materials and Methods

1.1. Materials

TRAIN foresees three different mobility schemes for scientists, either outgoing or ingoing and the re-integration into the oncology field. In order to receive a fellowship, the applicant must complete five forms and provide a PubMed ID (PMID) list of a maximum of the 20 most relevant publications related to the selected research fields. As a matter of fact, there are 20 different research areas described by as many keywords. Reviewers must carry out this selection as well, however a maximum of five PMID for each keyword can be inserted to provide proof of their expertise. The E-utility Web Service provided by the National Center for Biotechnology Information (NCBI) [6] was used to retrieve significant data about each publication, inclusive of MeSH descriptors and qualifiers. In particular, eUtilsServiceSoapClient, eSummaryRequest and SummaryResult classes were used in order to call the service, request the publication details and retrieve these details. MeSH, as a metadata system, is used to index scientific literature in biomedical fields [7]. It is available for download in various formats, such as XML, but it does not supply any Web Service utility, thus a database has been developed in order to retrieve data from the XML file and for an improved integration with the system created. To achieve a better evaluation of the reviewers' expertise and to present applicants in a more complete form, data acquired with the PubMed E-Utility has been enhanced with their bibliographic information provided by the Web Of Knowledge (WOK), such as the number of citations for each publication, which was manually retrieved. This is highly significant, in ranking scientific literature: indeed, it objectively presents how fundamental a publication is considered.

After taking into account all the requirements, an Entity-Relation diagram (E-R diagram) was designed for the future database development. Particular attention was given to the Publication entity, which merges all the information from the different sources listed above. Thus, the Publication entity contains the PMID, title, number of authors, authors, abstract, and it is linked to the Descriptor and the Qualifier entities, characterised by their MeSH identifiers. This E-R diagram was later implemented, as a database, in SQL Server 2008. A feasibility study was carried out together with the other parties involved and a web-based application was chosen as the interface for the future users of this program. Thanks to the wide diffusion of Internet [8], [9], even on tablets and smartphones, websites are easily reached by users and they can be accessed with different devices. Moreover, since users would probably not be acquainted with the IT, the interface was designed to be appealing and user-friendly, to encourage its utilization, and to supply an intuitive tool for the completion of the forms. Visual Studio 2010 was adopted to implement the platform.

Hence, the evaluating tool is given sufficient data for a complete analysis on both the pertinence of the reviewer's publications to the applicant field and the impact factor of their scientific work so far.

1.2. Methods

Throughout this section, the authors will extensively delineate the setting up of the tool for the management of the publications, especially concerning their relevance and aptness to the selected research field.

After the creation of the web pages dedicated to the application for both reviewers and candidates, a function called "Find_Publication_Details" was developed, in order to retrieve the necessary publication details. This function calls the E-Utility Web Service to obtain a publication summary which encloses numerous items characterised by different types. These items also contain the MeSH Descriptors and Qualifiers of each publication. Since the provided keywords were not defined by MeSH Descriptors and Qualifiers, a tool already developed by the MEDINFO laboratory (10) was utilized in order to achieve these associations and save them into the database, even though not every keyword could be directly linked. Each keyword is saved into a table named "Keywords" together with its unique identifier and, if present, its DescriptorUI. Since reviewers must choose one or more keywords to describe their works and publications, two tables were created to depict this association. The first table is the "Keyword_Exp", where the expert's unique identifier is associated to the selected keywords, while the "Keyword_Pub" table describes the link between the publication and the related keywords. These tables are necessary for the ensuing evaluation steps, since there is a coherence control for each keyword, expert and publication involved. This check is performed by a process involving different automatic and manual steps. If the DescriptorUI for the keyword is present, then the DescriptorUI for the publication is directly compared with the former. Conversely, if the DescriptorUI was not identified for that specific keyword, a web interface, where the keyword itself and the MeSH Descriptors for the publication are shown, was provided. Thanks to this interface, TRAIN administrators could easily check if the selected keyword corresponded to the publication's MeSH Descriptors and therefore accept or reject the reviewer. In both cases, potential reviewers who did not provide relevant publications for the selected research areas were discarded.

Another manual stage was represented by the collection of the number of citations for each publication of the reviewers into the database. Such number was retrieved by the TRAIN administrators from the Web of Knowledge website and subsequently, inserted into a dedicated form of the TRAIN website. The saved numbers were then utilized to calculate a citation related index inspired by the *h*-index, which, in fact, quantifies the scientific impact of a scientist's work [11]. This index was automatically calculated, thanks to the above mentioned number of citations. It represents the number of papers (n) which have been cited at least a number (n) of times. Therefore, the resulting index could range from 0 to 5, since the reviewers can upload a maximum of 5 papers.

Through another web interface, it was possible for TRAIN administrators to finally accept or deny a candidacy for reviewers. As a matter of fact, the results of the indexes calculation could be visualized and accordingly the reviewer's suitability for the selected keyword could be decided. Moreover, after the acceptance of the reviewers, the system classified them in descending matching order, based on the results of the previous steps. Consequently, the administrators made a manual association of fellowship candidates and reviewers based on referees' rankings, in order to have the most accurate assignment possible.

2. Results

During the first phase of the TRAIN project, an association between research areas provided by the administrators and the MeSH DescriptorUIs was attained for 80% of the keywords. As a matter of fact, for keywords, such as “Medical Oncology”, a direct correspondence, D008495, was found, while for others like “Imaging” a synonym, “Diagnostic Imaging” (D003952), was selected. For the remaining 20%, e.g. “Management, Intellectual Property, Exploitation, Technology Transfer”, a manual approach was used to determine the reviewer’s expertise. The complete set of the 20 research areas can be found at [12].

TRAIN announced four calls for applicants, opening a total number of 26 fellowships consisting of:

- 12 outgoing fellowships, for Italian post-doctoral scientists wishing to improve their research abroad;
- 4 incoming fellowships, for foreign post-doctoral scientists wishing to complete their research studies in Italy;
- 10 re-integration fellowships, addressed to Italian post-doctoral scientists wishing to return to Italy, after research studies in a foreign country.

In order to evaluate the proposals submitted to the website, TRAIN announced an open call for experts who wished to participate. The TRAIN administrators also sent some solicitations to experts indicated by the "Istituto Superiore di Sanità" and the "Organization of the European Cancer Institutes". Overall, 435 experts took part.

Molecular and Cell Biology presents the highest number of experts registered, 52, while Palliative Care and Rehabilitation and Pharmacogenomics the lowest, 10. The mean value of candidates is 21.75, while the standard deviation is 11.73.

The accepted experts were 205. Among the solicited reviewers, 45 did not upload any publications, as a demonstration of their non-willingness to participate to the project. Since nine research areas had more than 20 experts registered, the aforementioned match algorithm between the keywords and the MeSH Descriptors was carried out in order to level the different categories. For the other fields, it was not necessary. Thanks to this selection, 162 individuals were discarded. 23 out of the remaining 228 did not have a sufficient citation related index. The established threshold was, in fact, 2.

3. Discussion

The evaluation tool was developed in order to obtain a higher objectiveness in proposal reviews. As a matter of fact, thanks to this tool, the choice of reviewers was based on their publications and field of expertise and not only on their candidacy. However, the website administrators could use such a ranking solely as a suggestion and could also choose autonomously the reviewers for each proposal. During the TRAIN project, 340 reviews were carried out; therefore, each expert evaluated at least one proposal. All types of users considered the tool as both valuable and efficient. As a matter of fact, it saved administrators’ time for the associations, and a fewer number of reviewers’ rejections compared to similar tools emerged.

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References

[1] Lombardo C, Albanese D, Belardelli F, d'Alessandro F, Giacomini M, Rondanina T, et al. Training and mobility: a priority for the Organisation of the European Cancer Institutes. How a national mobility initiative could enhance EU cooperation in cancer research contributing to the development of an European Research Area: the example of The I. Tumori [Internet]. [cited 2014 Jan 9];94(2):147–53. Available from: http://www.ncbi.nlm.nih.gov/pubmed/18564599

[2] Lombardo C, Bottero S, D'Alessandro F, Giacomini M, Guderzo A, Moretti F, et al. TRAIN: Training through Research Application Italian iNitiative. Int. J. Biol. Markers [Internet]. [cited 2014 Jan 9];26(2):136–8. Available from: https://www.ncbi.nlm.nih.gov/m/pubmed/21623583/?i=3&from=/18564599/related

[3] Mimno D, McCallum A. Expertise modeling for matching papers with reviewers. Proc. 13th ACM SIGKDD Int. Conf. Knowl. Discov. data Min. - KDD '07 [Internet]. New York, New York, USA: ACM Press; 2007 [cited 2014 Jan 23]. p. 500. Available from: http://dl.acm.org/citation.cfm?id=1281192.1281247

[4] Dumais ST, Nielsen J. Automating the assignment of submitted manuscripts to reviewers. Proc. 15th Annu. Int. ACM SIGIR Conf. Res. Dev. Inf. Retr. - SIGIR '92 [Internet]. New York, New York, USA: ACM Press; 1992 [cited 2014 Jan 23]. p. 233–44. Available from: http://dl.acm.org/citation.cfm?id=133160.133205

[5] Hartvigsen D, Wei JC, Czuchlewski R. The Conference Paper-Reviewer Assignment Problem. Decis. Sci. [Internet]. 1999 Jun [cited 2014 Jan 23];30(3):865–76. Available from: http://doi.wiley.com/10.1111/j.1540-5915.1999.tb00910.x

[6] Sayers E, Miller V. Overview of the E-utility Web Service (SOAP) [Internet]. National Center for Biotechnology Information (US); 2012 [cited 2014 Jan 9]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK43082/

[7] Fact SheetMedical Subject Headings (MeSH®) [Internet]. U.S. National Library of Medicine; [cited 2014 Jan 9]. Available from: http://www.nlm.nih.gov/pubs/factsheets/mesh.html

[8] Vecchio DT, Gazzarata R, Alloisio S, Giacomini M. From the research to the users Prevention & IT. Int. J. Evid. Based Healthc. 2009;7(3):226.

[9] Giacomini M, Pastorino L, Soumetz FC, Mielczarski JA, Mielczarski E, Rangelow I, et al. Data Modeling for Tools and Technologies for the Analysis and Synthesis of NANOstructures (TASNANO) Project. J. Inf. Technol. Res. [Internet]. IGI Global; 2009 [cited 2013 Nov 25];2(3):49–70. Available from: http://www.igi-global.com/article/data-modeling-tools-technologies-analysis/4142

[10] Gazzarata R, Pivetti S, Giacomini M. A mesh-based health care prevention information retrieval system. NETTAB 2012 "Integrated Bio-Search." 2012. p. 18–20.

[11] Hirsch JE. An index to quantify an individual's scientific research output. Proc. Natl. Acad. Sci. U. S. A. [Internet]. 2005 Nov 15 [cited 2014 Jan 9];102(46):16569–72. Available from: http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1283832&tool=pmcentrez&rendertype=abstract

[12] Train Research Areas [Internet]. [cited 2014 Jan 31]. Available from: http://trainoncology.eu/ResearchAreasSUBAbouttrain.aspx

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Monitoring health IT integration – the effect of an EMR on laboratory service timeliness across six Australian hospitals

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Abstract. The Electronic Medical Record (EMR) incorporates computerised provider order entry systems which allow clinicians to order diagnostic tests electronically, thus eliminating the need for cumbersome handwritten orders. In many situations the EMR relies on a manual transition of information across systems (e.g., integration with the Laboratory Information System). This study, based in a laboratory setting requiring such a transition across systems, aimed to compare the data entry time (from when a specimen arrives in the Central Specimen Reception [CSR] area of the laboratory, to when it is forwarded on for processing), along with a laboratory turnaround time (TAT) (from the time a specimen is received to the time a verified result is issued) for paper and EMR orders, for two high volume tests, across six hospitals. Results showed that the median data entry time for all hospitals combined, was three minutes shorter for EMR entered orders than paper orders. This difference was consistent and significant for Electrolytes, Urea, Creatinine (EUC) and Automated Differential (including full blood count) tests in 2010 and 2011. These decreases contributed to significantly lower median Laboratory TATs for EMR orders (for EUC tests the difference in medians was 12 minutes in 2010 and six minutes in 2011; for Automated Differential tests, the difference was four minutes in 2010 and two minutes in 2011).

Keywords. Health informatics, Laboratory, Pathology, Evaluation studies, Electronic Medical Record, Computerized Provider Order Entry.

Introduction

The World Health Organization's World Alliance for Patient Safety has highlighted the importance of pathology services to the global patient safety agenda emphasising the role of the laboratory in: i) ensuring reliable and accurate results delivered in a timely fashion; ii) informing clinical management decisions; and iii) the safe administration of blood products and medications.[1] The Electronic Medical Record (EMR) incorporates computerised provider order entry (CPOE) systems which allow clinicians

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to order diagnostic tests electronically, thus eliminating the need for cumbersome handwritten orders which have a huge potential for error.[2] There is considerable support for the introduction of EMR across healthcare settings in Australia and internationally, not least because of their contribution to the improved timeliness of laboratory services.[3]

Turnaround times (TAT) are one of the most frequently used measures of laboratory performance. They are often a central criteria of how clinicians judge the quality of the laboratory service.[4] The traditional concept of a laboratory TAT is generally measured from the time a specimen is received in the Central Specimen Reception (CSR) area of the laboratory to the time a verified result is available. Evidence of the impact of electronic ordering in this regard has been widely documented.[5,6] In this study we aimed to incorporate an examination of the data entry time – from the time a specimen arrives in the CSR to the time that it leaves the CSR – along with an evaluation of the traditional laboratory TAT. This will provide a means of comparing the impact of EMR (relative to the paper-based system) on data entry processes within the CSR and its effect on laboratory TAT more generally. This is particularly important for situations where operational systems across the hospital (e.g., between Laboratory Information Systems [LIS] and the EMR) require some level of manual transition (e.g., barcode scan and time stamp entry) to achieve integration between systems. Such transitions remain a common problem for many hospitals in Australia and internationally, and have potential implications for the safety and effectiveness of laboratory services.[7,8]

1. Methods

1.1. Project setting

The project was undertaken across six hospitals involving a single pathology laboratory provider with multiple sites. The hospitals in the study involved three large metropolitan general hospitals: A (567 beds), E (654 beds), and F (538 beds); two specialist hospitals B (187 beds) and C (159 beds); and one smaller regional hospital D (197 beds). An EMR, which allowed clinicians to create electronic orders, was introduced in October 2008 to Hospital E followed subsequently by all hospitals involved in the study. The EMR was initially based on the Cerner PowerChart system Version 2007.16, and upgraded in May 2011 to Version 2010.02.16. The Laboratory Information System (LIS) was the Integrated Software Solutions (ISS) Omnilab v9.4.2 SR10 system. The two systems require a manual transition (e.g., barcode scan and time stamp entry) of information at the CSR. The Department of Health Quality Use of Pathology Program 2012 funded the project. Ethics approval was provided by the Local Health District Human Research Ethics Committee (HREC: Project No. 11/146).

1.2. Data extraction and analysis

A data extraction from the LIS involved all laboratory tests ordered by the six hospitals for the period of August/September across the years 2008 to 2011. Two high volume tests were selected for further study: a) Electrolytes, Urea, Creatinine (EUC) in the clinical chemistry department of the pathology service; and b) Automated Differential (including full blood count) in the Haematology department. Data analyses to compare

times were conducted using IBM SPSS Statistics 20.0.0 and Microsoft Excel 2007, and used Mann-Whitney U tests with a significance level set at 0.05.

2. Results

The results (see Table 1 and Table 2) showed that the median data entry time for all hospitals was three minutes faster for EMR orders as compared to paper orders. This was true for both EUC and Automated Differential in 2010 and 2011. The increases in laboratory TAT for Hospitals A, B and C, coincided with the introduction of a new chemistry analyser in January 2011 into the clinical chemistry departments servicing those hospitals. The new analyser incorporated an instrument with a longer analytical cycle time.

Table 1 A comparison of data entry times and TAT for EUC tests. August/september 2008 to 2011

Clinical Chemistry				2008		2009		2010		2011	
Hosp	**EUC**			**EMR**	**Paper**	**EMR**	**Paper**	**EMR**	**Paper**	**EMR**	**Paper**
A	TAT (mins)	Data Entry	Median (IQR)	.	14 (6,28)	.	9 (5,15)	5 (3,9)	8 (5,13)	5 (2,11)	8 (4,13)
		Lab TAT		.	42 (29,60)	.	47 (32,68)	43 (27,70)	56 (38,83)	58 (47,75)	64 (52,84)
	Test Count			.	20325	.	19757	16926	3058	17252	3616
B	TAT (mins)	Data Entry	Median (IQR)	.	12 (4,25)	.	9 (5,14)	6 (2,10)	8 (4,12)	5 (2,10)	6 (3,11)
		Lab TAT		.	42 (29,61)	.	49 (35,69)	44 (30,67)	51 (37,73)	61 (48,78)	65 (50,85)
	Test Count			.	2152	.	2205	1486	504	1435	481
C	TAT (mins)	Data Entry	Median (IQR)	.	10 (4,21)	.	9 (5,14)	5 (3,9)	8 (5,13)	5 (2,9)	8 (4,14)
		Lab TAT		.	40 (27,60)	.	51 (36,71)	43 (30,63)	59 (40,86)	64 (50,82)	70 (53,93)
	Test Count			.	4953	.	5142	4475	663	3886	714
D	TAT (mins)	Data Entry	Median (IQR)	.	1 (0,2)	10 (7,18)	12 (8,22)	6 (4,14)	8 (5,16)	4 (1,12)	9 (4,20)
		Lab TAT		.	52 (38,70)	66 (47,89)	74 (53,101)	68 (50,89)	74 (54,97)	59 (43,80)	70 (55,91)
	Test Count			.	5160	4560	357	4880	321	5134	646
E	TAT (mins)	Data Entry	Median (IQR)	.	10 (4,22)	10 (3,22)	15 (6,29)	10 (5,19)	15 (8,25)	7 (2,17)	13 (5,26)
		Lab TAT		.	50 (36,67)	52 (36,70)	58 (42,80)	79 (53,120)	89 (62,131)	67 (49,93)	81 (59,111)
	Test Count			.	24266	19459	4482	20798	5071	23179	3747
F	TAT (mins)	Data Entry	Median (IQR)	.	12 (5,22)	14 (8,21)	12 (8,21)	9 (4,17)	9 (4,17)	6 (2,12)	7 (3,14)
		Lab TAT		.	65 (50,83)	65 (51,81)	72 (56,93)	87 (61,119)	88 (65,120)	61 (47,77)	65 (52,81)
	Test Count			.	19517	15776	3950	15503	4017	16418	3345
Overall	TAT (mins)	Data Entry	Median					7	10	6	9
								z=35.16, p<.001		z=33.56, p<.001	
		Lab TAT						66	78	62	68
								z=29.67, p<.001		z=30.45, p<.001	
	Test Count							64068	13634	67304	12549

EUC: Electrolytes, Urea, Creatinine; TAT: Turnaround Time; IQR: Inter-quartile Range (25th percentile, 75th percentile)
Mann-Whitney U tests of significance

Table 2, A comparison of data entry times and laboratory TAT for Automated Differential tests. August/September 2008 to 2011

Haematology				2008		2009		2010		2011	
Hosp	**Automated Differential**			**EMR**	**Paper**	**EMR**	**Paper**	**EMR**	**Paper**	**EMR**	**Paper**
A	TAT (mins)	Data Entry	Median (IQR)	.	14 (6,29)	.	9 (5,15)	5 (3,9)	9 (5,13)	5 (2,11)	8 (4,14)
		Lab TAT		.	45 (28,68)	.	33 (23,45)	28 (19,41)	32 (23,44)	29 (21,40)	30 (23,40)
	Test Count			.	19561	.	19121	15836	3160	16237	3771
B	TAT in mins	Data Entry	Median (IQR)	.	16 (6,32)	.	9 (5,15)	6 (2,10)	7 (4,12)	6 (2,11)	8 (4,14)
		Lab TAT		.	51 (31,77)	.	35 (25,48)	32 (21,49)	32 (22,46)	30 (21,43)	31 (23,43)
	Test Count			.	3087	.	2996	1642	1333	1647	1376
C	TAT (mins)	Data Entry	Median (IQR)	.	12 (5,24)	.	9 (5,15)	5 (3,10)	9 (5,14)	4 (2,9)	9 (5,14)
		Lab TAT		.	46 (30,69)	.	36 (25,52)	33 (22,53)	33 (23,47)	32 (21,50)	32 (24,43)
	Test Count			.	3963	.	3809	3378	636	3056	751
D	TAT (mins)	Data Entry	Median (IQR)	.	1 (0,2)	10 (7,19)	12 (8,23)	6 (4,13)	7 (5,15)	4 (1,12)	9 (4,19)
		Lab TAT		.	29 (16,53)	42 (23,73)	47 (30,83)	43 (23,114)	50 (28,222)	26 (14,49)	33 (20,55)
	Test Count			.	4979	4419	346	4744	329	5231	688
E	TAT (mins)	Data Entry	Median (IQR)	.	10 (4,22)	10 (3,22)	15 (6,29)	10 (5,19)	15 (8,25)	7 (2,17)	13 (5,26)
		Lab TAT		.	45 (30,67)	43 (26,65)	47 (31,69)	38 (26,54)	44 (31,61)	37 (24,52)	44 (30,62)
	Test Count			.	22367	17305	4791	19490	5453	21473	4373
F	TAT (mins)	Data Entry	Median (IQR)	.	12 (4,22)	13 (8,21)	12 (8,20)	9 (4,16)	8 (4,17)	6 (2,12)	6 (3,13)
		Lab TAT		.	74 (44,154)	71 (47,134)	73 (42,238)	78 (50,138)	78 (44,204)	58 (35,138)	64 (34,184)
	Test Count			.	20139	15838	4662	15811	4417	16717	3733
Overall	TAT (mins)	Data Entry	Median					7	10	6	9
								z=34.41, p<.001		z=35.35, p<.001	
		Lab TAT						40	44	36	38
								z=12.79, p<.001		z=11.70, p<.001	
	Test Count							60901	15328	64361	14692

TAT: Turnaround Time; IQR: Inter-quartile Range (25th percentile, 75th percentile); Mann-Whitney U tests of significance

3. Discussion

This study showed that the median data entry time (the time from when the specimen arrives in the CSR until the order is entered into the LIS) for all hospitals combined, was three minutes shorter for EMR than paper. This difference was significant for both EUC and Automated Differential in 2010 and 2011. These decreases contributed to significantly lower median Laboratory TATs for EMR orders (for EUC tests, the difference in medians was 12 minutes in 2010 and six minutes in 2011; for Automated Differential tests, the difference in medians was four minutes in 2010 and two minutes in 2011).

The integration of systems is a key factor influencing the usability of health information technology. Such integration is not always seamless. Healthcare settings are often required make do with *hybrid* solutions (sometimes temporarily as in the case of this study setting, other times more long term) involving a combination of paper-based and electronic tasks. Such situations may impose risks that undermine the effective use of information systems and the way that tasks are *allocated, prioritised, sequenced* and *coordinated*.[9] The possible risks therefore need to be identified and

regularly monitored.[10] It is reasonable to assume that the expected introduction of an integrated solution into the sites investigated in this study, will lead to further gains in the timeliness of test result delivery. Future research in this area would also benefit from broader comparisons of TATs, including those measured from the time of clinician request to the issue of a laboratory result.

4. Conclusion

The design, configuration and implementation of information systems can have a major impact on the way a laboratory service functions, and of its ability to contribute to safe and quality patient care. Maintaining and enhancing the timeliness of services, is a key feature for the successful design, implementation and sustainability of new information technologies, and thus an important subject for continued evaluation.

References

[1] McCay L, Lemer C, Wu AW. Laboratory safety and the WHO World Alliance for Patient Safety. Clinica Chimica Acta 2009;404(1):6-11.
[2] Westbrook JI, Georgiou A, Dimos A, et al. Computerised pathology test order-entry reduces laboratory turnaround times and influences tests ordered by hospital clinicians: a controlled before and after study. Journal of Clinical Pathology 2006;59(May):533-36.
[3] Becich MJ. Information management: moving from test results to clinical information. Clinical Leadership & Management Review 2000;14(6):296-300.
[4] Hawkins RC. Laboratory turnaround time. Clinical Biochemist Reviews 2007;28:179-94.
[5] Georgiou A, Williamson M, Westbrook J, et al. The impact of computerised physician order entry systems on pathology services: a systematic review Int J Med Inf 2007;76(7):514-29.
[6] Westbrook JI, Georgiou A, Rob M. Test turnaround times and mortality rates 12 and 24 months after the introduction of a computerised provider order entry system. Methods Inf Med 2009;48:211-15.
[7] ECRI Institute. Top 10 Health Technology Hazards for 2013 Available at www.ecri.org/2013/2013hazards Accessed 27 March 2013. Health Devices, 2012:1-23.
[8] Committee on Patient Safety and Health Information Technology; Institute of Medicine. *Health IT and Patient Safety: Building Safer Systems for Better Care*. Washington DC, USA: National Academies Press, 2011.
[9] Georgiou A, Westbrook JI, Braithwaite J. Time matters - a theoretical and empirical examination of the temporal landscape of a hospital pathology service and the impact of e-health. Social Science & Medicine 2011;72:1603-10.
[10] Georgiou A, Ampt A, Creswick N, et al. Computerized provider order entry - what are health professionals concerned about? A qualitative study in an Australian hospital Int J Med Inf 2009;78(1):60-70.

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Evaluation of system quality of hospital information system: A case study on nurses' experiences

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Abstract. In this study, we aimed at measuring the nurses' experiences on the system quality of the hospital information system (HIS). This applied, cross-sectional study was conducted in a case hospital in Iran. We developed a three part questionnaire including demographic information, nurses' experiences and satisfaction about different factors of system quality of a HIS. We asked the participants to rate their responses using five-point Likert scale. A total of 120 questionnaires were sent out for all 120 eligible nurses, with 80 completed copies returned. The data was finally analyzed using descriptive statistics. Regarding the interface quality, the most of nurses (37.5%) stated that data entry through input devices was somewhat quick. We found that HIS developers should pay more attention to the technical aspects of HIS and their correspondence with the nurses' needs, especially in terms of documentation, online assistance, response time, system reliability and flexibility, integration with current and new duties, as well as ability of the system to prevent data lose and handle bugs.

Keywords. Hospital information system, System quality, Evaluation, Nurses' experiences, user satisfaction

Introduction

Hospital information systems (HIS) should be designed to support the hospitals' and users' needs. To this end, the regular and accurate evaluation of these systems (including user satisfaction) is necessary [1, 2]. According to Delone & McLean model usage of an IS and user satisfaction are completely dependent on three factors including information quality, service quality and finally system quality [3]. Ribiere has, also, emphasized that the system quality of a HIS should be studied regarding the interface, functions and performance of a system [4]. The previous researches have indicated that nurses play an important role in adopting and evaluating HISs [5]. According to the

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prior studies, the poor HIS design may cause nurses' resistance and reduce satisfaction [6]. Therefore, nurses' attitude towards using HIS and its design has significant impacts on the successful implementation of the HIS [7]. In this study, we aimed to measure the nurses' experiences on the system quality as a factor affecting nurses' satisfaction with a HIS.

1. Methods

This descriptive cross-sectional study was conducted in a teaching hospital affiliated with Mashhad University of Medical Sciences (East of Iran) in 2013. We developed a three part questionnaire with 38 questions regarding nurses' experiences about different factors of system quality of a HIS and their satisfaction. To determine the factors of system quality, we reviewed the related literature [4, 6, 7, 8]. We defined the "system quality" as the technical quality of the HIS including the quality of interfaces, functions and performance of the system [4, 6]. The nurses were asked to express their experiences about and satisfaction with these factors and sub factors at a five-point scale. (Very low=1, very high=5). To ensure the validity, relevant studies were reviewed to ensure whether a comprehensive list of measures was included. The questionnaire was then validated by a panel of three experts (one senior nurse and two experienced researchers in health information management and technology). Furthermore, a pilot study was conducted to test the questionnaire. The nurses were, also, invited to make comments on the clarity and comprehensibility of the questionnaire. The test-retest reliability was 85 percent.

We collected empirical data targeting nurses with over three years' experience in using the HIS. Totally of 120 questionnaires were sent out for all 120 eligible nurses, with 80 completed copies returned (response rate = 66.6%). Additionally information sheets describing the nature of the study, the anonymous nature of the questionnaire and confidentiality of data were given to all participants. The data regarding nurses' experiences were finally analyzed using descriptive statistics by the SPSS software. Additionally, we computed the mean score of the nurses' satisfaction.

2. Results

Most of the respondents were females (69%) and 49.4% of them were between 25 and 35 years old, and all respondents had bachelor's degrees or higher. The mean number of years working with the HIS was 7. The findings showed that most of nurses considered the importance of the HIS to do their job as "very important" (50%) and "important" (20%).

As for screen interface, most users (51.3%) believed that the volume of output per screen in the HIS is somewhat suitable. Online assistances' sufficiency was considered low (37.5%) and 42.5% of respondents expressed that these assistances were somewhat complete (Table 1). Based on this table, 55% of nurses stated that integration of functions with their daily tasks was somewhat suitable. Most nurses identified that the system reliability and its ability to handle bugs, to prevent losing data and to prevent losing time were low (47.5%, 51.3% and 38.8% respectively). As shown in Table 2, nurses had the highest satisfaction rate about the screen interface (mean= 4), and the lowest satisfaction rate (mean= 2.4) for functions of the HIS with their daily tasks.

Table 1. Nurses' experiences on quality of HIS

Factors	Sub factors	Characteristics	No(%) of Responses					
			Very high	High	Somewhat	Low	Very low	Missing
Interfaces' quality	Data entry devices	Reasonability	20(25)	35(43.8)	17(21.3)	2(2.5)	1(1.3)	5(6.3)
		Applicability	17(21.3)	46(57.5)	12(15)	2(2.5)	1(1.3)	2(2.5)
		Speed	11(13.8)	20(25)	30(37.5)	12(15)	1(1.3)	6(7.5)
	Format of printed output	Easy to read	17(21.3)	43(53.8)	14(17.5)	1(1.3)	0	5(6.3)
		Current	9(11.3)	42(52.5)	22(27.5)	1(1.3)	0	6(7.5)
		Appropriateness	15(18.8)	37(46.3)	16(20)	5(6.3)	2(2.5)	5(6.3)
		Easy to customize	4(5)	30(37.5)	20(25)	15(18.8)	4(5)	7(8.8)
	Screen Interface	Well -designed screen layout	9(11.3)	43(53.8)	26(32.5)	2(2.5)	0	0(0)
		Pleasant screen color	7(8.8)	42(52.5)	28(35)	3(3.8)	0	0(0)
		Readability of information	14(17.5)	57(71.3)	8(10)	1(1.3)	0	0(0)
		Easy to use menus	6(7.5)	51(63.8)	21(26.3)	2(2.5)	0	0(0)
		Suitability amount of information per screen	5(6.3)	23(28.8)	41(51.3)	10(12.5)	1(1.3)	0(0)
	Usability	Simplicity	15(18.8)	41(51.3)	17(21.3)	6(7.5)	1(1.3)	0(0)
		Intuitiveness	11(13.8)	39(48.8)	23(28.8)	4(5)	3(3.8)	0(0)
		User-friendly	13(16.3)	27(33.8)	28(35)	8(10)	3(3.8)	1(1.3)
	Language	Simplicity	21(26.3)	46(57.5)	5(6.3)	3(3.8)	2(2.5)	3(3.8)
		Understandability	28(46.7)	39(48.8)	12(15)	1(1.3)	0	0(0)
		Adapted	11(13.8)	35(43.8)	26(32.5)	4(5)	4(5)	0(0)
	Documentation	Clarity	12(15)	28(46.7)	30(37.5)	8(10)	1(1.3)	1(1.3)
		Availability	7(8.8)	27(33.8)	31(38.8)	13(16.3)	0	2(2.5)
		Completeness	4(5)	24(30)	40(50)	9(11.3)	1(1.3)	2(2.5)
		Current	5(6.3)	29(36.3)	38(47.5)	3(3.8)	2(2.5)	3(3.8)
	On-line assistance	Completeness	10(12.5)	22(27.5)	34(42.5)	11(13.8)	3(3.8)	0(0)
		Understandability	6(7.5)	31(38.8)	31(38.8)	4(5)	4(5)	4(5)
		Sufficiency	10(12.5)	11(13.8)	22(27.5)	30(37.5)	6(7.5)	1(1.3)
Functions' quality	Reversibility	Simplicity	9(11.3)	31(38.8)	25(31.3)	12(15)	3(3.8)	0(0)
		Security	2(2.5)	35(43.8)	29(36.3)	10(12.5)	2(2.5)	2(2.5)
		Speed	4(5)	26(32.5)	32(40)	9(11.3)	7(8.8)	2(2.5)
	Integration with current duties	appropriateness	11(13.8)	18(22.5)	44(55)	6(7.5)	1(1.3)	0(0)
	Integration of new functions/feature	appropriateness	3(3.8)	13(16.3)	42(52.5)	12(15)	8(10)	2(2.5)
Performance' Quality	Response time	Speed	6(7.5)	27(33.8)	35(43.8)	11(13.8)	1(1.3)	0(0)
		Reasonability	7(8.8)	31(38.8)	29(36.3)	5(6.3)	3(3.8)	5(6.3)
	Reliability	Security	2(2.5)	27(33.8)	39(48.8)	9(11.3)	1(1.3)	2(2.5)
		Ability to handle computer bugs or abrupt disconnection	1(1.3)	7(8.8)	13(16.3)	38(47.5)	20(25)	1(1.3)
		Ability to prevent losing Data	5(6.3)	15(18.8)	13(16.3)	41(51.3)	6(7.5)	0(0)
		Ability to prevent losing time	4(5)	13(16.3)	21(26.3)	31(38.8)	11(13.8)	0(0)
	Flexibility	Versatility	4(5)	33(55)	31(38.8)	11(13.8)	0	1(1.3)
		Sufficiency	4(5)	24(30)	36(45)	11(13.8)	1(1.3)	4(5)

Table 2. Nurses' satisfaction with system quality of HIS

Factors	Sub factors	Mean
User-Interface	Data entry devices	3.7
	Format of printed Output	3.8
	Screen interface	4.0
	Usability	3.7
	Language	3.4
	Documentation	3.4
	On-line assistance	3.4
Functions	Reversibility	3.1
	Integration with current duties	2.4
	Integration of new functions /features	2.6
Performance	Response time	3.5
	System reliability	2.6
	System flexibility	3.3

3. Discussion

As the findings show, most of nurses knew the documentation of HIS somewhat completely and expressed difficulties in documents availability. The system documentation is of a significant role to create user satisfaction and make working with it more efficient, to decrease expenditures and confusion, removing failures and improving management control [6], increasing users' skills to use the system, improving the efficiency, decreasing the user's dependence on IT departments, increasing the adoption and usage of a system and enhancing the end users' satisfaction [9]. The majority of our nurses considered the usability of HIS desirable. Freed introduces the lack of attractiveness of a HIS as the factor resulting in the failure of the system [10]. Previous researchers have shown that a poor HIS design, difficult-to-use interface and low usability of a HIS result in the nurses' dissatisfaction [7]. Therefore, nurses' feedbacks regarding the usability and user-friendliness of a HIS should be continually monitored.

The majority of nurses believed that the integration of HIS functions did not properly correspond with their daily tasks. Moreover, Brender says that the functions of a HIS should correspond with the duties and operations of users in their work environment; otherwise, the dissatisfaction and human errors are increased. He asserts that a HIS should be capable to support the users in their daily tasks efficiently [11].

The participating nurses consider the response time of the system somewhat fast. Friedman and Gustafson assert that the system should provide the users with fast and feasible access to their required data [12]. Chow et al. has, also, pointed out delayed log-in times and inefficient processes led to nurses' reduced efficiency while using the system in a busy ward environment [7]. Most nurses identified that the system's reliability and its ability to handle bugs, to prevent losing data and to prevent losing time is low. Furthermore, Sheild et al. pointed out that the greatest anxiety of the personnel in electronic documentation of patients' data originates from fear of losing the data [13]. Our findings indicate that the highest level of satisfaction belongs to screen interface and its lowest is related to the integration of system with the daily duties of users, the integration of new functions and features as well as system reliability. Chow et al., also, states that nurses' satisfaction was affected by system usability and usefulness. On the other hand, nurses' motivational attitudes to using the

computerized system are related to their enhanced satisfaction with the system [7]. As stated by Liu et al., deficiency in the HIS design will result in nurses' dissatisfaction [14]. Our findings are subject to some limitations. First, this study was conducted at only one teaching hospital, restricting its generalization to other hospitals. Future researches should explore different hospitals. Second, the data are derived from questionnaires provided for participants with more than three years' experience using HIS. In conclusion, the following suggestions are presented:

It is better to use menus and colored graphic pictures in the design of different parts of a system, which leads to the attractiveness and simplicity of the system as well as its usability for the nurses. Documentations and instructions for HISs should be made more practical, simpler and easily accessible for the nurses. Online assistance should be used as much as possible. To provide the nurses with the possibility of revising of the errors and wrong information, the system should be easily reversible and flexible in the shortest time. Moreover, in order to increase the system's response time, advanced hardware and proper communication line should be applied. The personnel supporting the HIS should constantly be available to the users so that losing the data is minimized. The designers of a system should pay attention to the possibility of adding new features to the system with regard to meeting new needs in future.

References

[1] Sadoughi F, Kimiafar K, Ahmadi M, Shakeri MT. Determining of Factors Influencing the Success and Failure of Hospital Information System and Their Evaluation Methods: A Systematic Review. Iran Red Crescent Med J. 2013;**15**(12):e11716. Epub 2013-12-05.

[2] Aggelidis VP, Chatzoglou PD. Methods for evaluating hospital information systems: a literature review. *EuroMed Journal of Business* 2008;**3**(1):99-118.

[3] Delone WH, McLean ER. The DeLone and McLean model of information systems success: A ten-year update. *Journal of management information systems*. 2003;**19**(4):9-30.

[4] Ribiere V, LaSalle AJ, Khorramshahgol R, Gousty Y, editors. Hospital information systems quality: a customer satisfaction assessment tool. Proceedings of the 32nd Annual Hawaii International Conference onSystems Sciences; 1999.

[5] Kimiafar Kh, Sadoughi F, Sheikhtaheri A, Sarbaz M. Prioritizing Factors Influencing Nurses' Satisfaction With Hospital Information Systems: A Fuzzy Analytic Hierarchy Process Approach. Computers Informatics Nursing. 2014;**32**(4):174-81.

[6] Hsiao J-L, Chang H-C, Chen R-F. A Study of Factors Affecting Acceptance of Hospital Information Systems: A Nursing Perspective. *J Nurs Res* 2011;**19**(2):150-60.

[7] Chow SK, Chin WY, Lee HY, Leung HC, Tang FH. Nurses' perceptions and attitudes towards computerisation in a private hospital. *J Clin Nurs* 2012;**21**(11-12):1685-96.

[8] Waneka R, Spetz J. Hospital information technology systems' impact on nurses and nursing care. *J Nurs Adm* 2010;**40**(12):509-14.

[9] Etezadi-Amoli J, Farhoomand AF. A structural model of end user computing satisfaction and user performance. *Inform Manage* 1996;**30**(2):65-73.

[10] Freed DH. Certain death: Ten predictors of hospital information system failure. *Health Care Manag* 2006;**25**(1):26.

[11] Brender J. Evaluation Methods to Monitor Success and Failure Factors in Health Information System's Development. Health Information Systems: Concepts, Methodologies, Tools, and Applications: IGI Global; 2010. p. 605-26.

[12] Friedman RB, Gustafson DH. Computers in clinical medicine, a critical review. *Comput Biomed Res* 1977;**10**(3):199-204.

[13] Shield RR, Goldman RE, Anthony DA, Wang N, Doyle RJ, Borkan J. Gradual Electronic Health Record Implementation: New Insights on Physician and Patient Adaptation. *Ann Fam Med* 2010;**8**(4):316-26.

[14] Liu JE, Pothiban L, Lu Z, Khamphonsiri T. Computer knowledge, attitudes, and skills of nurses in People's Hospital of Beijing Medical University. *Comput Nurs* 2000;**18**(4):197-206.

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EHR and Usability of Health Data to benefit Patient and Public Health

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Abstract. Digitalized information in health sector can improve primary care quality and facilitate public health researches to benefit society. The state of the art encourages the development of ICT solutions for a greater usability of de-identified health data. Several governments are implementing effective strategies such as Open Government Data and Linked Open Data in order to access public data and promote new economic activities. Legal and technical analyses emphasize the urgent need for a deeper focus on harmonization such that health data can actually empower patient and scientific research. The mentioned goal is possible if three conditions are achieved: harmonization of law, harmonization of legal and technical rules and harmonization of Electronic Health Record system design.

Keywords. E-Health, Electronic Health Record, Patient rights, Data Protection, Open Data.

Introduction

Rationalization of public health expenditure, organization of complex systems, collaboration among health professionals using telemedicine tools, access to information on care, availability of personal and clinical data collected on Electronic Health Records. These are only a few aspects examined by the European Commission during the last fifteen years with the goal to create inclusive societies where good health and high levels of services are no longer a Chimera [1]. These challenges characterize modern society, currently connoted by phenomena such as international mobility, multiculturalism and multilingualism. The implications, particularly those related to health care, are extremely important for stakeholders and policy makers as patients.

"Redesigning health in Europe for 2020" [2], a 2012 report of the eHealth Task Force, underlines the relevance of a more efficient use of ICT in healthcare, mainly in order to enhance benefits for patients. "Enacting individual ownership of personal health data", publishing health data, connecting everything, integrating social care and welfare and reducing inequalities among people constitute "the five levers for change" addressed by the e-Health Task Force. Data collected in e-Health systems, structured in such a way that they can interoperable and shareable among users, are of great value: (i) for consumers/patients, which gain the right of "a state of complete physical, mental and social well-being [...]" [3], (ii) for the community, which contribute to the

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efficiency and the efficacy of national health systems (in this case, experts refer to "secondary use" of health data). Methods to achieve these two objectives are obviously different, since different needs exist for the two mentioned actors. In fact, patients health status available in form of suitable data allow physician and medical staff to perform the necessary procedures. Moreover, health system granting anonymity and aggregate data are used by policy makers to plan policies and by experts to develop scientific (clinical, pharmaceutical, epidemiological ...) researches.

In this scenario, a key role is played by EHRs, electronic tools collecting data and information on health life of citizens. EHR benefits are common known by among scholars and practitioners: digitalized personal health information can improve primary care and facilitate secondary use to benefit society.

In the last decade, several national and European projects have been developed fostering the creation of infrastructures for local EHR systems, to demonstrate "cross-border interoperability between EHR systems in Europe" (for example epSOS project [4]) and to develop the use of medical standards (such as HL7, DICOM, MLMs, GLIF etc. [5]) in order to guarantee an highest level of quality and efficacy in health care [6]. Electronic Health Records represent a big source of information about both patient health and citizens' behaviours. Consequently, EHRs data provide a type of documentation particularly interesting for public health and secondary uses. It is extremely important to investigate the possibility to get health "Open Data", not only starting from the information already available into national health systems (as management data), but also including data collected into EHRs. At the same time, it is imperative to focus the attention on data treatment and protection, particularly for consumer/patient who benefits of the mentioned technologies. In the European Digital Agenda the Open Data is a key strategy. The publication of public data - electronically stored information, available in non-proprietary format fortified with appropriate metadata so that they can be processed in a automated way - facilitate the access to information, promote the transparency and the cooperation among institutions and stakeholders (as business/industry, citizens, NPOs and NGOs, science or education) and promote useful applications for the Community.

The state of the art encourages the implementation of ICT solutions for a greater usability of de-identified health data. Nevertheless, the digitalization of health information requires the adoption of appropriate security measures and the formalization of a juridical framework aimed to treat and protect personal data [7]. New challenges arise in term of *privacy* and *security*: de-identification, authorized access, data governance and the need for transparency are "the challenges associated with research and health system uses in the EHR context" [8]. This study aim to: (i) reconstruct the legal and technological framework on the interoperability of EHRs with a particular attention to privacy and security issues; (ii) investigate the requirements for applying Open Data and Linked Open Data models [9-10] to health sector and to Electronic Health Record systems.

1. Methods

The research is structured on different levels.

The first level is focused on exploring existing European and Italian political actions and legislative acts on e-Health, Electronic Health Record, data protection and their latest developments. The following approaches have been used: (i) review of the

significant European documents (non exhaustive) [11]: Communication "eEurope 2002", Communication "eEurope 2005", Directive 2002/58/EC, Communication "eHealth Action Plan", Communication "i2010", Communication on promoting data protection by PETs, Communication "Europe 2020", Communication "A Digital Agenda for Europe", Directive 2011/24/EC, Communication "eHealth Action Plan 2012-2020"; (ii) review of the Italian (binding and non binding) documents in force [12]: d.lgs. 196/2003; "Linee guida in tema di fascicolo sanitario elettronico e di *dossier* sanitario" written by the Italian Data Protection Authority; "Il Fascicolo Sanitario Elettronico. Linee guida nazionali" recommended by the Italian Ministry of Health; decree 179/2012 and decree 69/2013.

The second level of investigation addresses the process of standardization in health care through the analysis of selected European and national (Austria, Denmark and Italy) projects on Electronic Health Record [4, 13-15].

The third level of analysis concerns security issues and usability of health data as technological challenges. Accordingly, a particular attention is for the adoption of Privacy Enhancing Technologies (PETs) and Privacy by Design (PbD) principles in e-Health field [16-22]. Moreover, ongoing studies and consideration regard the adaptability of Open Data and Linked Open Data (LOD) principles to EHR systems. Data recorded in the EHR are sensitive, this is why a possible "opening" of health information need to be considered carefully.

2. Results

Improving healthcare is a common goal of patients and health care policy makers. Health data development will meet both interests only if patient right to privacy is granted. Legal and technical analyses emphasize the urgent need for a deeper focus on harmonization such that health data can actually empower patient and scientific research. As figure 1 shows, it is essential to move along three kinds of harmonization: (i) harmonization of law, (ii) harmonization of legal and technical rules, (iii) harmonization of EHR system design. Currently, European (but also Italian) initiatives are inclined to draft legal "code" in order to fix cases and best practices on EHRs and data protection treatment. Accordingly, there is a strong attention on the adoption of Privacy Enhancing Technologies and the implementation of Privacy by Design. Moreover, the 25th January 2012 the European Commission launched out the "Proposal for a Regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data" to harmonize existing rules on privacy according to the technological progresses and the changed way to collect, access and use data. The interoperability of IT systems relies not only on the data models but also on the capacity of these systems to share security and data protection policies. In fact, different IT systems can share information only if they share organizational rules which regard the tasks of people, who are directly involved in providing healthcare and IT services. The semantics aspects of roles and declarative rules in an interoperability framework between different domains need to be formalized and shared.

Implementing "Privacy by default" and "Privacy by Design" is a "win/win" [19] way to eliminate ICT obstacles on designing of EHR advanced systems and to achieve a good balance between private and public interests. Evidences prove that is still necessary to develop the mentioned ideas to e-health field. In this perspective,

consumer plays a key role not only as final beneficiary of the considered measures but also as architect of privacy, using privacy-friendly tools. Data minimization principles, separation between identification and data content, use of pseudonyms and anonymity techniques and/or deletion of personal data in a short time implement proper prevention mechanisms which makes it suitable also for secondary uses .

Secondary uses of health data require maximum *transparency* for the patient, who need to rely on the ability to safeguard their privacy. European and Italian legislation are favourable to secondary uses of health data that are de-identified health information. EHR databases collect a lot of these data; it is really essential adapting legal concepts and ICT models to these new technologies. The concept of *usability* of health information for secondary purposes call the Open Data movement to the center of many government programs. In particular, the Italian Ministry of Health in Italy joined the "Open data" strategy spreading public data (such as data related to "ASL" [public hospitals], pharmacies and drugstores, drugs, plant protection products and medical devices) for the improvement of services. Although these information are extremely useful, the information regarding citizens' health to improve knowledge on diseases and to facilitate the prevention are more relevant in order to optimize the care pathways, to monitor services, and so on. Particularly significant are Linked Open Data, a method by which it is possible to aggregate data that come from distributed sources and to obtain interoperability between data repositories allowing all applications to access content in a standard way.



Figure 1. Improving healthcare through EHR and health data use

3. Discussion

Open Government Data is the major current movement which aim to open public data and to make them available in machine-readable formats for re-use by public or private professionals. Linked Open Data is the technology used for this open process of information; it is the way by which knowledge is linked with other knowledge.

LOD are already available for libraries, biomedicine, government data (Public Sector Information), but are Linked Open Data adaptable to EHR systems?

From a legal prospective, it is essential to guarantee data protection. If the EHR systems adopt de-identify personal health data in a strong way, health data can be used for secondary goals. From a technical point of view, benefits are noteworthy but use of

standardization process need to be implemented systematically by EHR systems. The current state of the art of Electronic Health Record is evolving; however, more attention to privacy by default and standardization process are required for primary and secondary uses of health information.

References

[1] Callens S., The EU legal framework on e-health, Cambridge University Press. 2010; 561-588.
[2] eHealth Task Force Report, Redesigning health in Europe for 2020, Luxemburg; 2012.
[3] Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.
[4] European Patients Open Services project [Internet]. epSOS - the European eHealth Project. Stockholm; [cited 2014 Apr 10]. Available from: http://www.epsos.eu/
[5] ITU-T Technology Watch Report, Standards and eHealth, Geneva; 2011.
[6] Palfrey J., Gasser U., Interop. The promise and perils of highly interconnected systems, Basic Books, New York; 2012.
[7] European Commission, Directorate-General Justice, Freedom And Security, Comparative Study On Different Approaches To New Privacy Challenges, In Particular In The Light Of Technological Developments, Final Report, Centre for Public Reform, Final version; 2010.
[8] Cavoukian A., Alvarez R. C., Embedding Privacy Into The Design Of Electronic Health Records To Enable Multiple Functionalities – Win/Win, Toronto; 2012.
[9] Bauer F., Kaltenböck M., Linked Open Data. The essential, A Quick Start Guide for Decision Maker, Vienna; 2012.
[10] Heath T., Bizer C., Linked Data: Evolving the Web into a Global Data Space. Synthesis Lectures on the Semantic Web: Theory and Technology, Morgan & Claypool; 2011.
[11] European Publications Office [Internet]. Eurelx. Access to European Union Law. Brussels; [updated daily; cited 2014 Apr 10]. Available from: www.eur-lex.europa.eu/
[12] Istituto Poligrafico e Zecca dello Stato s.p.a. [Internet]. Normattiva. Il portale della normative vigente. Roma; [updated daily; cited 2014 Apr 10]. Available from: www.normattiva.it
[13] ELGA GmbH [Internet]. ELGA - Meine elektronische Gesundheitsakte. MeineEntscheidung! Wien; [cited 2014 Apr 10]. Available from: http://www.elga.gv.at/
[14] Consiglio Nazionale delle Ricerche - Dipartimento delle Tecnologie dell'Informazione e delle Comunicazioni [Internet]. ICT&Health. Roma; [cited 2014 Apr 10]. Available from: http://ehealth.icar.cnr.it/
[15] MedCom [Internet]. MedCom Det danske Sundhedsdatanet. Odense; [cited 2014 Apr 10]. Available from: http://www.medcom.dk/wm109991
[16] Cavoukian A., Chanliau M., Privacy and Security by Design: A Convergence of Paradigms, Toronto; 2013.
[17] Cavoukian A., Emam K. El, A Positive-Sum Paradigm in Action in the Health Sector, Toronto; 2010.
[18] Cavoukian A., Moving Forward From PETs to PETs Plus: The Time for Change is Now, Toronto; 2009.
[19] Cavoukian A., Privacy by Design … Take the Challenge, Toronto; 2009.
[20] Information and Privacy Commissioner of Ontario, Dutch Registratierkamer, Privacy Enhancing Technologies - The Path to Anonymity, Registratiekamer, The Netherlands; 1995.
[21] London Economics, Study on the economic benefits of privacy enhancing technologies (PETs), Final Report to The European Commission DG Justice, Freedom and Security; 2010.
[22] Pagallo U., On the Principle of Privacy by Design and its Limits: Technology, Ethics and the Rule of Law, Gutwirth S., Leenes R., De Hert P., Poullet Y., editors, European Data Protection: In Good Health?, Dordrecht, Springer; 2012.
[23] Organisation For Economic Co-Operation And Development, Guidelines on the Protection of Privacy and Transborder Flows of Personal Data; 1980.
[24] Forum Europe [Internet]. The 4th Annual European Data Protection and Privacy Conference. Shaping the Future Privacy Landscape. Brussels; [cited 2014 Apr 10]. Available from: http://www.eu-ems.com/summary.asp?event_id=147&page_id=1227
[25] Computer, Privacy & Data Protection [Internet]. 7th Intenational Conference Computer, Privacy & Data Protection: Reforming Data Protection: The Global Perspective. Brussels; [cited 2014 Apr 10]. Available from: http://www.cpdpconferences.org

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PAT: An Intelligent Authoring Tool for Facilitating Clinical Trial Design

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Abstract. Great investments are made by both private and public funds and a wealth of research findings is published, the research and development pipeline phases quite low productivity and tremendous delays. In this paper, we present a novel authoring tool which has been designed and developed for facilitating study design. Its underlying models are based on a thorough analysis of existing clinical trial protocols (CTPs) and eligibility criteria (EC) published in clinicaltrials.gov by domain experts. Moreover, its integration with intelligent decision support services and mechanisms linking the study design process with healthcare patient data as well as its direct access to literature designate it as a powerful tool offering great support to researchers during clinical trial design.

Keywords. Clinical trial, patient recruitment, semantics, decision support systems

Introduction

Clinical research aims, among others, at revealing the therapeutic potential of substances, methodologies and devices in order for them to be developed into real world therapies. A recent study indicates that over $139 billion are spent annually on health research in the USA [12] with the estimated average cost per drug candidate being *more than € 1 billion*, while recently reported figures show that the overall required investment may reach even € 8 billion [1]. The prolonged therapy investigation and development process (being 11.3 years [2] on average) and the low productivity that clinical research faces (1 out of 5,000 compounds under research enter the market [3]), which is highly affected by bad study design (such as missing, poorly scientifically justified or inconsistent parameters and vague and/or rigid eligibility criteria) leaves millions of patients remaining untreated or following treatments of low/medium efficacy or side effects which affect their health. Weng et al. [4] stress out that key issues, which need to be addressed in clinical trials include incompleteness, ambiguity and inconsistency with most errors being identified within the protocol writing process. A major determinant for the success of a trial, is the set of EC specified for the study. EC are quite often poorly justified, vague, ambiguous or overly rigid. In fact, an analysis of inclusion and exclusion criteria across several trials [5] showed that more than 36% of the medication related criteria, 64% of the medical

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comorbidity related ones and 78% of the age related ones are poorly justified. In fact, vague and/or ambiguous criteria may increase patient risks and weaken the ability to utilize the criteria to establish appropriate labeling. Moreover, overly rigid criteria may limit the generalizability potential of the study results, lead to a study population failing to represent the real world patient population, limit patient accrual and, hence, study costs, duration and feasibility.

Within this context, this paper focuses on presenting a series of novel mechanisms integrated and visualized through an authoring tool, which aims at improving three important processes in clinical research; specification of study parameters, determination of the eligible patient population and patient recruitment. It comprises part of the work performed within the PONTE project, which has been has been partially funded by the European Commission's 7th Framework Programme under contract number 247945 and worked towards the intelligent design of clinical trials.

1. Methods

The PONTE Authoring Tool (PAT) is a GUI specially designed to expose the functionality of the underlying PONTE platform's components to the end user. It facilitates the *CTP management* and the *design,* the specification of *study parameters* (e.g., study duration, number of patients), the *description of the eligible study population* and the determination *of healthcare entities* which will constitute the *pool for the patient recruitment* process. PAT is also used *as a collaborative environment* (essential for multicenter trials) as users can collaboratively work on CTP authoring.

The following methodological steps have been followed in order to define the technical and functional requirements of the PAT: (i) A **round of interviews with clinical research experts** took place in order to sketch out the CTP structure, the dependencies among its parameters and their semantic relations. The initial basis for these interviews was a series of CTP templates provided by the PONTE project clinical experts. These templates were analysed in terms of structure and information organisation. The analysis also involved identification of the informational elements which could benefit from decision support and specification of the dependencies (both direct and indirect ones) among the parameters in the CTP. Each expert (8 in total) focused on a specific set of parameters and indicated a series of questions that they often need to have answers for, prior to the specification of the parameter. (ii) **Thorough analysis of the information available at the clinicaltrials.gov [11] site**. The xml description of the studies was downloaded and the variety of values for study parameters (such as study type, blinding methods, control types and endpoints, among others) was analysed. A particular part of the analysis involved the EC, in terms of structure, categorisation, level of detail and individual parameters specified. The analysis was based on 1000 criteria selected across all studies at the portal. In order to ensure that different types of criteria are fed in the analysis, the respective studies were chosen so that a wide spectrum of disorders and active substances is covered. The analysis of those data (in terms of structure, terminology and types used) was taken into consideration to build the EC Ontology [6]. Hence, we followed an ontology based approach for capturing the semantics and allowing for semantic inference, in order to enable researchers to apply EC questions to Electronic Health Records connected to PONTE. (iii) The "access from anywhere", "collaboration among experts" requirements, as posed by the PONTE clinical experts, together with the "diversity in

the structure of data to handle", made apparent the third step regarding the technology used to **implement the PAT as a web tool following the Model View Controller (MVC) Design Pattern approach** [7]. MVC is an architecture that separates the representation of information from the user's interaction with it. The central idea behind MVC is code reusability and separation of concerns. The PAT Web Client uses JavaScript technology in order to provide a rich user-friendly browser based interface. This is done through the PAT Web Client Library which utilises the jQuery library[2] and Ajax[3] programming in order to create a more interactive and dynamic interface. Its server implementation (PAT Web Server Application) is developed using JAVA EE and runs on Apache Tomcat Application Server.

2. Results

Figure 1 depicts the PAT architecture and its 3 main modules: (i) The **PAT Web Client** is the part of the application running on the web browser. It contains a JavaScript library component (PAT Web Client Library) implementing the *presentation logic* of the application, providing rich user interaction capabilities and communicating with the server-side components. (ii) The **PAT Web Server Application** running on a web server host implements the core functionality of PAT and communicates with the rest of the PONTE platform. It encapsulates the *user interface rendering logic* and the orchestration of user actions, and business workflows. It contains the Request Handler which receives requests from the browser (PAT Web Client), creates the corresponding user interface elements from the UI Controls Library and renders the response back to the browser. The Request Handler is also responsible for communicating with the Authentication /Authorisation module in order to establish a security context for the execution of the request handling. The PAT Business Logic is implementing the core application logic and is responsible for interacting with the other PONTE components such as the Decision Support or the Ontology Based Search Engine components. The Business Logic also uses the PAT Local Storage to temporarily store the CTP parameters filled in by the users and other application state information. (iii) The **PAT Local Storage module** contains a local database which provides *persistence services* for the needs of the PAT Web Server Application. All CTP parameters are persisted on the local storage throughout the authoring lifecycle.

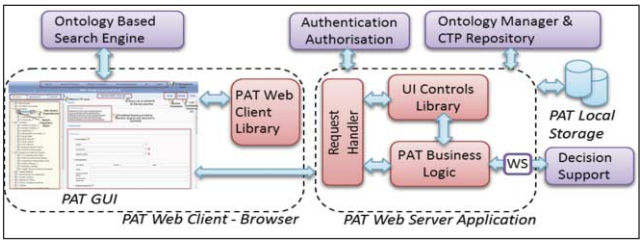


Figure 1. Internal PAT Architecture

As mentioned above, PAT facilitates the user in filling in each section of the CTP by providing useful information wherever possible, in order to ensure *CTP parameters*

[2] http://jquery.com/
[3] http://en.wikipedia.org/wiki/Ajax_(programming)

consistency, study efficacy and patient safety. In brief, PAT allows the PIs to manage their CTPs and the healthcare entities they cooperate with for patient recruitment purposes. It presents the user with three different CTP views: a hierarchical one (based on the CTP structure), a dependency one (based on dependencies between parameters) and a semantic one (built around three key concepts: the investigational active substance, the study disorder and the drug target). Hence, the PIs are offered a very flexible interface to navigate across the study parameters and fill in their data. Validation checks are provided whenever PIs save their work at a section or the CTP as a whole. For each section, PAT presents to the PI a set of automatically generated questions, the answer to which, may facilitate their (research) work. These questions are directly linked with the semantic search engine GoPONTE [9], to automatically retrieve the results of the selected ones.

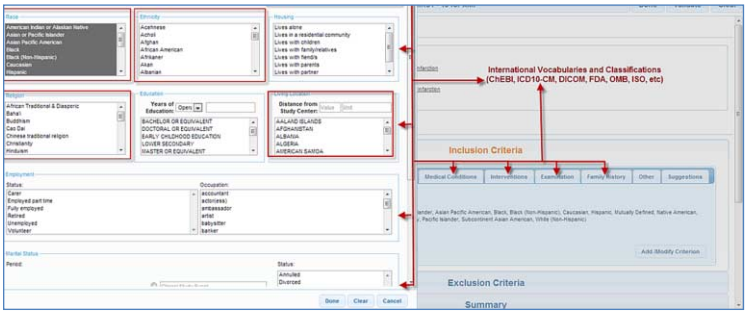


Figure 2. The EC categorization and links to vocabularies in PAT

PAT allows the specification of the study EC (Figure 2) based on the aforementioned EC-Ontology [6] and using international vocabularies and classifications for each EC category. It also communicates with the decision support mechanisms in order to present the user with suggestions regarding the EC. At any point during CTP design, the PI may request for a size estimation of the eligible patient population at each collaborating healthcare entities, based on the current EC specified. When the study design is completed, the PI can finalise the CTP and submit it to the Ethics committee. Upon approval of the CTP, patient recruitment may be initiated.

3. Discussion

Given the complexity of the study design, the variety of EC and the greatly heterogeneous data required for analysis and processing, the development of services and solutions to facilitate researchers in CTP design comprises a great challenge. PAT encapsulates intelligent, semantically-assisted mechanisms for study parameter specification and EC determination. The thorough analysis of CTP templates performed by experienced clinical experts, allowed for the development of a model, based on which PAT organizes CTPs around 3 different views: the hierarchy of its parameters, dependencies among them and their semantic linking with the CTP main concepts (investigational active substance, study disorder and drug target). These views were considered as “very helpful” during trial design by the experts, as they allowed for “easy and fast detection of inconsistencies” and “less time consuming parameter specification” although the dependencies should be further enriched and the 3 main concepts could be expanded to also include “clinical trials” and “patient” concepts. The

CTP parameters are directly linked with literature through templates of questions [10] that researchers would be interested in finding answers for, during design. According to the clinical experts, this functionality boost the scientific validity of the parameters and allows for faster referencing of the CTP. Nevertheless it was noted that this functionality could be enhanced through the introduction of more questions and the linking with data sources beyond literature, such as drug data sheets.

Analysis of the EC across studies published at clinicaltrials.gov, together with reviewing of the extracted patterns by clinical experts, led to a series of EC templates for describing the study population. PAT links with mechanisms applying these criteria onto patient data at healthcare entities (i.e., hospitals, clinics, etc.) in order to provide an estimation of the eligible population size. This functionality was considered of great value by the clinical experts (especially PIs) as it provides an indication about the *feasibility of the study* as well as the *potential market share*. Furthermore, it offers automatic retrieval of eligible patients who could potentially participate in the trial. According to the clinical experts, this is expected to significantly reduce the patient recruitment resources, both in terms of time and effort required, but also, will allow for fast and effective site recruitment. The EC model and resulting templates were evaluated as well structured and capable to cover frequently used criteria with a modest degree of complexity. However, further analysis is required in order to capture even more complicated EC but also to enrich the underlying vocabularies.

4. References

[1] Herper, M., 2012. The Truly Staggering Cost Of Inventing New Drugs, s.l.: Forbes

[2] J. D. Masi, R. Hansen, and H. Grabowski. The Price of Innovation: New Estimates of Drug Development Costs. Journal of Health Economics, 22:151{185, 2003.

[3] PhRMADrug Discovery and Development: Understanding the R&D process Pharmaceutical Research and Manufacturers of America. 2007. 2007.

[4] C Weng, DW. McDonald, J.H. Gennari, Participatory Design of A Collaborative Clinical Trial Protocol Writing System, IT in Health Care: Socio-technical Approaches 2nd International Conference, 13-14 September 2004, Portland, Oregon

[5] Van Spall, Harriette (21 Mar 2007). "Eligibility criteria of randomized controlled trials published in high-impact general medical journals: a systematic sampling review.".The Journal of American Medical Association 297 (11): 1233–40

[6] Chondrogiannis, E., Andronikou, V., Mourtzoukos, K., Tagaris, T., & Varvarigou, T. (2012). *A novel Query Rewriting Mechanism for Semantically interlinking Clinical Research with Electronic Health Records*. Proceedings of the 2nd International Conference on Web Intelligence, Mining and Semantics. Craiova: ACM. doi:10.1145/2254129.2254189

[7] MSDN Model-View-Controller, "*Microsoft Developer Network: Model-View-Controller,*" 2014. MSDN Model-View-Controller, "Microsoft Developer Network: Model-View-Controller," 2014. [Online]. Available: msdn.microsoft.com/en-us/library/ff649643.aspx.

[8] Tagaris, A., Chondrogiannis, E., Andronikou, V., Tsatsaronis, G., Mourtzoukos, K., Roumier, Varvarigou, T. (2012). *Semantic Interoperability between Clinical Research and Healthcare: the PONTE approach.* Semantic Interoperability in Medical Informatics (SIMI2012). Workshop co-located with the ESWC2012.

[9] Tsatsaronis, G., Mourtzoukos, K., Andronikou, V., Tagaris, T., Varlamis, I., Schroeder, M., Matskanis, N. (2012). *PONTE: A Context-Aware Approach for Automated Clinical Trial Protocol Design.* 38th International Conference on Very Large Databases.

[10] Roumier, J., Liebman, M., Tsatsaronis, G., Matskanis, N., Tagaris, A., Mourtzoukos, K., .Schroeder, M. (2012). *Semantically-assisted Hypothesis Validation in Clinical Research.* Lisbon: eChallenges 2012.

[11] ClinicalTrials.gov A service of the U.S. National Institutes of Health (US) [cited 2014 May 4]. Available from: http://clinicaltrials.gov

[12] Research America, ARRA Saves Research from Decline, Available from: http://www.researchamerica.org/uploads/healthdollar09.pdf

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Enhancing informatics competency under uncertainty at the point of decision: a knowing about knowing vision

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Abstract. Most informatics activity is aimed at reducing unnecessary errors, mistakes and misjudgements at the point of decision, insofar as these arise from inappropriate accessing and processing of data and information. Healthcare professionals use the results of scientific research, when available, and 'big data', when rigorously analysed, as inputs into the probability judgements that need to be made in decision making under uncertainty. But these judgements are needed irrespective of the state of 'the evidence' and personalised evidence on person/patient-important criteria is very often poor or lacking. This final stage in 'translation to the bedside' has received relatively little attention in the medical, nursing, or health informatics literature, until the recent appearance of 'cognitive informatics'. Positive experience and feed-back from several thousand students who have experienced exercises in assigning probabilities informs our future vision in which better decisions result from healthcare professionals – indeed all of us – having accepted that probability assignment is a skill, with the internal coherence and external correspondence of the probabilities assigned as twin evaluative criteria. As a route to improved correspondence – in the absence of the systematic recording and monitoring of real world judgments that would be the normal pathway to quality improvement - a 'Prober' is a set of statements to which the respondent supplies their personal probabilities that a statement is true. They receive the proper Brier score and its decomposition as analytical feedback, along with graphic representations of their discrimination and calibration, the two key components of good correspondence. Provided with estimates of their sensitivity (mean probability true for true statements) and specificity (1 minus mean probability true for false statements) they can visualise themselves as a 'test' when making diagnostic and prognostic judgements , thereby being given the cognitive foundation for such reflection in their clinical practice, including 'reflection in action'. They acknowledge that an appropriate balance of intuition and analysis is required, as in Hammond's Cognitive Continuum, and are made aware of the cognitive and motivated biases that can prevent us knowing 'how much we know about how much we know', with its deleterious effect on decision quality. Probability exercises, such as 'Probers', are proposed as an enhancement of professional courses and virtual learning environments, such as the TIGER initiative in nursing, through which the competency portfolio of all those seeking to deliver high quality person/patient-centred care can be expanded.

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Keywords. Probability, judgement, coherence, correspondence, calibration, discrimination

Introduction

Our vision is of the better decisions that will characterise the coming era of person/patient-centred care as a result of healthcare professionals – indeed all of us - accepting that, in decision making, we are necessarily Bayesians.[1] We accept that the assessments of the future chances which permeate decisions are ontologically personal and subjective, whatever the extent to which they are epistemologically-based on robust frequencies and however widely they are inter-subjectively agreed. All parties have rejected the temptations of right-wrong thinking, reflected in testing by non-probabilistic Multiple Choice Questions, along with the unwarranted confidence, trust and denial it often generates. Healthcare professionals treat the results of scientific research, when available, and 'big data', when rigorously analysed, as relevant inputs into the probability judgements that need to be made irrespective of the state of 'the evidence'. It is accepted that competence in making probability judgements is the key to improved handling of uncertainty at the point of decision so it is part of the training and education of clinicians.

Most informatics activity is ultimately aimed at reducing unnecessary errors, mistakes and misjudgements at the point of decision, insofar as these arise from inappropriate accessing and processing of data and information. For some criteria and some conditions high-quality 'evidence- based' probabilities can be acquired directly or through a nomogram or 'risk calculator' (preferably a *probability* calculator). [2] But in many cases the clinician will need to use their personal belief probability judgements to remedy the absence of, or to better personalise, the available estimates.

This frequently necessary final stage in 'bench to bedside translation' has received relatively little attention in the medical, nursing or health informatics literature. The widespread assumption has been that this is an intuitive competence that can, and can only, be acquired intuitively, through experience. However, this ignores a significant literature on how the quality of probability judgements can be assessed, on the empirical evidence on clinician performance in this respect, [3,4] on the possible sources of limited performance, and on possible routes to improved quality. Since it will take time to overcome the institutional-professional barriers to systematic judgemental recording and monitoring in practice – the normal route to competence improvement - our vision is pessimistic in this respect. However, as part of the increasing interest in 'cognitive informatics', clinicians can be provided with the cognitive basis for reflecting continuously on their judgemental practice and performance, both 'in action' and outside it, [5,6] accepting that an appropriate balance of intuition and analysis is required, as in Hammond's Cognitive Continuum, [7–9] as well as an awareness of the likely cognitive as well as motivated biases that may hinder them knowing 'how much they know about how much they know'. [10] Probability exercises (such as 'Probers') are therefore an integral part of our vision, enhancing professional courses and virtual learning environments, such as The TIGER Initiative in nursing.[11]

In relation to the evaluation of probability assessments - and assessor - Kenneth Hammond and others have emphasised that two distinct criteria are relevant, and drawn attention to the fact that, for a variety of reasons, including different meta-theoretic

paradigms, the two have attracted different sets of adherents. [12] There are those who wish to judge probabilities primarily by their *internal coherence* and those who wish to judge them primarily by their *external correspondence*. The vast majority of those who emphasise coherence are pessimistic about judgemental competence, because clinicians typically perform poorly on coherence tests, such as calculating the predictive value of a test result, given the sensitivity of the test and the prevalence of the target condition. Most optimists emphasise external correspondence, arguing that abstract tests of coherence are not 'ecologically valid', [13] since the items are not representative of those that actually arise. But there are also pessimists among those who favour the correspondence criterion, doubting whether experience will be productive in the absence of quick and unbiased feedback. [14,15] The 'clinical versus actuarial' controversy, associated primarily with the name of Paul Meehl, [16] rumbles on.

1. Methods

In the case of the coherence criterion, teaching of the way in which probabilities should be combined is required. Correspondence can only be taught through probabilistic exercises with relevant feedback. A Prober is a set of statements to which the respondent supplies their personal probability that a statement such as 'The true positive rate indicates the sensitivity of a test' is true. The set used currently consists of 50 statements relating mainly to research methods. A variety of probability response sets are available for use in the software. A compromise between response granularity and item set size is necessary to achieve a reasonable number of observations for an individual at each probability. We currently use seven discrete probabilities: 0, 10, 30, 50, 70, 90 and 100%. Respondents are advised that they should enter their honest probabilities and in order to avoid 'motivated biasing', they will receive full marks for completion of the exercise. In any case, the accompanying teaching makes clear that the assessments are scored by a proper scoring rule (Brier's) which ensures that respondent's expected score will always be maximised by reporting honest beliefs [17].

After completion the respondent can learn whether each statement was actually true or false, along with short elaborations, mainly in the case of false items. The main, analytical feedback comes in the form of the Brier score and its decomposition, [18] (Figure 1a) One key measure is that of *discrimination*, the difference between the average probabilities assigned to true and false items, plotted on the right and left axes respectively. (These represent the sensitivity and 1 minus the specificity of the judge interpreted as a 'test'.) Graphically discrimination is represented by the slope of the line joining them. This can be compared with the 45 degree slope of the diagonal which indicates perfect discrimination. An associated diagram (Figure 1b) provides information relevant to the other key competence, *calibration*. Calibration is measured by the degree to which the 'frequency correct' matches 'probability assigned'. For example, if a respondent assigned 70% to 10 statements, then perfect calibration exists if 7 of these are actually true. Deviations from 7 in *either* direction indicate poorer calibration. Accompanying teaching stresses that calibration should not be improved at the expense of using whatever discrimination ability is possessed

2. Results

The latest in 35 years of Probers use has been in the Translational Health Masters course at the Sydney School of Public Health. In 2012 and 2013, 63 students responded. (Completion rates were high as the exercises were a compulsory assignment). Their Brier scores ranged from .1 to .55 (where 0 is perfect and 1 is worst possible.) The mean score of .25 (SD .08) is actually that which would be achieved by assigning .5 probability to all 50 statements, so that on average the population did no better than chance. The average sensitivity (mean probability true assigned to true statements) was 75% and average specificity (1 minus probability true assigned to false statements was 64%. Only one of the 63 had a specificity exceeding sensitivity and hence a discrimination line with a negative slope.

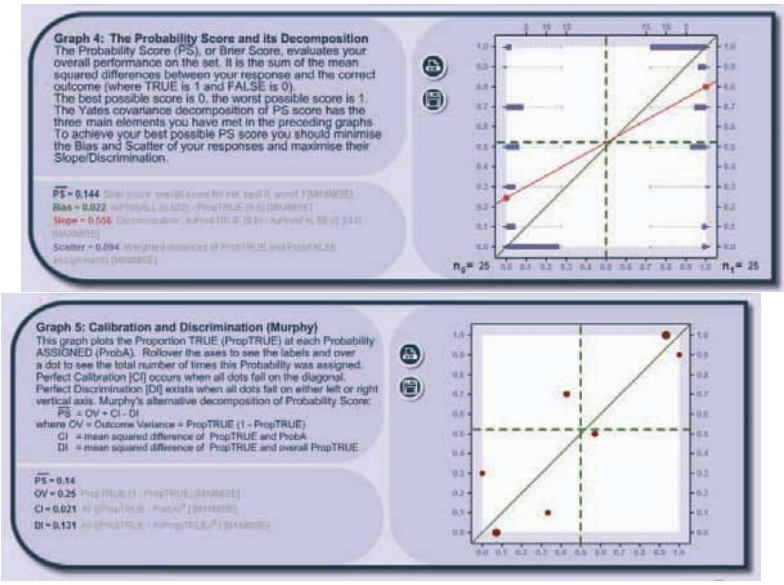


Figure 1 Student showing good discrimination (top) and calibration botton

As in previous settings there was no indication of respondent difficulty in completing the task at a practical level. Feedback comments have been solely about the unfamiliar nature of the task, without questioning of its relevance, and mainly doubts about whether using numerical probabilities and regarding it as a skill would be acceptable 'where I work' because it would be disruptive of organisational routines and/or professional hierarchies

3. Discussion

Having arrived at a numerical estimate of, say, 30%, the Prober-aware health professional will recall that if all their 30%s were monitored and collated the frequency correct should be 30%. They will be able to reflect 'in action' on their *calibration.* In relation to their whole set of judgements and outside any specific case, they can ask themselves whether they assigned a (much) higher average probability to the occasions

when the target outcome occurred, than the average assigned when it did not occur. They will be able to reflect, outside of action, on their sensitivity and specificity and overall *discrimination* competence.

Where is the 'evaluation' of Probers? Real world evaluation requires the systematic recording and monitoring of judgements that seems almost impossible in larger clinical settings. In our vision the 'anatomy of judgment' is taught alongside the anatomy of the human body in clinical curricula. Probers are part of the new cognitive informatics.

References

[1] J. Dowie The Bayesian approach to decision making, in A. Killoran, C. Swann, M. Kelly, Editors. *Public Health Evidence: Tackling Health Inequalities*, Oxford, Oxford University Press; 2006. p. 309–21

[2] J Dowie, Against risk, *Risk Decision and Policy* 4 (1999) 57–73

[3] J.G. Dolan, D.R. Bordley, A.I. Mushlin, An evaluation of clinicians' subjective prior probability estimates. *Medical Decision Making* 6 (1986) 216–23

[4] T.G.Tape, J. Kripal, R.S.Wigton, Comparing methods of learning clinical prediction from case simulations. *Medical Decision Making,* 12 (1992) 213–221

[5] D Schön *The Reflective Practitioner. How professionals think in action*, London, Temple Smith, 1983

[6] P Benner *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*, London, Addison-Wesley, 1984

[7] K.R.Hammond *Human Judgment and Social Policy: Irreducible Uncertainty, Inevitable Error, Unavoidable Injustice,* New York, Oxford University Press; 1996

[8] J. Dowie, M.K.Kaltoft Deciding how to decide – and how to support decisions. *Nuffield Trust Webinar*. http://www.slideshare.net/NuffieldTrust/jack-dowie-211111. 2011

[9] J. Dowie, JUDEMAKIA : a personal map of the world of judgement and decision making. https://www.dropbox.com/s/ph800ycdah5no92/Judemakia pdf.pdf.2006

[10] A. Tversky, D Kahneman, Judgment under uncertainty: heuristics and biases, *Science* 185 (1974) 1124–31

[11] M.K.Kaltoft Nursing Informatics AND Nursing Ethics : Addressing their disconnect through an enhanced TIGER-vision, *Studies in Health Technology and Informatics*, *192* (2013), 879–883

[12] K.R. Hammond How convergence of research paradigms can improve research on diagnostic judgment. *Medical Decision Making* 1996 16 (1996) 281–287

[13] Hammond KR. Ecological Validity: Then and Now.1998 http://www.brunswik.org/notes/essay2.html

[14] B Brehmer, In one word: not from experience. *Acta Psychologica* 45 (1980) 223–41

[15] I. Fischer, D.V. Budescu, When do those who know more also know more about how much they know? The development of confidence and performance in categorical decision tasks. *Organisational. Behavior and Human Processes* 98 (2005) 39–53

[16] P.E. Meehl, Causes and effects of my disturbing little book. *Journal of Personality Assessment*, 50 (1986) 370–5

[17] G.W. Fischer, Scoring-rule feedback and the overconfidence syndrome in subjective probability forecasting *Organisational. Behavior and Human Performance* 29 (1982) 352–69

[18] J.F.Yates, External Correspondence: Decompositions of the Mean Probability Score, *Organisational. Behavior and Human Performance* 30 (1982) 132–56.

[19] A.S. Elstein, Beyond Multiple-choice Questions and essays: the need for a new way to assess clinical competence, *Academic Medicine*. 68 (1993) 244–9

Access To obtain access to the Prober set, email jack.dowie@sydney.edu.au **Conflicts of Interest** Prober is ©Maldaba Ltd; Contact: info@maldaba.co.uk . Jack Dowie has a financial interest in Prober, but has not benefited from its use in any of the specified settings. **Authorship** JD and MKK jointly planned the paper's structure and content. JD's first draft was extensively revised with MKK. GS and JBN also provided comments. All authors approved the final version.

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Consumer Acceptance of Accountable-eHealth Systems

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Abstract. In this paper, we present the results of a survey conducted to measure the attitudes of eHealth consumers towards Accountable-eHealth systems, which are designed for information privacy management. We developed a research model that identify the factors contributing to system acceptance from quantitative data of 187 completed survey responses from university students studying non-health-related courses at university (Queensland, Australia). The research model is validated using structural equation modeling and can be used to identify how specific characteristics of Accountable-eHealth systems would affect their overall acceptance by future eHealth consumers.

Keywords. eHealth, privacy, information accountability, consumer adoption

Introduction

Accountable-eHealth (AeH) systems [1] are designed to tackle the information privacy conundrum in eHealth. Their goal is to deviate from the restrictive information models where rigid barriers are put in place for the protection of information privacy to a more open and accountable model that promotes *appropriate–use* of information. The AeH model builds an environment where healthcare professionals (HCP) access information deemed necessary for healthcare delivery but are held accountable for inappropriate use. It works on the basis of an incentive for consumers, i.e. patients, to alleviate concerns of privacy violations, and disincentives for HCPs to misuse information, which are delivered through the presence of transparency and accountability (i.e. penalties).

Although AeH systems are technologically feasible [1], their adoption by future stakeholders is unclear. The understanding of factors that influence technology acceptance is essential for its successful adoption [2]. Although increasing HCPs' eHealth adoption is a critical aspect in itself, low consumer adoption rates can also be attributed as a critical impediment to eHealth [3]. Although there is ample evidence and concerns pertaining to the technological perspective of information privacy in eHealth [4], there are only a few studies conducted in regards to consumer adoption [5-7]. It is therefore important to measure the attitudes of consumers towards eHealth systems and the system characteristics, which directly affect system acceptance once implemented. Consumers may see an increased opportunity to use eHealth systems because they

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empower consumers to participate in information sharing and decision making, which enables them to be more involved and to contribute to quality care delivery [6].

This paper first studies the factors contributing to the acceptance of AeH systems by eHealth consumers and presents an empirical research model. The primary goal is to validate the research model that tests the factors influencing the acceptance of AeH systems.

1. Method

The research method was a quantitative online questionnaire survey. The questions included in the questionnaire were either adopted from previous technology acceptance research [8] or have been developed specifically for this study. All participants were students studying in non-health-related undergraduate and postgraduate courses at a university in Queensland, Australia. The analysis of the data was done using the partial least squares (PLS) method. The analysis tool used was smartPLS 2.0 [9].

1.1. Theoretical foundations and research model

The hypotheses for this research study were based on technology acceptance research in general and in the healthcare domain, focusing on consumers' acceptance of technology. The hypotheses are related to the structural relationships amongst the model constructs. The theoretical model was based on the Unified Theory of Acceptance and Use of Technology (UTAUT) [8]. Motivated by Schaper and Pervan [10], we use three contexts to identify research constructs that influence the acceptance of AeH systems: individual; information privacy: and information (see Figure 1).

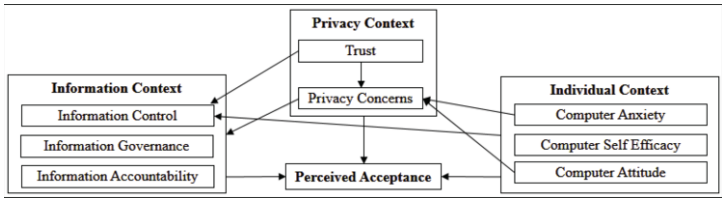


Figure 1. Hypothesized research model

The individual context consists of three constructs: Computer/EHR Self-Efficacy (CSE), Computer/EHR Anxiety (ANX) and Computer/EHR Attitude (ATT). These constructs are drawn directly from UTAUT [8] and adapted to fit our study. Previous studies that tested consumer acceptance of health ICT acceptance have reported that someone's feelings, perceptions, or beliefs about technology can affect her perceived acceptance of that technology [11]. Considering the findings from previous studies [6, 12-18], we make 8 hypotheses from this context as seen on Table 1. The information privacy context consists of two constructs: Privacy Concerns (PC) and Third Party Trust (TPT). Studies on information privacy related to technology acceptance are mostly based on the big five personality traits [18-20]. But these studies were primarily focused on domains such as corporate use of personal information [21]. Information privacy research in the healthcare domain, however, focuses on issues such as information sharing, information access and use and information control [21]. Therefore here, we adopt similar construct

items to measure the privacy concerns of individuals. We make 9 hypotheses in relation to this context (see Table 1). The information context is unique to our study. It contains three constructs: Information Control (IC), Information Governance (IG) and Information Accountability (IA), which capture the characteristics of AeH systems. We define IG as the perception that usage rules on how HCPs use a patient's healthcare information should be enforced. IC is defined as the perception of the ability of the owner or of the subject of the information to control their healthcare information–a measure used to increase confidence and trust in eHealth systems [4]. IA is defines as the perception that accountability measures must be put in place for inappropriate use of information. We hypothesize three relationships related to these three constructs as listed in Table 1.

It is assumed that the Perceived Acceptance (ACC), our dependent construct, has a direct effect on the actual acceptance by consumers, similar to behavioral intention in [8], since the actual acceptance of the designed AeH system cannot be tested as part of this research study.

Table 1. Research hypotheses and path coefficients from PLS analysis

Hypothesis	Path	t-Values	Path Coefficient
H1 – CSE will have a direct positive effect on consumers' perception on IC	CSE → IC	3.299	0.229**
H2 – CSE will have a direct effect on consumers' perceived ACC	CSE →ACC	2.268	0.125*
H3 – ANX will have a direct positive effect on consumers' perceived PC	ANX →PC	2.601	0.176**
H4 – ANX will have a direct negative effect on perceived ACC	ANX →ACC	3.339	-0.228**
H5 – ANX will have a direct negative effect on IC	ANX →IC	1.149	0.092
H6 – ATT will have a direct negative effect on consumers' perceived PC	ATT → PC	4.919	-0.361***
H7 – ATT will have a direct positive effect on consumers' perceived ACC	ATT →ACC	9.595	0.544***
H8 – ATT will have a direct positive effect on IC	ATT →IC	3.421	0.298**
H9 – PC will have a direct positive effect on consumers' perception of IG	PC →IG	4.566	0.476***
H10 – PC will have a direct positive effect on consumers' perception of IC	PC →IC	4.959	0.393***
H11 – PC will have a direct positive effect on consumers' perception of IA	PC →IA	3.863	0.302**
H12 – PC will have a direct negative effect on consumers' perceived ACC	PC →ACC	1.972	-0.131*
H13 – TPT will have a direct negative effect on consumers' perceived PC	TPT →PC	4.189	-0.276***
H14 – TPT will have a direct negative effect on consumers' perception on IG	TPT →IG	1.065	0.150
H15 – TPT will have a direct negative effect on consumers' perception on IC	TPT →IC	4.133	-0.288***
H16 – TPT will have a direct negative effect on consumers' perception on IA	TPT →IA	0.076	0.007
H17 – TPT will have a direct negative effect on consumers' perceived ACC	TPT →ACC	2.299	0.111*
H18 – IG will have a direct positive effect on consumers' perceived ACC	IG →ACC	0.532	0.023
H19 – IC will have a direct positive effect on consumers' perceived ACC	IC →ACC	2.020	0.108*
H20 – IA will have a direct positive effect on consumers' perceived ACC	IA →ACC	1.305	-0.061

Notes: *p < 0.05, **p < 0.01, ***p < 0.001

2. Results and Analysis

A total of 186 valid responses were received. The age of the respondents ranged from a minimum of 17 to a maximum of 65 with a mean of 27 (SD = 10.1).

2.1. Assessment of the measurement model

The first step in testing the hypotheses was the assessment of the measurement model, which involves determining the construct reliability, and the discriminant and convergent validity of the model. This was done by, first, calculating the individual item loadings which were greater than the acceptable level of 0.3; composite reliabilities, which were greater than the required threshold of 0.707; and the average variances

extracted for all constructs (AVE), which were greater than the required 0.5 threshold. Second, discriminant and convergent validity was determined using the correlations of the constructs and cross loading of the constructs, which were less than the square root of the AVE and greater than those of other constructs, respectively. The measurement model was, thus, deemed reliable.

2.2. Assessment of the structural model

The assessment of the structural model reveals the significance of the hypotheses. The process involves testing the predictive power of the model and the significance of the relationships (path model) between model constructs. The predictive power of the model was established by performing a PLS analysis. The R^2 values for each of the dependent variables were produced as a result.

The results revealed that the model was capable of explaining 69.8% of ACC of AeH systems, which is a highly satisfactory level in technology acceptance research. The model was also able to predict 36.1% of variance in PC, 38.6% of variance in IC, 19.4% of variance in IG and 8.9% of variance in IA. To establish the relationships between the model constructs, the path coefficients and t-values for each of the structural model paths were calculated. A bootstrapping resampling technique was used to calculate the t-values, which are summarized in Table 1 together with the results of the PLS analysis.

3. Discussion and Conclusion

The results revealed that five (H5, H14, H16, H18 and H20) of the twenty tested hypotheses were not supported. PC exhibited a significant negative effect on ACC. This indicates that if an eHealth consumer felt concerned about her privacy in a system, she is less likely to adopt the system, thus confirming our thesis that information privacy concerns of consumers are a significant issue for eHealth systems. The results revealed that there were no positive or negative effects from the information context towards ACC except from IC, which had a significant positive effect. PC had significant positive effects on IG, IC and IA, supporting our hypotheses H9 – H11. This indicates that if an eHealth consumer is concerned about privacy, she believes that the countermeasures put in place in AeH systems are required. TPT also plays a significant role in the research model presented. The level of trust the respondents had on third parties had a significant negative effect on PC and IC, thus supporting our hypotheses H13 and H15 respectively. This indicates that privacy concerns are high when trust levels are low and that the respondents believed that they should have the control of their own health information. Therefore, by allowing consumers to keep the control of their information, AeH systems cater for a need that would improve system acceptance, which is supported by the evidence relating to H19 where IC shows a significant contribution to ACC. We believe that once consumers are exposed to an AeH system, IA and IG may also show positive contributing effects on ACC.

The constructs of the individual context also show significant effects on PC, IC and ACC. ANX shows a significant positive relationship with PC and a significant negative relationship with ACC. Therefore, if an eHealth consumer's anxiety level in relation to the system is high, her privacy concerns will be high and she is less likely to accept the system. Similar arguments can be made in relation to ATT, which is reflected through

H6 and H7. ATT showed a significant positive effect on IC. As seen from a supported H1, CSE also positively affects IC.

The research model presented in this paper identified several key constructs that influence the acceptance of AeH systems by eHealth consumers. However, to address the limitation of non-generalizability, a cohort of consumers with a wider age range should be used in future studies. Such studies conducted using this empirical model can give valuable insights into how consumers behave in relation to AeH systems. The results of those studies can improve implementation of AeH systems.

References

[1] Gajanayake R, Iannella T, Lane B, Sahama T. Accountable-eHealth systems: The next step forward for privacy. Electronic Journal of Health Informatics 2013.
[2] Rogers EM. Diffusion of innovations: Simon and Schuster; 1995.
[3] Barlass T. Patients reject eHealth system. The Sydney Morning Herald. 2012 August 12; Sect. IT Pro.
[4] Petkovic M, Ibraimi L. Privacy and Security in e-Health Applications. 2011. In: E-Health, Assistive Technologies and Applications for Assisted Living: Challenges and Solutions [Internet]. [23-48].
[5] Wilkowska W, Ziefle M, editors. Perception of privacy and security for acceptance of E-health technologies: Exploratory analysis for diverse user groups. Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2011 5th International Conference on; 2011: IEEE.
[6] Or CKL, Karsh BT. A systematic review of patient acceptance of consumer health information technology. J Am Med Inform Assoc. 2009; 16(4):550-60.
[7] Gustafson DH, Hawkins RP, Boberg EW, McTavish F, Owens B, Wise M, et al. CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved. Int J Med Inform. 2002; 65(3):169-77.
[8] Venkatesh V, Morris MG, Gordon BD, Davis FD. User Acceptance of Information Technology: Toward a Unified View. MIS Quarterly. 2003; 27(3):425-78.
[9] Ringle CM, Wende S, Will S. SmartPLS 2.0 (M3) Beta. 2.0 ed. Hamburg 2005.
[10] Schaper L, Pervan G. ICT and OTs: A model of information and communication technology acceptance and utilisation by occupational therapists. Int J Med Inform. 2007; 76:S212-S21.
[11] Holden RJ, Karsh BT. A theoretical model of health information technology usage behaviour with implications for patient safety. Behav Inf Technol. 2009; 28(1):21-38.
[12] Compeau D, Higgins C. Computer self-efficacy: Development of a measure and initial test. MIS Quarterly. 1995:189-211.
[13] Hsu MH, Chiu CM. Internet self-efficacy and electronic service acceptance. Decision Support Systems. 2004; 38(3):369-81.
[14] Hu PJH, Chau PYK, Sheng ORL, Tam KY. Examining the technology acceptance model using physician acceptance of telemedicine technology. Journal of Management Information Systems. 1999:91-112.
[15] Lai TY, Larson EL, Rockoff ML, Bakken S. User Acceptance of HIV TIDES—tailored interventions for management of depressive symptoms in persons living with HIV/AIDS. J Am Med Inform Assoc. 2008; 15(2):217-26.
[16] Finkelstein J, Khare R, Ansell J, editors. Feasibility and patients' acceptance of home automated telemanagement of oral anticoagulation therapy. AMIA Annual Symposium Proceedings; 2003: American Medical Informatics Association.
[17] Lober W, Zierler B, Herbaugh A, Shinstrom S, Stolyar A, Kim E, et al., editors. Barriers to the use of a personal health record by an elderly population. AMIA Annual Symposium Proceedings; 2006: American Medical Informatics Association.
[18] Korzaan ML, Boswell KT. The influence of personality traits and information privacy concerns on behavioral intentions. The Journal of Computer Information Systems. 2008; 48(4):15-24.
[19] Smith HJ, Milberg SJ, Burke SJ. Information privacy: measuring individuals' concerns about organizational practices. MIS Quarterly. 1996:167-96.
[20] Graeff TR, Harmon S. Collecting and using personal data: consumers' awareness and concerns. Journal of Consumer Marketing. 2002; 19(4):302-18.
[21] Angst CM, Agarwal R. Adoption of Electronic Health Records in the Presence of Privacy Concerns: The Elaboration Likelihood Model and Individual Persuasion. MIS Quarterly. 2009; 33(2):339-70. PubMed PMID: 38224406.

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Protocol Feasibility Workflow Using an Automated Multi-country Patient Cohort System

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Abstract. The Electronic Health Record for Clinical Research (EHR4CR) project aims to improve the current process of clinical trials, providing a technological platform that supports the design and execution of trials. For the protocol feasibility scenario, the system currently allows the user to create a set of in-/exclusion criteria to find patients matching these criteria across sites located in several countries. The automated multi-country patient cohort system developed in EHR4CR implies substantial changes on the current protocol feasibility process, which will be reflected in this study.

Keywords. Clinical Trials as Topic, Feasibility Study, Electronic Health Record, Workflow

Introduction

Clinical Trials (CTs) hold a key position in the development, improvement and production of new medication and therapeutic procedures. The cost of the design and execution of CTs has been increasing during the last years [1]. Furthermore, CTs are very often delayed or the initial budget substantially increased due to various reasons such as poor or defective study designs, lack of information or communication problems in the phase of protocol feasibility (PF) [2].

Every CT starts with a feasibility study, also called PF. In this phase, it is evaluated whether it is feasible to run the CT in a particular geographical region. This evaluation includes timelines, targets and cost [3]. Over the last few years, research has been intensified on patient recruitment and trial execution, whereas the PF phase has been placed in a secondary position. However, according to the experts, the PF phase holds a great need and potential for improvement [4].

The EHR4CR project [5] aims to improve the current process of CTs providing a technological platform that allows both research and medical institutions to efficiently perform all the steps involved in the design and execution of CTs. This is achieved

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through a better leveraging of routinely collected clinical data in the trial design and execution life-cycle [6].

For the PF scenario of the EHR4CR project, the system currently allows the user to build queries based upon in-/exclusion criteria and find patients matching these criteria across several countries and sites [7]. The purpose of this study is to demonstrate how an automated multi-country patient cohort system, such as the EHR4CR system, changes the current PF process by automatizing many of the steps implied.

1. Methods

Our first activity was to define the current (as-is) process in order to estimate how the EHR4CR system can improve it. There is no established general PF workflow and almost every one of the nine companies of the European Federation of Pharmaceutical Industries and Associations (EFPIA) companies participating in the project (see Acknowledgements) follows a slightly different process. With the purpose of defining a common new (to-be) process we have followed the DELPHI method [8] executing it in two phases (first Nov-Dec 2013, second Dec 2013-Jan 2014). Representatives of the nine EFPIA companies involved in the EHR4CR project participated in the study and answered the two questionnaires correspondent to the DELPHI phases. The first questionnaire contained one task and the second two tasks and four questions, all free text written, described below:

- First phase/questionnaire: Task to describe the current process of PF identifying all the steps and actors involved.
- Second phase/questionnaire: It contained the as-is common process resulted from the first questionnaire and the proposed to-be process supported by the EHR4CR system. The language used for modelling these processes was the Business Process Model and Notation (BPMN) v2.0 [9]. The clinical trial experts had to review the two processes and decide whether it fulfilled all the steps involved in PF. Additionally, they were asked about how the EHR4CR system could be improved and which modifications would be necessary so that the EHR4CR system in the future can cover all of the steps involved in PF.

2. Results

As a result of the two DELPHI phases, we obtained the concerted as-is and to-be protocol feasibility processes, as well as some interesting new possible features for the EHR4CR system that will be analysed in the discussion. The actors and process steps involved in the as-is and to-be processes are described as follows:

2.1. Actors

- Feasibility project team (FPT): a team consisting of a feasibility leader, statisticians, business intelligence consultants and other feasibility experts.
- Country feasibility manager(s) (CFM(s)): one to several country feasibility expert(s). If there is only one, he/she is also called “Global feasibility manager”, having the overview about all potential countries. If there are

several CFMs, each of them usually is responsible for one to some countries. Depending on this role's interpretation, some tasks of the CFM(s) might be taken over by the FPT.

- Site feasibility manager (SFM): a site feasibility expert.
- Principal investigator (PI): responsible person for investigation and research at the site.

2.2. As-is PF process

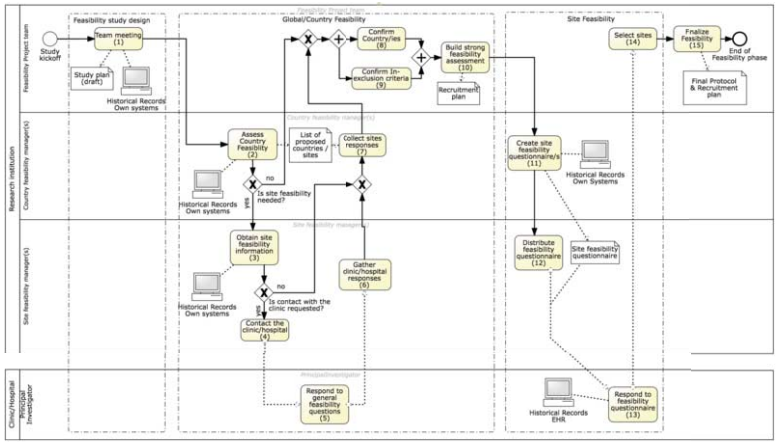


Figure 1. As-is PF process.

The process takes place at two companies or sites: the sponsor (research institution) and site (clinic/hospital). It depicts information gathering and refinement of the PF from the early plan, drafted by the FPT, down to the expert's knowledge and opinion (SFM, PI) and back to the FPT.

The PF phase starts with (a) preliminary meeting(s) (1) where the outline of the study is drafted by the FPT. Secondly, the CFM(s) perform(s) the assessment of countries that should participate in the study (2). This task may, in some companies and cases, need the assistance of a SFM. If so, the SFM checks historical records and company-owned systems (3). Eventually, PIs at the clinics are asked about predisposition for the trial and general feasibility questions (4, 5, and 6). Subsequently, the CFM(s) collect(s) the information from the sites and elaborate(s) an assessment of countries (7).

At this stage, the FPT has collected enough information to determine the in-/exclusion criteria for candidate sites and patients (8) and confirms the list of participating countries (9). With this a detailed (also called "strong") feasibility assessment is built, which is reflected in a document called recruitment plan or "extended synopsis" (10).

The CFM(s) receive(s) the recruitment plan and use(s) it as a basis to create a feasibility questionnaire with the support of historical records and company-owned systems (11). This questionnaire contains structural and organizational questions as well as a commitment of number of patients that will be enrolled at the site for this specific study and it is distributed by the SFM (12) via email, fax or company-owned

systems. In some cases, telephone calls or personal meetings are arranged between the SFM and the PI in which these questionnaires are answered (13).

According to the responses of the PIs, the FPT decides which sites are included in the study (14) and finalizes the feasibility phase with the creation of the final recruitment plan and feasibility assessment (15).

2.3. To-be PF process using the EHR4CR system

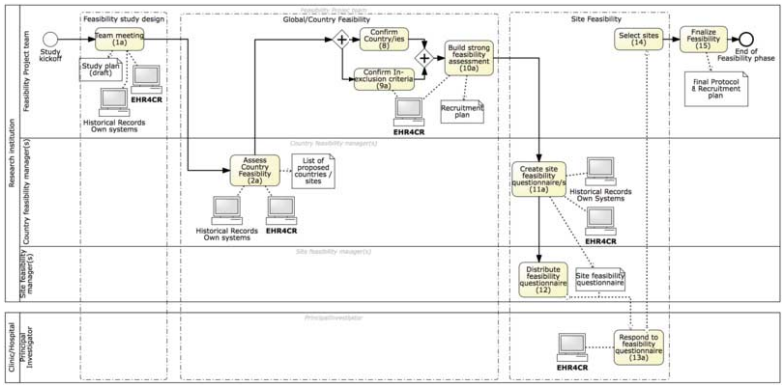


Figure 2. To-be PF process using the EHR4CR system.

The to-be PF basically includes the same process steps as the as-is PF. Out of the 15 initial steps, 5 could be deleted, because the country feasibility assessment is entirely performed by the CFM(s) now. Task numbers stayed the same to ease diagram comparison. Tasks that have changed due to additional support of the EHR4CR system are enriched by an ‘a’ in their task number.

In the proposed process, the FPT creates the study plan using historical records and their own systems as well as the EHR4CR query builder and historical records stored in the EHR4CR system (1a). Then, as explained above, the CFM(s) assess(es) country feasibility running queries through the EHR4CR system (2a) and create(s) a list of potentially eligible countries.

The EHR4CR system supports the determination of criteria (8, 9a) and the design of the recruitment plan (10a) with the execution of queries and the extraction of the query criteria in a human readable way [10].

The CFM(s) then create(s) the feasibility questionnaire using the recruitment plan, historical records, company-owned systems, and the EHR4CR system (11a), which is still distributed by the SFM following the as-is process (12). The PIs respond to this questionnaire now with the help of the EHR4CR system, from which they can retrieve information about historic patient counts by running selected criteria for their own site (13a).

Similar to the current process, the FPT decides which sites must be included in the study based upon the responses of the PIs to the questionnaires, (14) and finalizes the feasibility phase with the creation of the final recruitment plan and feasibility assessment (15).

3. Discussion

Our study demonstrates that EHR4CR can strongly support the PF phase of clinical trials by providing a tool that facilitates the design of feasibility queries and automatizes the country selection phase. Besides, we have identified interesting features not initially addressed in the EHR4CR project plan: To store results from executed trials and generate analytics from them, the possibility to send feasibility questionnaires through EHR4CR and eventually the creation of these questionnaires through the platform. This is relevant since experts interviewed emphasized the fact that approaching the local staff is both laborious and delaying.

By including the EHR4CR platform, the design of clinical trials, especially the eligibility criteria, can be based more on precise data than on experience and estimations. This might lead to a lesser number of protocol amendments needed.

The EHR4CR system is in a pilot stage and an evaluation of the system is still required, therefore it is soon to perform a substantial change of the current PF workflow. Nevertheless, with the modifications and additional features we have identified, EHR4CR could go from a country/site feasibility information tool to an ultimate feasibility system that covers all the steps of the process.

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References

[1] J. A. DiMasi, R. W. Hansen, and H. G. Grabowski, “The price of innovation: new estimates of drug development costs,” *J. Health Econ.*, vol. 22, no. 2, pp. 151–185, Mar. 2003.

[2] K. A. Getz, J. Wenger, R. A. Campo, E. S. Seguine, and K. I. Kaitin, “Assessing the Impact of Protocol Design Changes on Clinical Trial Performance:,” *Am. J. Ther.*, vol. 15, no. 5, pp. 450–457, Sep. 2008.

[3] V. Rajadhyaksha, “Conducting Feasibilities in Clinical Trials: An Investment to Ensure a Good Study,” *Perspect. Clin. Res.*, vol. 1, no. 3, pp. 106–109, 2010.

[4] D. Kalra, A. Schmidt, H. W. W. Potts, D. Dupont, M. Sundgren, G. De Moor, and EHR4CR Research Consortium, “Case report from the EHR4CR project—A European survey on electronic health records systems for clinical research,” *IHealth Connect.*, vol. 1, no. 2, pp. 108–113, 2011.

[5] “EHR4CR: Electronic Health Records for Clinical Research.” [Online]. Available: http://www.ehr4cr.eu/. [Accessed: 07-Jan-2014].

[6] D. Ouagne, S. Hussain, E. Sadou, M.-C. Jaulent, and C. Daniel, “The Electronic Healthcare Record for Clinical Research (EHR4CR) information model and terminology,” *Stud. Health Technol. Inform.*, vol. 180, pp. 534–538, 2012.

[7] P. Coorevits, M. Sundgren, G. O. Klein, A. Bahr, B. Claerhout, C. Daniel, M. Dugas, D. Dupont, A. Schmidt, P. Singleton, G. De Moor, and D. Kalra, “Electronic health records: new opportunities for clinical research,” *J. Intern. Med.*, vol. 274, no. 6, pp. 547–560, Dec. 2013.

[8] N. Dalkey, “An experimental study of group opinion: The Delphi method,” *Futures*, vol. 1, no. 5, pp. 408–426, Sep. 1969.

[9] “BPMN Specification - Business Process Model and Notation.” [Online]. Available: http://www.bpmn.org/. [Accessed: 09-Jan-2014].

[10] R. Bache, S. Miles, and A. Taweel, “An adaptable architecture for patient cohort identification from diverse data sources,” *J. Am. Med. Inform. Assoc.*, pp. amiajnl–2013–001858, Sep. 2013.

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Determinants of continuance intention in a post-adoption satisfaction evaluation of a clinical information system

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Abstract: *Purpose*: The evaluation of end-user satisfaction is an essential part of any clinical information system (CIS) project. The purpose of this study is to evaluate the determinants of CIS continuance intention in a late post-adoption phase at the Georges Pompidou University Hospital (HEGP) in Paris. *Methods*: We designed an electronic survey instrument based on an IT post-adoption model (ITPAM) developed from three previous models, i.e., the Delone and McLean Information Success Model, the Davis TAM model and the Bhattacherjee information system continuance intention model. *Results*: 419 questionnaires were collected from CIS users directly involved in patient care. The perceived CIS quality, usefulness and user satisfaction are significantly lower for medical professions than other professional groups. Continuance intention is very high within all professional subgroups. In a multiple regression analysis, the global satisfaction (R^2=.780) was positively and significantly correlated with CIS quality, confirmation of expectations and perceived CIS usefulness. The continuance intention (R^2=.392) was positively and significantly correlated with perceived CIS usefulness, confirmation of expectations and global satisfaction. *Conclusion*: In a late post-adoption CIS deployment phase, continuance intention does not significantly depend on individual end user characteristics but is significantly associated with the perceived CIS usefulness, confirmation of expectations and global satisfaction.

Keywords: CIS acceptance, Post-adoption evaluation, Continuance intention

1. Introduction

Regular evaluation of end user satisfaction is an essential part of any clinical information system (CIS) deployment project. It should be performed regularly during the various phases of CIS planning, deployment, and consolidation, in particular, before/after major changes of CIS versions [1–3]. The selected evaluation dimensions and the importance given to each dimension should be adjusted in accordance with the phase of the deployment cycle concerned and the end user profession. At the initial stage, the evaluation should be performed as closely as possible to the point of care to take into account characteristics of the system [4]. In a post-deployment phase, major

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usability and error issues are supposed to be corrected and a meaningful use level reached. However, major software releases might be a source of functional or performance regressions. Budget restrictions might affect end user training and support and subsequently satisfaction and intent to continue.

Several information technology (IT) evaluation models have been proposed to predict the behavioral intension of professionals to use a given system (acceptance model), measure satisfaction with a deployed system or try to predict the future behavior of their users (continuance intention). They include the theory of planned behavior (TPB), information success model (ISM) [5], technology acceptance model (TAM, TAM2) [2], unified theory of acceptance and use of technology (UTAUT) [6], expectation confirmation theory (ECT), and the information system continuance intention (ISCI) [7]. Most evaluation studies have been targeted at the prediction of future use or of the early adoption of a CIS [1–3]. In this study, we attempt to measure and analyze the determinants of continuance intention using an IT post-adoption model of satisfaction and behavioral intention to pursue with a deployed CIS. The evaluation model relies on evaluation constructs from the TAM, ISM and ISCI models. The survey was achieved in a late post-adoption phase (i.e., > 10 years) at the Georges Pompidou University hospital (HEGP).

2. Materials and Methods

2.1. The HEGP clinical information system

HEGP is an 800 bed acute care university hospital located in southwest Paris that opened in July 2000 from the merging of three aging facilities. Its integrated clinical information system consists of five major components: (1) an admission, discharge and transfer (ADT) component; (2) an electronic multimedia health record (EHR); (3) a computerized provider order entry component (CPOE); (4) a resource and appointment scheduling system; and (5) an integrated clinical data warehouse (CDW). The first three components are based on the DxCare® software suite from Medasys®, the fourth on OneCall® from McKesson®, and the fifth on i2b2 [8,9]. The production environment was operational at the opening of the hospital in 2000 and the CDW in 2009.

2.2. Survey instrument and research hypotheses

This semi-quantitative survey consisted of 50 questions selected among items of previously published/validated instruments from the literature and two previous evaluation studies performed at HEGP in 2004 and 2008 [10,11]. The six dimensions of evaluation included CIS quality, perceived usefulness, confirmation of expectations, user support, user satisfaction, and continuance intention. Seven-point Likert scales (1=Strongly disagree, 2=Disagree, 3=Somewhat disagree, 4=Neither disagree nor agree, 5=Somewhat agree, 6=Agree, 7=Strongly agree) were used for the 24 items entering in the six evaluation constructs. The information technology post-adoption model (ITPAM) of continuance intention is summarized in figure 1 with the 14 hypothesis tested.

2.3. Data and survey instruments

Four acceptance evaluations were performed at HEGP in 2004, 2008, 2011 and 2013. The results obtained in 2011 and 2013 were very similar, and we report here the combined results for 2011 and 2013. These two surveys were achieved through the hospital intranet. Targeted reminders were sent out to all CIS users. Three main user categories all directly concerned about patient care were considered: (1) medical professions (MED), including physicians, pharmacists, biologists and radiologists; (2) nursing professions (NUR); (3) medico-administrative personnel (MDA), mainly secretaries and social workers. We excluded personnel without partial or complete access to the clinical electronic health record (e.g., admission agents) and those reporting access to none of the 16 CIS functions considered in this survey.

The answers of 419 CIS users (response rate: 18.7%) were used for the statistical analysis. For users who had answered in both 2011 and 2013 surveys, only the mean of the two responses was used. Statistical analyses were performed with R®, Statview®, and XLSTAT®. The validity of the different items used in each construct was tested with the Cronbach's alpha coefficient. Except for user support (α =.67), alpha coefficients were considered acceptable for other constructs (.79< α <.95).

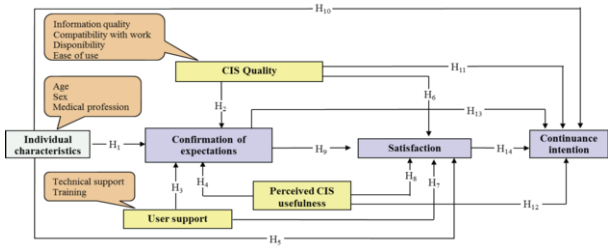


Figure 1: The information technology post-adoption model (ITPAM) of continuance intention.

3. Results

The group of 419 responders consisted of 102 medical end users, 222 nurses, and 95 medico-administrative employees with a mean age of 39.7 years (table 1). 79.0% of respondents were female. 83.53% of CIS users worked full time.

Table 1: Responders' characteristics

Sample size	MED 102	NUR 222	MDA 95	p-value	Total 419
Male Sex (%)	48.03	15.81	4.20	<.0001	21.00
Full time activity (%)	83.80	90.30	90.01	.226	83.53
Mean Age (SD)	46.02 (11,54)	36.32 (10.98)	40.62 (10.21)	<.0001	39.66 (11.63)
Seniority at work (SD)	7,69 (4,42)	6.99 (4.66)	7.89 (4.12)	.193	7.37 (4.49)

Acceptance dimensions evaluation: Mean scores for all constructs were over 4 on the 1-7 Likert scale (table 2). The lowest value was observed for the perceived quality of training (mean: 4.08). The mean scores for all constructs were lower for medical professions than for nursing and medico-administrative categories of personnel. The differences among the three groups are significant for CIS quality, perceived usefulness, confirmation of expectations and user satisfaction. The continuance intention is very high in every professional category.

Table 2: Influence of the professional category on the evaluation dimensions

	MED	NUR	MDA	F-test	P-value	Total
Sample size	**102**	**222**	**95**			**419**
CIS quality	4.49 (1.28)	4.99 (0.93)	5.12 (0.90)	11.309	<.0001	4.90 (1.04)
Information quality	4.71 (1.58)	4.97 (1.18)	5.12 (1.07)	2.831	.062	4.94 (1.27)
Compatibility with	4.39 (1.67)	5.05 (1.24)	5.19 (1.05)	11.216	<.0001	4.92 (1.35)
Availability	4.70 (1.39)	5.04 (0.99)	5.19 (0.96)	5.473	.004	4.99 (1.11)
Ease of use	4.17 (1.42)	4.90 (1.26)	4.98 (1.25)	13.203	<.0001	4.74 (1.33)
Perceived CIS	4.81 (1.63)	4.93 (1.14)	5.22 (0.99)	2.889	.063	4.97 (1.25)
Confirmation of	3.93 (1.46)	4.58 (1.14)	4.50 (1.01)	10.693	<.0001	4.40 (1.23)
Facilitating	4.21 (1.34)	4.27 (1.30)	4.73 (1.24)	5.143	.006	4.35 (1.31)
User satisfaction	4.52 (1.66)	5.13 (1.12)	5.13 (1.09)	8.992	.000	4.98 (1.29)
Continuance	5.70 (1.41)	5.90 (0.99)	5.99 (0.93)	1.844	.159	5.87 (1.10)

Model testing results: In simple regressions, the global satisfaction was negatively and significantly associated with belonging to a medical profession and age and positively and significantly associated with CIS quality, user support, perceived CIS usefulness, and the confirmation of expectations (table 3). In multiple regressions, the global satisfaction (R^2=.780) was positively and significantly correlated with CIS

Table 3: Multiple regression and stepwise analysis of post adoption model (419 answers)

Dimension	Hypo-thesis	Simple regression *r (p)*	Multiple regression *r (p)*	Stepwise regression *r (p)*
Global satisfaction				
Age (years)	H_5	-.060 (.217)	-.002 (.574)	
Male sex (yes=1, no=0)	H_5	-.120 (.014)	.044 (.580)	
Medical profession (yes=1, no=0)	H_5	-.204 (<.0001)	-.024 (.768)	
CIS quality	H_6	.871 (<.0001)	.852 (<.0001)	.872 (<.0001)
Facilitating conditions (user	H_7	.495 (<.0001)	.034 (.229)	
Perceived CIS usefulness	H_8	.636 (<.0001)	.074 (.027)	.081 (.013)
Confirmation of expectations	H_9	.693 (<.0001)	.174 (<.0001)	.171 (<.0001)
Adjusted R^2 (p-value)			**.780 (<.0001)**	**.779 (<.0001)**
CIS continuance intention				
Age (years)	H_{10}	.007 (.879)	.001 (.870)	
Male sex (yes=1, no=0)	H_{10}	-.070 (.153)	-.010 (.927)	
Medical profession (yes=1, no=0)	H_{10}	-.088 (.071)	.062 (.5586)	
CIS quality	H_{11}	.556 (<.0001)	.149 (.090)	
Perceived CIS usefulness	H_{12}	.556 (<.0001)	.251 (<.0001)	.273 (<.0001)
Confirmation of expectations	H_{13}	.499 (<.0001)	.116 (.022)	.128 (.009)
Global satisfaction	H_{14}	.555 (.0001)	.140 (.046)	.220 (<.0001)
Adjusted R^2 (p-value)			***.392 (<.0001)***	***.387 (<.0001)***

r: regression coefficient

quality, confirmation of expectations, and perceived CIS usefulness but no more with the three user characteristics (age, sex and medical profession). The high R^2 values of global satisfaction (0.780) explained by the ITPAM model is in good argument for its soundness, in particular, if we consider the three main constructs: CIS quality, perceived CIS usefulness and confirmation of expectations. The facilitating condition construct, based on user support and training, appeared to be related to satisfaction in the simple regression, but its effect was no longer significant in multiple regressions.

4. Discussion and conclusion

IT acceptance evaluation studies that were initiated in the seventies on the basis of social psychology theories have been applied to many domains [2,3]. They are of particular importance for evaluating the success of clinical information systems, determining the best predictors of acceptance and managing the necessary changes associated with their deployment. However, most studies concentrate on pre- or early deployment phases (e.g., behavioral intention to use a system) and/or target end users. The present study gives the results of two late-deployment evaluations, for a multi-professional group, on the acceptance of a fully integrated CIS, considered here as a black box including its EHR, CPOE, CDSS, PACS. In such a "paperless targeted" environment, the measurement of use is of much less importance because the end user may not have very many choices, i.e., to manage themselves the EHR or to delegate some of their tasks to other clinical professionals. Subjective use was therefore replaced by intent to continue to use in the ITPAM model as proposed in the ISCI model [7]. The three main determinants of the variance of continuance intention by the ITPAM model are perceived CIS usefulness, confirmation of expectations and global satisfaction. The CIS quality construct was significant in single but not in multiple regressions as if in a quasi-mandatory situation, end users felt it necessary to pursue. Future perspectives of this work include testing the ITPAM model in other hospital environments. One must also certainly consider other determinants of continuance intention not present in the current survey but that could still improve the percentage of explained variance.

References

[1] Van der Meijden MJ, Tange HJ, Troost J, *et al.* Determinants of Success of Inpatient Clinical Information Systems: A Literature Review. *J Am Med Inform Assoc JAMIA* 10 (2003), 235–43.
[2] Holden RJ, Karsh B-T. The technology acceptance model: its past and its future in health care. *J Biomed Inform* 43 (2010), 159–72.
[3] Pynoo B, Devolder P, Voet T, *et al.* Assessing hospital physicians' acceptance of clinical information systems: a review of the relevant literature. *Psychol Belg* 53(2) (2013), 15-31.
[4] Ammenwerth E, Iller C, Mahler C. IT-adoption and the interaction of task, technology and individuals: a fit framework and a case study. *BMC Med Inform Decis Mak* 6 (2006), 3.
[5] Delone WH. The DeLone and McLean model of information systems success: a ten-year update. *J Manag Inf Syst* 19 (2003), 9–30.
[6] Vankatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. *MIS Q* 27 (2003), 425-78.
[7] Bhattacherjee A. Understanding Information Systems Continuance: An Expectation-Confirmation Model. *MIS Q* 25 (2001), 351.
[8] Degoulet P, Marin L, Lavril M, *et al.* The HEGP component-based clinical information system. *Int J Med Inf* 69 (2003), 115–26.
[9] Zapletal E, Rodon N, Grabar N, *et al.* Methodology of integration of a clinical data warehouse with a clinical information system: the HEGP case. *Stud Health Technol Inform* 160 (2010),193–7.
[10] Palm J-M, Dart T, Dupuis I, *et al.* Clinical information system post-adoption evaluation at the georges pompidou university hospital. *AMIA Annu Symp Proc* (2010), 582–6.
[11] Palm JM, Colombet I, Sicotte C, *et al.* Determinants of User Satisfaction with a Clinical Information System. *AMIA Annu Symp Proc* (2006), 614–8.

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Electronic Processing of Informed Consents in a Global Pharmaceutical Company Environment

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Abstract. We present an electronic capture tool to process informed consents, which are mandatory recorded when running a clinical trial. This tool aims at the extraction of information expressing the duration of the consent given by the patient to authorize the exploitation of biomarker-related information collected during clinical trials. The system integrates a language detection module (LDM) to route a document into the appropriate information extraction module (IEM). The IEM is based on language-specific sets of linguistic rules for the identification of relevant textual facts. The achieved accuracy of both the LDM and IEM is 99%. The architecture of the system is described in detail.

Keywords. Informed consent, information retrieval, language detection

Introduction

Almost all potential volunteers or simple patients enrolled in some biomedical study have been handed a stack of papers containing informed consent (IC) [1] to sign. Today, most of collected questionaries' forms are paper-based, as it is the most convenient instrument to persistently store such legal & medical information in the long run. The exponential growth of paper-based documents pledges the integration process of paper-based collections with digital documents for further processing. Furthermore, if the collected documents are issued in the framework of an international research it adds an additional difficulty of information sharing, due to the multilingual formats and the needed compliance with local or government regulations in each of the respective locations with data are issued.

We believe that the application of natural language processing (NLP) technologies is the best solution to provide an easy access to the information in digitalized document [1], [2]. NLP approaches to tackle information extraction tasks can be split between

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data-driven and manually crafted models. In any case, a predefined domain-oriented text corpus is required to tune and/or assess these models. Therefore to perform our experiments, we rely on simple and robust pattern matching. Such methods are cost effective when no data is available to train a machine-learning model [3] .

An additional source of complexity is introduced by the Optical Character Recognition (OCR) needed to transform the source-digitalized document into machine-readable contents. Thus the collection must be regarded as a relatively noisy content. Again micro-grammars have been shown to perform well on noisy documents such as clinical records [4], [5] and OCRized corpora [6]. Such a dimension is key in our experiments, as it has been shown that the quality of information extraction is directly related to the quality of an OCRized document [7]. Similarly, retrieval effectiveness of search engines is also directly dependent on the ability to handle corruption and to restore quality in the indexed collection [8]. Finally, in a case where the collected document set contains documents in different languages, a language detection pre-processing step is mandatory.

To meet the above-mentioned challenges such as multilingual environment, variations of quality of the OCRized documents, we developed a robust system based on a language detection module to detect document's language and on name entity recognition (NER) method.

1. Data and Methods

In this section, we describe the data we needed to process as well the original pipeline we developed to perform the language-specific information extraction tasks.

1.1. Data overview

A collection of documents' sets (146 documents), see Table 1, which contain occurrences of information expressing the duration of a consent in 10 languages, was used in our experiments. The collection was acquired using a random sample strategy. The resulting set is however very heterogeneous. For example informed consents in Chinese varied depending on the country, thus the Taiwanese documents were in traditional Chinese while documents generated to recruit patients from China were in modern Chinese. Within a given language, various types of forms were provided. Thus, only for the English language: different forms are used in the UK or the US. Further, within the body of the forms, we find legal statements likely to supersede other passages (e.g. specific regulations in particular States in the United States).

The quality check of the supplied corpora revealed some semantic interoperability inconsistencies. For instance, some documents had no information about the time duration, see Table 1. Difficulties were also introduced by the OCR module, which resulted sometimes in error in metadata needed to describe the encoding of the document (e.g. a Russian document marked up with a Latin encoding format).

1.2. Architecture

The overall architecture of the tool with the following components is shown in Figure 1:

- FilesConverter is the module which converts files either of .doc or .rtf extension to a plain text;
- LanguageDetector is the module responsible for the detection of language in the given text. This module is based on a Language Detection (LD) API [9]. The achieved accuracy[2] is the main advantage of LD over its competitors such as Apache Tika and Compact Language Detector. Furthermore, LD has a relatively wide linguistic coverage with more than 50 languages;
- SentenceSplitter splits the text into sentences. By operating at the sentence level, entity mention extraction tasks will be faster and more focused. It should be noticed that traditional Chinese sentences have a specific punctuation where dot is represented by the mark "。", see Figure 2;
- RulesModule is responsible for providing list of rules for the detected language and applying them to text;
- TextTagger tags detected patterns in sentences, see Figure 2.

From a functional point of view the application we developed receives a bulk of documents in .doc or .rtf format and output a .csv file containing the filename, the sentence containing the time duration, the language assigned to the document and a status/feedback flag to record a possible error during the annotation process.

1.3. Language Detection

The language detector is especially important because some documents may contain texts written in more than one language. Thus, some non-English documents, sometimes, contained section in two languages: English and non-English. In these cases, we experimentally defined a threshold: when a candidate language at rank 1 receives a score very similar to a candidate language at rank 2, and if language at rank 1 is English, then we force the system to assign the language proposed in rank 2.

1.4. Information Extraction Rules

A total of 198 regular expressions, to detect time duration, were written, see Table 1.

Some languages such as French or Polish required the duplication of regular expressions due to misspellings introduced by earlier steps (e.g. at Document Authoring or OCRization). Some specific characters, such as accents and cedillas were substituted with the same character without the diacritics (e.g. *ç->c, é->e*).

Additionally, due to some overlapping between Traditional and Modern Chinese rules, the Chinese set includes both of them. The construction of rules is based on the key-words observation and as well as on local culture of using numbers as words or digits in particular languages. The rules combine a set of trigger words (e.g. up to, during, years) and specific micro-grammars such as the recognition of digit sequences (e.g. 12, 15) as proposed to identify named entities [10], [11].

[2] http://blog.mikemccandless.com/2011/10/accuracy-and-performance-of-googles.html .

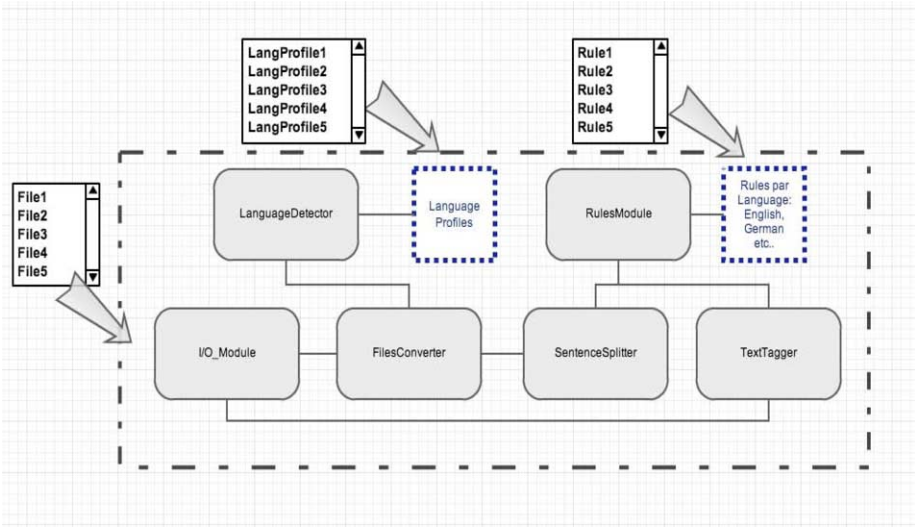


Figure 1. Components of the electronic capture tool of informed consents service. The dotted blue line represents dynamic modules, which can be modified without recompilation of the whole service. This adds an appropriate flexibility to maintain the application.

Table 1. Distribution of rules per language

Language	# of rules	# of provided documents / # documents with no consent
English	3	25/2
German	39	18
French	59	23
Russian	28	8/2
Chinese (Traditional+Modern)	29	6/2
Spanish	5	9
Portuguese	8	11/10
Polish	13	15
Greek	15	10
Swedish	2	8


危險性是抽血的可能副作用。抽血的危險性包括血量、疼痛或淤青，有極少數人可能在針孔部位出現小血塊或感染。研究期間最多會抽血五次，每次抽取大約4到6 ml (約一茶匙) 的血液。

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□日後願意繼續提供諾華公司做事其他基因研究(屆時將再請您另簽一份同意書，且該份 同意書和研究計畫必須先通過三軍總醫院人體試驗委員會的審查）

Figure 2. An output fragment of the web-based interactive version of the service (Chinese).

2. Results and Discussions

The selected language-detection achieved an average precision of 99% for the language classification task. The high accuracy of 98% achieved on the full dataset by information extraction module showed that the authored rules set have excellent effectiveness. Table 1 shows that the most modest and standardized language in documents is English. The relatively high number of rules needed to process French documents compare to others can be explained by high frequency of diacritics along with numbers written in words (*un, deux, trois* etc.). At the same time Russian and German had more variations of key words compared to English. Chinese rules required deeper linguistic investigations due to the analytical nature [12] of the language.

The processing time for a document depends on several parameters such as: text encoding, number of languages in the text and, finally, number of rules defined for the given language. On average, a document is fully processed, from OCRization to language recognition and information extraction, in less than 5 seconds.

As a conclusion, the proposed system successfully demonstrated its power. The system is indeed able to process noisy textual contents in order to identify consents' durations in a highly multilingual environment, which go beyond traditional work with European languages such as French or German, and expand to Russian as well as Asian language with the very same architecture. Today, the system has been successfully deployed at Novartis Institute for Biomedical Research as a bulk-processing tool to support database curation of clinical trial contents.

References

[1] E.J Emanuel, D. Wendler, C. Grady, What makes clinical research ethical?, *JAMA: the journal of the American Medical Association* ***283*** (2000), 2701-11.

[2] P. Haug, S. Koehler, L. M. Lau, P. Wang, R. Rocha, S. Huff, editors, A natural language understanding system combining syntactic and semantic techniques, *Proceedings of the Annual Symposium on Computer Application in Medical Care* (1994).

[3] A.-L. Veuthey, A. Bridge, J. Gobeill, P. Ruch, J.R. McEntyre, L. Bougueleret, et al., Application of text-mining for updating protein post-translational modification annotation in UniProtKB, *BMC bioinformatics* ***14*** (2013), 104.

[4] P. Ruch, R. Baud, A. Geissbühler, Evaluating and reducing the effect of data corruption when applying bag of words approaches to medical records, *International Journal of Medical Informatics* ***67*** (2002), 75-83.

[5] P. Ruch, R. Baud, A. Geissbühler, Using lexical disambiguation and named-entity recognition to improve spelling correction in the electronic patient record, *Artificial intelligence in medicine* **29** (2003), 169-84.

[6] R. Ananthanarayanan, V. Chenthamarakshan, P. M. Deshpande, R. Krishnapuram, editors, Rule based synonyms for entity extraction from noisy text, *Proceedings of the second workshop on Analytics for noisy unstructured text data* (2008).

[7] R. Pereda, Information Extraction in an Optical Character Recognition Context, Diss. University of Nevada, Las Vegas 2011.

[8] P. Ruch, J. Gobeill, C. Lovis, A. Geissbühler, Automatic medical encoding with SNOMED categories. *BMC medical informatics and decision making*, **8**(Suppl 1), (2008), S6.

[9] C. Flanagan, S. N. Freund, editors, Type-based race detection for Java. *ACM SIGPLAN Notices* (2000).

[10] P. Ruch, J. Wagner, P. Bouillon, R. H. Baud, A.-M. Rassinoux, J.-R. Scherrer, editors, MEDTAG: tag-like semantics for medical document indexing, *Proceedings of the AMIA Symposium*; (1999).

[11] P. Ruch, R. H. Baud, A.-M. Rassinoux, P. Bouillon, Robert G, editors, Medical document anonymization with a semantic lexicon, *Proceedings of the AMIA Symposium* (2000).

[12] C. N. Li, S. A. Thompson, *Mandarin Chinese: A functional reference grammar,* University of California Pr., 1989.

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11. Technology and System Evaluation

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The Influence of Similarity between Concepts in Evolving Biomedical Ontologies for Mapping Adaptation

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Abstract. Biomedical ontologies continuously evolve which demands maintain associated mappings up-to-date. This article studies whether similarity calculated between values of concept attributes issued from successive ontology versions plays a role in deciding mapping adaptation actions. We empirically analyse the evolution of official mappings established between large biomedical ontologies. The results point out the relevance of this factor for mapping adaptation.

Keywords. mapping adaptation, mapping evolution, mapping maintenance, similarity metrics, ontology alignment, ontology evolution, ontology versions

Introduction

Ontology mappings play a key role in enabling semantic interoperability for exchanging and retrieving data between biomedical systems [1]. They link concepts of domain-related ontologies allowing systems to interpret data annotated with different ontologies. However, to remain useful and reflect the most up-to-date knowledge of the domain, these ontologies evolve and new versions are periodically released. This potentially impacts existing mappings demanding methods to ensure, as automatic as possible, their semantic consistency over time.

We have designed the *DyKOSMap* framework to adapt ontology mappings through a set of ***Mapping Adaptation Actions (MAAs)*** [2]. Our approach aims at deciding which action to apply when some ontology change affects the source concept of a mapping. Existing tools enable to calculate simple and complex ontology changes given two successive ontology versions [3]. Indeed, various factors may influence the action decision for each correspondence individually [2]. We have studied how different types of ontology changes correlate with the adaptation actions [4][5][6]. Nevertheless, the complete understanding of this phenomenon demands further studies inquiring other factors to take into account in the mapping adaptation process.

This article reports on the influence of the similarity relatedness for mapping adaptation. We calculate the similarity between textual statements from source concepts of mappings with textual statements of parents, children and sibling concepts issued from a new ontology version. These statements are attribute values

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characterizing the concepts. For instance, an attribute a_i, of type name, contains the value *"cardio vascular disease"*. We investigate whether the MAAs correlate with the behaviour of similarity values observed. We hypothesize that the similarity aspect stands for an element that may help deciding the adequate actions to adapt mappings.

1. Methods

An ontology O consists of a set of concepts interrelated by directed relationships. Each concept c_i^j at time j has a unique identifier, and a set of attributes $ATT(c_i)=\{a_1, a_2,..., a_n\}$ (*e.g.,* name, definition, synonym, *etc*.). We define a set of concepts of an ontology O_X at time j as $CNC(O_X^j) = \{c_1^j, c_2^j,..., c_n^j\}$. A relationship r interconnects two concepts and has a specific type, *e.g.,* "subsumption", "part-of", *etc*.

The context CT of a concept c_i in the ontology stands for the union of the sets of $sup(c_i)$, $sub(c_i)$ and $sib(c_i)$ concepts of c_i, as following:

$$CT(c_i) = sup(c_i) \cup sub(c_i) \cup sib(c_i)$$

where :$sup(c_i) = \{c_k | c_k \in CNC(O), c_i \sqsubset c_k \wedge c_i \neq c_k\}$, $sub(c_i) = \{c_k | c_k \in CNC(O), c_k \sqsubset c_i \wedge c_i \neq c_k\}$, $sib(c_i) = \{c_k | c_k \in CNC(O), sup(c_k) \cap sup(c_i) \neq \varnothing\}$ to which $c_i \sqsubset c_k$ stands for "c_i is narrower or more specific than c_j", *e.g.,* "*hypotension*" is more specific than *"vascular disease*".

An ontology mapping $M_{S,T}^j$, established at time j, interrelates a set of given concepts by semantic correspondences. A correspondence $cor_{st} = (c_s, c_t, conf, semType)$ links two concepts $c_s \in CNC(O_S^j)$ and $c_t \in CNC(O_T^j)$ through the *semType* relation. The *conf* denotes the similarity value between c_s and c_t indicating the confidence of their relation. We consider the following types of semantic relation: *unmappable* [$\perp$], *equivalent* [=], *narrow-to-broad* [$\leq$], *broad-to-narrow* [$\geq$] and *overlapped* [$\approx$].

We have expressed behaviours of mapping adaptation as ***Mapping Adaptation Actions*** [2] (*cf.* Figure 1). In *MoveM* the source concept c_s is replaced by another concept c_k. Similarly, in *DeriveM* the original mapping remains and a new one appears connecting a concept c_k with c_t. In both actions, $c_k^1 \in CT(c_s^1)$. In *RemoveM* the mapping is deleted and the action *ModifySemTypeM* consists in modifying the type of semantic relation. The *no-action* refers to the cases where correspondences remain unchanged.

We conduct our experiments using various releases of official mappings established between biomedical ontologies including: SNOMED-CT (SCT), MeSH, ICD-9-CM (ICD9) and ICD-10-CM (ICD10). In particular, mappings interconnect SCT(2010)-ICD9(2009) and SCT(2012)-ICD9(2011); MeSH(2012)-ICD10(2011) and MeSH(2013)-ICD10(2011). We observe the evolution of the biomedical ontologies and mappings through the following procedure:

- **Calculate MAAs:** Given all mappings between two ontologies, for each one impacted by some ontology change, we determine a list of MAAs. We remove those where the source concept remains unchanged from one ontology version to another, or where ontology changes simultaneously affect both source and target concepts. We use the *COnto-Diff* tool to calculate ontology changes [3]. Having successive releases of mappings allows us to calculate the MAAs for each correspondence. We compare the elements composing a correspondence (identifier of source and target concept, and relation type). For instance, given a correspondence at time j, we search its elements in the mapping at time $j+1$. If we fail to find, we sign the *RemoveM* action for such correspondence. We use a similar approach to determine the other MAAs.

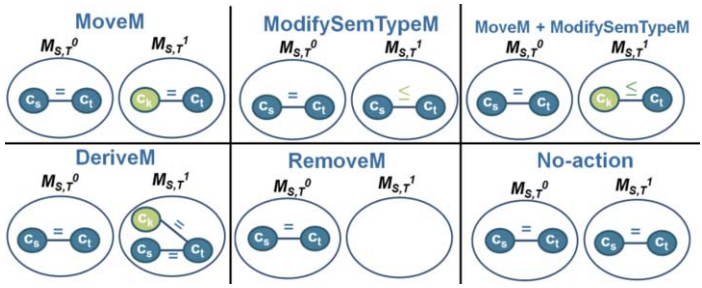


Figure 1. Mapping Adaptation Actions

- **Identify relevant attributes:** For each source concept impacted by ontology changes, we identify a minimal set of 3 relevant attributes representing the most relevant attributes for a given correspondence, since this is established on partial information (*e.g.*, some attributes) defining concepts. These source concept attributes consist of the most similar to the ones in the target concept. We pre-selected groups of attributes to calculate the similarity value. For instance, we do not compare the ICD9 attribute "Exclude" with the SCT attribute "Name", if a correspondence exists.
- **Calculate similarity:** For each relevant attribute of a source concept c_s in an impacted mapping at time j_0, we calculate the similarity with attributes issued from concepts in the context of c_s at time j_1. To this end, we explore string-based similarity metrics, especially the *bi-gram* because this measure performs well on ontology matching tasks [7]. The similarity function receives two attribute values and returns a value ranging from 0 to 1. The higher the result is, the more similar these attributes are. We analyze the density of calculated similarity values ranging from 0 to 1 for each MAAs by using the kernel density estimation method [8]. The density stands for a smoothing distribution of frequencies of the similarity values similar to a histogram. We observe the similarity's influence on the MAAs by studying the following scenarios:

1. **REL_ATTS_changedCT:** For each impacted correspondence, we search the highest similarity value calculated among the relevant attributes identified with all attributes issued of changed concepts in the context of c_s at time j_1. We register such maximum similarity value for the MAAs applied.
2. **Best_REL_ATT_changedCT:** This is similar to scenario 1, but we only consider the best relevant attribute for calculating the similarity (*i.e.,* the most significant attribute for c_s regarding the c_t). We aim to examine the influence of this particular attribute with respect to all relevant attributes.
3. **REL_ATTS_unchangedCT:** This scenario also performs similar to scenario 1, but examines the unchanged part of the context of c_s (*i.e.*, all unchanged concepts in the context).
4. **Best_REL_ATT_unchangedCT:** Similar to scenario 2, we observe the similarity density only considering the best relevant attribute with the unchanged context.
5. **REL_ATTS_conceptMAA:** This scenario applies only for *MoveM* and *DeriveM* since they involve a concept c_k^1 (denoted *conceptMAA*) which replaces the concept c_s. We calculate the density of the highest similarity values among the relevant attributes and the attributes characterizing c_k^1.

6. **Best_REL_ATT_conceptMAA:** This is similar to scenario 5, but we only consider the best relevant attribute.

We repeated this procedure for both set of mappings (SCT-ICD9 and MeSH-ICD10). The total number for each type of MAAs analyzed remained: *MoveM* (635); *DeriveM* (768); *ModSemTypeM* (58), *RemoveM* (193) and *no-action* (9280).

2. Results

Figure 2 presents the obtained kernel estimation based density of the similarity values for the *DeriveM* and *MoveM* actions. For *DeriveM,* we observe a similar behaviour of the density of similarity values in scenarios 1 (**REL_ATTS_changedCT**) and 2 (**Best_ REL_ATT__changedCT**), revealing a high frequency of low similarity values. We explain this by the fact that most frequently the changed CT set is empty so similarity values remain zero. In scenarios 3 (**REL_ATTS_unchangedCT**) and 4 (**Best_ REL_ATT_unchangedCT**), we observe the contrary behaviour with a bigger density of high similarity values. This shows that the original source concepts appear similar with unchanged concepts in the context. Scenario 4 presents a lower density of high similarity values compared with scenario 3. We point out a higher density of medium similarity in scenario 5 (**REL_ATTS_conceptMAA**) compared with scenario 6. This reveals that the best relevant attributes frequently are not the most similar ones to *conceptMAA*. Results for scenarios in *MoveM* indicate a similar behaviour of the *DeriveM* except for the scenario 1 (**REL_ATTS_changedCT**). This underscores that when finding similarity with the changed CT a *MoveM* action occurs.

Figure 3 presents the achieved results for the *ModSemTypeM, RemoveM* and *no-action*. For the *ModSemTypeM,* scenarios 1 (**REL_ATTS_changedCT**) and 2 (**Best REL_ATT_changedCT**) behave very similar, with a high density of low similarity values. On the contrary, scenario 3 (**REL_ATTS_unchangedCT**) shows a higher density of high similarity values which remains lower for the scenario 4. All scenarios for *RemoveM* behave very similar presenting a high density of low similarity values. This may rely on the fact that when correspondences evolve by *RemoveM* action, the whole context contained unchanged or not similar concepts that could be candidates for replacing the source concept. When *no-action* is applied, the scenarios with the changed context (1 and 2) show a high density of low similarity values also because of the inexistence of changed concepts. However, we observe a high density of high similarity values in the scenarios with unchanged context (3 and 4) despite that correspondences remained unchanged (*i.e.* any mapping adaptation action was applied).

3. Discussion

Our results pointed out well-defined behaviours with respect to the density of similarity values for the MAAs. We found the similarity between ontology versions a relevant factor for mapping adaptation. This might help deciding which action applying, but seems insufficient for a completely automatic mapping adaptation. For example, for *DeriveM* and *MoveM* actions (*cf.* Figure 2), the density of the highest similarity values in scenarios 3 and 4 (unchanged context) is bigger than the density observed in scenarios 5 and 6 (*conceptMAA*). We expected that the similarity value with the concept where a *DeriveM* or *MoveM* action happens would remain higher than the

similarity found with unchanged concepts. On the other hand, the similarity aspect can help deciding for a *RemoveM* action (*cf.* Figure 3). In addition, we expected to observe a more determinant influence of the best relevant attributes in the studied scenarios. We conclude that a system for mapping adaptation must combine the similarity with other aspects to achieve enough facts enabling to trigger different MAAs. Our future work involves studying these further factors.

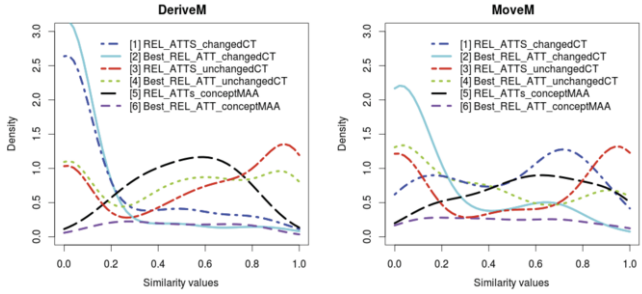


Figure 2. Similarity values density between concept attributes for *DeriveM* and *MoveM* actions

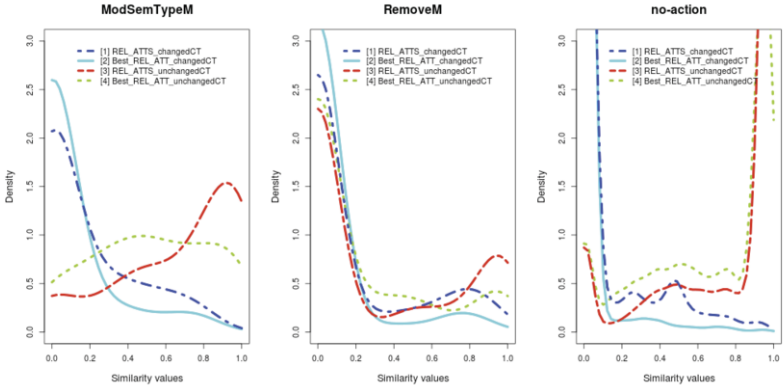


Figure 3. Similarity value density between concept attributes for *ModifySemTypeM, RemoveM* and *no-action*

References

[1] Burgun, A., Bodenreider, O.: Accessing and integrating data and knowledge for biomedical research. *Yearbook of medical informatics*. (2008), 91–101.

[2] Dos Reis, J.C., Dinh, D., Pruski, C., Da Silveira, M., Reynaud-Delaître, C.: Mapping adaptation actions for the automatic reconciliation of dynamic ontologies. *CIKM.* (2013), pp. 599–608.

[3] Hartung, M., Groß, A., Rahm, E.: COnto-Diff: Generation of Complex Evolution Mappings for Life Science Ontologies. *Journal of biomedical informatics.* 46 (2013), 15–32.

[4] Gross, A., Hartung, M., Thor, A., Rahm, E.: How do computed ontology mappings evolve ? A case study for life science ontologies. *IWOD workshop at ISWC.* (2012), pp. 1–12.

[5] Dos Reis, J.C., Pruski, C., Da Silveira, M., Reynaud-Delaître, C.: Understanding semantic mapping evolution by observing changes in biomedical ontologies. *JBI*. 47 (2014), 71-82.

[6] Dos Reis, J.C., Pruski, C., Da Silveira, M., Reynaud-Delaître, C.: Characterizing Semantic Mappings Adaptation via Biomedical KOS Evolution: A Case Study Investigating SNOMED CT and ICD. *AMIA Symposium.* (2013), pp. 333–342.

[7] Cheatham, M., Hitzler, P.: String similarity metrics for ontology alignment. *ISWC*. (2013), pp. 294–309.

[8] Sheather, S.J., Jones, M.C.: A Reliable Data-Based Bandwidth Selection Method for Kernel Density Estimation. *Royal Statistical Society*. 53 (1991), 683–690.

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An Approach to Compare Bio-Ontologies Portals

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Abstract. Background: main biomedical information retrieval systems are based on controlled vocabularies and most specifically on terminologies or ontologies (T/O). These classification structures allow indexing, coding, annotating different kind of documents. Many T/O have been created for different purposes and it became a problem for finding specific concepts in the multitude of existing nomenclatures. The NCBO (National Center for Biomedical Ontologies) BioPortal and the CISMeF (Catalogue et Index des Sites Médicaux de langue Française) HeTOP projects have been developed to tackle this issue. Objective: the present work consists in comparing both portals. Methods: we hereby are proposing a set of criteria to compare bio-ontologies portals in terms of goals, features, technologies and usability. Results: BioPortal and HeTOP have been compared based on the given criteria. While both portals are designed to store and make T/O available to the community and are sharing many basic features, they differ on several points mainly because of their basic purposes. Conclusion: thanks to the comparison criteria, we can assume that a merge between BioPortal and HeTOP is possible in terms of functionalities. The main difficulties will be about merging the data repositories and applying different policies on T/O content.

Keywords. Controlled Vocabulary, Internet, Information Storage and Retrieval, Terminology as subject, Health terminologies and ontologies, Crosslingual access to health information, Portal

Introduction

Because of the constant growth of biomedical data it became mandatory to index or annotate it with controlled and structured vocabularies in order to store it and to retrieve it intelligently. A key aspect in addressing semantic interoperability for biomedical data is the use of terminologies or ontologies (T/O) as a common data structure [1] [2]. Many T/O have been created in the last decade for different purposes: indexing or annotating documents, organising knowledge, inferring facts, etc.

Several tools have been created to store, search and use multiple T/O simultaneously. Among them, the UMLS (Unified Medical Language System) [3], the EBI Ontology Lookup Service [4], the NCBO BioPortal[2] [5] or the CISMeF HeTOP[3] [6].

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[2] http://bioportal.bioontology.org

The NCBO project (National Center for Biomedical Ontology) of the university of Stanford and the CISMeF (Catalogue et Index des Sites Médicaux de langue Française, Rouen University Hospital, France) have invested considerable efforts in the development of tools and services based on T/O to assist health professionals to search resources on the Internet and to use T/O. Both groups have developed web portals, respectively BioPortal and HeTOP that offer various services to find, index, browse, visualise and annotate T/O.

This article aims to compare BioPortal and HeTOP by defining objective comparison points based on their functionalities and features. Thus, it could be possible to define a strategy to merge both portals into one unique solution, offering the best services for human users and programmes.

1. Methods

1.1. BioPortal - http://bioportal.bioontology.org

Developed by the NCBO, BioPortal is a repository of biomedical ontologies which hosts more than 350 ontologies in different formats [7], [8].

These ontologies are regularly updated by users and accessible via a web site for the humans and web-based services for programmes. BioPortal is a library of community ontologies [9] designed as a "one-stop shop" repository. Users have access to the ontologies with or without restriction (depending on the level of restriction set by the editor) and can access to editing, comment, rating and content adding operations.

1.2. HeTOP - http://www.hetop.org

HeTOP (Health Terminology/Ontology Portal) [6], is a T/O portal developed by the CISMeF team. It hosts more than 55 T/O in several languages. Most of the T/O are international or French national references such as MeSH, ICD-10, or CCAM. These T/O are regularly updated and are accessible via a web site and a web-based service. HeTOP has been designed as reference multi-terminology and multi-lingual portal [10] to help librarians, translators, students and health professionals to retrieve resources and knowledge across a high variety of complex health fields.

1.3. Criteria and Comparison Approach

As far as we know, there is no existing method to compare such applications. The work of [2] has inspired us for establishing a criteria list for comparing BioPortal and HeTOP properties (technologies, methodologies, policies, target users, final purposes, features,\dots) but also from other similar portals. We categorised all the criteria in four groups: (i) Content, (ii) Functions & Tools, (iii) User Interface & Usability, (iv) Methods & Technologies.

[3] http://www.hetop.eu

2. Results[4]

2.1. Content Comparison

The comparison of content reveals 3 important differences between BioPortal and HeTOP: (i) The volume of data is more important in BioPortal considering the T/O numbers or concept numbers (respectively 5,960,457 and 1,951,834). However, since T/O have various number of concepts and terms (terms are preferred terms plus synonyms, in any language) and since HeTOP is dealing with multilingual content, T/O numbers are not suited comparison indicators: the more relevant figures are the number of terms and the total number of relations. Indeed, BioPortal and HeTOP have around the same number of terms (about 6,600,000). Unfortunately, it is not possible to easily calculate the total number of relations in BioPortal. (ii) T/O formats and update frequencies are quite different in BioPortal compared to HeTOP. While BioPortal is focused on ontologies and takes advantage of standard formats and programmes, HeTOP is also hosting heterogeneous representation formats such as Microsoft Excel files, XML files or database dumps. A special work has to be done for every new T/O source: this can not be executed automatically and it implies expertise and development. (iii) One major difference between BioPortal and HeTOP is the expertise brought to every T/O. While BioPortal is automatically importing ontologies and does not change anything, except new automatic mappings and some manual users mappings, each HeTOP hosted T/O undergoes a series of process to leverage its content and meta-data (new translations, synonyms, definitions, relations, mappings, etc.).

2.2. Functions & Tools Comparison

Despite the similarity of basic tools for both portals, some details and tools differ slightly but have a direct consequence for the human users. (i) The BioPortal search engine only searches for exact terms in English (among preferred terms and synonyms) while HeTOP search engine is able to add wildcards to search for terms containing the query, in two languages simultaneously. This has a direct impact on how users can search terms; for instance, if one searches "myopathy" (in English) in the NCIT[5], BioPortal retrieves 5 terms whereas HeTOP retrieves 25; because wildcards are handled, HeTOP search engine is actually querying "*myopathy*" and retrieves terms such as "Cardiomyopathy".

2.3. User Interface & Usability Comparison

To compare the user experience using both portals, we compared two functions involving time responses. First, a comparison have been made between search engines performances in terms of response time and result numbers; we picked and performed 10 random queries on both search engines and we measured the user experience time (with the FireBug Mozilla Firefox plug-in) and noted the results. No options have been selected in both portals and the searches have been made among all T/O, in English and in French in HeTOP and only in English in BioPortal (no possible multilingual search).

[4] The complete results list is available at http://www.chu-rouen.fr/cismef/papers/comp_bioportal_hetop_table.pdf

[5] National Cancer Institute thesaurus, edited by the NCI: http://ncit.nci.nih.gov/

Results are 5.57 sec/19.7 (average response time/number of results) and 3.17 sec/359.4 respectively for BioPortal and HeTOP.

About multilingualism, within BioPortal, T/O in other languages than English are mostly available as "views" of the corresponding English T/O (e.g., the French MeSH is a view of the MeSH) but it is impossible to get the French term while browsing the English one and vice-versa. Within HeTOP, T/O are not language specific (e.g., the MeSH exists only once with the available translated terms). Therefore it is easy from the English term to get to the French one and vice-versa. The whole user interface is internationalised and the search can be performed per language. Switching from one language to another is context sensitive.

2.4. Methods & Technical Comparison

While BioPortal is based on a RDF triple store data model, HeTOP has a meta-model for T/O, which encapsulates specific T/O models into an Oracle 11g r2 relational database. Both portals are coupled to a web-based service. About code license, APIs are open for BioPortal and proprietary for HeTOP.

3. Discussion & Conclusion

As described above, BioPortal and HeTOP are sharing many features such as T/O browsing, tab representation and resources access tools. Both portals are valuable tools to support research projects. However, their policies and basic purposes are significantly different. While BioPortal is opened to the community T/O, HeTOP is focusing on reference T/O with experts interventions. Thus, BioPortal only accepts ontologies (at least files in ontology formats) whereas HeTOP provides access to non-ontological sources. BioPortal has been created as a "one-stop shop" repository and can be instantiated in other environments using the virtual appliance. On the contrary, HeTOP is a static server/web site acting such as a platform to help various kinds of users for different goals. Moreover, HeTOP is focusing on T/O content, working hard with experts and curators to leverage lexicons, mappings and other knowledge resources. This has a direct consequence on data volume and restriction policies related to download, versioning or updates.

Several criteria of this comparison study are focusing on usability: a portal dedicated to be used by experts or lay people has to be understandable and usable with less efforts and knowledge. A special work is made on HeTOP to deal with it: many T/O meta-data labels (attributes, relations, ...) are translated in several languages and well defined.

On the other hand, BioPortal is more open than HeTOP: users can upload ontologies and annotate concepts and they have more options. BioPortal proposes persistent concept URL thanks to the REST technology. However, HeTOP is more user-oriented with high quality and multilingual T/O content, it is also faster (search engine and navigation) and maybe more adapted to lay people and students which means that it is more reliable and more friendly to use on a daily basis. Unfortunately, no evaluation on user's satisfaction has been performed on HeTOP nor BioPortal; it is an ongoing work for HeTOP with a set of online questions.

This study helps to understand both portals philosophies and functionalities. Furthermore, it allows to point at BioPortal and HeTOP advantages and drawbacks.

Despite the differences, we can assume that a merge is possible. The vast majority of policy points and functionalities could be kept in both approaches to create a single portal. The main difficulty would be the technical choices to merge a RDF data store and a relational database with much specificity.

To tackle this, it would be possible to integrate the two data layers in a unique system coupled to a single API. This merge would have a great cost but it would be a considerable benefit for the biomedical community and T/O users.

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References

[1] Bodenreider O & Stevens R. Bio-ontologies: Current Trends and Future Directions. Briefings in Bioinformatics. 2006;7:256-274

[2] Rubin DL, Shah NH & Noy NF. Biomedical ontologies: a functional perspective. Briefings in Bioinformatics. 2008;9(2):75-90.

[3] Bodenreider O. The Unified Medical Language System (UMLS): integrating biomedical terminology. Nucleic Acids Res. 2004. PMID: 14681409

[4] Côté R, Reisinger F, Martens L, Barsnes H, Vizcaino JA, Hermjakob H. The Ontology Lookup Service: bigger and better. Nucleic Acids Res. 2010. PMID: 20460452

[5] Rubin DL, Lewis SE, Mungall CJ, Misra S, Westerfield M, Ashburner M, Sim I, Hute CG, Solbrig H, Storey MA, Smith B, Day-Richter J, Noy NF & Musen MA. National Center for Biomedical Ontology: Advancing Biomedicine through Structured Organization of Scientific Knowledge. OMICS A Journal of Integrative Biology. 2006;10(2):185-198.

[6] Grosjean J, Merabti T, Dahamna B, Kergourlay I, Thirion B, Soualmia LF & Darmoni SJ. Health Multi-Terminology Portal: a semantics added-value for patient safety. Patient Safety Informatics - Adverse Drug Events, Human Factors and IT Tools for Patient Medication Safety. 2011;166 of Studies in Health Technology and Informatics:129-138.

[7] Noy NF, Shah NH, Whetzel PL, Dai B, Dorf M, Griffith NB, Jonquet C, Rubin DL, Storey MA, Chute CG & Musen MA. BioPortal: ontologies and integrated data resources at the click of a mouse. Nucleic Acids Research. 2009;37 (web server):170-173.

[8] Whetzel PL, Noy NF, Shah NH, Alexander PR, Nyulas C, Tudorache T & Musen MA. BioPortal: enhanced functionality via new Web services from the National Center for Biomedical Ontology to access and use ontologies in software applications. Nucleic Acids Research. 2011;39 (web server):541-545.

[9] D'Aquin M & Noy NF. Where to Publish and Find Ontologies? A Survey of Ontology Libraries. Journal of Web Semantics. 2012;11:96-111.

[10] Grosjean J, Merabti T, Griffon N, Dahamna B, Soualmia LF & Darmoni SJ. Multi-terminology cross-lingual model to create the Health Terminology/Ontology Portal. American Medical Informatics Association Annual Symposium, Chicago, USA. 2012:1753.

[6] http://www.lirmm.fr/sifr/

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Automatic annotation of ICD-to-MedDRA mappings with SKOS predicates

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Abstract. Robust alignments between ICD and MedDRA are essential to enable the secondary use of clinical data for pharmacovigilance research. UMLS makes available ICD-to-MedDRA mappings, but they are only poorly specified, which introduces difficulties when exploited in an automatic way. SKOS vocabulary can help achieve quality and machine-processable mappings. We have developed an algorithm based on several simple rules which annotates automatically ICD-to-MedDRA mappings with SKOS predicates. The method was tested and evaluated on a sample of ICD-10-to MedDRA mappings extracted from UMLS. The algorithm demonstrated satisfying performances, especially for skos:exactMatch properties, which suggests that automatic methods can be used to improve the quality of terminology mappings.

Keywords. ICD-10, MedDRA, SKOS, UMLS, terminology mapping.

Introduction

Aligning biomedical terminologies is a necessary step to achieve semantic interoperability between health information systems, which determines data integration, data reuse and data sharing [1-2]. Objectives such as secondary use of electronic health record (EHR) data for clinical research, statistical or billing purposes cannot be reached without robust mappings, enabling the – if possible automatic – translation of data from one coding system to another. In the field of drug safety and pharmacovigilance, alignments from the *International Classification of Diseases* (ICD) [3] to the *Medical Dictionary for Drug Regulatory Activities* (MedDRA) are requested. MedDRA is used to record adverse drug reactions (ADR) data and is recommended for the electronic transmission of safety reports [4], while ICD is frequently used to capture clinical information in healthcare settings. An alignment between ICD and MedDRA is for instance a prerequisite to use medical data available in EHR systems for ADR reporting [5] or for mining EHRs or administrative data to detect ADRs [6]. Mappings with ICD-9 and ICD-9-CM were included in previous versions of MedDRA, but they are not maintained and do not cover more recent versions of ICD, such as the widely used ICD-10 and the future ICD-11 (under development).

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The most reliable and up-to-date resource currently available to align ICD to MedDRA is undoubtedly the Unified Medical Language System (UMLS) Metathesaurus[2]. Initiatives such as OMOP or BioPortal[3] are also useful, but are less exhaustive. These resources however suffer from important limitations: they do not specify the meaning of the alignment relation being stated, its source and if it has been validated by experts. This is one major inconvenient of UMLS: the codes from several terminologies that are associated with the same UMLS concept (CUI) as possible "synonyms" may correspond to exact match terms, lexical variants, more granular or more general terms, or even to terms related to associated conditions. Such imprecise mappings are only poorly exploitable in an automatic way, leading to unexpected results when used in reasoning algorithms.

Using vocabularies such as SKOS (Simple Knowledge Organization System) [8] appears essential to achieve quality mappings. SKOS provides a precise and machine-processable typology of mapping relations, which enables to exploit the capabilities of semantic reasoning methods when translating data from one terminology to another. For instance, SKOS makes it possible to use logical rules such as subsumption and transitivity to infer non-asserted mappings based on asserted mappings and hierarchical relations between terms inside terminologies. Typically, if A has skos:exactMatch B, and C is-a A, then one can infer that C has skos:broadMatch B. Expressing mappings using SKOS is also essential to evaluate the logical consistency of mappings using semantic reasoning methods, *i.e.* for quality assessment [5].

The problem is that expressing mappings with SKOS requires huge resources if performed manually. To alleviate the manual effort, we have developed an algorithm based on several simple rules, which annotates automatically ICD-to-MedDRA mappings extracted from UMLS with SKOS predicates. In the following, we describe the method we followed to build this algorithm and we present the results in terms of number of SKOS predicates generated and qualitative evaluation. We finally discuss some issues raised by this method and related to the quality of terminologies.

1. Methods

To build the algorithm and evaluate its performances, we used the alignments between ICD-10 and MedDRA 16.0 available in the UMLS 2013AA Release. We extracted from the metathesaurus ICD-10 codes (13,505) and MedDRA codes (93,948); we then performed a junction query associating both codes when the CUI was the same. Because our target use case was to enable automatic EHR data extraction for ADR reporting, we only focused on mappings relating ICD-10 terms to LLT (lowest level term) and PT (preferred term) MedDRA levels, which are recommended for the coding of ADRs [9-10]. ICD-10 codes related to classification titles such as "A00-A09 (Intestinal infectious diseases)" were also ignored (291 codes).

The rules used by the algorithm to generate SKOS predicates are not logical in nature but pragmatic: they have been chosen not because of their formal consistency, but because they appear to work with a satisfying degree of success. They were defined using an iterative method including the following steps: intuitive definition of candidate rules based on a small sample (around fifty) of ICD-to-MedDRA mappings;

[2] http://www.nlm.nih.gov/research/umls/
[3] http://omop.fnih.org/, http://bioportal.bioontology.org/

formalization of these rules in an algorithmic format; testing of the algorithm on a bigger sample; expert evaluation of the results; refinement of the rules. Three iterations were performed to achieve the current version of the algorithm. The algorithm makes use of four out of the five mapping properties available in SKOS: skos:exactMatch, skos:broadMatch, skos:narrowMatch, skos:relatedMatch. skos:closeMatch is not used. The rules used to generate SKOS mapping relations are described below. ICD is an ICD-10 term which is mapped to one or several (*n*) MedDRA terms $\{MED_1, ..., MED_n\}$.

Case 1: n=1 --> ICD EXACTMATCH MED_1 ---- rule 1 ----

Case 2: n>1

Case 2.1: ICD has a string match with MED_x --> ICD EXACTMATCH MED_x ---- rule 2 ----

Case 2.1.1: MED_x is a LLT ---- rule 3 ----

--> ICD BROADMATCH $PT(MED_x)$, *where* $PT(MED_x)$ *is the PT above* MED_x *in MedDRA*

--> ICD RELATEDMATCH $\{LLT(MED_x)_1, ..., LLT(MED_x)_m\}$, *where* $\{LLT(MED_x)_1, ..., LLT(MED_x)_m\}$ *are the LLTs brothers of* MED_x *in MedDRA*

Case 2.1.2: MED_x is a PT ---- rule 4 ----

--> ICD NARROWMATCH $\{LLT(MED_x)_1, ..., LLT(MED_x)_m\}$, *where* $\{LLT(MED_x)_1, ..., LLT(MED_x)_m\}$ *are the LLTs under* MED_x *in MedDRA*

Case 2.2: no string match exists between ICD and $\{MED_1, ..., MED_n\}$

Case 2.2.1: $\{MED_1, ..., MED_n\}$ are all LLTs ---- rule 5 ----

--> ICD RELATEDMATCH $\{MED_1, ..., MED_n\}$

Case 2.2.2: $\{MED_1, ..., MED_n\}$ include a PT MED_x ---- rule 6 ----

--> ICD EXACTMATCH MED_x

--> ICD NARROWMATCH $\{LLT(MED_x)_1, ..., LLT(MED_x)_m\}$, *where* $\{LLT(MED_x)_1, ..., LLT(MED_x)_m\}$ *are the LLTs under* MED_x *in MedDRA*

The algorithm works as follows: for a given ICD code, we get a skos:exactMatch if there is only one MedDRA candidate (1), or, in case several MedDRA candidates are available (2), if there is an exact string match (2.1) or a PT (2.2.2). Any remaining MedDRA candidate in a higher level of MedDRA hierarchy is annotated as a skos:broadMatch (2.1.1), in the same level as a skos:relatedMatch (2.1.1 and 2.2.1), in a lower level as a skos:narrowMatch (2.1.2 and 2.2.2).

Some rules (rules 3, 4 and 6) are based on the assumption that the LLTs subsumed by a PT express *more precise* medical concepts, *i.e.* it is assumed that there is always a skos:broadMatch relation between LLTs and PTs, which is not always true since some LLTs are pure synonyms or lexical variants of the PT they relate to [11-12]. This assumption was adapted to the goal of getting a skos:exactMatch mapping for the largest possible number of ICD-10 terms. As a consequence, we also consider that LLTs refer to *different* medical conditions (rules 3 and 5), which, again, is not always true. We will come back to this issue in the Discussion.

2. Results

Using the method described above, 11,647 ICD-to-MedDRA mappings were extracted from UMLS, corresponding to 4,603 ICD-10 codes and to 10,078 MedDRA terms, included in 4,178 distinct CUIs (the same ICD-10 term can be mapped to several MedDRA term, and conversely). It means that approximately 32% of ICD-10 codes

(national Clinical-Modifications are not considered) are mapped to MedDRA (PT or LLT level) in UMLS. The nature and proportion of SKOS predicates generated by the algorithm is described in the table below.

Table 1. Number of SKOS predicates generated by the algorithm and results of the expert evaluation.

Nb of SKOS predicates	exactMatch	narrowMatch	relatedMatch	broadMatch	Total
Generated	3769	3663	3645	569	11646
Evaluated sample	88	64	83	22	257
Validated by expert	82	25	13	10	130
95% confidence interval	$93.2^{\pm 5.3}$ %	$39.1^{\pm 12.0}$ %	$15.7^{\pm 7.8}$ %	$45.5^{\pm 20.8}$ %	50.6 %

Table 2. Example of SKOS properties generated by the algorithm.

ICD-10	MedDRA			SKOS match	evaluation
A00.9 Cholera, unspecified	10008634	LLT	Cholera, unspecified	exact	☑
	10008631	PT	Cholera	broad	☑
	10047397	LLT	Vibrio cholera gastroenteritis	related	☑
	10045658	LLT	Unspecified cholera	~~related~~	exact
A01.0 Typhoid fever	10045275	PT	Typhoid fever	exact	☑
	10045272	LLT	Typhoid	~~narrow~~	exact
	10039446	LLT	Salmonella typhi infection	~~narrow~~	exact
A02.0 Salmonella enteritis	10039433	LLT	Salmonella enteritis	exact	☑
	10039434	LLT	Salmonella gastroenteritis	related	☑
	10017914	PT	Gastroenteritis salmonella	~~broad~~	related
	10039443	LLT	Salmonella poisoning	related	☑

The results were evaluated on a random sample (257 mappings) by a medical terminology expert. All categories included, approximately 50% of the generated SKOS predicates proved to be correct, which is much better than chance level (equal to 25%, considering that only one of the four possible properties is correct in each case). skos:exactMatch properties, which are the most important for terminology alignment, were generated for 82% of ICD-10 terms for which mappings were available. Almost all are correct ($93.2^{\pm 5.3}$ %). The performances of the algorithm are less convincing for the other SKOS properties: only 15% of skos:relatedmatch and around 40% of skos:narrowMatch and skos:broadMatch predicates are correct.

3. Discussion

The algorithm described in this paper demonstrates satisfying performances, especially for the generation of skos:exactMatch properties, which suggests that automatic methods can be used to improve the quality of terminology mappings. The algorithm was tested on ICD-to-MedDRA mappings extracted from UMLS, but it can in principle be used for other terminologies and mapping sources.

Performances are more limited for other SKOS properties. This result is partly explained by the assumption that LLTs are more granular terms than PTs, which is not always verified. For example, *Cholera, unspecified* (LLT) is one subkind of *Cholera* (PT), but *Typhoid* (LLT) and *Salmonella typhi infection* (LLT) are synonyms of *Typhoid fever* (PT). In the former case, the algorithm (in that case rules 3 and 4 respectively) generates a correct SKOS predicate (namely skos:broadMatch), but not in the latter case: the correct mapping relation between the ICD-10 term *Typhoid fever*

and the MedDRA LLTs *Typhoid* and *Salmonella typhi infection* is skos:exactMatch, because both refer to the same entity as the PT *Typhoid fever* (see Table 2).

An obvious way to improve the performances of our algorithm is consequently to distinguish between LLTs that are more granular terms and LLTs that are synonyms of PTs, to restrain the application of the rules described below to the former category, and to apply the same SKOS predicate when an ICD term is mapped to MedDRA terms that are synonyms. Considering that MedDRA 16.0 contains more than 70,000 LLTs, making such a distinction however requires a huge effort.

In addition, the current organization of MedDRA raises other issues. In some cases the semantic relation between LLTs and PTs is neither synonymy nor subsomption. For instance, *Salmonella enteritis* (LLT) is not a synonym or a specific kind of *Gastroenteritis salmonella* (PT), but refers to a related condition: both are kinds of Salmonella infections. One also finds cases where LLTs correspond not to *narrower* but to *broader* categories than PTs. This is for instance the case of the *Typhoid and paratyphoid fevers* (LLT), which is below *Typhoid fever* (PT) in MedDRA hierarchy, but corresponds to a broader category of disease. In ICD-10 and SNOMED-CT, *Typhoid fever* is under *Typhoid and paratyphoid fevers*.

Those elements suggest that the performances of algorithms such as the one presented here mainly depend on the quality of terminologies being aligned. Building terminologies with more systematic principles and more transparent hierarchical relations facilitates their alignment. Formal knowledge representation languages such as the Web Ontology language (OWL) can help in this task.

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References

[1] K.W. Fung, O. Bodenreider, Utilizing the UMLS for semantic mapping between terminologies, *AMIA Annual Symposium Proceedings* (2005), 266.
[2] K.W. Fung, O. Bodenreider, A.R. Aronson, W.T. Hole, S. Srinivasan, Combining lexical and semantic methods of inter-terminology mapping using the UMLS, *Stud Health Technol Inform* 129(2007), 605-609.
[3] International Classification of Diseases (ICD) Information Sheet, World Health Organization website. http://www.who.int/classifications/icd/factsheet/
[4] ICH guideline E2B (R2), Electronic transmission of individual case safety reports - Message specification (ICH ICSR DTD Version 2.1), Final Version 2.3, Document Revision February 1, 2001.
[5] G. Declerck, S. Hussain, Y. Parès, C. Daniel, M. Yuksel, A.A. Sinaci, G.B.L. Erturkmen, M.C. Jaulent. Semantic-sensitive extraction of EHR data to support ADE reporting, *SWAT4LS Proceedings* (2012).
[6] C.M. Hohl, A. Karpov, L. Reddekopp, J. Stausberg, ICD-10 codes used to identify adverse drug events in administrative data: a systematic review, *JAMIA* (2013), *doi:10.1136/amiajnl-2013-002116*.
[7] H. Sun, J. De Roo, M. Twagirumukiza, G. Mels, K. Depraetere, B. De Vloed, D. Colaert, Validation rules for assessing and improving SKOS mapping quality, *SWAT4LS Proceedings* (2013).
[8] A. Miles, S. Bechhofer, SKOS simple knowledge organization system reference, W3C Recommendation, 18 August 2009. http://www.w3.org/TR/2009/REC-skos-reference-20090818/
[9] ICH guideline E2B (R2), Electronic transmission of individual case safety reports - Message specification (ICH ICSR DTD Version 2.1), Final Version 2.3, Document Revision February 1, 2001.
[10] MedDRA 16.0. Term Selection: Points to Consider. ICH-Endorsed Guide, Release 4.5, April 2013.
[11] Merrill G. The MedDRA Paradox. AMIA Annu Symp Proc. 2008 6:470-4.
[12] MedDRA Introductory Guide Version 16.0. MSSO-DI-6003-16.0.0. March 2013.

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Ontology patterns-based transformation of clinical information

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Abstract. The semantic interoperability of clinical information requires methods able to transform heterogeneous data sources from both technological and structural perspectives, into representations that facilitate the sharing of meaning. The SemanticHealthNet (SHN) project proposes using semantic content patterns for representing clinical information based on a model of meaning, preventing users from a deep knowledge on ontology and description logics formalism. In this work we propose a flexible transformation method that uses semantic content patterns to guide the mapping between the source data and a target domain ontology. As use case we show how one of the semantic content patterns proposed in SHN can be used to transform heterogeneous data about medication administration.

Keywords. Ontology, Ontology patterns, semantic interoperability

Introduction

Semantic interoperability of clinical information has become a major challenge in the medical informatics community [1]. The current state of the art shows that clinical data sources are heterogeneous in two ways: (1) different technologies are used to represent the data (i.e., relational databases, XML, etc.); (2) different types of data structures and terminologies are used within technologically homogenous environments. Both issues have to be addressed, since they are an impediment to reach the semantic interoperability of clinical information.

The EU network SemanticHealthNet (SHN, http://www.semantichealthnet.eu/) aims to improve semantic interoperability and proposes the representation of the meaning of clinical data by ontologies and semantic content patterns. Such patterns aim at assisting in information modelling, preventing users from fully understanding the underlying, complex, ontological expressions. Additionally, SHN proposes their formal representation based on description logics to detect semantic equivalences across

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content expressed in a variety of information models and terminologies. Traditionally, popular formats like XML or relational databases have limitations to fully represent the meaning of clinical data, which complicates their exploitation in semantic interoperability settings. Given that clinical data is mainly available in the traditional formats (i.e., XML, relational databases), approaches and tools that allow their semantic representation are needed.

Most of existing approaches and tools [2-4] perform a generic transformation of the data, without taking into account their underlying model of meaning. Transformation methods are usually based on defining the mappings between the corresponding schemas. In relational databases one might propose to transform tables into ontology classes, records into individuals, and columns into properties. Such a transformation is not more than a change of format, because the real meaning of the entities represented is completely ignored in such a process, which is therefore not enough to achieve semantic interoperability.

In previous work, we have proposed an ontology-driven method for transforming relational and archetype-based data into semantic representations [5]. Our experience in [6] revealed that the definition and execution of the mappings required a significant repetitive effort, that simple mappings between source and target entities (i.e., database table to ontology class) were not enough, and that the reuse of those mappings was not easy. In this paper, we describe a more powerful approach for the definition and execution of the mappings, based on the SHN proposal, which uses semantic content patterns as proxy for representing clinical information based on a formal model of meaning. Our use case will be one pattern created within SHN to transform heterogeneous data about medication administration [7].

1. Methods

Our methodological approach is illustrated in Figure 1. The definition of the mapping rules is the central part of the approach. The rules permit to associate entities of the source data schema with ontology classes and properties, and they define how the source data are transformed into OWL ontology individuals. OWL individuals have a set of axioms about class membership, property values and individual identity associated, and such axioms are generated in the transformation process.

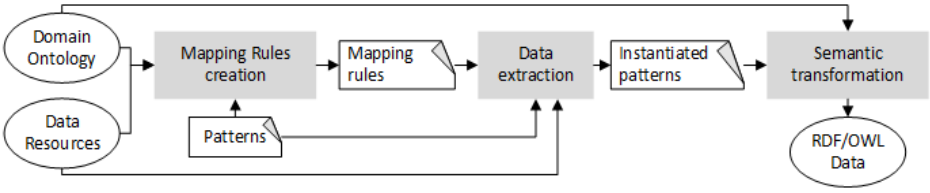


Figure 1. Overview of the methodological approach

Besides, we propose defining more complex mapping rules by combining some basic ones, which we call semantic patterns. Such patterns define the template for the creation of OWL individuals with specific types of axioms. A pattern is created from an ontological representation of a domain, which includes formal descriptions of types of entities and their relations. We use them to obtain an abstraction of the whole domain, including, on the one hand (types of) entities of the domain proper, such as drugs, disorders, procedures etc., as well as information entities (informational artefacts

like record entries) on the other hand. Table 1 shows an excerpt of the *Medication Administration Pattern* defined within SHN, represented as Subject-Predicate-Object (SPO) triples. It gives the complete definition of a medication administration according to the ontological framework defined in SHN. It allows drug prescription either by product or by active ingredient.

Table 1. Excerpt of the representation of the SHN *Medication Administration Pattern*.

Subject	Predicate	Object
btl:Plan	isRealizedBy	sct:MedicationAdministration
sct:MedicationAdministration	hasFocusOn	sct:PharmaceuticalProduct
sct:PharmaceuticalProduct	hasComponent	sct:Substance
sct:MedicationAdministration	hasStartTime	btl:PointInTime
sct:MedicationAdministration	hasEndTime	btl:PointInTime
sct:MedicationAdministration	hasDuration	btl:Duration

We represent the patterns using the Ontology Pre-Processing Language version 2 (OPPL2), which is capable of modifying OWL ontologies and allows the definition of reusable, executable patterns [8]. An excerpt of the OPPL2 pattern for the SHN Medication Administration one is shown in Figure 2. It has two input variables, namely, ?medRecord and ?product, which are, respectively, a medical record and a subclass of PharmaceuticalProduct. This pattern associates the product with the medical record through the ontological axiom shown in the ADD clause. The result of this pattern is that ?medRecord is a *Plan* 'realized by' a *Medication Administration* 'to a patient' of a product parametrized by the variable ?product. The prefixes btl, sct and shn refer to BioTopLite, SNOMED CT and SHN ontologies respectively. Finally, the mapping rules defined between the pattern and the data source contain the access routes to the data source elements that will be used to create the ontology instances. Once the data is extracted, we instantiate the templates represented by the patterns with it. These instantiated templates are the new individuals to be created. This will be explained later.

```
?medRecord:INDIVIDUAL, ?product:CLASS[subClassOf sct:PharmaceuticalProduct]
  BEGIN
    ADD ?medRecord Type btl:Plan
          and btl:hasRealization only (sct:MedAdmin and btl:hasPatient some ?product);
  END
```

Figure 2. Example of OPPL2 pattern

2. Results

Next, we illustrate how we use semantic patterns to guide the mapping definition assuming medication administration data captured using two heterogeneous but similar models, the SHN and epSOS (http://www.epsos.eu/) archetypes, whose structures are described in Figure 3. Both models are represented according to OpenEHR, but they have a different structure. For example, in epSOS the focus of the medication order is the drug product, which can be optionally refined by one or more active ingredients. In the SHN model the focus is on active ingredients. As data exemplar we will represent "Aspirin + caffeine" product administration starting on October 10th, 2013. Figure 4 (1) shows an excerpt of the OpenEHR data extract. In order to transform the data rendered according to both SHN and OpenEHR into their semantic representation (i.e. target ontology), we have represented the medication administration pattern in OPPL (Figure 4 (2)). The pattern has fixed and variable parts. The variables depend on the

source data and the OPPL pattern represents them like ?product or ?substance and will be bound to the clinical data source. The scope of these variables is restricted to entities of the target ontology.

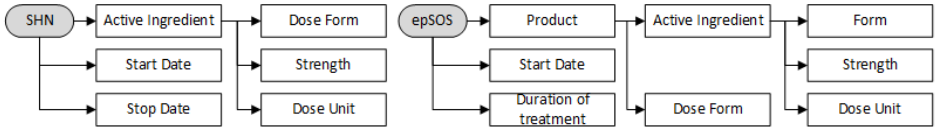


Figure 3. Structure of medication administration models created in SHN and epSOS projects

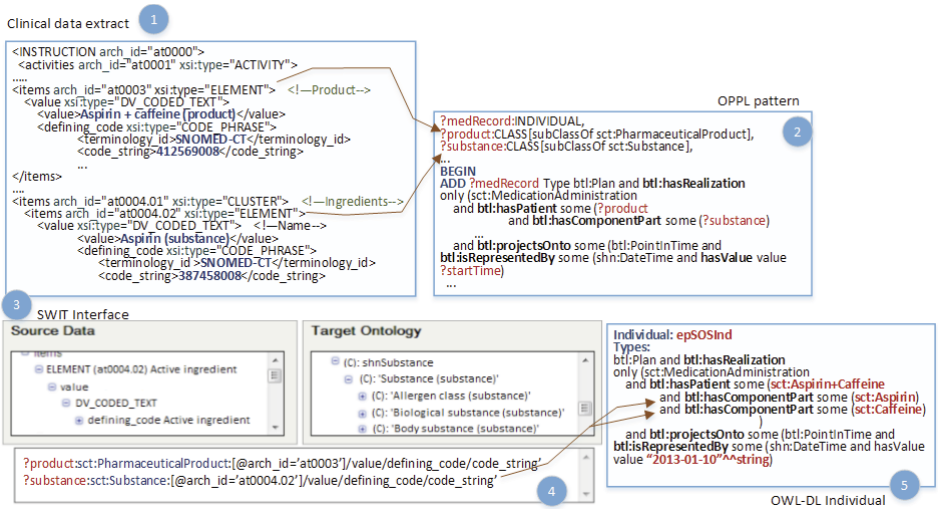


Figure 4. Overview of the mapping process

Figure 4 depicts the process for transforming the data for the epSOS model into the SHN semantic representation. For each relevant entity of the source data schema (3), we define its mapping onto the variables of the pattern. For instance, the variable ?product is mapped onto the ELEMENT at0003, which contains the label and code for 'Aspirin + Caffeine (product)'. The representation of such mapping can be found in (4) and for the case of archetypes the variable has an XPath expression associated. The OWL individual obtained is shown in (5). For the SHN model, the mapping is partially different, since the SHN model does not represent product, only substances. When a variable cannot be mapped, as is the case of ?product, such variable is bound to sct:PharmaceuticalProduct.

We have developed the SWIT tool (http://sele.inf.um.es/swit), which implements this methodology for the mapping and transformation of clinical data, and provides users with a step by step process to perform the final transformation and allows reusing the mappings defined. Figure 4, see (3) and (4), provides a partial view of the interface for defining the mappings.

3. Discussion and Conclusions

We have presented a method, which allows the semantic transformation of data rendered according to representations with implicit semantics, and it is based on mappings between the source data and a target ontology representing the domain knowledge. Here, we have enhanced our approach with semantic patterns that provide a friendlier view on the ontology by avoiding the handling of complicated representational formalisms at the target side, thus guiding and facilitating the mapping process. We have used the semantic content patterns developed within SHN to facilitate the representation of clinical data based on formal principles and improve semantic interoperability across heterogeneous data representations. Given that the transformation process is able to create content in OWL format, that is, OWL axioms, a constructive language like OPPL2 is appropriate for this task, because: (1) it has enough expressivity; (2) its API reduces the implementation and execution effort (the patterns can be reused in the tool); (3) it permits exploiting inferencing and automated reasoning in the transformation process; (4) the patterns are directly connected to the underlying ontology.

Although as a proof of concept, in this work the use of the medication administration pattern as guide simplifies the mapping process. The effectiveness of such patterns to guide the mapping, will depend on how close-to-user their representations are. However, their building and maintenance should be ideally supported by a community of experts. Further work would be required to ensure the quality of manually defined mappings. In the case of archetype-based data sources, the availability of quality terminology bindings could facilitate the definition of the mappings and developing quality assurance methods.

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References

[1] Stroetmann VN, et al. Semantic Interoperability for better health and safer healthcare. Deployment and Research Roadmap for Europe. 2009. http://www.empirica.com/publikationen/documents/2009/semantic-health-report.pdf (accessed Feb. 2013)
[2] D2RQ. Accessing Relational Databases as Virtual RDF Graphs. http://d2rq.org/ (accessed Feb. 2013)
[3] Triplify. http://triplify.org/ (accessed Feb. 2013)
[4] Mapping Relational Data to RDF in Virtuoso. http://virtuoso.openlinksw.com/dataspace/doc/dav/wiki/Main/VOSSQLRDF (accessed Feb. 2013)
[5] Miñarro-Giménez JA, Fernández-Breis JT. Ontology-Driven Method for Integrating Biomedical Repositories. *Advances in Artificial Intelligence*. Springer Berlin Heidelberg; 2011. 473–82
[6] Fernández-Breis JT, et al. Leveraging electronic healthcare record standards and semantic web technologies for the identification of patient cohorts. *J Am Med Inform Assoc*. 20(2013), 288–296.
[7] SemanticHealthNet deliverable 4.2: Ontology/Information models covering the HF use case. 2013.
[8] Egaña M, et al. Applying Ontology Design Patterns in Bio-ontologies. *Proceedings of the 16th International Conference on Knowledge Engineering: Practice and Patterns*. Berlin, Heidelberg: Springer-Verlag; 2008. 7–16.

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Describing Localized Diseases in Medical Ontology: An FMA-based Algorithm

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Abstract. ONTOLURGENCES is a termino-ontological resource developed to index and retrieve information in electronic Emergency Medical Record. In this project, we improved the ontology coverage to accommodate both anatomical and pathophysiological concepts in emergency medicine. This work lead to the automatic addition of 3,470 concepts and their underlying semantic formalization. In our method, we reuse and select the anatomical concepts relevant to emergency from FMA: To capture the anatomical specific concepts, (i) we involved Emergency practitioners and identified the key concepts from this domain; (ii) we applied an automatic algorithm to define the semantic relationships and integrated the result in the existing ontology.

Keywords. Ontology, Anatomy modeling, Physiopathology Modeling, FMA,

Introduction

In the LERUDI project, we have developed a terminological and Ontological Resource (TOR) relevant to emergency health care: ONTOLURGENCES. This model provides (i) all concepts applicable to this specific domain, (ii) the concept relationships, and (iii) the corresponding concept name in the Electronic Health Record (EHR). ONTOLURGENCES allows the annotation and indexing of the EHR document, and also the information retrieval (IR) in indexed files [1].

In this article, we aim at accommodating both pathophysiological and anatomical points of view in the TOR. These two points of view play a key role in the characterization of medical pathologies: by definition, a disease is a biological process anatomically localized by its cause or its observable events. The work of building a medical ontology must integrate and explicitly model them. However, significant challenges had to be tackled in order to achieve successfully the modeling. Practically, if the key concepts of anatomy (the human body and its division into finer elements)

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and pathophysiology are accessible, their accurate modeling becomes quickly complex and error prone. In addition, ensuring logical as well as semantic consistency when modeling both points of view added to this complexity.

To overcome these difficulties, we chose to reuse a reference resource, the Foundational Model of Anatomy (FMA) to model systematically the anatomical concepts in ONTOLURGENCES. Then, we followed the following method: (i) we analyze as accurately as possible the pathophysiological approach/point of view in emergency medicine and develop accordingly the pathophysiological axis of the ontology, (ii) we construct the localized diseases axis reusing the FMA diseases.

In Section 1, we describe both resources involved in our project, ONTOLURGENCES and FMA; in Section 2, we develop the proposed methodology; in Section 3, we provide the first results of this project and discuss them briefly; and finally, in Section 4, we conclude and propose some perspectives.

1. Used Resources

The used resources are the ontology of emergency, ONTOLURGENCES, and the OWL version of the FMA.

OntolUrgences v3.03 was completed in July 20132, and is the test version of our/this work. It includes: 10,191 classes, 60 Object Properties, 1 Data property, and 11,591 logical axioms including 11,339 subclass axioms, and 89 equivalent class axioms. OntolUrgences is built with core-ontology OntoMénélas 4[3] [2].

FMA (Foundational Model of Anatomy) is a "reference ontology about human anatomy" [3][4]. Its goal is to modelize canonical human anatomy, i.e. " the ideal or canonical anatomy to which each individual and its parts should conform" [4]. It contains more than 85,000 classes, 140 relationships connecting the classes, and more than 120,000 terms. We used the FMA v3.2.1 in OWL Full, and available on downloading site[4]. Its metrics are the following : 84,454 classes, 237,382 individuals, 132 Object Properties, 167 Data property, and 1,719,576 axioms including 87,803 subclass axioms. The large number of axioms and instances are related to the OWL full nature of this version of the FMA where each class is both son and individual of the superclass.

2. Method

Our Method is as follows: firstly, we organize all the concepts of diseases covered by the ontology in a subsumption tree representing the pathophysiological perspective as understood by emergency physicians – e.g. CardiacAneurysm is-a aneurysm. Then, the algorithm of the building branch of localized diseases occurs in two steps:

1. Building of the branch of localized diseases with defined concepts;
2. Building of the branch of anatomy necessary for the expression of axioms – e.g. the heart itself.

[2] http://purl.oclc.org/NET/spim/ontologies/public/OntolUrgences/
[3] http://purl.oclc.org/NET/spim/ontologies/public/OntoMenelas/
[4] http://sig.biostr.washington.edu/projects/fma/release/v3.2.1/alt_formats.html

In the following paragraphs of this section, we provide details on some notations and application conditions of our algorithm, and we develop the 2 steps.

2.1. Notation and vocabulary

- *O* is the work ontology, and O_{fma}, the OWL modelization of the FMA;
- We note the namespace of the ontology *O* `onto:` and that of the FMA `fma:`. So, `onto:Cancer` and `fma:Heart` are respectively valid URIs in the ontology *O* and in the ontology O_{fma};
- In the rest of the paper, the terms 'class' and 'concept' are interchangeable;
- We also use the set notation for axioms (statements in functional writing OWL2 [5]) when we describe ontology objects. For example : $Declaration(Class(fma:Heart)) \in O_{fma}$

2.2. Initial hypotheses about the ontology

The main motivation is the automatic enrichment of our medical ontology based on the FMA anatomical location. Thus, the initial step is the annotation of each concept of the ontology by an FMA identifier: medical experts have added annotation `onto:pourFMA` to each disease of ontology *O* to locate.

2.2.1. Creation of diseases hierarchy

The general idea is to build a concept "DiseaseOf" for each location copied from the FMA. For example, if we copy `fma:Heart`, we will create a concept `onto:DiseaseOfHeart`. However, the anatomical hierarchy FMA does not translate directly into a hierarchy of diseases. You must use the whole-part hierarchy to be medically relevant. For example, if a patient experiences chest pain, he has a disease of an organ of the thorax (heart / lung). Following the anatomical subsumption, we could infer that lung disease is a disease of an organ. If, in absolute terms, the subsumption is not false, it has no medical relevance, therefore no interest. Conversely, with a whole-part relationship, we infer that the lung disease is a disease of lower respiratory tract or a chest disease and will be medically relevant. For this, we use whole-part relationships of the FMA. They are 4 [5]: (i) `fma:part_of`, (ii) `fma:regional_part_of`, (iii) `fma:systemic_part_of`, (iv) `fma:constitutional_part_of`. In the following, we use the generic name "part_of". The algorithm is as the following:

- Given a concept X, if there is a relationship "part_of" from this starting concept to a concept Y, then we create the concept DiseaseOfY as father of the concept DiseaseOfX. For example, if we have the axiom *ObjectP ropertyAssertion(fma:part_of fma:Lung fma:Thorax)*, then we create axiom *SubClassOf(onto:DiseaseOfLung onto:DiseaseOfThorax)*;
- To ensure the final connectivity of the graph, if the concept has no relation "part_of" then we follow the classical subsumption relationship.

This new hierarchy is connected under the concept `onto:Disease`.

In addition, it is possible to transform these concepts in defined concepts such as restrictions are relations to the FMA. For example, `onto:DiseaseOfLung` is semantically

[5] http ://www.w3.org/TR/owl2-syntax/

defined as "a localized disease on one and only one instance of the lung." For this, we use the relationship onto:localizedOn defined between disease and location. Given a concept fma:Lung and a concept fma:Thorax such as *fma:Lung part_of fma:Thorax* then the concept onto:DiseaseOfLung is a concept defined by the following axiom:

EquivalentClass(onto:DiseaseOfLung
ObjectIntersectionOf(onto:DiseaseOfThorax
ObjectSomeValuesFrom(onto:localizedOn fma:Lung)
ObjectAllValuesFrom(onto:localizedOn fma:Lung)))

2.2.2. Copying the FMA

For each concept with an annotation onto:pourFMA, we copy in *O* the set of annotations axioms of the classes of FMA and all its relative superclasses to fma:Physical_anatomical_entity. Once this concept is reached, the hierarchy must be stored in the original ontology. In our case, it's stored under onto:StructureAnatomique, but the exact concept is of course dependent on the ontology in which the FMA is merged. Note that we retain the original FMA URI to keep all the benefits of Linked Data URI.

3. Results

The builded ontology has 12,396 Classes, 60 Object Properties, 1 Data property and 17072 axioms, among them, 13332 subclass axioms and 3559 equivalent classes axioms. These numbers are interesting to compare with those of ontology in its previous version, particularly in the axioms of equivalent classes, 89 versus 3559 that reflect the creation of new defined concepts (see Figure 1).

One of the advantages of our algorithm is that it is incremental: it is possible to apply the algorithm on an result ontology itself. In other words, it's not necessary to keep a "non-algorithm" version in order to apply it several times. Each concept is re-covered and the axioms and restrictions are created if necessary. Moreover, the trees derived from the FMA are reduced to keep only the concepts used.

4. Discussion and conclusion

Evaluation of this work was done in-house and was first used to develop the presented algorithm. The model complexity of the FMA and understanding of what it could give has led many cycles of development. The first result is that we actually have at our disposal an algorithm that avoids us a long, tedious and error-prone task.

The next step is to work on improvements of the algorithm in order to propose an organization of the localized disease hierarchy "more medical": this goes by putting forward in the algorithm the systemic part_of which is close to the specialty description of medicine. We work on this topic in order to minimize manual final intervention on the ontology. The final goal is, if possible, to eliminate any manual intervention on the localized disease hierarchy.

The long term step of the evaluation could be to take the new version of OntolUrgences in LERUDI project and make a comparison of indexing some patients computerized records with the old version versus the new. But this would require that

the French terms are all associated with ontology concepts, especially those of the FMA. This is currently not the case. We are considering for this to use translations made by CISMeF on EHTOP[6] portal and to propose them to the FMA consortium to enrich her ontology with French terms.

A long term perspective is the application of this algorithm on an ontology of another medical field.

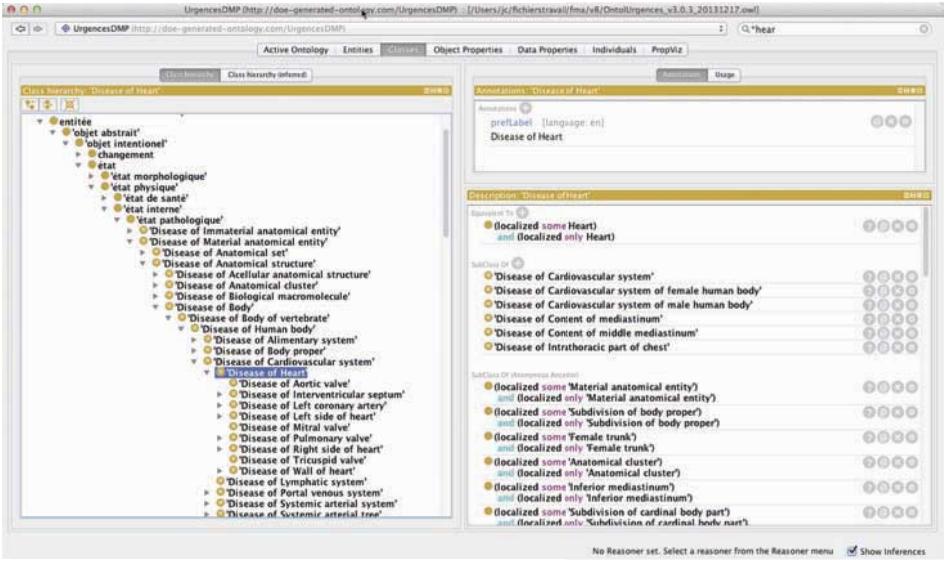


Figure 1. Screenshot of ontology in Protégé view at the "Disease of Heart" concept. Seen above the tree diseases back to the concepts of the core ontology OntoMénélas. At the window descriptions, we see the description of the concept and defined much of locations inherited from super classes. Given the number of possible inferences in the ontology, location reasoning is precalculated.

References

[1] Charlet J., Declerck G., Dhombres F., Gayet P., Miroux P. & Vandenbussche P.-Y. Building a Medical Ontology to support Information Retrieval: Terminological and metamodelization issues. In: Proc. of the10th International Conference on Terminology and Artificial Intelligence, Paris, France, 2013, p171-8.

[2] Bouaud J., Bachimont B., Charlet J. & Zweigenbaum P. (1995). Methodological principles for structuring an “ontology”. In Proceedings of the IJCAI’95 Workshop on “Basic Ontological Issues in Knowledge Sharing”, Montréal, Canada.

[3] Rosse C. & Mejino J. L. V. Jr. (2003). A reference ontology for biomedical informatics : the Foundational Model of Anatomy. Journal of biomedical informatics, 36(6), 478–500.

[4] Rosse C. & Mejino J. L. V. Jr. (2008). The Foundational Model of Anatomy Ontology. In A. Burger, D. Davidson & R. Baldock, Eds., Anatomy Ontologies for Bioinformatics : Principles and Practice, chapter 4, p. 59–118. New York : Springer.

[5] Mejino J. V., Agoncillo A. V., Rickard K. L. & Rosse C. (2003). Representing complexity in part-whole relationships within the Foundational Model of Anatomy. AMIA ... Annual Symposium proceedings / AMIA Symposium. AMIA Symposium, p. 450–4.

[6] http://www.ehtop.eu/

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Implementing reusable software components for SNOMED CT diagram and expression concept representations

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Abstract. SNOMED CT is a vital component in the future of semantic interoperability in healthcare as it provides the meaning to EHRs via its semantically rich, controlled terminology. Communicating the concepts of this terminology to both humans and machines is crucial therefore formal guidelines for diagram and expression representations have been developed by the curators of SNOMED CT. This paper presents a novel, model-based approach to implementing these guidelines that allows simultaneous editing of a concept via both diagram and expression editors. The implemented extensible software component can be embedded both both desktop and web applications.

Keywords. SNOMED CT, diagram representation, Compositional Grammar, software modelling, reusable implementation, Snow Owl

Introduction

SNOMED Clinical Terms (SNOMED CT) [1] is considered the most comprehensive, multilingual clinical healthcare terminology in the world. It is maintained by the International Health Terminology Standards Development Organization (IHTSDO) [1] with the primary purpose to ensure interoperability and to provide the semantics to an interoperable electronic health record. SNOMED CT can be characterized as a multilingual thesaurus with an ontological foundation structured as a multi-axial subtype hierarchy. The ontology is composed of rational statements in the form of $Concept_1$ - *Relation* - $Concept_2$ where multiple relation types can connect the concepts. Concept relationships can express hierarchical or other types of relationships enabling not only the hierarchical grouping of the related concepts but also logical reasoning via programmatic classification.

As communicating the concepts of SNOMED CT is a very important aspect of the development of the terminology, IHTSDO has developed specifications for representing concepts both as diagrams [2] as well as textual expressions [3] defined by a formal compositional grammar. Both representations are meant to formalize communication while eliminating ambiguity; the diagrammatic representation is targeted for humans whereas the expression is designed primarily to be machine-

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readable. In addition to conformance to the specifications, the authors aimed to satisfy the following requirements:

- Concepts simultaneously editable via the expression and diagram editors while keeping both representations in sync
- Editing possible both locally and remotely over the internet
- Support for concurrent modification in case of a distributed deployment
- Embeddable into both desktop and web applications
- Extensible to accommodate future extensions of the specifications or additional user requirements

1. Methods

Each SNOMED CT concept encapsulates a unique clinical meaning, which is identified by a unique and immutable numeric identifier. Concept identifiers do not carry implicit meaning; the meaning of the concept is defined by its relationships to other concepts within the terminology. Each concept can have multiple human-readable descriptions including the unique and mandatory *Fully Specified Name*. For example:

CONCEPT
Concept ID – 22298006
Fully Specified Name - Myocardial infarction (disorder)
DESCRIPTIONS
Preferred Term - Myocardial infarction
Synonyms - Myocardial infarct, MI - Myocardial infarction, Infarction of heart, Cardiac infarction, Heart attack
RELATIONSHIPS
Myocardial infarction **IS A**
Myocardial disease (disorder)
Necrosis of anatomical site (disorder)
Ischemic heart disease (disorder)
The defining **ATTRIBUTES** are
Associated morphology - Infarct (morphologic abnormality)
Finding site - Myocardium structure (body structure)

1.1. SNOMED CT Compositional Grammar and Diagramming

SNOMED CT concepts can be described as a SNOMED CT Compositional Grammar expression. The syntax of SNOMED CT Compositional Grammar [3] is specified in Augmented Backus-Naur Form (ABNF). A concept definition minimally consists of the concept identifier, optionally followed by a human-readable description of the concept. Multiple parentage is expressed by concatenating the parents using the plus sign and refinements to the concepts can be appended after a colon following the concept:

57809008|Myocardial disease| + 414545008|Ischemic heart disease| +
609410002|Necrosis of anatomical site|:
116676008|Associated morphology| = 55641003|Infarct|,
363698007|Finding site| = 74281007|Myocardium structure|

The diagramming guidelines define the graphical notation for representing a concept definition where the concept being defined is shown at the top left connected to a series of expressions via operators. It is allowed to omit the defined concept. Hollow arrows represent parentage by pointing to the parent concept, whereas other types of relationships are represented by a rounded rectangle between two regular arrows pointing from source to target.

1.2. Solution Approach

The authors have selected the Eclipse Modeling Project as the technological foundation for implementing the Model-View-Controller (MVC) [4] pattern required by the editors. At the core of the Eclipse Modeling Project lies the Eclipse Modeling Framework (EMF) [5], a modeling framework and code generation facility built around its Ecore meta-model. Ecore is an implementation of the Object Management Group (OMG) Essential Meta-Object Facility (EMOF) standard [6]. Ecore models are extensible by definition and can either be built from scratch or generated from existing XML schemas, UML models, Xtext domain specific languages (DSLs) or annotated Java interfaces. Models described by Ecore have built-in support for reflective editing, change notification, validation and serialization. The authors have defined a common model as an Xtext DSL [7] by adopting the SNOMED CT Compositional Grammar syntax. Xtext then generates an EMF model for the DSL, which serves as the common target for both the diagram and expression editors.

User modification of the diagram or textual expressions generates events that are caught by listeners. These listeners notify the editor to perform the necessary modifications on the model. Grammar changes are converted using an Xtext DSL *Parser* that is also responsible for validating the input. As long as the expression is invalid, the graphical editing is disabled. Notifications about model changes have been developed via EMF Adapters [5] that implement the Observer design pattern [4]. For creating the textual representation of the model, an Xtext *Serializer* is configured which is capable of converting the given model and formatting the output based on the grammar rules. Figure 1 shows the implemented architecture and the communication between the main components of the library.

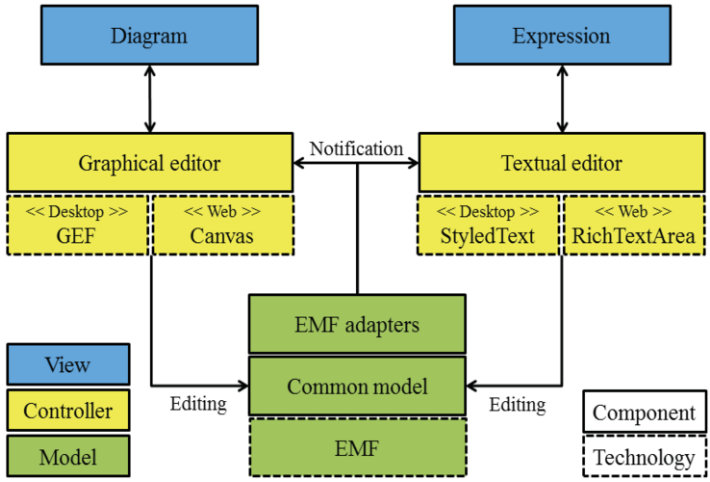


Figure 1. Editing and notification.

1.3. Desktop and Web Clients

For desktop editing the authors have selected the Eclipse Graphical Editing Framework (GEF) [7] as it tightly integrates with EMF. The actual diagram elements have been developed as custom figures. For the expression entry the *StyledText* component was used. For the web editing the Vaadin framework [8] was selected. The framework is suitable for creating efficient and desktop-like applications and it supports the creation of customized Google Web Toolkit (GWT) [9] components. The textual editor is a customized *RichTextArea* widget, while the graphical editor implements the *Canvas* component. The client side (web browser) is responsible for the representation of the data and user event creation, while the server side handles the events from the client, updates the model based on the events, inform the editors if the model was changed and performs the model conversion and validation.

2. Results

The implemented editors do not make assumptions whether the model has been accessed locally or remotely which makes it suitable for a standalone environment as well as for client-server architectures. Via the notification mechanism, both editors are kept in sync. Validation of the user modifications is carried out automatically and the errors are shown both in the expression and in a pop-up window. The invalid part of expression is highlighted and underlined with a red squiggle and error messages are shown in the lower right corner in a pop-up window.

A demo web application is shown in Figure 2. In addition to the web application, the created desktop component was also embedded into Snow Owl [10] (Figure 3), a commercial medical ontology authoring solution. The selected concept in the left side concept navigator is visualized. The expressions or the diagrams can be exported or printed directly from both the web and desktop components.

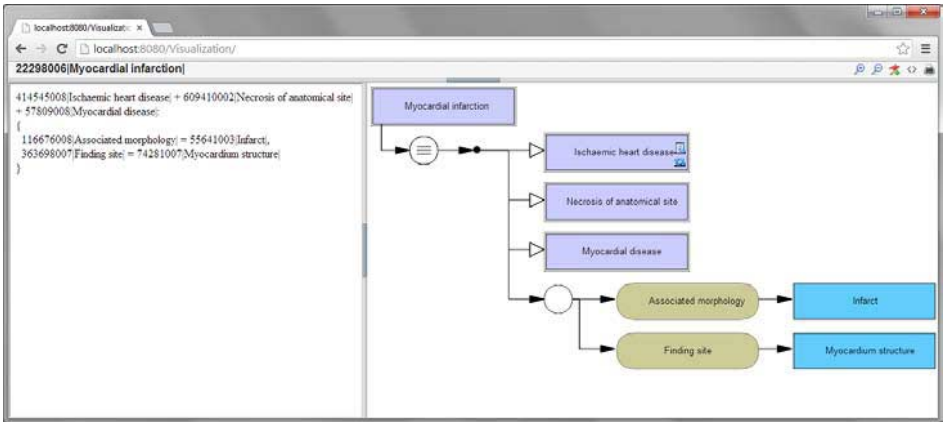


Figure 2. Component in a web application.

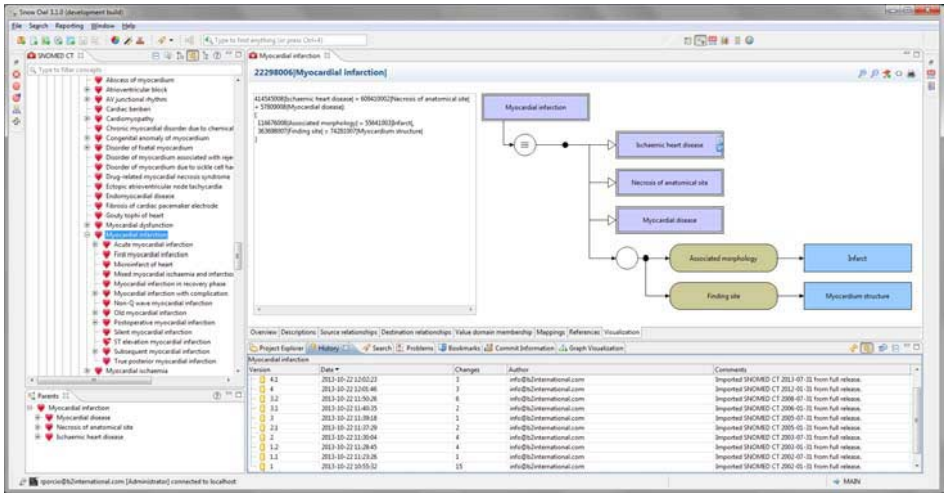


Figure 3. Desktop component embedded in a commercial application.

3. Discussion

Java components have been implemented to simultaneously view and edit SNOMED CT concepts both as a diagram and as an expression. The solution conforms to the relevant IHTSDO specifications. The heavily utilized Eclipse modeling software libraries proved to be an excellent choice to fulfill the requirements as the implemented common EMF model supports concurrent editing, change notification, validation and serialization. The Java library developed can be embedded both into desktop as well as into web applications. The introduced approach and the developed model can also be extended to accommodate future requirements of the evolving standards. The authors are not aware of any implementation at present that conforms to the formal specifications published by IHTSDO while fulfilling the non-functional requirements stated in this document.

References

[1] International Health Terminology Standards Development Organization [Internet]. Welcome to IHTSDO. IHTSDO; [updated 2014 Jan 20; cited 2014 Jan 21]. Available from: http://www.ihtsdo.org

[2] International Health Terminology Standards Development Organization [Internet]. SNOMED CT Diagramming Guideline. IHTSDO; [cited 2014 Jan 21]. Available from: http://www.ihtsdo.org

[3] International Health Terminology Standards Development Organization [Internet]. SNOMED CT Technical Implementation Guide. IHTSDO; [cited 2014 Jan 21]. Available from: http://www.ihtsdo.org

[4] Gamma E, Helm R, Johnson R, Vlissides J. Design Patterns: Elements of Reusable Object-Oriented Software. Boston: Pearson Education; 1994.

[5] Steinberg D, Budinsky F, Paternostro M, Merks E. EMF - Eclipse Modeling Framework. 2nd ed. New Jersey: Pearson Education; 2008.

[6] Object Management Group [Internet]. OMG's MetaObject Facility. OMG; [updated 2014 Jan 09; cited 2014 Jan 20]. Available from: http://www.omg.org/mof/

[7] Gronback RC. Eclipse Modeling Project – A Domain-Specific Language (DSL) Toolkit. New Jersey: Pearson Education; 2009.

[8] Holan J, Kvasnovsky O. Vaadin 7 Cookbook. Birmingham: Packt Publishing Ltd; 2013.

[9] Google [Internet]. Google Web Toolkit Project. Google; [updated 2014 Jan 14; cited 2014 Jan 20]. Available from: http://www.gwtproject.org

[10] B2i Healthcare Ltd [Internet]. Snow Owl Terminology Authoring Tool. B2i Healthcare Ltd; [updated 2013 Sep 17; cited 2014 Jan 21]. Available from: http://www.b2international.com/portal/snow-owl

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Effective Ways for the Transmission of Infection Prevention Data According to German Legal Specifications via the Medical Terminology SNOMED CT used with HL7 CDA Templates

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Abstract: According to German legal specifications each national federal state is obliged to transmit infection prevention data to the relevant health authority. In case of reasonable suspicion, affection or death by infectious diseases specific information is differently communicated by laboratories and physicians. Proprietary ways of transmission inherit threats like deficient or incomplete availability of data. At least these circumstances imply non-predictable health-related hazards for the population. The international established medical terminology SNOMED CT can contribute semantic interoperability and a highly specific description of diagnoses and procedures. The applicability of SNOMED CT shall be tested in the domain of diagnostic findings respective notifiable infectious agents. In addition, specific hierarchical links from the agents to the associated infectious diseases inside the terminology are expected and verified. As the carrier of the information, HL7's Clinical Document Architecture (CDA) is used by designing appropriate CDA templates to define the contents of the notifiable disease documentation. The results demonstrate that the entirety of the notifiable infectious agents is displayed in the terminology SNOMED CT by relating codes at 100 percent. Furthermore, each single term is hierarchically connected to the relating infectious diseases. The use of SNOMED CT for the purpose of infection prevention in Germany is tied to licensing and license costs. Irrespective of these facts, the use of SNOMED CT shows obvious advantages in this field and an implementation of the terminology can be recommended.

Keywords: Infection prevention, SNOMED CT, HL7 CDA

Introduction

The quality of national medical treatment is highly dependable on the availability of relevant health data in sufficient time. Therapy decisions are based on required clinical information. In Germany, the transmission of health data is provided by different types of media. The common use of standardized information technology is not state of the

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art in whole parts of the country [1]. The leading actors in the German Health Care System (GHCS) have determined the use of insufficient standards that are often incompatible among themselves. Proprietary systems with inadequate networking abilities are often found in particular software utilization [2]. Due to diverging political interests of the stakeholders, essential changes or decisions take a lot of time in the GHCS. Because of this, the spreading of new technologies or standards is insufficient. Currently, there are a few German research publications available that try to remove the drawback and to improve the general conditions [3].

One part of the health care system that is extremely bound to the secure availability of special medical information is the prevention of infections. In Germany, all necessary regulations and obligations concerning this field are determined in the law on the prevention of infections (IfSG). The IfSG´ s 6th and 7th article summarize the modalities in the management of notifiable infectious agent data and infectious diseases data [4][5].

The IfSG doesn´t specify that a single and unique communication form that has to be used throughout the whole country. In case of reasonable suspicion, infection or death by an infectious disease specific data is transferred via the local health authority, the federal state health authority and at least the Robert-Koch-Institute (RKI) in Berlin [6]. The latter is the national health authority with main competence in the prevention and the handling of infectious diseases.

Concerning the electronic interchange of relevant data semantic interoperability between the interfaces is needed to assure the proper ascertainment and transmission [7]. The international established medical terminology SNOMED CT offers a highly specific description of diagnoses and procedures. Clinical information can be comprehensively displayed and exchanged via SNOMED CT. The greater benefit lies in providing a free from breakage electronic exchange of medical information between the involved organizations in the healthcare system [8].

In this approach, the applicability of SNOMED CT shall be tested in the domain of diagnostic findings respective notifiable infectious agents determined in the German IfSG. In addition, it is expected that specific hierarchical links from the agents to the associated infectious diseases can be verified inside the terminology. If SNOMED CT fulfills the requirements it provides a serious room for improvement in the management of infectious data in Germany.

1. Methods

A German version of SNOMED CT that is validated by the IHTSDO is not available at present. Within this research, all notifiable infectious agents specified in the IfSG are translated into English language and entered into the "CliniClue®" SNOMED CT browser [9]. In the browser, we use the SNOMED International edition (2013-01-31).

After discovering each determined infectious agent in the browser we regard the possible connections to the relating infectious diseases. The method is reproduced via using terms like "infection" plus the infectious agent in the meaning of post-coordination. As the carrier of the information, HL7's Clinical Document Architecture (CDA) is used by designing appropriate CDA templates to define the contents of the Notifiable Disease Documentation [10]. In this context, CDA sections have to be built that reproduce the paper documents normally used by physicians. For quality assurance purposes the terminology codes have been verified by two healthcare experts.

2. Results

The entirety of the notifiable infectious agents that are mentioned in the German IfSG is represented in the terminology SNOMED CT at 100 percent. Each agent is determined by a special SNOMED CT Concept-ID. A section of the research results are shown in Table 1.

Table 1. Section of IfSG notifiable infectious agents displayed in SNOMED CT Concept-ID´s

Agent	SNOMED CT Concept-ID	Agent	SNOMED CT Concept-ID
Adenovirus	50842006	Legionella species	115514004
Bacillus anthracis	21927003	Legionella pneumophila	80897008
Borrelia recurrentis	34726005	Leptospira interrogans	116401006

In the next step each single infectious agent is hierarchically connected to relating infectious diseases through phrases like “infection”. The connection is demonstrated via the example of the IfSG notified infectious agent “Rotavirus”. The Rotavirus causes one quarter of all gastro-enteretic disease hospital treatments of babies and children under the age of five around the world. In Germany, this infectious agent is a severe cause of morbidity as well [11]. First, the terms “rotavirus” and “infection” are entered into the search field. In the browser the preferred term “rotavirus infection of children” is suggested. The concept itself is directly linked to its definition by a relationship icon key. The rotavirus infection is defined as a “viral gastroenteritis due to Rotavirus”. The presented example shows that it is possible to create logical links between the infectious agent and the infectious disease in the terminology SNOMED CT. The SNOMED CT terminology links are shown in Figure 1.

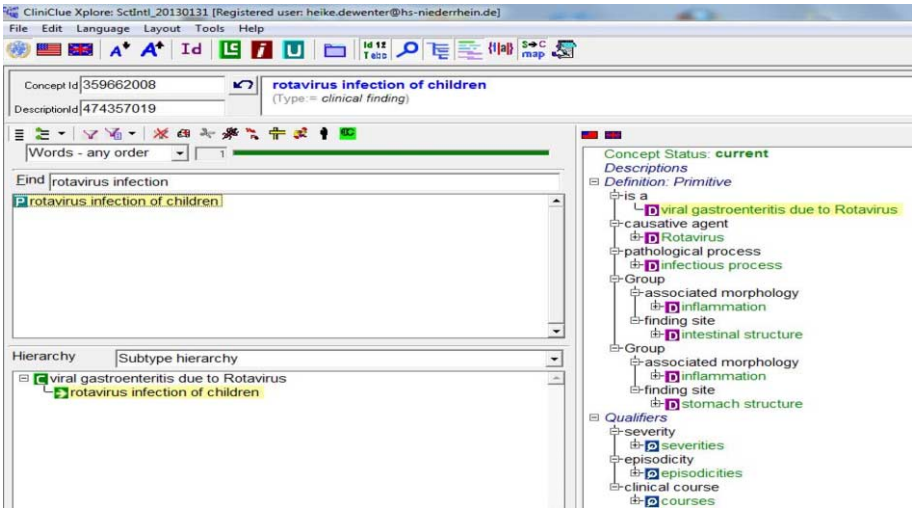


Figure 1. Link between infectious agent and infectious disease in SNOMED CT

In a further step, sections were created that are based on the document used by physicians. These sections are demonstrated in Figure 2.

Name	Typ	Card	Conf	Template Name	Template OID
Diagnose	Section Level	0..1	C	Diagnose Section Notifyable Diseases	1.2.276.0.76.10.3013
__Problemliste	Entry Level	1..1	R	Problem Concern Act Notifyable Diseases	1.2.276.0.76.10.4002
____Diagnose	Entry Level	1..*	R	Diagnosis Observation Notifyable Diseases	1.2.276.0.76.10.4003
____Symptom	Entry Level	0..*	O	Symptoms Observation Notifyable Diseases	1.2.276.0.76.10.4004
Angaben zum Tod	Section Level	0..1	O	Summary Of Death Section	1.2.276.0.76.10.3014
Zusatzangaben	Section Level	0..1	C	Annotation Comment Section	1.2.276.0.76.10.3015
Betreuung	Section Level	0..1	O	Care process or plan Section	1.2.276.0.76.10.3016
Tätigkeit	Section Level	0..1	O	Social History Section	1.2.276.0.76.10.3017
Impfstatus	Section Level	0..1	O	Immunizations Section	1.2.276.0.76.10.3012
Exposition	Section Level	0..1	O	Exposition Section	1.2.276.0.76.10.3018
Spende	Section Level	0..1	O	History Of Donation Section	1.2.276.0.76.10.3019
Ausführendes Laboratorium	Section Level	0..1	O	Performing Laboratory Section	1.2.276.0.76.10.3020

Figure 2. CDA sections

The ICD-10-German Modification provides several attributes indicating that the concept is associated with reports on infectious diseases. Therefore we used this information to build value sets according to the implementation guide. A template was defined used to instantiate these informations via CDA as shown in Figure 3.

```
<observationclassCode="OBS" moodCode="EVN">
  <templateId root="1.2.276.0.76.10.4003"/>
  <id root="08edb7c0-2111-43f2-a784-9a5fdfaa67f0"/>
  <code code="282291009" codeSystem="2.16.840.1.113883.6.96" displayName="Diagnosis"/>
   <text>
      <reference value="#DIAG1"/>
   </text>
   <statusCode code="completed"/>
   <effectiveTime>
      <low value="20130722"/>
   </effectiveTime>
   <value xsi:type="CD" code="B05" codeSystem="1.2.276.0.76.5.413" displayName="Masern"/>
</observation>
```

Figure 3 . CDA template for the section diagnosis. Codes from ICD-10-German Modification (GM) and SNOMED CT are possible

3. Discussion

The results demonstrate that SNOMED CT is suitable for the display of relevant diagnosis data and it is possible to create logical links between agents and infectious diseases. An unimpeded information transfer depends on the correct insertion of SNOMED CT terms in HL7 documents. Relevant instructions have been provided by the TermInfo Project Group in a corresponding implementation guide [12].

Due to the absence of a validated German version of SNOMED CT the results of this investigation are transferrable to a limited extend. A further barrier can be found in the fact that Germany is not a member of the International Health Terminology Standards Development Organization (IHTSDO). The use of SNOMED CT for the purpose of infection prevention in Germany could be tied to license costs. Irrespective of these facts, the use of SNOMED CT shows obvious advantages in this field and an implementation of the terminology can be recommended. Additionally, it is possible to

examine the potential of SNOMED CT concerning laboratory tests in comparison with other recognized medical terminologies, for example LOINC®. Additionally, the results offer a possible linkage between SNOMED CT Codes with ICD-10-GM concepts concerning the infection prevention task.

The German implementation guide "Notifiable Disease Documentation" provides a next step towards semantic interoperability using HL7 CDA V.2 and SNOMED CT. It has been developed in the frame of the research project "Implementing the supra-regional real time operation of an electronic reporting procedure for the transaction of infectious diseases and infectious agent data from the laboratories to the responsible local health authority". The activities focus on local conditions in the federal state North Rhine/Westphalia and they are sponsored by the responsible ministry of health (MGEPA NRW). The research findings will provide more structured data for the RKI in Berlin respective the underlying use cases.

References

[1] E-Health Planungsstudie Interoperabilität [Internet]. Executive Summary. Fraunhofer; [updated 2012 Sep 24; cited 2013 Sep 26]. Available from: http://www.bmg.bund.de/fileadmin/dateien/Pressemitteilungen/2012/2012_03/120924_PM_69_Anlage_E-Health_-_Planungsstudie_Interoperabilitaet.pdf

[2] Pedersen S, Hasselbrink W [Internet]. Interoperabilität für Informationssysteme im Gesundheitswesen auf Basis medizinischer Standards [updated 2004 Jan 9; cited 2013 Sep 27]. Available from: http://drpedersen.de/publikationen/Susanne/IFE2004.pdf

[3] Dewenter H, Thun S: Potentiale der internationalen medizinischen Terminologie SNOMED CT im Kontext der Herausforderungen im deutschen Gesundheitswesen. In: Duesberg F, editor. eHealth 2014. Informations- und Kommunikationstechnologien im Gesundheitswesen. Solingen: medical future; 2014. p. 26-33.

[4] Deutsches Bundesministerium der Justiz [Internet]. Infektionsschutzgesetz (IfSG). Artikel 6. BUND; [updated 2000 Jul 20; cited 2013 Sep 06]. Available from: http://www.gesetze-im-internet.de/ifsg/__6.html.

[5] Deutsches Bundesministerium der Justiz [Internet]. Infektionsschutzgesetz (IfSG). Artikel 7. BUND; [updated 2000 Jul 20; cited 2013 Sep 06]. Available from: http://www.gesetze-im-internet.de/ifsg/__7.html.

[6] Robert-Koch-Institut Deutschland [Internet]. Meldebögen. RKI; [updated 2008 Mar 19; cited 2013 Mar 22]. Available from: http://www.rki.de/DE/Content/Infekt/IfSG/Meldeboegen/Meldungen_node.html.

[7] Thun S. Integrierte Behandlungspfade. In Johner, C., Haas, P., editors. Praxishandbuch IT im Gesundheitswesen. München: Carl Hanser; 2009, p. 179-188

[8] IHTSDO [Internet] SNOMED CT Value Proposition. IHTSDO; [updated 2013 Mar 22; cited 2013 Mar 22]. Available from: http://www.ihtsdo.org/snomed-ct/whysnomedct/snomedfeatures/

[9] CliniClue® [Internet] CliniClue® SNOMED CT Browser. Clinical Information Consultancy Ltd; [updated 2011; cited 2013 Mar 20] Available from: www.cliniclue.com.

[10] HL7 Germany [Internet]. Ballot Document "Notifable Disease Documentation". HL7 Germany; [updated 2013 Dez 03; cited 2013 Dez 10]. Available from: http://wiki.hl7.de/index.php/IG:Übermittlung_meldepflichtiger_Krankheiten.

[11] Robert-Koch-Institut Deutschland [Internet]. Rotaviren. RKI; [updated 2013 Feb 01; cited 2013 Sep 06] Available from: http://www.rki.de/DE/Content/Infekt/NRZ/Konsiliar/Rotaviren/rotaviren_node.html.

[12] [TermInfo [Internet] Using SNOMED CT in HL7 Version 3. Implementation Guide. Release 1.5. HL7 International; [updated 2012 Jul 18; cited 2014 Jan 27]. Available from: http://wiki.hl7.org/index.php?title=Using_SNOMED_CT_in_HL7_Version_3;_Implementation_Guide,_Release_1.5.

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What's in a Class? Lessons Learnt from the ICD – SNOMED CT Harmonisation

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Abstract. The upcoming ICD-11 will be harmonized with SNOMED CT via a common ontological layer (CO). We provide evidence for our hypothesis that this cannot be appropriately done by simple ontology alignment, due to diverging ontological commitment between the two terminology systems. Whereas the common ontology describes clinical situations, ICD-11 linearization codes are best to be interpreted as diagnostic statements. For the binding between ICD codes and classes from the ontological layer, a query-based approach is favoured.

Keywords. ICD, SNOMED CT, Ontology, Terminology, Classification

Background

On a global scale, the International Classification of Diseases (ICD) is being used for morbidity and mortality statistics, as well as for billing in many jurisdictions. The WHO is currently preparing ICD's 11th release [1]. This process is different from past revisions in several aspects, regarding web-based authoring workflows [2], but also its overall architecture, which is more comprehensive and flexible:

ICD's *Foundation Component* (**FC**) is the central hub in which the terminological content needed for the creation of multiple, purpose-specific views or linear serializations called *Linearizations* (**LIN**s) are pooled, together with a rich set of additional data defined by a content model including text definitions, diagnostic criteria and classification rules. FC hierarchies are heterogeneous. They are neither mutually exclusive nor exhaustive. In contrast, LINs manifest the properties of strict mono-hierarchies with exclusions and residual classes (NEC, NOS), demanded for statistical classifications. LINs will support statistics and a smooth transition from ICD 10 to 11.

ICD 11 FC and, indirectly, the linearizations (LINs) will rely on a common model of meaning, the *Common Ontology* (**CO**). According to an agreement by a WHO – IHTSDO expert group, the Joint Advisory Group (JAG) [3] the CO will be built on ontological principles and shared with a subset of SNOMED CT [4].

That terminology systems do not restrict themselves to collections of terms but commit to ontological principles and use logical axioms dates back to the pioneering GALEN project [5]. In the meantime this tendency has been stimulated by the Semantic Web, especially the OWL language [6] and Description Logics [7]. The emergence of *Applied Ontology* as a new discipline [8] bridges between the theoretical

achievements of analytic philosophy and the need to create theoretical foundations for semantic artefacts, both formally rigid and usable in real-world information systems. In this it follows the precedent of endeavours such as the Gene Ontology [9] in particular and the OBO Foundry [10] in general.

1. Ontological principles

What are the implications of this for the harmonization of ICD-11 and SNOMED CT? The following aspects are fundamental for ontology-based artefacts:

Logical framework: Description logics require a clear distinction between individual entities, classes of individuals, and relations. They require distinguishing the *subclass* relation between classes, the *membership* relation between an individual and a class, and *object properties*, which relate individuals.

Ontological commitment: With the view on the target domain, a precise and unambiguous understanding about the kinds of entities to be represented is required [11]. Top-level classes such a *Process* or *Material Entity* should be clearly characterized, as well as domain top-level classes, like *Procedure*, *Finding*, *Disorder* (such as in SNOMED CT). In this vein, the JAG and the SNOMED community have concluded that *Finding* and *Disorder* concepts in SNOMED CT should be interpreted as a special kind of *Process*, *viz. Clinical situations*, i.e. phases of a patient's life in which one or more well-distinguished conditions of clinical interest (e.g. a phenotype, a pathological body part, a risk, a disease process) are fully present [12].

Taxonomic order. There is a clear criterion for the arrangement of classes into taxonomies: *A* is a subclass of *B* if and only if all members of *A* are also members of *B*, i.e. if and only if a clinical situation fits the definition of *A* it also fits the definition of *B*.

2. The nature of statistical classifications

It is tempting to consider statistical classifications like ICD as just another case of terminologies, to be underpinned by an ontology conforming to the above principles. Our initial postulate that all is-a links in ICD should coincide with direct or inferred is-a links in SNOMED CT cannot be sustained, due to the complexity of the SNOMED CT architecture and the idiosyncrasies of ICD. To serve their intended purposes, ICD linearizations must conform to different principles. Our analysis has shown:

- For statistical reporting, LINs maintain hierarchies of disjoint and mutually exhaustive classes at each level. To achieve this, even when the logical meaning of the classes is not disjoint and the list of classes cannot be guaranteed exhaustive, exclusions are required that cannot be interpreted in strict logical terms. For example, "*Hypertensive heart disease*" is in the cardiovascular chapter, but "*Gestational hypertension*" is under *Pregnancy, childbirth and puerperium*. Using OWL, the ICD-specific meaning of "Hypertensive heart disease" could be harmonized with the SCT concept "Hypertensive heart disease" by the axiom:

  icd:*HypertensiveHeartDisease*" equivalentTo
  sct:*HypertensiveHeartDisease*" and not sct:*GestationalHypertension*

  This would, then allow to infer – from the ICD code "*Hypertensive heart disease*"

– that the patient is not pregnant. This contradicts the current pragmatics of ICD coding as much as guidelines for its proper use.

- Numerous ICD classes seem to be motivated by convenience or epidemiological principles rather than by ontology or logic. Figure 1 shows a part of the malignancy section of ICD 11 *Joint Linearization for Mortality and Morbidity Statistics*. The plural labels in all levels but the lowermost one (with codes), suggests an interpretation as simple groupings of codes.
- Parent-child relations in ICD linearizations are sometimes only approximate, e.g. AB80.58 *Postthrombotic syndrome* as a child of AB80.5 *Chronic peripheral venous insufficiency*. A situation after an acute deep vein thrombosis, due to a coagulopathy, may not always imply chronic venous insufficiency. However, such cases have been judged sufficiently rare to be disregarded for statistical reporting.
- LIN Classes mix epistemic and ontological issues: the three sibling classes 1E10.1 *Suspected rabies*, 1E10.2 *Probable rabies*, 1E10.3 *Confirmed rabies* are under 1E10 *Rabies*, which is a child of *Infections due to Rabies virus*. Under ontological scrutiny, it is prohibitive that the situation of a patient, of whom rabies is merely suspected, is classified as a rabies situation. This so-called epistemic intrusion [13] is characteristic of terminology systems that blend the reference to a type of domain entity with the state of knowledge or belief of the terminology user.

The examples demonstrate a general problem, *viz.* to interpret classification "classes" in strictly logical terms such as by assuming description logics semantics,

- Neoplasms
- Malignant neoplasms
- Malignant neoplasms, stated or presumed to be primary, of specified sites, except of lymphoid, haematopoietic and related tissues
- Malignant neoplasms of digestive organs
- Malignant neoplasms of liver and intrahepatic bile ducts
- 2C90 Malignant neoplasm of liver
- 2C91 Malignant neoplasm of intra-hepatic bile ducts
- 2C9Y Other specified malignant neoplasms of liver and intrahepatic bile ducts
- 2C9Z Malignant neoplasms of liver and intrahepatic bile ducts without mention of type

Fig. 1. Sample hierarchy from a ICD-11 linearization draft

where the notion of "class" is different.

One could criticize ICD as being ontologically improper. But then one would misjudge its function and risk rendering it less rather than more useful for its purposes. The following aspects should be taken into consideration:

- Non-disruptive evolution. Health statistics over time should be affected as minimally as possible by changes in the underlying coding vocabulary. ICD has evolved for more than 120 years, which explains most of its structure. , especially the single-hierarchy principle.
- Honest limits on precision ("unavoidable vagueness"). Medical statements are often fuzzy and diagnoses are approximate, especially where sophisticated diagnostic procedures are not available, which is the case in many low- and middle-income countries. Epidemiological data always bear a certain bias, which reduces the relevance of a certain "improperness" in the hierarchies

- Use case and action orientation. There are diseases that are difficult to diagnose, and where suspicion requires action, such as in the case of rabies. This explains why in some cases epistemic criteria are distinctive and required for ICD's proper use. Statistical reporting will fail to reflect the realities of medical practice if such cases cannot be recorded accurately.

ICD as used (ICD 11 LINs and previous tabular ICD versions) is not an ontology and should not be criticized for not conforming to all criteria for ontology or terminology well-formedness [10,14]. The structure of ICD LINs is the result of an evolutionary process, driven by users' needs. It would be more appropriate to consider the ICD LINs as classifications of diagnostic statements rather than of diseases. As such, there are analogies with information models, e.g. openEHR archetypes or HL7 clinical models. Under this assumption, the meaning of a hierarchical link between *A* and *B* changes radically. Whereas a domain ontology would reject a subclass relation between *A* and *B* as soon as there is one single member of *A* that is not member of *B*, this would be tolerable between nodes of information models, as they represent information entities and not the clinical reality. Revisiting the rabies example, the subclass link between 1E10.1 and 1E10 would be justified if the latter is rephrased as *Information about rabies*, while the former would have to be interpreted as *Suspected information about rabies*. "Suspected" modifies the information entity, not the disease.

A decision that ICD LINs commit to information entities (on clinical entities) has the promise of a clear solution, but several problems remain to be solved:

- The relation between LIN codes and the underlying CO classes must be formalised, and the attribution of unintentional meanings to codes has to be avoided. E.g., although hypertension excludes hypertension in pregnancy, coding patients as having hypertension should not imply that they are not pregnant. We suggest using queries such as that below to select just those CO codes that apply.

SELECT *?code* WHERE (*?code* **is_subcode_of** *Hypertensive heart disease*)
MINUS (*?code* **is_subcode_of** *Disorders of Pregnancy*)

- The problem of representing codes with epistemic content such as "suspected…" needs to be further addressed so as not to imply the existence of entities that may not exist. One approach is to use expressions of the form "*Information structure* that **is_about_situation** only *Rabies situation***"** since such expressions do not imply that there actually is any rabies, only that it is not something else. However, there are technical difficulties in such models, as they lead to the possibility of statements that are not about anything at all. A second possibility is to allow hypothetical entities. More satisfactory but more complicated would be the use of a higher order logic so that the uncertainty can be correctly targeted on the statement or belief rather than on the underlying state of the world. However, this is likely to remain beyond the scope of easily used computational logics for the near future, so that approximations using description logic are required.
- It would have to be decided whether ICD codes that refer to classes of information are considered individuals (related by the transitive relation **is_subcode_of** [15]), whereas, e.g., the *SemanticHealthNet* project treats them as classes of information objects [16]. Related to this question is whether a distinction between a model of codes and an information model proper should be made.
- The fine details of the algorithms for deriving and maintaining the residual classes and exclusions required in the LINs and their relation to the FC.

3. Conclusion

Although ICD has been criticised for not conforming to ontological or other principles of well-formedness, there is, nevertheless, a clear advantage of harmonising the ICD with SNOMED CT, arising from computable re-use of structured clinical data for several purposes. However, on the way towards such a harmonisation it has become clear that ICD cannot be understood as an ill-formed clinical ontology. Statistical classifications are closer to clinical models and must meet specific criteria for their use in statistical reporting and epidemiology. Therefore, if harmonisation is to be achieved, a multi-layer architecture is required. For the layer that corresponds most closely to the hierarchies in the existing ICD versions – the linearizations – there are good reasons that their codes should be considered information entities, linked to but distinct from domain entities, that are represented in the subset of SNOMED CT which will form the IHTSDO / WHO common ontology (CO). Further work will focus on the formalization of the binding between ICD codes and CO classes, almost certainly based on queries against the ontology as illustrated in the SELECT statement above.

Acknowledgments

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References

[1] The International Classification of Diseases 11th Revision is due by 2015. The World Health Organization http://www.who.int/classifications/icd/revision/en/ (last accessed 1 May 2014).
[2] Tudorache T, Falconer S, Nyulas C, Storey MA, Ustün TB, Musen MA. Supporting the Collaborative Authoring of ICD-11 with Web Protégé, Proceedings of the AMIA Annual Symposium 2010, 802-806.
[3] Rodrigues JM et al. Sharing Ontology between ICD 11 and SNOMED CT will enable seamless re-use and semantic interoperability. Studies in Health Technology and Informatics 2013;192:343-346.
[4] International Health Terminology Standards Development Organisation (IHTSDO): SNOMED CT: http://www.ihtsdo.org/snomed-ct/ (last accessed 1 May 2014).
[5] Rector A, Rossi-Mori A, Consorti MF, Zanstra P. Practical development of re-usable terminologies: GALEN-IN-USE and the GALEN Organisation, Int. Journal of Medical Informatics 48 (1998), 71-84.
[6] W3C OWL Working Group: OWL 2 Web Ontology Language Document Overview 2009, http://www.w3.org/TR/owl2-overview/ (last accessed 1 May 2014).
[7] Baader F et al. The Description Logic Handbook: Theory, Implementation, and Applications, 2nd Edition. Cambridge University Press, 2nd ed. 2007.
[8] Smith B. Applied Ontology: A New Discipline is Born, Philosophy Today 12 (29), 1998,5-6.
[9] Ashburner M et al. Gene Ontology: tool for the unification of biology. Nature Genetics 2000, 25:25.
[10] OBO foundry principles: http://obofoundry.org/ontologies.shtml (last accessed 1 May 2014).
[11] Schulz S, Cornet R, Spackman K. Consolidating SNOMED CT's ontological commitment. Applied Ontology 6, 2011, 1-11.
[12] Schulz S, Rector A, Rodrigues JM, Spackman K, Competing interpretations of disorder codes in SNOMED CT and ICD. AMIA Annu Symp Proc. 2012, 819-827.
[13] Bodenreider O, Smith B, Burgun A. The ontology-epistemology divide: A case study in medical terminology. Proceedings of FOIS 2004: IOS Press, 2004, 185-195.
[14] Cimino JJ. Desiderata for controlled medical vocabularies in the twenty-first century. Methods of Information in Medicine 37(4-5), 1998, 394-403
[15] Rector AL, Qamar R, Marley T. Binding ontologies and coding systems to electronic health records and messages. Applied Ontology 4 (1), 2009, 51-69
[16] Schulz S, Martinez-Costa, C. How Ontologies Can Improve Semantic Interoperability in Health Care. Lecture Notes in Computer Science Volume 8268, 2013, 1-10.

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ICD-11 and SNOMED CT Common Ontology: Circulatory System

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Abstract. The improvement of semantic interoperability between data in electronic health records and aggregated data for health statistics requires efforts to carefully align the two domain terminologies ICD and SNOMED CT. Both represent a new generation of ontology-based terminologies and classifications. The proposed alignment of these two systems and, in consequence, the validity of their cross-utilisation, requires a specific resource, named Common Ontology. We present the ICD-11 SNOMED CT Common Ontology building process including: a) the principles proposed for aligning the two systems with the help of a common model of meaning, b) the design of this common ontology, and c) preliminary results of the application to the diseases of the circulatory system.

Keywords. ICD, SNOMED CT, Ontology, Terminology, Classification

Introduction

The increasing availability of machine-readable data in medicine, health care and public health has put the desideratum of **Semantic Interoperability** on the top of the Health Informatics agenda. It targets the preservation of meaning between heterogeneous patient-related and aggregated population data across different vocabularies and coding systems. This coincides with the current revision process of the disease classification system ICD [1], which continues being the most important semantic standard for health statistics, but which is also used – in several national modifications and extensions – for morbidity documentation and billing. This occurs in a time in which the international clinical terminology standard SNOMED CT (SCT) [2]

[3] has gradually been gaining ground. SCT, maintained by the IHTSDO as an international medical terminology standard, promises to provide codes and formalisms to represent the whole health care process.

Clinicians, documentation specialists, epidemiologists and health care administrators may rightly ask why they should use SCT in parallel to ICD and local procedure classification systems. This concern was one of the drivers for a collaboration agreement between the maintainers of ICD and SCT, *viz.* WHO and IHTSDO. This agreement has fuelled the identification of a common basis between both terminological systems and culminated in the decision to create a **Common Ontology (CO)** [4]. We here report on the current state of this common ontology.

1. Materials and Methods

1.1. ICD-11 – SNOMED CT Harmonization

In 2007, the WHO launched the revision of the International Classification of Diseases – ICD-11 [5]. This revision process is different from previous ones in that the authoring is computerized and supported by ontology-driven tools [6] and distinguishes between a multi-hierarchical ICD Foundation Component (FC), from which multiple purpose-specific mono-hierarchical Linearizations can be derived.

After the WHO – IHTSDO agreement and the establishment of a Joint Advisory Group (JAG), it was decided that the *Foundation Component* is intended to have at its core a common ontology which is a subset of SCT, which is an example of bringing a medical ontology into practice. This is in line with the tendency of a new generation of biomedical vocabularies to be built on the principles of applied ontology [7][8][9] [10] [11] and a model of meaning based on descriptive logic [12], using formalisms and languages from the Semantic Web community like OWL [13]. Due to the broad scope and a high degree of granularity of SCT it was decided that for initial testing, a subset would be sufficient to play the role of test set, provided that some gaps (e.g. rare diseases) be filled. We chose the diseases of the circulatory system for evaluation.

As the source from which the common ontology should be drawn the SCT hierarchies *Clinical Findings*, *Disorders* had been identified. The JAG collected evidence that these concepts denote, first of all, clinical situations, i.e. phases of a patient's life in which a given condition of clinical relevance is present [14].

2. Results

The architecture of the coordination between ICD-11 and SNOMED-CT based on the common ontology is illustrated in fig. 1.

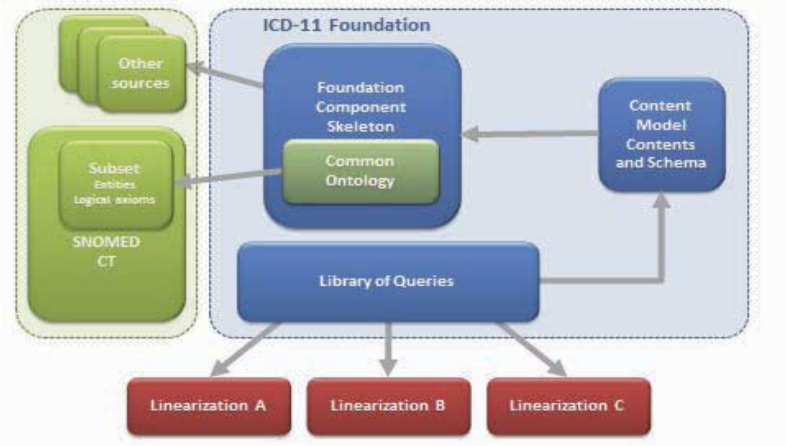


Fig. 1 Architecture of Common Ontology based ICD 11 SNOMED CT coordination

Concisely, it is characterised by the following:

- The linearizations for mortality and morbidity or for primary care are sets of exclusive or disjoint and exhaustive classes meaning that each class is present only once giving a mono-hierarchical look as in ICD-10. It is enforced by classification rules (exclusion statements and residual categories ("not elsewhere classified"; "not otherwise specified")
- The FC is organised around the common ontology coming from a subset of SCT and further on from external ontology sources. This skeleton is populated by the content of all linearizations structured by the common ontology and therefore having multi-hierarchical views. There are two additional elements to this skeleton: the content model and a queries library of SQL style queries needed to relate the linearizations statistical classes with their exclusion and residual rules which cannot be interpreted in strictly logical terms to the CO by preferring "negation as failure" over logical negation.
- The Common Ontology is a subset of SCT classes and logical axioms, from SCT clinical findings and disorder branches. This subset is defined by identifying SCT concept candidates to provide a full definition of the classes of the FC. As in SCT, the Common Ontology is multi-hierarchical.

The workflow is the following, iterating over each ICD-11-FC class:

1. From ICD-11 FC classes as defined on ICD11 browser [15] identify candidate SCT concepts from which the meaning of FC classes can be the same or reconstructed as queries.
   a. Examine the ability of the SCT model of meaning to represent the ICD-11 textual definitions.
   b. Try to fully define all SCT primitive expressions identified in this step and submit for SCT editorial validation.
2. Construct valid SCT formal expressions to reflect the meaning of the ICD-11 textual definitions, to be pre-coordinated in SCT.

3. Specify the queries for ICD-11 FC classes in Boolean constructs of queries against SCT axioms and assess for comprehensiveness, consistency and accuracy.
4. Assure that all expressions in SCT representing subchapters in ICD-11 aggregate to the SCT pre-coordinated expression for the ICD-11 chapter concept. When necessary, submit potential revisions to the SCT concepts model and expansions of SCT content for editorial revision and detailed annotation for future reference.
5. Add all SCT editorial expansions into the common ontology.

2.1. Application to the Circulatory System Disease use case

The application of the method to the circulatory system chapter of ICD-11 has been finalised for steps 1 and 2 for most entities. It is ongoing for ENT, Respiratory, Infectious diseases, Dermatology and Gynaecology and Obstetrics: they concern 22 % of ICD-11 beta draft entities.

The overall results show that among 1582 ICD-11 FC circulatory chapter entities 1412 (89.3%) can be represented by the SCT model of meaning either directly or through a pre-coordinated/post –coordinated alignment between the two systems. 114 (7.2%) are residuals which have to be cleaned from the FC and 56 (3.5%) needs a revision of SCT formal model of meaning. We propose two contradictory examples:

1. The defining relationships of SCT allow the full representation of both the ICD-11 FC class and the SCT concept. An example is FC *Coronary vaso-spastic disease with angina* is necessarily and sufficiently defined as SCT 87343002 *Prinzmetal angina (disorder)*.
2. The SCT defining relationships are not providing a complete ontological representation of both entities, and the concept model or pre-coordinated SCT content must be expanded. An Example is ICD-11 *Acute myocardial infarction, STEMI anterior wall and SCT 401303003 |Acute ST segment elevation myocardial infarction (disorder) and SCT 54329005 | Acute anterior myocardial infarction.*

3. Conclusion

What the ICD-11 SCT common ontology proposes is definitely not the development of yet another ontology. Instead, the goal is to define an applied ontology refurbished from a SCT subset common to on the one hand, ICD-11, the semantic standard for health statistics in mortality, morbidity, documentation and billing, and on the other hand, SCT, the most fine grained medical terminology system.

This will require certain refinement / redesign efforts on both the IHTSDO and WHO side. The test on the ICD-11 beta draft circulatory chapter shows that this could affect around 15 % of the ICD-11. The maintenance will be shared by WHO and IHTSDO. New ontology sources will have to be taken in consideration.

Further on, this FC with the common ontology shall be used for the maintenance of all of the existing WHO ICD as well as the ICD-(10/11) national modifications thereby easing international comparisons and backward compatibility with current systems.

Acknowledgments

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References

[1] The World Health Organization, The International Classification of Diseases 11th Revision is due by 2017, http://www.who.int/classifications/icd/revision/en/ (last accessed 29 Apr 2013).
[2] International Health Terminology Standards Development Organisation (IHTSDO): SNOMED CT: http://www.ihtsdo.org/snomed-ct/ (last accessed 20 Jan 2014).
[3] SNOMED CT browser: https:/uts.nlm.nih.gov/ (last accessed 28 Apr 2014)
[4] J.M.Rodrigues, S.Schulz, A.Rector, K.Spackman, T.B.Üstün, C.G.Chute, V.Della Mea, J.Millar, K.Brand Persson, Sharing Ontology between ICD 11 and SNOMED CT will enable seamless re-use and semantic interoperability. Studies in Health Technology and Informatics 2013;192:343-346.
[5] J.M.Rodrigues, A.Kumar, C.Bousquet, B.Trombert, Using the CEN/ISO standard for categorial structure to harmonise the development of WHO international terminologies, *Studies in Health Technology and Informatics* **150** (2009), 255-259.
[6] T.Tudorache, S.Falconer, C.Nyulas, M.A.Storey, T.B.Ustün, M.A.Musen, Supporting the Collaborative Authoring of ICD-11 with Web Protégé, Proceedings of the AMIA Annual Symposium 2010, 802-806.
[7] B.Smith, Applied Ontology: A New Discipline is Born, *Philosophy Today*, **29**(12) (1998), 5-6.
[8] M.Ashburner et al. Gene Ontology: tool for the unification of biology. *Nature Genetics* **25**(2000), 25:29.
[9] OBO foundry principles: http://obofoundry.org/ontologies.shtml (last accessed 5 Feb 2014).
[10] A.Rector, A.Rossi, M.F. Consorti, P.Zanstra, Practical development of re-usable terminologies: GALEN-IN-USE and the GALEN Organisation, *International Journal of Medical Informatics* **48** (1998), 71-84.
[11] S.Schulz, R.Cornet, K.Spackman, Consolidating SNOMED CT's ontological commitment, *Applied Ontology* **6** (2011), 1-11.
[12] F.Baader et al. The Description Logic Handbook: Theory, Implementation, and Applications, 2nd Edition. Cambridge University Press, 2nd ed., 2007.
[13] W3C OWL Working Group: OWL 2 Web Ontology Language Document Overview 2009, http://www.w3.org/TR/owl2-overview/ (last accessed 28 Apr 2014).
[14] S.Schulz, A.Rector, J.M.Rodrigues, K.Spackman, Competing interpretations of disorder codes in SNOMED CT and ICD. AMIA Annu Symp Proc. 2012, 819-827.
[15] The World Health Organization, ICD11 beta draft: http://www.who.int/classifications/icd11 (last accessed 28 Apr 2014)

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Does SNOMED CT post-coordination scale?

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Abstract. SNOMED CT is a compositional terminology. Construction of post-coordinated expressions allows users to specify new meaning by referencing existing SNOMED CT concepts. The use of post-coordinated expressions in information systems requires special software, a reasoner, to give the exact relations between post-coordinated expressions and existing SNOMED CT content. Thus, the performance characteristics of reasoners are important for implementation of post-coordination in information systems. This study aims to test how reasoners perform when a large number of post-coordinated expressions are added to SNOMED CT. The time needed to classify an ontology consisting of SNOMED CT plus an increasing number of post-coordinated expressions is measured. The best performing reasoner in this test classifies SNOMED CT plus 1 million post-coordinated expressions in 42 seconds. The time to classify grows a little less than quadratic as the size of the ontology increases. In conclusion, classification time is not a problem using current reasoners and current SNOMED CT releases even if a large number of post-coordinated expressions are added.

Keywords. Post-coordination, SNOMED CT

Introduction

SNOMED CT is a compositional reference terminology which allows the construction of expressions to represent meaning beyond what has been given a unique concept identifier by IHTSDO, the owner of SNOMED CT, or by a national release center or by a local extension [1]. This composition is often called post-coordination and is considered necessary in order to achieve coverage in practical tests [2-4].

Organizations with large-scale implementations of SNOMED CT in clinical practice like Kaiser Permanente and Hospital Italiano de Buenos Aires have seen the need to extend SNOMED CT in order to cover clinical use cases and to meet interface terminology needs [5, 6]. Both organizations have created extensions to SNOMED CT in the magnitude of tens of thousands of concepts.

Enumerating all sensible combinations of SNOMED CT concepts is not possible due to the combinatorial explosion [e.g. 7]. For example, pain may be qualified by severity (7 severities), pain character (149), body site (25851 sites), and course (31). This results in some 800 million possible, although maybe not always sensible, ways to express different kinds of pain. Thus, while post-coordination seems to be necessary

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for coverage of the clinical domain the large amount of possible combinations poses a potential problem for implementers of SNOMED CT, and the means to manage post-coordination in a scalable manner have to be made available to implementers.

Expression repositories may provide a solution [1, 7]. Expression repositories are systems which cache results of some of the time-consuming tasks involved in the use of post-coordinated expressions in information systems. As the systems only provide a cache, expression repositories require no manual curation. An example of such a time-consuming task is classification of post-coordinated expressions, i.e. putting the expressions into the correct positions in the subclass (aka. IsA) hierarchy by identifying the correct and only the correct parents and children. Expression repositories rely on software called reasoners doing the work of classification. The scalability of the expression repository is thus dependent on the scalability of the reasoner software.

Previous studies have benchmarked and compared reasoners for classification of large-scale ontologies [8, 9], and when new reasoners are presented they are usually benchmarked towards existing reasoners [e.g. 10, 11]. Apart from classification performance, reasoners differ in the description logic (DL) being supported, soundness and completeness, available APIs etc. The previous studies we found often estimate performance for classifying the international release of SNOMED CT as well as some other well-known ontologies. Previous studies have also examined the statistical average-case complexity of reasoning as the size of the ontology grows, for example Ian Horrocks' Masters Thesis [12], but we are unaware of any studies where the performance of reasoners for SNOMED CT with massive post-coordination is assessed.

The aim of this study is to assess the feasibility of the use of post-coordination in practice by testing the scalability of using current reasoners to classify SNOMED CT together with a repeated addition of post-coordinated content in an as realistic as possible manner.

1. Methods

To assess how SNOMED CT classification time changes when post-coordinated expressions are added, a set of post-coordinated expressions was created as follows. For each role group of a clinical finding with finding site and associated morphology, the direct descendants of the specified finding site and associated morphology were retrieved, and a cross product of the retrieved values was generated. For example, acute interstitial nephritis is defined with one role group containing associated morphology = acute inflammation, which has 14 direct descendants, and finding site = structure of interstitial tissue of kidney, which has 3 direct descendants. This results in 3x14=42 refined post-coordinated expressions. Applying this method to all clinical findings resulted in over 7 million expressions, which were then randomly ordered. The generated expressions were regarded as fully defined, and no test was performed to determine whether the generated post-coordinated expression equalled any pre-coordinated SNOMED CT concept.

A Java™ program was developed to gradually add the randomly generated post-coordinated expressions and measure time needed for classification by various reasoners. Two tests were performed. Firstly, 10,000 expressions were added at a time after which classification time was measured. This was repeated until either 1,000,000 post-coordinated expressions had been added or a total time of 4 hours had passed. To reduce the random effects in the test, for example due to other processes running on the

system, the full test was run 3 times and the minimum time from the three test runs was used for analysis. The second test aimed at further exploring the potential for large-scale post-coordination. By adding 1,000,000 post-coordinated expressions seven times or until the reasoner or underlying system would fail in the given system environment.

The time span measured was the time from just before starting classification until the time just after finishing classification.

Classification time measurements for the tested reasoners were plotted on a log-log-scale diagram with ontology size on the x-axis and classification time on the y-axis. To determine the order of the polynomial describing classification time, a least-square-method linear estimation was applied to log(time) versus log(size) data to estimate the slope of the logarithmic curve.

The Java program was executed on a Linux system running a 3.9.6 64-bit kernel and OpenJDK 1.7.0_45. The system had two Intel Xeon processors with 2x4 processor cores and 96 GB internal memory. A default of 25.9 GB was assigned to the test process. Linear estimation and graph plotting was done with the R statistical computing environment.

In these tests the 2013-07-31 International Release of SNOMED CT was used. The release was translated to OWL RDF/XML using the OWL-transformation Perl script provided with the International Release. The OWL ontology contained 297,315 class expression axioms (229,247 subclass axioms, 68068 equivalent-class axioms). The resulting file was loaded into the Java application using OWL API version 3.4.9.

In order to automate creation of post-coordinated expression test cases, the SNOMED CT Release Format 2 files were imported into a MySQL 5.5 database.

Reasoners that provide an OWL API were selected for the experiment: ELK [10], HermiT [13], and Snorocket [11] (see Table 1). The reasoners allow reasoning with different (or slightly different) subsets of DL, use different reasoning algorithms, and represent different stages of the development of reasoning tools. The ELK and Snorocket reasoners allow parallelization of the reasoning task. ELK supports incremental reasoning but this feature was not used when comparing to other reasoners. The primary purpose of this study was not to compare reasoners performance but to assess and describe how SNOMED CT classification behaves with increasingly sized ontologies, using different OWL reasoners for increased test validity.

Table 1. Reasoners used in the test

Reasoner	Version	DL
ELK 0.4.1 [10]	Consequence reasoning	EL+
Snorocket 2.1.1 [11]	Completion rules	EL+
HermIT 1.3.8 [13]	Hyper-tableau	SHOIQ+

2. Results

The time for classification of the SNOMED CT release without additional post-coordinated content ranged from approximately 3.6 seconds for the more recent ELK reasoner to over 30 minutes (1,900 s) for the HermiT reasoner (see Table 2). When adding 100,000 expressions classification time increased 67 % for ELK and 180 % for Snorocket. Only the ELK reasoner managed to complete the test within 4 hours taking 42 seconds to classify SNOMED CT plus 1,000,000 post-coordinated expressions (see

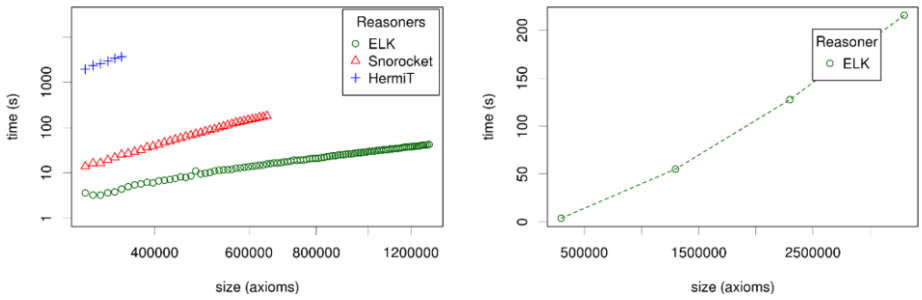


Figure 1. Classification time vs. size of ontology, log axes (left), large additions (right).

Figure 1). The Snorocket reasoner managed to classify about 650,000 concepts in about 3 minutes (180 s) before reaching the 4 hour test limit.

The slope of the curve when a logarithmic transformation had been applied ranged between 1.6 and 4.0 (see Figure 1 and Table 2, Standard Error in parentheses). Thus in the best case classification time grows less than quadratic with the size of the ontology.

Table 2. Classification time results (seconds)

Reasoner	SNOMED CT only	S. CT+100,000 post-coordinated	Number of iterations/4h	Order of growth (S.E.)
ELK 0.4.1 [10]	3.6	6.0	101	1.6 (0.019)
Snorocket 2.1.1 [11]	14	39	36	3.3 (0.026)
HermIT 1.3.8 [13]	1900	-	6	4.0 (0.19)

In the second test, when adding even larger amounts of post-coordinated expressions to the ontology, only the best performing reasoned, ELK, was used. The application managed to classify 3.3 million concepts, i.e. the SNOMED CT release plus 3 million post-coordinated expressions, in about 3 and a half minutes (220 s) before reaching a state were almost all time was used for Java garbage collection.

3. Discussion

As post-coordination is necessary for practical implementation of SNOMED CT [2-6] the resulting terminology will be significantly larger than the 300,000 concepts in the international release. Although the exact size of the ontology of "SNOMED CT-in-action" is yet to be found through implementation experiences, the ability of systems to deal with the increased load of a larger ontology becomes crucial to successful implementation. The results from this study indicate that use of post-coordinated expressions in information systems does not pose a technical problem for at least some current OWL reasoners even if a large amount of post-coordinated content is added.

With efficient reasoners, expression repository systems can further improve effectiveness through various sorts of caching including syntactic comparison of expressions, transitive closure tables, branch numbering, etc. [1].

All post-coordinated expressions used in this test had the same form, i.e. clinical findings refined by finding site and associated morphology. The post-coordinated expressions in the test were created using only refinement of existing content and not by adding additional relationships from the Concept Model or by creating intersections of existing content. In practice, post-coordinated expressions will most probably be much more varied in both form and content. Whether it is harder or easier to classify

this kind of expressions in relation to the more varied ones most probably used in practice is currently unknown and is a subject for further investigation.

One way of making a more representative set of post-coordinated expressions would be to extrapolate from existing sets of post-coordinated content rather than existing pre-coordinated SNOMED CT concepts.

There are increasingly strong requests for making the DL language underlying SNOMED CT more expressive, including concrete domains, number restrictions, negation, and universal restriction. This will reduce the number of reasoners being able to fulfill the task. This is particularly problematic as reasoners optimized for EL reasoning such as ELK and Snorocket seem to be the top performers in this and other studies. Before accepting these requests for new language facilities the implications for, among other things, post-coordination must be carefully considered.

Does SNOMED CT post-coordination scale? Yes, it does. Post-coordination with SNOMED CT is possible even when a large amount of expressions is added. Caveats exist though. These results does no longer hold if new constructs are added to the chosen dialect of DL.

References

[1] IHTSDO, "Technical Implementation Guide, January 2014." [Online]. Available: http://www.ihtsdo.org/tig. [Accessed: 7-Feb-2014].

[2] G. Wade and S. T. Rosenbloom, "Experiences mapping a legacy interface terminology to SNOMED CT," *BMC Med Inform Decis Mak*, vol. 8 Suppl 1, p. S3, 2008.

[3] N. F. de Keizer, F. Bakhshi-Raiez, E. de Jonge, and R. Cornet, "Post-coordination in practice: evaluating compositional terminological system-based registration of ICU reasons for admission," *Int J Med Inform*, vol. 77, no. 12, pp. 828–835, Dec. 2008.

[4] J. R. Campbell, J. Xu, and K. W. Fung, "Can SNOMED CT fulfill the vision of a compositional terminology? Analyzing the use case for problem list," *AMIA Annu Symp Proc*, vol. 2011, pp. 181–188, 2011.

[5] R. H. Dolin, J. E. Mattison, S. Cohn, et al., "Kaiser Permanente's Convergent Medical Terminology," *Stud Health Technol Inform*, vol. 107, no. Pt 1, pp. 346–350, 2004.

[6] A. L. Osornio, D. Luna, M. L. Gambarte, A. Gomez, G. Reynoso, and F. G. B. de Quirós, "Creation of a local interface terminology to SNOMED CT," *Stud Health Technol Inform*, vol. 129, no. Pt 1, pp. 765–769, 2007.

[7] D. Karlsson, M. Nyström, and B. Kron, "An integrated Expression Repository EHR system," in *SNOMED CT Implementation Showcase 2012*, Stockholm, Sweden, 2012.

[8] K. Dentler, R. Cornet, A. ten Teije, and N. de Keizer, "Comparison of reasoners for large ontologies in the OWL 2 EL profile," *Semantic Web*, vol. 2, no. 2, pp. 71–87, Jan. 2011.

[9] R. S. Gonçalves, S. Bail, E. Jimenez-Ruiz, N. Matentzoglu, B. Parsia, B. Glimm, and Y. Kazakov, "OWL Reasoner Evaluation (ORE) Workshop 2013 Results: Short Report," in *2nd OWL Reasoner Evaluation Workshop (ORE 2013)*, p. 1.

[10] Y. Kazakov, M. Krötzsch, and F. Simancík, "Concurrent classification of EL ontologies," in *Proceedings of the 10th international conference on The semantic web - Volume Part I*, Berlin, Heidelberg, 2011, pp. 305–320.

[11] M. Lawley and C. Bousquet, "Fast classification in Protégé: Snorocket as an OWL 2 EL reasoner," in *Australasian Ontology Workshop 2010 (AOW 2010): Advances in Ontologies*, Adelaide, Australia, vol. 122, pp. 45–50.

[12] I. Horrocks, "A comparison of two terminological knowledge representation systems," Master's thesis, University of Manchester, 1995.

[13] B. Motik, R. Shearer, and I. Horrocks, "Hypertableau Reasoning for Description Logics," *J. Artif. Int. Res.*, vol. 36, no. 1, pp. 165-228, Sep. 2009.

12. Text Mining

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Towards a Light-Weight Query Engine for Accessing Health Sensor Data in a Fall Prevention System

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Abstract. Connecting various sensors in sensor networks has become popular during the last decade. An important aspect next to storing and creating data is information access by domain experts, such as researchers, caretakers and physicians. In this work we present the design and prototypic implementation of a light-weight query engine using natural language processing for accessing health-related sensor data in a fall prevention system.

Keywords. Natural language processing, eHealth, electronic health records, sensor networks, sensor fusion

Introduction

The last decade saw a dramatic change in the way we collect health data. Mobile phones became smart phones providing end-users with a growing number of cheap sensors. Medical devices, such as blood pressure meters, glucose meters or scales are now shipped with Bluetooth or WiFi connectivity, making it easily possible to create sensor networks. Platforms such as the Microsoft KINECT brought motion sensing from the labs to the living room. Finally, the rise of the Internet of Things (IoT) is turning everyday-objects into sensing devices. Connecting sensors in networks and aggregating this data in cloud-based environments for further analysis has a wide area of applications in the health area such as continuous monitoring of an individual's health or providing smart environments for elderly people.

The 3-year EU-funded project *iStoppFalls* investigates the use of state-of-the-art sensors to reduce the risk of fall in elderly people using video-game-based physical exercises. End-users are equipped with a smart TV, a PC running computer games fostering physical activity, a wearable Senior Mobility Monitor[2] (SMM) with a necklace to track daily activity as well as movements during the games, and a set-top-box orchestrating the whole client environment. The PC is connected to a Microsoft KINECT sensor tracking movements in front of the television visually. Data of the various sensors are aggregated in a knowledge-based platform (KBS) that carries out analyses [1] and provides end-user with feedback on their health. The system has been tested iteratively in two field trials [2]. Starting in January 2013, the system is evaluated in a randomized clinical trial.

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[2] Equipped with an accelerometer

The knowledge-based system collects 189 different types of sensor data. Based on the experiences of the first evaluation, we wanted to evaluate an effective method to provide domain experts (researchers and technicians handling equipment) to access data online. Research [3] [4] has shown, that natural language query interfaces are an attractive alternative to classic graphical user interface. Sun [5] has shown, how such a query interface can be used to visualise statistical information.

In this work we discuss the design and implementation of a natural language query interface in the field of health-related sensor data.

1. Methods

1.1. Requirements analysis

We defined three primary design goals: (1): the query engine should not be restricted to the area of fall prevention. (2): the query engine should have a *light-weight* design. Software developers with a strong background in object-oriented design should be able to extend the capabilities of the engine without having a deep understanding of natural language processing. (3): the system should not introduce another data storage aside from the storage where the sensor data is stored to leverage system administration.

We asked four researchers (male; age 41.5+/-5.36 years) to suggest queries to a hypothetical query engine. We asked them to formulate queries as if it was possible to search their data using natural language. Our intention was two-fold. (1): to determine the vocabulary people are using and (2): to determine the structure of the queries.

We received 167 queries as a result. We then looked for common patterns in grammar and intention of the queries. We identified three common patterns: (1) filtering entities using a set of criteria (e.g. *Show me the number of active patients assigned to each physician);* (2) Aggregating entities based on a set of criteria (e.g. *Number of patients recruited* or *patients recruited in Germany per month);* and (3) comparison of given entities (e.g. *correlation of weight and BMI);*

We finally could rewrite 145 queries into a standardized format using a controlled English vocabulary. 22 queries have been discarded either because of being too complex or not verbose enough.

1.2. Designing the prototype

Sensor data in *iStoppFalls* is stored in a relational database system using both, an Entity-Value-Attribute (EAV) and a traditional data model. Moreover, raw level data is stored in a dedicated file system space. We call this data model the *operational data model* (ODM). The knowledge-based system is built on the open-source web application framework *Django,* thus data is accessed through an object-relational mapper which is provided by the framework.

Following the technique used by Facebook in their social graph search [6], we decided to design a formal context-free grammar to define all queries that could be understood by the query engine. The grammar is built on the patterns we observed during the requirements' analysis and is built around the concepts of *entities, filters* and *operators. Entities* are references to database entities, *filters* filter them and *operators* do aggregations, such as sum, maximum, minimum or average. Thus, *number of users who are male and assigned to group Germany* would refer to an operator (*number),* an

entity (users), and two filters (*male, assigned to Group Germany*). We also allowed entities to be linked to each other as it is reflected in the operational data model. For instance, a user is assigned sensors, thus a query "*users who are male and who are using tablets"* would be a valid linked query.

We first intended to derive the grammar dynamically from the operational data model. However, we introduced a *conceptual data model* enhancing the *operational data model.* While we looked into different options (Search index using Natural language generation [7], representation as a Resource Description Graph (RDF) [8]) we designed the conceptual data model as an object-oriented class model representing a directed graph. *Entities, filters and operators* are represented as *concept classes* with links to each other. Moreover *each* concept class taps into the operational data model to retrieve data. A *concept class* comes with a natural language name used for generating the grammar, an n-gram language model used as basis for identifying references to a concept in a query. Moreover, it contains a link to an *operational data model* for retrieving data. Based on the conceptual data model the full context-free grammar is automatically derived.

1.3. Query rephraser

We did not expect people to know the exact grammar of the queries the engine understood. Moreover we did not want to make any assumptions on how people would formulate a query. Therefore we decided, following [6] to create a *query rephraser* that took an input consisting of a potentially incomplete query and would reformulate it into the most probable understandable query.

We designed the query rephraser as follows: The original query is tokenized. We then extract a list of references to concepts by applying n-gram similarity search based on the n-gram model. Each match is associated with a ranking score between 0 and 1. Moreover, we perform *query extension,* thus if a reference to a *filter* is found, the reference to the corresponding entity is added automatically. For instance, *"active users"* would contain three references. *Active* might refer to a *filter* filtering either *sensors* or *users*. *Users* might refer to end-users or researchers. Based on query extension and relevance ranking, this would produce "active subjects", "active devices" and "backend users" as most probable rephrased queries.

The prototype has been developed as a Python-based web application. Python Natural Language Toolkit (NLTK) [9] has been used for the design of the grammar and query parsing. The open-source package *python-ngram* [10] has been used for representation and the search of language models. The user interface was developed as web application. Based on findings of Ward [11] that showed how auto-complete features can support users, we provided end-users with query suggestions while they type.

2. Results

Fig. 1 provides an overview of the system architecture and illustrates how the rest of the *iStoppFalls* system is connected to the engine.

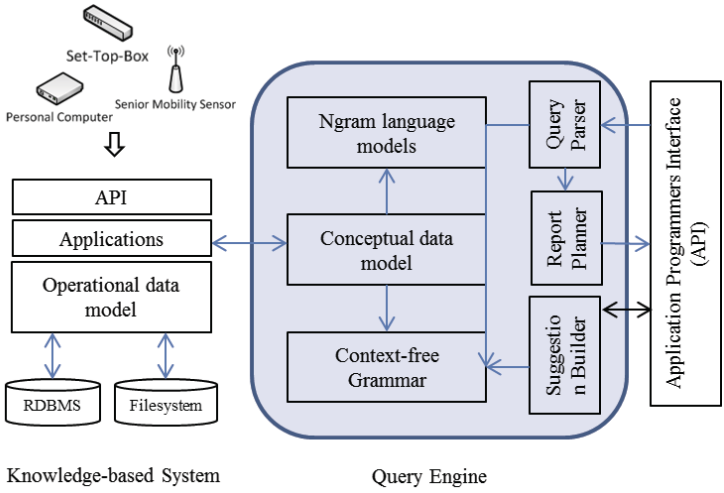


Figure 1. Overview of the system architecture; sensor data is stored in the knowledge-based system on the left. The query engine sits on top of the knowledge-based system accessing data stored in the operational data model.

The overall life cycle of a query is as follows: A query request is submitted to the Application Programmers Interface (API). The given query is matched against the most probable interpretable query by the suggestion builder. A list of the five most probable queries is returned to the client. The user then selects the most appropriate query which is then submitted to the query parser. The query parser translates the query into subsequent data calls to the operational data model and returns a list of matched datasets. The matched datasets are passed on to a report planner which creates an appropriate representation of the results. Currently this is limited to lists of results.

Fig. 2 shows the web-based user interface for domain experts. Suggestions are presented to end-users as they are formulating their query. The first entry shows the most probable suggestion.

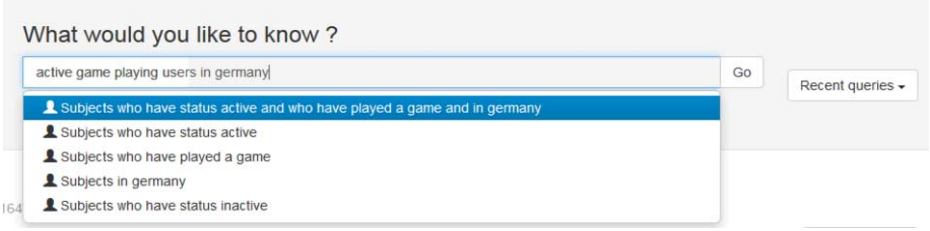


Figure 2. Query interface as presented to end-users. This illustrates how a given user query is gradually expanded as the user continues typing. The query engine stores any suggestions that have already been created in a cache to boost performance.

The user then selects a query and presses *Go*. The query engine translates and executes the query and returns a list of matched entities. These are then passed on to a report planner that renders the results in an understandable way.

3. Discussion

We presented an implementation of a query interface for querying structured sensor data. Our intention was to provide an easy online access to data for researchers and to reduce the effort for implementing highly complex user interfaces. We chose to use natural language as input for its simplicity and convenience. The query engine allows researchers to investigate sensor data online without exactly knowing the underlying data model. Query rephrasing helps users to learn the language of the system and to express proper queries.

The prototype has been released for usage in the *iStoppfalls* project. However, user acceptance and usability has not been evaluated yet. Therefore, further research should include a usability study in order to investigate if a natural language query interface is more usable as compared with a more traditional user interface design approach.

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References

[1] Drobics M, Ejupi A, Kreiner K. Modern fall prediction algorithms: Self-adaptive exercise training plans based on fall related data analysed over time. Journal of Aging and Physical Activity. 2012 (20): 124

[2] Kreiner K, De Rosario H, Gossy C, Ejupi A. Play up! A smart knowledge-based system using games for preventing falls in elderly people. Proceedings of the eHealth 2013; 2013 May 23-25; Vienna Austria. OCG c2013. p. 243-248.

[3] Androutsopoulos I, Ritchie G D, Thanisch P. Natural Language Interfaces to Databases - An Introduction. Journal of Natural Language Engineering. 1995; (1): 29-81.

[4] Kaufmann E., Bernstein A. Evaluating the usability of natural language query languages and interfaces to Semantic Web knowledge bases. Web Semantics: Science, Services and Agents on the World Wide Web .2010 (Nov); 8(4): p. 377-393.

[5] Sun Y, Leigh J, Johnson A, Lee Sangyoon. Articulate: A semi-automated model for translating Natural Language queries into meaningful visualizations. Proceedings of the 10th International Symposium on Smart Graphics; 2010 Jun 24-26 Banff, Canada; Springer c2010. p.184-195

[6] Li X. Under the hood: The natural language interface of Graph Search [Internet]. 2013 [updated 2013 Apr 29; cited 2014 May 09]. Available from: https://www.facebook.com/notes/facebook-engineering/under-the-hood-the-natural-language-interface-of-graph-search/10151432733048920

[7] Leidner J L, Kamkova D. Making Structured Data Searchable via Natural Language Generation.. In: Larsen L.L.,editor. Flexible Query Answering Systems. Berlin Heidelberg: Springer; 2013. p. 495-506. (Lecture Notes in Computer Science; vol 8132).

[8] Lassila O, Swick R R. Resource Description Framework (RDF) Model and Syntax Specification [Internet]. 1999 [updated 1999 Feb 22; cited 2014 May 09]. Available from: http://www.w3.org/TR/1999/REC-rdf-syntax-19990222/.

[9] Bird S. NLTK: the natural language toolkit. Proceedings of the COLING/ACL on Interactive presentation sessions; 2006 May 17-18; Sydney Australia. p. 69-72.

[10] Poulter G. Python NGram 3.3 documentation [Internet]. 2011 [cited 2011 May 09]. Available from: http://pythonhosted.org//ngram/

[11] Ward D, Hahn J, Feist K. Autocomplete as Research Tool: A Study on Providing Search Suggestions. Web Semantics: Science, Services and Agents on the World Wide Web. 2012; 31 (4): p. 6-19.

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A Framework for Integrating Heterogeneous Clinical Data for a Disease Area into a Central Data Warehouse

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Abstract. Structured collection of clinical facts is a common approach in clinical research. Especially in the analysis of rare diseases it is often necessary to aggregate study data from several sites in order to achieve a statistically significant cohort size. In this paper we describe a framework how to approach an integration of heterogeneous clinical data into a central register. This enables site-spanning queries for the occurrence of specific clinical facts and thus supports clinical research. The framework consists of three sequential steps, starting from a formal data harmonization process, to the data transformation methods and finally the integration into a proper data warehouse. We implemented reusable software templates that are based on our best practices in several projects in integrating heterogeneous clinical data. Our methods potentially increase the efficiency and quality for future data integration projects by reducing the implementation effort as well as the project management effort by usage of our approaches as a guideline.

Keywords. Data Warehouse,Data Integration,Data Harmonization, Clinical Research

Introduction

Nowadays, the usage of digital data acquisition systems in health care is increasingly growing. In the United States, the percentage of office-based physicians with Electronic Medical Records (EMR) systems reached a peak in 2012 with estimated 72 % [1]. Furthermore, open source electronic data capture systems, such as *REDCap* [2] are used to collect data in clinical trials. Both types of data, patient records and data from trials, represent facts that can be used for research purposes beyond clinical trials. It is assumable that the structured collection of relevant clinical data for a specific disease area has the potential to improve research efficiency in its specific field.

In order to have a significant number of cases to analyze a specific research question, it is often necessary to accumulate patient data from several institutions. Each hospital might focus on different aspects of clinical facts, having a varying data granularity. They might furthermore use varying data structures and storage methods which results in a highly heterogeneous collection of clinical data lacking semantic interoperability. There also might be connectivity constraints or privacy concerns in

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multi-centered databases. Thus, a central registry, e.g. in the form of a dedicated data warehouse (DW) is required to integrate data from several sites. However, the necessary integration into a unified structure, which can be accessed efficiently is challenging. The complexity of these tasks often leads to individual solutions for each data integration project. In order to define a general approach with the help of our best practice methods, we developed a framework to use as a guideline for a threefold approach: (1) harmonizing digitally recorded medical data from multiple sites to a harmonized target structure; (2) implementing a transformation from the clinical source data to the target structure; (3) setting up a central data warehouse system that is suitable for the storage of clinical facts.

1. Methods

We established integrated data platforms in three different disease areas and in three different national and international research networks:

- EURenOmics, international research consortium for rare kidney diseases [3]
- German Center for Lung Research (DZL) that focus on prevention, diagnosis and therapy of serious lung diseases [4]
- CLIOMMICS doing advanced research on system medicine for multiple myeloma with the help of *omics* based data [5].

Continuous improvement of our methods in analyzing, processing and implementation finally resulted in this framework. We divided it into three sequential parts and developed methods and tools for each part.

1.1. Harmonization of multi-centered clinical data

Each site that is collecting clinical data about a specific disease area might have a different purpose why data are captured. Often the amount and granularity of the acquired data, the laboratory focus as well as the research question might be completely different. Because of this diversity we need to *harmonize* all collected data from all locations. A detailed analysis of each data source is necessary to identify the meaning, data structure, and granularity for each clinical fact. Then the domain experts need to come to an agreement on *what* data are relevant to answer the specific research question and *how* they are organized. As obvious as this might sound, it is the most critical step in the whole process. As a result, a list of research relevant items, eventually grouped by elementary categories, should be available. This list, from now on denoted as ontology, is supposed to make sense to a domain expert. Finally, the ontology needs to be mapped with both, the documented syntax as well as the semantics of each individual data set.

This approach is supposed to be used as a process of continuous improvement. This means that the initial version of the ontology is allowed to have a low granularity whereas future versions are evolving continuously since the domain experts will come to agreements that affect the quantity and quality of the ontology.

The process of data harmonization usually involves many experts, mostly physicians and biometricians, but also study nurses as well as a medical informatician.

The latter focuses on the technical practicability while the discussion of the central ontology structure is ongoing. This target data structure might include sections such as

- Patient's demographics
- Laboratory results
- Common clinical data / health values
- Family history
- Treatment data (prescription / acceptance)

1.2. Transformation from Clinical Data Sources into the Target Structure

After a careful identification of the relevant clinical data, each clinical site needs to run through a process of three steps: (1) extract its clinical data from its site specific source; (2) transform its data into the format of the target ontology structure; and (3) load the results into the DW. For step (3) we act on the assumption that a DW is used as a common central data repository. This process is described as Extract-Transform-Load (ETL) and will be applied with an advanced open source tool. Within this tool we developed advanced and highly flexible methods enabling us to accelerate the initial ETL implementation.

1.3. Setting up the Data Warehouse

The general purpose of a DW is to collect data from several locations and in different formats in order to analyze its data as fast, convenient, and extensive as possible. Further helpful requirements are a data export function for user-defined queries on specific clinical facts as well as high usability on both, installation and the user-interface. For economic reasons an open source solution is preferred.

2. Results

2.1. A spreadsheet for managing data harmonization

As a helpful utility we created a comprehensive data harmonization table in Excel in order to provide a semantic matching between the several data sources and the target structure. In this table the previously mentioned target ontology marks the main structure and is extended with fields for the data type, e.g. String or Integer, a short description and, if appropriate, the accepted range of values. A *comments* field is also recommended. In case of ontology elements that have a limited number of values, e.g. categories or bivalent statements, it is important to state each of them in a separate row. This way, an individual handling for each element can be provided. This table can be used independently of a disease area.

Now, the harmonization table is expanded with the data sources by adding one data column for each participating hospital. Each data row, containing one specific ontology element, must be analyzed by the respective participant to identify the level of compatibility to the target ontology. There a three levels to differentiate: (1) complete, (2) sufficient and (3) no coverage. While level 1 compatibility can be easily mapped to the target ontology and level 3 is a lack of data, the most challenging part is sufficient

data coverage (2). Here, the data is basically available but cannot be matched directly and thus, some kind of data transformation is necessary. This might involve a recalculation of numerical values, e.g. for unit conversions, re-interpretation of area-specific date formats or a value re-interpretation due to a coding mechanism.

In General, the alignment of clinical data from each hospital site to the target ontology must be validated completely manually by one or more local domain experts. An automatic alignment is hard to realize and thus not recommended because of two reasons: (1) a computational semantic analysis of the meta data description cannot guarantee an 100 per cent match and (2) the context and purpose of the data records might be in a completely different focus and thus, might lead to misleading conclusions.

2.2. Talend Open Studio as a flexible open source ETL tool

The task to transform the source into the target data structure might be challenging. Therefore, there is a need for a powerful ETL tool. We created a well-structured and documented workflow in the sophisticated open-source ETL tool Talend Open Studio [6]. In order to enhance reutilization we implemented templates for the ETL tool in a way that it is capable to use a set of Excel files to describe different aspects of the target ontology, like descriptions for data types, dynamic and static categories and black-listed items.

This tool reduces massively the effort to implement filters for a specific hospital and is highly optimized on the database structure of the selected DW. Once the filters are set, the ETL tool can generate a stand-alone program to run the data import anywhere, without installing the complete ETL tool. This is especially useful for a physician with missing technical abilities.

2.3. An open source data warehouse as the central clinical data repository

The last element in the process chain of our framework is the central data repository for the clinical facts corresponding to the ontology. Our requirements, mentioned in the section Methods, were satisfied best by i2b2 [7], an advanced open source software framework for clinical researchers that provides a database structure as well as a web based interface especially for integration of clinical facts.

We took advantage of the ontology editor provided by an i2b2 plug-in to describe the target ontology structure. The i2b2 tailor-suited ETL jobs (section 2.2) are not only providing the correct transforming from the source into target data formats, but are also linking the clinical fact correctly to the corresponding ontology elements, based on a concept coding system provided by i2b2.

We also benefit from the well-designed usability. I2b2 provides a graphical user interface (GUI) that allows ontology queries by dragging and dropping clinical facts from the ontology tree into the filter widgets. Finally, our last requirement is fulfilled by a plug-in that enables the export of the clinical facts based on user-defined queries.

3. Discussion

Integrating heterogeneous clinical data into a central data repository is considered a necessary step for clinical research. We developed a best practice framework that breaks the complexity down into three consecutive basic steps consisting of (1) creating a harmonization table, (2) setting up an ETL process and finally (3) putting the resulting data structure into a central repository that enables custom queries. Furthermore, we provided spreadsheets and ETL templates [8] to support an individual implementation, based on the software tools of our choice. This may decrease the work load and improves the understanding of the complexity behind data integration.

The Integrated Data Repository Toolkit (IDRT) [9] project has intersections with our methods, but lacks in support of early steps of data harmonization. We focused specifically on the individual process of integrating heterogeneous data from multi-centered sites.

The framework we introduced in this paper still has potential for improvements in several directions. Data privacy is a critical element in each patient data based analysis. In our work we assumed that this issue has already been taken care of. This may not apply in all cases; therefore the framework can be enhanced by privacy issues, like patient's consents and pseudo nomination.

The implemented ETL solutions we described are depending on i2b2. Another solution might be more appropriate, e.g. when professional support or extended features of a DW are needed. An adaption of the ETL implementation to common commercial systems is possible.

References

[1] Hsiao C, Hing E. Use and characteristics of electronic health record systems among office-based physician practices: United States, 2001-2012. NCHS Data Brief 2012; (111):1–8

[2] Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. Journal of Biomedical Informatics 2009; 42(2):377–81. Available from: URL:http://www.sciencedirect.com/science/article/pii/S1532046408001226

[3] European Union 7th Framework Programme. EURenOmics [cited 2014 Jan 30]. Available from: URL:http://www.eurenomics.eu

[4] Deutsches Zentrum für Lungenforschung. DZL: The German Center for Lung Research [cited 2014 Jan 30]. Available from: URL:http://www.dzl.de

[5] Bundesministerium für Bildung und Forschung (BMBF). e:Med: Maßnahmen zur Etablierung der Systemmedizin [cited 2014 Jan 30]. Available from: URL:http://www.gesundheitsforschung-bmbf.de/de/5111.php

[6] Talend Open Studio: Talend Inc.; 2014. Available from: URL:http://www.talend.com

[7] Partners HealthCare System in Boston, Mass. i2b2: Informatics for Integrating Biology & the Bedside [cited 2014 Jan 30]. Available from: URL:http://www.i2b2.org

[8] Institute of Medical Biometry and Informatics, University of Heidelberg. Integration of Heterogeneous Phenotype Data [cited 2014 Feb 4]. Available from: URL:http://www.klinikum.uni-heidelberg.de/index.php?id=136562&L=1

[9] Goltz U, Magnor MA, Appelrath H, Matthies HK, Balke, Wolf-Tilo & Wolf, Lars C., editors. Integrated Data Repository Toolkit: Werkzeuge zur Nachnutzung medizinischer Daten für die Forschung: GI; 2012. (LNI)

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The Effect Object Paradigm – a Means to Support Medication Safety with Clinical Decision Support

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Abstract. Background: In many countries, officially approved drug information known as summary of product characteristics (SPC) is mostly available in text form, which cannot be used for Clinical Decision Support Systems (CDSS). It may be essential however to substantiate CDSS advice with such legally binding text snippets. In an attempt to link various drug data sources including SPC towards a CDSS to support medication safety in psychiatric patients we arrived at the notion of an effect object. Methods: A requirements analysis revealed data items and data structure which are needed from the patient and from the drug information source for the CDSS functionality. Published drug data modelling approaches were analyzed and found unsuitable. A conceptional database modeling approach using top down and bottom up modeling was performed. Results: The schema based data model implemented within the django framework centered on SPC "effect objects" which comprise all SPC data required for the respective CDSS function such as search for contraindications in the proposed medication. Today six effect objects have been defined for contraindications and warnings, missing indications, adverse effects, drug-drug interactions, dosing and pharmacokinetics. Conclusion: The transformation of SPC data to a database-driven "effect objects" structure permits decoupling between the CDSS functions and different underlying data sources and supports the design of reusable, stable and verified CDSS functions.

Keywords. Clinical Decision Support System, Medication Safety, Summary of Product Characteristics

Introduction

Clinical decision support Systems (CDSS) to avoid medication errors and improve patient safety have shown to be effective. It seems that CDSS are more successful for prescribing and initiating therapy than for the continuous monitoring of an existing therapy [1]. A CDSS to support medication safety should use the most recent drug

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database [2]. Several authors, however, demonstrated a discrepancy in timeliness of information in currently available digital drug databases e.g. for FDA warnings or pharmacogenomics data [3, 4]. The text based SPC itself may also be inconsistent [5, 6] and is not well suited for CDSS due to its free text format. Attempts to extract SPC drug information using natural language processing (NLP) have been proposed, but failed the required hundred percent reliability, thus requiring manual interpretation [7].

In the research project „Chemoinformatics-based optimization of the Patient Safety in drug therapy and personalized pharmacotherapy" in the Leading Edge Cluster "Erlangen Medical Valley EMN" to establish a medication safety CDSS for psychiatric patients we were faced with the task to integrate current SPC data and other drug knowledge sources for advanced decision support including prediction of metabolic pathways. We started with the German SPC and searched for a digital SPC representation which supports active decision support, facing the following questions:

1) Which drug data representation can best support CDSS with structured drug information and maintain the link to the text based sources of origin?
2) Which type and structure of SPC data is required to cover typical drug risk assessment functions such as adverse drug events or contraindications?

1. Methods

Based on real and constructed patient cases with drug safety risks we analysed the type, source and required coding of data elements needed for CDSS alerts such as checking contraindications or drug-drug interactions. Regarding available drug information we analyzed existing SPC formats, primarily the German mandatory SPC with its eleven standardized section headings and subheadings including therapeutic indications, method of administration, contraindications, warnings and precautions, but also the American SPL[8, 9] and the planned European PIM format [10]. Furthermore we checked previously proposed drug database models, e.g. [11-14] for their ability to support CDSS functions with SPC data. We were unable to find a model which accommodated our needs of simultaneous CDSS support and linkage to the text source of origin.

Therefore, we started an own conceptional database modeling effort using a sandwich modeling approach. Top-down we created a schema which supported the mapping of text based SPC data and other pharmacology text sources into the smallest unit of a freely definable text block containing a meaningful piece of drug information. Bottom up we extended this schema with the properties required for a clinical CDSS system which should take most of its input from the database, thus requiring only a minimum rule based part of the knowledge base. To achieve such a goal, text based data, e.g. from SPC or textbooks must be attributed with structured and categorized data items such as coded symptoms and diagnoses or numerical values for pharmacokinetic calculations. The resulting effect objects schema was implemented using the django framework on top of a MySQL Version 5.5.32 database. In further steps the schema has been filled with the contents of 800 German SPC obtained from UBM Medica and a small set of rule based functions plus a rules engine have been implemented in the same framework to complete the CDSS.

2. Results

The combined top down and bottom up modelling approach answered our second question regarding requirements for type and structure of SPC data to support drug risk CDSS functions. Results of the uppermost analysis level are given in table 1 and show also desired classification formats where applicable.

Table 1. Results of requirements analysis: which data in which classification is required from either the clinical patient database (P) or the respective drug SPC (S) or both.

Type of alert	Symptoms (ICD/ Alpha-ID)	Lab Values	ECG data	Drug Intolerance	Age/ Sex / Pregnancy	ATC / Dose schema /Q_0
Missing Indication	P/S				P/S	
Double medication	P/S					P/S
CI - Drug<>Drug						S
CI - Drug<>Diagnosis	P/S					
CI- Drug<>Laboratory value	P/S	P/S				
CI - Drug<>QT Prolongation			P/S			
CI – Drug<>Allergy				P		
CI - Drug <>Age / Gender / Pregnancy	P/S	P/S			P/S	
Drug-Drug Interaction			P/S			S
Adverse reaction		P/S	P/S	P	P/S	P/S
Dosage administration	P/S	P/S			P/S	P/S

The table reads as follows: To detect a contraindication between a pathologic patient laboratory value and a drug we need either the numeric lab value from the patient (P) and the lab value mentioned to be risky in the SPC (S) or a patient diagnosis coded in ICD which indicates a pathologic lab value (P) or a diagnosis mentioned in the SPC (S) which marks the pathologic lab as a contraindication or any combination of both.

The first question for an appropriate drug data representation could be successfully answered with an effect objects schema. Effect objects, as proposed in this modeling approach, share the properties required for the respective CDSS function (table 1). An indications effect object for example, would be the feeder for a rule based CDSS function to check if a given drug is indicated for the patient. This rule will simply compare patient diagnoses (coded in ICD) with those diagnoses mentioned in the application and dosing section of the SPC (parsed in the effect objects schema) which describe the diseases which can be treated with the drug. Such an indications object contains a circumscript free text block from the SPC section and the mapped coding information to one or more appropriate ICD and/or AlphaID codes. The Alpha-ID classification is a comprehensive and unique clinical coding system for diagnoses available from the German DIMDI [15]. Changes to this effect object will immediately influence the CDSS functionality. Similar effect objects have been created for contraindications and warnings, adverse effects, dosing and pharmacokinetics, more will follow when required.

The effect object schema has been implemented in a relational database environment and comprises 27 tables with 182 columns which center on the “effect object” (fig 1).

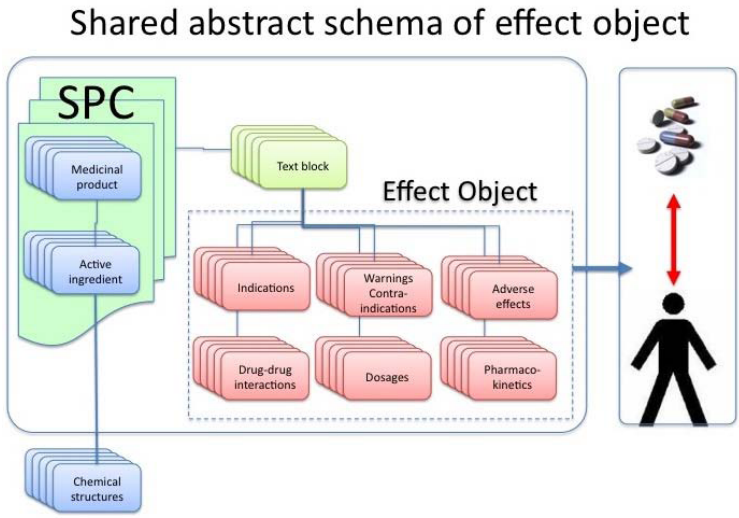


Figure 1. The proposed SPC effect object groups required and associated structured and/or coded data around the text block, a unit of information derived from an arbitrary drug knowledge source, e.g. the SPC. The effect object enables a CDSS to assess the interaction between the patient and a given drug.

3. Discussion

We propose the novel notion of an "effect object" to extract, annotate and classify deterministic text segments from arbitrary drug information sources such as SPCs to enable these data sources for clinical decision support.

Comparing to previously proposed data structures such as [11-14], often with a different focus, e.g. to model patient related drug data in an ICU system[13], we are able to maintain the link to the original text based source which can be essential in cases of legal action. In the realized CDSS function we present this direct text link for reference. Compared to the UK dm+d (NHS Dictionary of Medicines and Devices) modeling approach [16] which proposes a virtual medicinal product (VMP) to detach drug information from the underlying actual medicinal product (AMP) we focus on the direct support for a CDSS and not on the construction of a vocabulary. Compared to the openEHR approach [17] which proposes reusable openEHR archetypes within the digital patient data record (and has found only limited dissemination in current clinical information systems CIS) we do not focus on the patient data representation since our CDSS is designed to be interfaced with various CIS using a generic patient information object constructed according to the criteria mentioned in table 1.

The proposed effect object as an intermediate enables decoupling of the knowledge based functions within the CDSS from the various underlying information sources which can be exchanged or complemented without alteration to the verified decision support logic within the CDSS. It does not solve the semantic gap between textual data sources in unstructured format and the required semantic annotation and coding, which may require manual or automated coding of information, but enables reuse of already coded elements, which lay within the effect object.

We hope, that in the long term, the definition of effect objects may prompt pharmaceutical companies and the legislator to move forward to new SPC structures

which support semantic annotation and comprise own elements which resemble the proposed effect objects, thus offering better support for clinical decision making. Transformation steps on this pathway comprise:

1) Supplying structured and coded exact interpretation of extracted SPC data text blocks, e.g. coding for diagnoses in ICD or AlphaID
2) Partitioning such data similar to the prosed effect objects into clearly distinct classes such as contraindications or indications, which comprise the complete data for the respective object
3) Representing clear knowledge dependability and versioning of information regarding the new version of SPC

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References

[1] S.A. Pearson, A. Moxey, J. Robertson, I. Hains, M. Williamson, J. Reeve, D. Newby, Do computerised clinical decision support systems for prescribing change practice?, *BMC Health Serv Res*, **9** (2009) 154.
[2] A.F. Aly, K. Menges, C.H. Haas, L. Zimmermann, J. Kaltschmidt, M. Criegee-Rieck, Prerequisites for electronic systems evaluating safe and effective drug therapy. A contribution to the Action Plan of the Federal Health Ministry, *Bundesgesundheitsblatt Gesundheitsforschung* **54** (2011) 1170-1178.
[3] C.M. Cheng, B.J. Guglielmo, J. Maselli, A.D. Auerbach, Coverage of FDA medication boxed warnings in commonly used drug information resources, *Archives of internal medicine*, **170** (2010) 831-833.
[4] K.T. Vaughan, K.L. Scolaro, H.N. Anksorus, M.W. Roederer, An evaluation of pharmacogenomic information provided by five common drug information resources, *J Med Lib Assoc*, **102** (2014) 47-51.
[5] B. Pfistermeister, C. Schenk, J. Kornhuber, T. Burkle, M.F. Fromm, R. Maas, Different indications, warnings and precautions, and contraindications for the same drug-an international comparison of prescribing information for commonly used psychiatric drugs, *Pharmacoepidemiol Drug Saf*, **22** (2013) 329-333.
[6] V. Reggi, R. Balocco-Mattavelli, M. Bonati, I. Breton, A. Figueras, E. Jambert, C. Kopp, E. Montane, L. Rago, F. Rocchi, G. Prescribing information in 26 countries: a comparative study, *Eur J Clin Pharmacol*, **59** (2003) 263-270.
[7] S. Rubrichi, S. Quaglini, A. Spengler, P. Russo, P. Gallinari, A system for the extraction and representation of summary of product characteristics content, *Artif Intell Med*, **57** (2012).
[8] G. Schadow, HL7 Structured Product Labeling - electronic prescribing information for provider order entry decision support, *AMIA Annu Symp Proc*, (2005) 1108.
[9] G. Schadow, Structured product labeling improves detection of drug-intolerance issues, *J Am Med Inform Assoc*, **16** (2009) 211-219.
[10] E.M. Agency, PIM Concepts, PIM DES v2.1, 2010.
[11] W. Sujansky, A formal model for bridging heterogeneous relational databases in clinical medicine, Medical Information sciences, Standford University, Standford, 1996, pp. 302.
[12] C.G. Chute, J.S. Carter, M.S. Tuttle, M. Haber, S.H. Brown, Integrating pharmacokinetics knowledge into a drug ontology: as an extension to support pharmacogenomics, *AMIA Annu Symp Proc* (2003) 170-174.
[13] A. Michel, A. Junger, M. Benson, D.G. Brammen, G. Hempelmann, J. Dudeck, K. Marquardt, A data model for managing drug therapy within a patient data management system for intensive care units, *Comput Methods Programs Biomed*, **70** (2003) 71-79.
[14] O. Cure, J.-P. Giroud, Ontology-based Data Quality enhancement for Drug Databases, WWW2007, Banff, Canada, 2007.
[15] DIMDI, http://www.dimdi.de/static/de/klassi/alpha-id/.
[16] NHS, Dictionary of medicines and devices. Data Model, (2013).
[17] C.D. Kohl, S. Garde, P. Knaup, Facilitating secondary use of medical data by using openEHR archetypes, Studies in health technology and informatics, 160 (2010) 1117-1121.

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Breast Cancer and Quality of Life: Medical Information Extraction from Health Forums

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Abstract. Internet health forums are a rich textual resource with content generated through free exchanges among patients and, in certain cases, health professionals. We tackle the problem of retrieving clinically relevant information from such forums, with relevant topics being defined from clinical auto-questionnaires. Texts in forums are largely unstructured and noisy, calling for adapted preprocessing and query methods. We minimize the number of false negatives in queries by using a synonym tool to achieve query expansion of initial topic keywords. To avoid false positives, we propose a new measure based on a statistical comparison of frequent co-occurrences in a large reference corpus (Web) to keep only relevant expansions. Our work is motivated by a study of breast cancer patients' health-related quality of life (QoL). We consider topics defined from a breast-cancer specific QoL-questionnaire. We quantify and structure occurrences in posts of a specialized French forum and outline important future developments.

Keywords. breast cancer, quality of life study, query expansion, social media, text mining

Introduction

Health-related quality of life (QoL) is a multidimensional, subjective and dynamic concept with three main domains: physical, psychological and social functioning. Referring to the patient's perception of his treatment and illness, it constitutes a relevant alternative clinical endpoint. In 2012, the number of new cases of breast cancer in France amounts to 48,763 according to the French National Cancer Institute (INCa[2]). The overall relative survival rate 5 years after diagnosis is estimated at around 89% on average. Modern treatments are still exhausting to undergo such that many clinical research projects are now addressing the patients' QoL. We focus on stories told by patients in online health forums, where numerous topics deal with how to cope with symptoms of the illness and secondary treatment effects. Hancock et al. [1] showed that anonymous communication via computers facilitates the expression of affective states such as emotions, opinions and doubts compared to more traditional

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2 http://www.e-cancer.fr

communication contexts. Recently, the impact of social media on health outcomes has been studied extensively. Merolli et al. [2] survey the positive effects of social media in chronic disease management. Subirats et al. [3] affirm that social networks promote knowledge democratization and user-empowerment. In this study, we aim to capture topics of interest in patient stories related to breast cancer. Oncologists may have difficulty to obtain such useful patient-centred information directly from patients. It may 1) assist them to investigate how patients use forums in relation to their individual needs, 2) explain consistency or disparity between different patient health outcomes, 3) help collect patients' individual perceptions and preferences, 4) help improve the construction and validation of questionnaires for traditional clinical studies.

1. Methods

We seek for posts in specialized forums related to a list of topics of interest coming from questionnaires usually filled in by patients. The studied French *CancerDuSein.org* forum with data from 2011 to 2013 holds 16,961 posts from 675 users in more than 1,050 threads with a median of 7 replies per thread, at least 2 replies in 75% of the threads and more than 15 replies in less than 25% of the threads. A median number of 4 authors write the replies in a thread. Semi-automatic information extraction from these data remains a significant technological challenge. The text structure is not standardized (slang, spelling and grammatical errors, etc.) and simple text search for relating topics of interest and posts is not effective. Whereas a query such as *bouche sèche* (=*dry mouth*) returns many false negatives and misses related occurrences such as *langue sèche* (=*dry tongue*), too general queries like *bouche* return many false positives. Query expansion is therefore necessary, achieved in the following by using web resources to produce and validate topic expansions. Our method consists of 4 steps: 1) message collection, 2) manual topic identification and morphological expansion, 3) automatic synonym-based topic expansion, 4) global synthesis.

Step 1: Message collection. Classical preprocessing steps are applied to overcome difficulties owing to the specificity of the language. Named entities like user names or drugs[3] are identified. A part-of-speech tagger[4] is used to retrieve lemmas and to detect unknown words. We replace unknown words if a nearby word is found in a dictionary designed for the project (French words[5], named entities).

Step 2: Topic identification and morphological expansion. We define a list of topics of interest based on the breast-cancer specific module QLQ-BR23 of the QLQ-C30 questionnaire [6] proposed by the European Organisation for Research and Treatment of Cancer (EORTC), which evaluates functional scales, symptom scales and the global health status. An expert manually defines the topics using questionnaire items and scales. Initially, we represent a topic through a topic set $T_I=\{TTI\}$ composed of n_I initial topic terms TTI, each composed of one or several lemmas without stop words. Basic morphological variations (nouns, verbs, adjectives) with the same word stem are taken into account and yield n_M additional topic terms TTM in the morphologically expanded topic set $T_{IM}=\{TTI\}\cup\{TTM\}$. Topic sets will be used to formulate the query for detecting topic occurrences in forum posts, see Step 4.

3 http://medicament.comprendrechoisir.com/
4 http://www.cis.uni-muenchen.de/~schmid/tools/TreeTagger/
5 http://www.aspell.net

Step 3: Automatic synonymic topic expansion. Morphological variations do not cover all lexical variations found in forums. We extend T_{IM} by adding synonymic topic terms TTS such that $T_{IMS}=T_{IM}\cup\{TTS\}$. Medical terms from the MeSH[6] are eligible for substitution by any related term that appears in the same MeSH hierarchy level. However, the MeSH is limited to technical vocabulary used primarily by health professionals. In addition, we use an online synonym tool[7] to enrich our list of proposed topic expansions. Only synonyms containing no stop words are considered for expansion. Since synonymy depends strongly on the context, we propose a web-based validation to rank synonymic expansions. The originality of our approach is to focus not on the number of occurrences as done by [7,8], but on the similarity of contexts built for the initial topic set T_{IM} and for each potential expansion TTS. The contexts are constructed from the most frequent co-occurrences within a large corpus of documents. For T_{IM}, we use the n_I+n_M topic terms of T_{IM} as queries submitted to an internet search engine[8]. We define a topic context as a weighted feature space based on the top N_{snip} search engine snippets for each query. Features taken into account are unigrams and bigrams of lemmatized nouns, verbs and adjectives. The weight of a feature f is calculated according to its frequency in the (n_I+n_M) x N_{snip} snippets, written $N(f|T_{IM})$, and the frequency in the French language[9], written $N(f|Fr)$. A formula similar to the common Tf-Idf approach is applied to downweight weakly discriminant features:

$$weight(f\,|\,T_{IM}) = N(f\,|\,T_{IM})/(N_{snip}\times(n_I+n_m)\times\log N(f\,|\,Fr)) \quad (1)$$

In our experimentations, we double the weight of bigrams, which are strongly discriminant features. Denote by E_i, i=1,…,k the weight of the top k features f_i ordered by decreasing weight after removal of features that are part of the proposed topic expansion TTS (*expected weights*). The context of each topic expansion is constructed analogously: we submit the query <TTS> to the chosen internet search engine and replace T_{IM} by TTS and (n_I+n_M) by 1 in Eq. (1). Denote by O_i, i=1,…,k, the weight of the features f_i, i=1,...,k, in the expansion context (*observed weights*). To rank a topic expansion TTS with respect to its proximity to T_{IM}, various measures could be applied (cf. [8]). Here, we propose to use a similarity score S based on a variant of the chi-squared statistic

$$S = 1-\left(\sum_{i=1}^{k} E_i\right)^{-1}\times\sum_{i=1}^{k}\max(E_i-O_i,0)^2/E_i \quad (2)$$

The score S takes values between 0 for disjoint contexts and 1 for identical contexts. The truncation at 0 avoids penalizing occurrences that are more frequent in the expansion context than in the topic context. Elevating to the power 2 penalizes the situation where observed weights are considerably smaller than expected weights. We include those topic expansions TTS into the topic set T_{IMS} whose score is sufficiently high, e.g. $S > S_0$ for some fixed threshold $0<S_0<1$.

6 French version of the Medical Subject Headings http://mesh.inserm.fr/mesh/
7 http://synonymo.fr
8 http://www.yahoo.fr
9 http://eduscol.education.fr/cid50486/liste-de-frequence-lexicale.html

Step 4: Global synthesis. We detect topic occurrences in lemmatized forum posts based on queries built from the expanded topic set T_{IMS}. Keywords constituting a topic term are combined by the AND operator "&".Topic terms are then joined by the OR operator "|". The query must be matched in a range of at most N_{lem} lemmas in a post. Retrieved occurrences can be represented in terms of the number of occurrences per topic, message IDs, phrases of occurrence, etc.

2. Results

The QLQ-BR23 questionnaire with 23 items is represented by 13 topics, which are aggregated to form 5 topic groups: *body image*, *sexuality*, *secondary effects* (exempt *hair loss*), *hair loss*, *breast symptoms*. For each topic, we calculate the score S for at most 2500 topic expansions. The number of snippets is fixed to N_{snip}=40 for each search engine query. We compare contexts based on the k=50 most relevant features of the topic context. Our experimentations suggest adding synonymic expansions TTS with score superior to 0.2 to the set T_{IMS}. The final query used to retrieve occurrences in forum posts is composed of 31 initial topic terms in T_I, 70 additional morphological topic expansions in T_{IM} and 596 automatically validated synonymic topic expansions.

When fixing the score threshold S_0 below 0.2 (e.g., to 0.1), we found a considerable increase in the number of false positives such that precision degrades, whereas we also find a significant number of additional true positives leading to an improvement in recall. We decided for a manual selection of relevant topic expansions with score between 0.1 and 0.2 by an expert. Figure 1 presents the number of retrieved posts. We attribute these occurrences as follows: occurrences of initial topic terms given by T_I always count for type "initial", occurrences of morphological variants count for "morphological" but not for "automated", and only the remaining occurrences are attributed to "automated". The manual validation of a stratified subsample of size 400 by two experts results in a precision of 0.89 with a validation agreement of 0.86 (Cohen's kappa). Automatic topic expansion has significantly increased the number of retrieved posts without loss in precision. However, only a small number of posts related to sexuality and body image were detected.

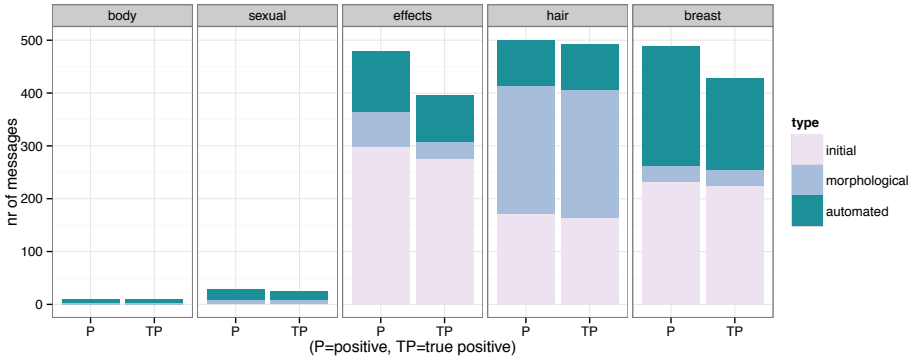


Figure 1. Number of retrieved forum posts by topic group and by type of topic term.

3. Discussion

A study of QoL through user content posted in health forums presents an interesting alternative to QoL analysis based on the collection of auto-questionnaires. The substantial number of occurrences retrieved for certain topics in our example is promising for a deeper analysis based on a classification of emotions (fear, joy…) associated to the occurrences. The small number of posts related to sexuality and body image is surprising. Lexical variations referring to such subjects may be more heterogeneous and hence more difficult to detect automatically. Moreover, the rare occurrence of these topics is an interesting result in itself since it hints at subjects that play a minor role in the actualities of patients' daily life. Moreover, self-censorship of forum users could be stronger on certain highly intimate subjects. In prospective studies, we intend to confirm the utility of our method by testing it against an appropriately chosen gold standard and by applying it to other data sets. For a proper statistical treatment of our results, we plan to develop classification methods for the retrieval of forum users' patient history from forum data. Finally, to reduce the number of false negatives returned by the topic query, it may be more efficient to construct topics not from existing questionnaires, but in a joint effort of clinical experts and text mining specialists to tailor topics for easier detection. Although forum content is usually publicly available, we stress that results of such approaches should be fully anonymized in order to respect the privacy of individual forum users.

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References

[1] Hancock T, Toma C, and Ellison N. The truth about lying in online dating profiles. Proceedings of the SIGCHI conference on Human factors in computing systems 2007;449–452.
[2] Merolli M, Gray K, Martin-Sanchez F. Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances. Journal of Biomedical Informatics 2013;46(6):957–969.
[3] Subirats L, Ceccaroni L, Lopez-Blazquez R, Miralles F, García-Rudolph A, Tormos JM. Circles of Health: Towards an advanced social network about disabilities of neurological origin. Journal of Biomedical Informatics 2013;46(6):1006–1029.
[4] Balahur A. Sentiment analysis in social media texts. 4th workshop on Computational Approaches to Subjectivity, Sentiment and Social Media Analysis 2013;120–128.
[5] Aaronson NK, Ahmedzai S, Bergman B, Bullinger B, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JC. QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. Journal of the National Cancer Institute 1993;85:365–376.
[6] Turney PD. Mining the Web for synonyms: PMI-IR versus LSA on TOEFL. Proceedings of ECML 2001;491–502.
[7] Roche M. Garbasevschi OM, WeMiT: Web-Mining for Translation. Proceedings of PAIS/ECAI, Conference on Prestigious Applications of Intelligent Systems 2012; Poster.
[8] Salton G, Buckley C. Term-weighting approaches in automatic text retrieval, Information Processing and Management 1998;24(5):513–523.

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Frame Semantics-based Study of Verbs across Medical Genres

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Abstract. The field of medicine gathers actors with different levels of expertise. These actors must interact, although their mutual understanding is not always completely successful. We propose to study corpora (with high and low levels of expertise) in order to observe their specificities. More specifically, we perform a contrastive analysis of verbs, and of the syntactic and semantic features of their participants, based on the Frame Semantics framework and the methodology implemented in FrameNet. In order to achieve this, we use an existing medical terminology to automatically annotate the semantics classes of participants of verbs, which we assume are indicative of semantics roles. Our results indicate that verbs show similar or very close semantics in some contexts, while in other contexts they behave differently. These results are important for studying the understanding of medical information by patients and for improving the communication between patients and medical doctors.

Keywords. Medical informatics, Consumer health informatics, Terminologies, Natural Language Processing, Frame Semantics, France

Introduction

The field of medicine gathers actors with various backgrounds, such as medical doctors, students, pharmacists, managers, biologists, nurses, imaging experts and of course patients. These actors have different levels of expertise ranging from low (typically, the patients) up to high (*eg*, medical doctors, pharmacists, medical students). Moreover, actors with different levels of expertise interact, while their mutual understanding might not always be completely successful. This specifically applies to patients and medical doctors [1,2]. We propose to perform a contrastive and comparative analysis of written medical corpora in French, which are differentiated according to their levels of expertise. More specifically, we concentrate on the study of selected verbs used in these corpora and aim to characterize their syntactic and semantic features. We assume that verbs are an excellent starting point for modeling the semantics of sentences. The description of verbs is based on the Frame Semantics (FS) framework [3]. The FS framework is increasingly used for the description of lexical units in different languages [4-6]. Until recently, French has been neglected with regard to this framework. Moreover, this framework can be adapted for processing

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data related to specialized languages [7-9]. FS puts forward the notion of "frames", which are defined as conceptual scenarios that underlie lexical realizations in language. For instance, in FrameNet [10], the frame CURE (Fig. 1) is described as a frame containing specific Frame Elements (FEs), (such as HEALER, AFFLICTION, PATIENT, TREATMENT), and including lexical units (LUs) such as *cure, alleviate, heal, healer, incurable, treat*.

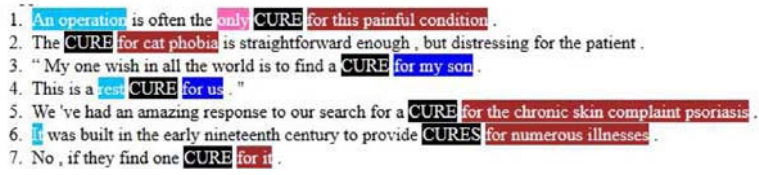


Figure 1. Examples of FrameNet frames for the verb *cure.*

According to our hypothesis, an FS-like modeling should allow us to describe the syntactic and semantic properties of verbs and uncover linguistic differences in corpora of different levels of expertise. Our study relies on the use of terminologies for annotation of verb arguments in corpora differentiated by their expertise levels, on Natural Language Processing (NLP) and on contrastive analysis of these verbs.

1. Material

Corpora. We study three medical corpora dealing with the specific field of cardiology. These corpora are distinguished according to their levels of expertise and discursive specificities [11]. *Expert* corpus (1,310,115 occurrences) contains expert documents written by medical experts for medical experts (its documents usually correspond to scientific publications, and has a high level of expertise); *student* corpus (395,215 occurrences) contains expert documents written by medical experts for medical students (its documents usually correspond to didactic support created for students, and has a middle level of expertise, in which technical terms are usually introduced and defined); *forum* corpus (1,638,167 occurrences) contains non-expert documents written by patients for patients (it contains messages from the Doctissimo forum *Hypertension Problemes Cardiaques*, and has an even lower level of expertise, although technical terms may also be used).

Semantic resources. We use the Snomed International terminology [12] because it contains an extensive set of terms in French (n=144,267). The terms are structured into several semantic axes, which we also exploit for the semantic annotation of the three corpora: *T* Topography or anatomical locations (*coeur (heart), vaisseau (vessel)*); *S* Social status (*mari (husband), ancien fumeur (former smoker)*); *P* Procedures (*césarienne (caesarean), transducteur à ultrasons (ultrasound transducer)*); *L* Living organisms, such as bacterias and viruses, but also human subjects (*patients, tu (you)*); *J* Professional occupations (*anesthésiste (anesthesiologist)*); *F* Functions of the organism (*pression artérielle (arterial pressure), insuffisance (deficiency)*); *D* Disorders (*obésité (obesity), hypertension artérielle (arterial hypertension)*); *C* Chemical products (*médicament (medication), sodium*); *A* Physical agents (*prothèses (prosthesis), cathéter (catheter)*). We expect these categories to be indicative of frame elements (FEs), while the individual terms should correspond to lexical units (LUs). For instance, the Snomed

category *Disorders* should allow us to discover and group under a single label LUs *(hypertension (hypertension), obésité (obesity))* related to the FE DISORDER.

2. Methods

Corpora pre-processing. The corpora are collected online and properly formatted. They are then tokenized and POS-tagged with the French Tree-tagger [13]: its output contains words assigned to parts of speech (verbs, nouns, adjectives) and lemmatized to their canonical forms (singular and masculine adjectival forms, infinitive verbal forms). In order to improve the results, we check the output of the POS-tagging with the Flemm tool [14].
Verb selection. Sets of lemmatized verbs are extracted and their frequencies are computed. The verb selection relies on the following principles: (1) Remove forms that do not correspond to verbs, such as POS-tagging errors (*cardiologuer, dolipraner, rhumer*), foreign words usually incorrectly lemmatized (*case-mixer, databaser, headacher*), and misspellings; (2) Remove verbs that do not convey a medical meaning (perception, movement, modal, or state verbs); (3) Check the meaning of the verbs in a medical dictionary [15], for which verbs or their nominal forms have to appear there [16]. For instance, the verb *consulter (consult)* is not recorded in the dictionary but its nominal form *consultation* is; (4) Keep those verbs that have a frequency of 30 occurrences in the corpora. Sentences containing the selected verbs are extracted.
Semantic annotation. The sets of sentences are annotated using the Ogmios platform [17]. In addition to the syntactic annotation, semantic annotation is obtained after the projection of the semantic resource: the categories label the arguments (likely to correspond to FEs), while the specific terms correspond to LUs. We assume that categories from Snomed are useful for the description of semantic frames in medical corpora and terms from this terminology are useful for the detection of relevant LUs.
Contrastive analysis of verbs. The semantically annotated sentences are analyzed manually in order to verify if the semantic roles and lexical units are correctly recognized. Wherever necessary, these annotations are enriched manually. This may apply to both missing or unrecognized LUs and FEs. Once the semantic annotation and labeling are completed, the verbs from different corpora are analyzed in order to study the differences and similarities which may exist between the medical discourse and the uses of verbs in these corpora.

3. Results and Discussion

During the verb selection, an important number of verbs were removed because they correspond to errors, misspellings, and non-medical meanings. The subset of verbs which convey medical meanings corresponds to 0.76% (n=47) of the original set. The final subset contains 21 verbs. From this subset, we selected four verbs for a fine-grained analysis: *observer (observe), détecter (detect), développer (develop)*, and *activer (activate)*. These verbs were selected for two reasons: they were found in a high number of contexts and these contexts seem to be diversified. Sentences corresponding to the selected verbs have been automatically annotated with the semantic resource indicative of FEs. The resulting annotation was checked and enriched manually. We observe that few errors are generated. The main limitations are due to partial

annotations *(facteur (factor))* instead of *facteur V de Leiden (Factor V Leiden))* and missing LUs *(site d'insertion (insertion site))* as TOPOGRAPHY, *risque (risk)* as FUNCTION, usually not recorded in the terminology. The syntactic information is also associated with the corresponding LUs (mainly nouns or noun phrases). Another limitation discovered at this step is due to the erroneous POS-tagging. For instance, among the 32 contexts in which the verb *activer* appears in the *forum* corpus, 15 correspond to its adjectival forms (*marche active (active walking)*). The contrastive analysis is performed manually. Among the most frequent labels for FEs, we can observe for instance that LIVING ORGANISM *L* is the most frequent label and appears in all corpora. Typically, it corresponds to human subjects. In the *expert corpus,* PROCEDURES, DISORDERS and CHEMICALS are also very important. Interestingly, with the verb *détecter,* the labels for FEs are identical in both corpora. Among the most frequent patterns of FEs with N0 (subject) and N1 (object) functions, we can observe some common patterns in different corpora (examples below with genuine misspellings):

P détecter D: *j'ai acheter un tensiomètre$_P$ qui détecte les anomalie cardiaque$_D$*

(I bought a blood pressure monitor$_P$ that detects cardiac abnormality$_D$

D développer D: *Une prééclampsie précoce ou sévère$_D$ augmente le risque de développer une hypertension chronique$_D$ et des maladies cardiovasculaires$_D$.*

(Early or severe pre-eclampsia$_D$ increases the risk to develop chronic hypertension$_D$ and cardiovacular diseases$_D$.)

Other patterns remain specific to a given corpus. More generally, the verb *développer* is used in six patterns common to the two corpora, and eight and five patterns specific to the *expert* and *forum* corpora respectively, while *détecter* appears in six common patterns and six specific to each of the corpora. No common pattern was identified for *activer*. Among the specific patterns, we can find:

développer T (forum corpus): *Certaines personnes réussissent à développer des branches de leurs coronaires$_T$*

développer P (expert corpus): procedures like *méthodes de surveillance du foetus, stratégie diagnostique individualisée, télémédecine* are developed with high priority within biomedical research, while this fact is missing in forum discussions.

F activer F: *les formes recombinante et synthétique du nésiritide$_F$ sont comparables dans leur capacité d'activer les récepteurs GC-A$_T$*

Another difference is that in *forum* corpus, we can find some contexts in which verbs do not instantiate all the expected FEs. The *student* corpus has intermediate position. We assume that when the verbs present common patterns within corpora, these verbs, although they have a medical meaning, can be correctly understood by patients; when the FEs are partially instantiated, differ from one corpus to the other, or show an important difference of frequency, this may indicate that the understanding may be partial and that more thorough explanations are needed for patients. The finding proposed by this study can be used for automatically processing documents designed for patients and for making the content of these documents more appropriate.

4. Conclusion and Future work

We proposed an NLP approach to automatically discover the participants of verbs and label them using an existing medical terminology assuming that the semantic classes of the terminology are indicative of frame elements (FEs) within the framework of Frame

Semantics. The study was performed with three medical corpora differentiated according to their levels of expertise: high expertise in the *expert,* low in the *forum* corpora and intermediate in the *student* corpus. The contrastive analysis of verbs was done on the basis of automatic annotations completed manually when necessary. The analysis indicates that some occurrences of verbs share FEs in the studied corpora, while others select different FEs according to corpora.

We plan to extend the study to other verbs and other syntactic positions (in addition to N0 and N1). In addition to the automatic semantic annotation performed in this study, the automatic distinction between core (mandatory) FEs and non-core (optional) FEs [18], and between the syntactic positions of the labeled entities are other directions. Our findings may be helpful for improving understanding between medical staff and patients, and adapting the content of scientific literature for patients. They can also be used for the syntactic simplification of medical documents.

References

[1] A McCray. Promoting health literacy. *Journal of American Medical Informatics Association 2005*, 12, 152-163.

[2] Q Zeng-Treiler, H Kim, S Goryachev, A Keselman, L Slaugther, and CA Smith. Text characteristics of clinical reports and their implications for the readability of personal health records. In *MEDINFO 2007,* 1117-1121, Brisbane, Australia.

[3] C Fillmore. *Frame Semantics, 1982*, 111--137.

[4] S Atkins, M Rundell, and H Sato. The contribution of framenet to practical lexicography. *International Journal of Lexicography 2003*, 16(3), 333-357.

[5] S Padó and G Pitel. Annotation précise du francais en sémantique de rôles par projection cross-linguistique. In *TALN 2007*.

[6] L Borin, D Dannélls, M Forsberg, M Toporowska Gronostaj, and D Kokkinakis. The past meets the present in the swedish framenet++. In *14th EURALEX International Congress 2010*, 269-281.

[7] AM Dolbey, M Ellsworth, and J Scheffczyk. *BioFrameNet: A domain-specific FrameNet extension with links to biomedical ontologies*. KR-MED 2006, 87-94.

[8] T Schmidt. *The Kicktionary – A Multilingual Lexical Resource of Football Language 2009*, 101-134.

[9] J Pimentel. Description de verbes juridiques au moyen de la sémantique des cadres. In *TOTH 2011*.

[10] J Ruppenhofer, M Ellsworth, MRL Petruck, CR. Johnson, and J Scheffczyk. Framenet II: Extended theory and practice. Technical report, FrameNet, 2006. J Pearson. *Terms in Context*, volume 1 of *Studies in Corpus Linguistics*. John Benjamins, Amsterdam/Philadelphia, 1998

[11] RA Côté. *Répertoire d'anatomopathologie de la SNOMED internationale, v3.4*. Université de Sherbrooke, Sherbrooke, Québec, 1996

[12] H Schmid. Probabilistic part-of-speech tagging using decision trees. In *ICNMLP,* pages 44--49, Manchester, UK., 1994

[13] F Namer. FLEMM : un analyseur flexionnel du français à base de règles. *Traitement automatique des langues (TAL)*, 2000 41(2):523-547.

[14] L. Manuila, A. Manuila, P. Lewalle, and M. Nicoulin. *Dictionnaire médical*. Masson, Paris, 2001.

[15] C Tellier. Verbes spécialisés en corpus médical: une méthode de description pour la rédaction d'articles terminologiques. Technical report, Université de Montréal, 2008.

[16] T Hamon and A Nazarenko. Le développement d'une plate-forme pour l'annotation spécialisée de documents web: retour d'expérience. *TAL 2008,* 49(2),127-154.

[17] F Hadouche, S Desgroseilliers, J Pimentel, M.-C. L'Homme, and G Lapalme. Identification des participants de lexies prédicatives : évaluation en performance et en temps d'un système automatique. In *TIA 2011*

[18] L Brouwers, L Bernhard D, Ligozat A.and T François. Simplification syntaxique de phrases pour le français. In TALN 2012, 211–224, Montpellier

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Discovering Health Knowledge in the BC Nurse Practitioners Encounter Codes

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Abstract. Integrating the Nurse Practitioner (NP) role into clinical practice settings is new in British Columbia (BC), Canada. Encounter codes are unique numeric codes assigned to specific types of patient care services performed by NPs. In this study we apply knowledge discovery techniques to analyze the encounter codes extracted from the BC Ministry of Health database to understand the most common practice activities carried out by NPs and what diseases patients sought care for from NPs. The analysis produced important information about NPs' practice patterns. This work leads to a better understanding of NP practice patterns in BC.

Keywords. Nurse Practitioner, Data Mining, Knowledge Discovery, Health Care

Introduction

A Nurse Practitioner (NP) is a registered nurse who has additional education and training in a specialty area such as family practice. The NP role has existed in many Canadian provinces and the United States for more than 40 years [1]. In Canada, NPs are part of the front-line team providing primary health care to Canadian citizens. The evidence accumulated over these years has consistently demonstrated that NPs provide safe and effective care. Researchers consistently find that patients are satisfied with the care received from NPs, trust NPs, feel that NPs take their problems seriously and discuss their concerns, have expert communication skills, and are approachable [2-4].

Since 2005, when legislation enabling the NP role was enacted in British Columbia, (BC) integrating the role into clinical practice settings has been a priority. To date, $62.6 million has been invested to support and resource the integration of NPs. At the same time, the BC Ministry of Health (MoH) developed encounter codes (ECs) to be used by NPs to track their practice activities. ECs are unique numbers assigned to specific types of patient care services performed by NPs. NPs are expected to submit an encounter code to the MoH at the end of each patient encounter.

The main objective of this paper is to answer the following two questions. 1) What are the most common practice activities carried out by NPs during encounters with patients? 2) What are the most common health conditions for which patients sought care for from NPs? To answer these questions we applied the knowledge discovery process proposed by Sangster-Gormley et al. [5] to extract useful NP practice information from the BC MoH database. The study results will provide the MoH with a better understanding of NP practice patterns.

1. Methods

The data set released by BC MoH was integrated based on practice records sent by 94 NPs in BC from the 2005-2010 fiscal years [6]. There are 470,762 records in the database. Since NPs started their practice late in 2005, the data only covered 4 months (January 1 to April 30, 2006) for this fiscal year and only 4 NPs submitted 2,214 ECs in the 2005 fiscal year. As a result, the amount of data for this year was small compared to other years. Thus, in this study, we excluded data from 2005. All the data we used were related only to NPs' practice. Among the variables in the database, ECs (called "Fee item" in the database) reflected NP practice activities and International Classification of Diseases 9 codes (ICD-9) indicated patients' diagnoses.

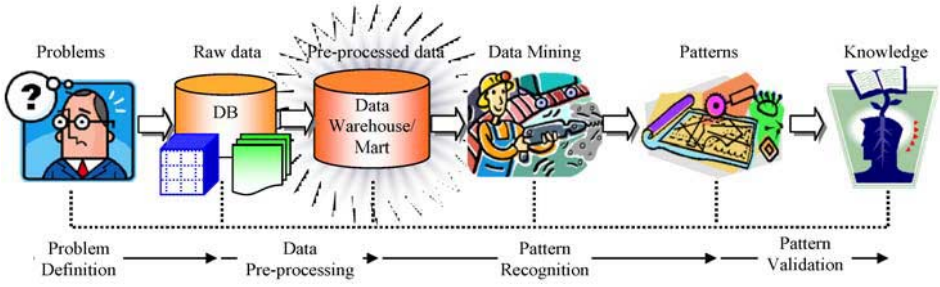


Figure 1. The NP practice knowledge discovery process

The NP practice knowledge discovery is a processing pipeline that involves 4 distinct stages including problem definition, data pre-processing phase, pattern recognition and pattern validation (see Figure 1).

Stage 1- Problem Definition

In this stage we are attempting to answer the following two questions: What are the most common practice activities carried out by NPs? What are the most common health conditions for which patients sought care for from NPs?

Stage 2- Data Pre-processing

In this stage raw data is transformed into an appropriate format for subsequent analysis. Among the variables in the database, ECs and ICD-9 codes reflected NP practice activities and displayed the types of diseases with which patients were diagnosed. Thus, they were extracted from the original data set and stored in a separate file for further analysis. Of all the submitted ECs, office visits were most commonly coded, and accounted for over 180,000 for all age groups in the five-year period (2006-2010). Providing information and education was the second most common activity coded. We further divided the codes into sub-groups based on certain criteria.

Stage 3- Pattern Recognition

(a). Association between Encounter Codes and ICD-9 Codes

Usually NPs send to MoH each patient's visit info, which includes 1-3 ECs and 1-3 ICD-9 Codes. The combination of ECs and ICD-9 Codes defines the patient encounter and disease conditions. Thus finding the relationship between ECs and ICD-9 codes can help us to understand better not only the content of ECs, but also the most common diseases that patient may have, for example in different age groups. In the data set,

office visits were categorized into five ECs according to patient ages: 36300 (0-1), 36301 (2-59), 36302 (60-69), 36303 (70-79) and 36304 (80+). Visits for the 2-59 age group (code 36301) dominated throughout the five-year period. The 60-69, 70-79 and 80+ age groups were the second, third, and fourth positions in each year. The trend is possibly due to the actual population of each age group. The year-to-year comparison clearly indicated NP's visit trend. For all the age categories, the number of visits increased steadily to reach the maximum in 2009. Yet, in 2010, office visits dropped to the second most of all the years for all age groups. It is unclear why this happened.

(b). Top ICD-9 Codes for Different Age Groups

- Age 0-1 group - The leading reasons for babies (age 0-1) to see an NP were for a routine child health check (ICD-9 V202), and to monitor their growth and development (ICD-9 05A). Numbers of acute upper respiratory infections were similar to those for growth and development, and this was the third most common reason for NP office visits in this age group.
- Age 2-59 group – General symptoms (ICD-9 780), acute upper respiratory infection (ICD-9 460/ 462/ 465), diabetes (ICD-9 250), depression (ICD-9 311), hypertension (ICD-9 401), together with anxiety/depression (ICD-9 50B/3000) were the main visiting reasons in the 2 to 59 age (EC 36301). Other ICD-9 codes were relatively close to the leading ones. The top ICD-9 codes each had several hundred to several thousand visits. The age difference in this group is much wider than that of other age groups, which may, therefore, lead to the visit numbers being more equally distributed among the top disease/symptoms.
- Age 60-69 group - Data for the 60-69 age group (EC 36302) indicated the dominance of hypertension (ICD-9 401) and diabetes mellitus (ICD-9 250), with over 2,700 visits each in the five-year period. Other reasons for visits, such as malignant neoplasm, had only about 800 or fewer visits. It is worth noting that visits for acute upper respiratory problems were uncommon for this and other older age groups.
- Age 70-79 group - Again hypertension and diabetes mellitus were the main reasons for people aged 70-79 to visit an NP (EC 36303). However diabetes fell behind hypertension by nearly 800 visits over the five years.
- Age 80+ group - Hypertension was the leading reason in people aged 80+ to visit an NP. The visit number due to diabetes mellitus decreased further to about half the amount for hypertension patients, in comparison to the 60-69 and 70-79 age groups.

(c). Mental Health, Chronic Disease Management, and Patient Education

Mental health and chronic disease management are the two new ECs which are accessible to NPs since 2010. Although the records have only two-year history, the visits of these two ECs have been among the top 10 direct care activities spanning 2006 to 2010. In the top 20 ICD-9 codes, depressive disorder, anxiety states and anxiety/depression are the top 3 ICD-9 codes.

The MoH has three ECs associated with Chronic Disease Management: 36641 (1 condition), 36642 (2-3 conditions), 36643 (> 3 conditions). The current database includes 36641 and 36642. Our data set did not include 36643. For 1 condition visits, essential hypertension, diabetes mellitus and chronic renal failure are the top three ICD-9 Codes. Considering visits for 2-3 comorbid conditions, diabetes mellitus

becomes the most common ICD-9 Code followed by hypertension. This is a reversal of the pattern for younger age groups. Chronic renal failure remains in third place.

Patient education, EC 36380 (information provision) and 36381 (provision of educational materials), was frequently reported. These two ECs showed up as the second (73,698 counts) and third (28,748 counts) most common NP activities over the five-year period. Both 36380 and 36381 ECs were used during 2006 to 2008, but the latter was missed in the 2009 and 2010 year, presumably abandoned. Due to the similarity in the actual activity definitions of the two codes, we believe the two types of activities were combined in the last two years. Therefore to make a validated comparison, the activity frequency counts for both codes in the early three years were added together in the graph below. The bar graph demonstrates the top four education types, with at least 2,600 activities, that were relatively larger than other activities. Diabetes mellitus was the most common ICD-9 Code (n=5,866); essential hypertension next (n>4,300); and chronic renal failure was third (n=3,000+).

Stage 4- Pattern Validation

Finally, domain experts were involved to interpret if the discovered patterns have meaning in the targeted scenario. In this study, a nurse practitioner educator (Dr. Sangster-Gormley) and a health informatics expert (Dr. Kuo) worked together in the validation process to interpret the accuracy/meaning of the patterns. For example, there are different trends evident when comparing the three ICD-9 codes (401, 585 and 250) to visits among the different age groups. Essential hypertension (ICD-9 401) and chronic renal failure (ICD-9 585) visits increase with age, whereas diabetes mellitus peaks in the 60-69 age group and then decreases (ICD-9 250) as patients get older.

Table 1. Trend analysis of diseases

Rank	ICD9 Description.	36300 age 0-1	36301 age 2-59	36302 age 60-69	36303 age 70-79	36304 age 80+
1	**401 Essential hypertension**		2.7%	11.2%	13.3%	13.6%
2	**250 Diabetes Mellitus**		3.0%	10.9%	9.2%	6.3%
3	**780 General symptoms**	2.9%	3.6%	2.8%	2.6%	2.8%
4	**585 Chronic renal failure**			1.7%	4.5%	6.0%
5	**465 Acute upper respiratory infections of multiple or unspecified site**	9.4%	1.7%			
6	**162 Malignant neoplasm of trachea, bronchus and lung**			3.1%	3.9%	1.6%
7	**820 Fracture of neck of femur**			0.6%	1.0%	3.4%
8	**311 Depressive disorder, not elsewhere classified**		2.9%	1.2%	0.7%	
9	**782 Symptoms involving skin and other integumentary tissue**	2.2%	0.4%	0.7%	0.4%	0.9%
10	**272 Disorders of lipoid metabolism**			2.1%	1.3%	0.6%
11	**382 Suppurative and unspecified otitis media**	3.5%				
12	**428 Heart Failure**				0.6%	2.7%

2. Results

Further to the information discovered in previous section, the study finds some interesting patterns as follows (see Table 1):

(1). Hypertension morbidity increases with increasing ages;
(2). Diabetes mellitus morbidity drops when people get older;
(3). Chronic renal failure increases in higher age groups;
(4). Depressive disorder decreases with increasing age;

(5). Heart failure morbidity shows a similar trend to chronic renal failure and increases with age.

The patterns shown in Table 1 were interpreted as follows: "*As people age, chronic conditions take a toll on their health. Therefore, it was not surprising for us to identify these patterns. They help to confirm the types of patients for whom NPs are providing care. We expected younger people to exhibit depressive disorders more frequently than older adults. However, we cannot explain why the number of people with diabetes mellitus decreased with age"*.

3. Conclusion

The study discovered the major patient groups and diseases that NPs have managed in the last five years. Elderly patients represent the major population served by NPs. Chronic diseases, such as diabetes and hypertension, were common reasons for older patients to visit NPs y, while growth monitoring of children were common reasons for NP visits and this is not unexpected. NPs' communication skills, health promotion activities, and accountability have made for easy accessibility for patients with chronic disease. Therefore, the NP role can be seen as an important and positive addition to the BC health care system.

In conclusion, we have summarized key activities of NPs over the past five years. However, this is not an evaluation study because outcome information is not available. This is the first time that NP EC data were examined, and our analysis reflects the most common reasons for patient visits: patient education, mental health and chronic disease management visits, and therapeutic communication.

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References

[1] J.C. Bauer, Nurse practitioners as an underutilized resource for health reform: Evidence-based demonstrations of cost-effectiveness, *Journal of the American Academy of Nurse Practitioners* **22** (2010), 228-231.

[2] S. Sidani, D. Doran, H. Porter, S. Lefort, L. O'Brien-Pallas, C. Zahn et al., Outcomes of nurse practitioners in acute care: an exploration, *Internet Journal of Advanced Nursing Practice* **1** (2007), 3.

[3] C. Thrasher, R. Purc-Stephenson, Patient satisfaction with nurse practitioner care in emergency departments in Canada, *Journal of the American Academy of Nurse Practitioners* **10** (2008), 231-237.

[4] R. Benkert, B. Hollie, C. Nordstrom, B. Wickson, and L. Bins-Emerick, Trust, mistrust, racial identity and patient satisfaction in urban African American primary care patients of nurse practitioners, *Journal of Nursing Scholarship* **41** (2009), 211-219.

[5] E. Sangster-Gormley, M.H. Kuo, E.M. Borycki, R. Schreiber, Use of knowledge discovery techniques to understand nurse practitioner practice patterns and their integration into a healthcare, *Studies in Health Technology and Informatics* **183** (2013), 111-5.

[6] British Columbia Ministry of Health (2012): Medical Services Plan (MSP) Payment Information File. Population Data BC. Data Extract. MOH (2012). http://www.popdata.bc.ca/data

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Requirements and tasks of cohorts and registers, the German KoRegIT project

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Abstract. Epidemiological cohorts and registers (KoReg) are long lasting and complex research projects, which need systematic and extensive planning and steering. The aim of the KoRegIT project was to develop a generic catalogue of requirements to support the organisational- and IT-structure of KoReg. The catalogue of requirements comprises the top level (TL) tasks of the core processes. All TL were classified into the following project phases: 1. Development, 2. Operation, 3. Completion. According to the defined TL tasks, the appropriate use cases (UC) were identified. The catalogue currently specifies 45 TL tasks and 207 UC. The UC were elaborated by a short and standardized description of the task, the involved actors (human or external systems), the preconditions, which have to be fulfilled in order to realize this task, the normal flow of the task and the post conditions. The developed catalogue was reviewed by representatives of different KoReg in Germany. The draft catalogue of requirements was revised according to the reviewer's feedback and discussion. The revised and complete catalogue with all elaborated UC was reviewed again by further experts. The developed KoRegIT catalogue of requirements offers a supporting tool to set-up the organisational structures and processes of KoReg as well as the definition of the needed IT-infrastructure. In addition it can be used to optimize or to expand these structures.

Keywords: cohort, register, IT-requirements, catalogue of requirements, processes, organisation

Introduction

Cohorts and registers (KoReg) are the basis for epidemiological and health services research as well as for networking regarding a specific disease [1]. They also represent an important tool to support and complement clinical studies. Most KoReg are long lasting and complex research projects, which need systematic and extensive planning and steering [2]. The core of KoReg consists of the data of interest. However, the or-

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ganisational structure and processes with the different participating groups and responsibilities are just as important as the data itself.

Literature of KoReg mainly addresses the study design and analyses. The different tasks related to building up, administrating, managing and maintaining the quality of a KoReg as well as collecting and analysing the data should be identified in detail. Based on the identified tasks the information and communication technology (ICT) needed can be derived. The selected IT-infrastructure should be flexible because the requirements will change over time. Therefore the planning and implementation of an adequate IT-infrastructure for KoReg is predicated on an accurate and comprehensive investigation of the requirements. The Project KoRegIT (sponsored by the TMF - Technology, Methods, and Infrastructure for Networked Medical Research) aims to close the gap of a generic catalogue of requirements for cohorts and registers.

1. Methods

At first, the systematic of the catalogue of requirements was determined based on the background and experiences of representatives of the German Competence Network for HIV/AIDS and the German Competence Network for Hepatitis [3]. Both belong to the core working group of the KoRegIT project. The German "Competence Networks in Medicine" was established as a model to promote scientific excellence in disease-oriented research. Within this frame the Competence Networks for HIV/AIDS in collaboration with the ZKS Cologne set up large national cohorts.

The determined systematic of the catalogue of requirements comprises the top level (TL) tasks of the core processes. The supporting processes are not included to reduce the complexity. The core processes of registers and cohorts are:

- the communication with the study sites
- the administration of the clinical subjects
- the management of the data from the survey to the monitoring step
- the analyses and use of the data

All TL tasks were classified to the following defined project phases [2] and sub-phases:

1. Development (planning and preparation)
2. Operation (implementation, use, development)
3. Completion

According to the defined TL tasks, the appropriate use cases (UC) were identified, e.g. the TL task "protocol development" has the UC "protocol template design", "protocol writing by working groups". Each UC was defined by a short and standardized description of the task, the involved actors (human or external systems), the preconditions, which have to be fulfilled to realize the task, the normal flow of the task and the post-conditions or expected results after completing the task (see table 1 for the description of the UC template).

The first part of the catalogue of requirements was developed as a draft list of TL tasks and UCs with a unique identifier (ID) assigned to each UC. Representatives of different cohorts and registers in Germany then reviewed this document. One of the involved reviewers represents the "German Cystic fibrosis Register" with more than 8,000 patients and 93 study sites, another reviewer is responsible for the development

of a tumour documentation system which is in use for several clinical cancer registers and the third reviewer represents the "German National Cohort", which is being set up with the objective of recruiting 200,000 citizens up to 30 years to identify widespread diseases. Comparing the catalogue with the own project to identify missing tasks and investigate the naming and classification of TL tasks and UCs performed these reviews. Serious points found were then discussed in detail with the core group regarding the implementation and against the background to develop a generic catalogue of requirements. The draft catalogue of requirements was revised according to the reviewer's feedback and the discussion.

This KoRegIT interim result was presented in a workshop organized by the TMF. The main participants were again representatives of different cohorts and registers. Feedbacks were collected during the workshop, and then discussed and the resulting essential points were added to the catalogue.

Table 1. Use case template [4]

Titel	Definition
Name	Name of the use case (UC)
Identifier*	Each UC gets an Identification number, e.g. UC 0020 (UC: use case number: 0020). Each UC is related to a TL task, which has its own title and identification number, e.g. UC 0020 is related to TL008.
Version*	Each UC gets a version number regarding the development´s progress or updates. The first release of the catalogue will have version 1.0 after all reviews and revisions. Further updates could be tracked by this number.
Description	Short description of the content, background and objective of the UC.
Involved actors	The actors represent the initiator and supporting staff achieving the UC. The initiator interacts with the implemented IT system/tool. The naming of the involved staff is related to its role.
Pre condition	All conditions which have to be fulfilled to perform the UC.
Standard process	Normal flow defining interactions between one or more actors and the application system of a specific UC. The process steps are numbered and described in a structured language.
Post condition/Result	The result that is expected after a successful achievement of the UC.
References/Notes	Short explanations or references for a better understanding of the UC. This additional information is optional.

*these points serve as a kind of metadata during the development and reviews of each UC of the catalogue

In order to consistently describe the UCs, the involved actors are defined according to their function and role. Table 2 shows an excerpt of the KoRegIT actors. All actors of a specific UC have a leading role. Supporting roles were not listed.

Table 2. Excerpt of the KoRegIT actors with their definition and roles

Actors*	Definition and role
Actors of the participating sites	
Attending physician/ Study Investigator	Identifies potential subjects, recruits and looks after them, collects the subjects´ data according to the KoReg guidelines.
Potential subject	Fulfills the KoReg inclusion and exclusion criteria, which are prerequisites for participation.
Subject (mainly patient)	Fulfills the KoReg inclusion and exclusion criteria as prerequisites for participation and has consented to participate. Selected data are collected and analyzed.
Study Nurse/Documentalist	Supports the physician/Study Investigator
Site management	Is responsible for the KoReg project and its implementation at site. Manages budget and resources at site.
Actors of the central structure of the KoReg	
Biometrician	Brings projects ideas, implements feasibility analyses, worked out project ideas together with the project manager and scientists,

	supports the project realization (amongst others together with the data manager), assesses collected data and supports the development of the scientific report.
Data manager	Supports planning and implementation of the projects, cares for an adequate data architecture and data quality, ensures data integrity and confidentiality.
Data protection officer	Ensures data protection by developing a data protection concept and by supporting its implementation
Monitor	Checks the correct implementation of the KoReg protocol in the participating sites as well as data quality
Cooperating actors	
Ethic commission	Investigates KoReg research projects in medical field according to the professional code for physicians and the compliance with ethical criteria. Gives recommendations if necessary.
Financial Sponsor	Finances the KoReg under the conditions that defined goals are achieved and specific requirements fulfilled.

*in the elaborate UCs committees and boards were mentioned beside the actors of the table above, e.g. decision-making body or structural board. These committees and boards are compiled of the specified actors.

The draft catalogue of requirements consists of two documents. First one is the mentioned list of TL and UC and the second document is the detailed specification of the first one with the elaboration of all specified UCs using the described template.

After several reviews and revisions the complete catalogue has been submitted again for a final review by the experts. Those experts have leading positions in German cohorts and registers. The additional reviewers were required for the assessment of completeness and comprehensibility of the catalogue, the compilation and classification of TL tasks and UCs, the classification of TL tasks to the appropriate phases, the level of detail of the UCs and there generality.

2. Results

The developed catalogue of requirements for KoRegIT describes the core processes and all typical and essential tasks that a cohort or register has to deal with. The catalogue currently specifies 45 TL tasks and 207 UCs. This catalogue is defined as a list of TL tasks and UC created with Microsoft Excel. Table 3 shows an excerpt of the KoRegIT TL task list within all phases. As an example, TL10 is represented with all its UCs.

Table 3. Extract of the KoRegIT top level (TL task) list.

Phase	Identifier	Name of top level (TL) task
Development		
Planning	TL002	Development and determination of the scientific question
	TL003	Protocol development
	TL001	Planning of organizational structures
	TL047	Financial planning
Preparation	TL006	Development of subjects information and informed consent documents
	TL009	Creation of a statistical analyses plan
	TL010	Preparation of data collection and data capture
	UC0034	Variables, values and integrity constrains determinations
	UC0241	Data scheme construction
	UC0203	Layout and sequence of the CRF and interview sheet determination
	UC0035	Visit plan composition
	UC0036	CRF construction
	UC0037	Interview sheet construction
	UC0170	Handbook for data survey and –documentation composition
	TL014	Set-up of organizational structure

	TL015	Recruitment of sites
	TL043	Training of site staff
Operating		
Implementation	TL020	Recruitment of clinical subjects
	TL021	Data collection and data capture
	TL023	Monitoring
	TL026	Data management (organization and maintenance of data)
Use	TL029	Statistical analyses
	TL030	Reporting
	TL031	Organization of publications and presentations
	TL046	Support of patient care
Development	TL032	Further Development of register/cohort
Completion	TL034	Archiving

The UC specification related to the excel sheet comprises detailed information and references regarding all KoReg tasks. Through the defined preconditions in all UC, all dependencies between the UCs were visible and could be used as a kind of schedule. In order to picture these dependencies as well as all TL tasks and UCs, the catalogue was additionally modelled using the 3LGM^2 system (3-Layer Graph-based Meta-model of the University Leipzig, Germany) [5].

Two different ways of use of the KoRegIT catalogue are conceivable in order to set up a KoReg IT-Infrastructure. First of all, the TL tasks and UCs could be compiled according to their associated functions. Secondly, the actors in their specific roles get a homogeneous computer-work-station, e.g. the data-manager to solve his tasks.

3. Discussion

The KoRegIT catalogue of requirements offers guidance and support for cohorts and registers in each phase of their lifecycle according to the organisational structure, the planning and implementation of the IT-Infrastructure as well as the optimization or extension of these structures. The KoRegIT catalogue of requirements should be therefore considered as a supporting tool from which requirements for a KoReg can be checked and the needed IT-Infrastructure derived. Furthermore, a reference-catalogue is given for individual adoption for cohorts and registers. The catalogue could also support the negotiations with financial sponsors and could give assistance to optimize or extend existing KoReg. The results of the KoRegIT project are thereby of interdisciplinary and international interest particularly for medical research networks.

References

[1] Dreyer NA, Garner S. Registries for robust evidence. JAMA 2009 Aug 19;302(7):790-1.
[2] Müller D, Augustin M, Banik N, Baumann W, Bestehorn K, Kieschke J, et al. [Memorandum registry for health services research]. Gesundheitswesen 2010 Nov;72(11):824-39.
[3] Stausberg J, Altmann U, Antony G, Drepper J, Sax U, Schutt A. Registers for Networked Medical Research in Germany: Situation and prospects. Appl Clin Inform 2010;1(4):408-18.
[4] Cockburn A. Use Cases effektiv erstellen. MITP Verlag; 2003.
[5] Winter A, Brigl B, Funkat G, Haber A, Heller O, Wendt T. 3LGM2-modeling to support management of health information systems. Int J Med Inform 2007 Feb;76(2-3):145-50.

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Monitoring Food Safety Violation Reports from Internet Forums

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Abstract. Food-borne illness is a growing public health concern in the world. Government bodies, which regulate and monitor the state of food safety, solicit citizen feedback about food hygiene practices followed by food establishments. They use traditional channels like call center, e-mail for such feedback collection. With the growing popularity of Web 2.0 and social media, citizens often post such feedback on internet forums, message boards etc. The system proposed in this paper applies text mining techniques to identify and mine such food safety complaints posted by citizens on web data sources thereby enabling the government agencies to gather more information about the state of food safety. In this paper, we discuss the architecture of our system and the text mining methods used. We also present results which demonstrate the effectiveness of this system in a real-world deployment.

Keywords. Food-borne illness, Food safety, Food safety violation, Text mining

Introduction

Food-borne illness is a growing public health concern around the world. The US Centers for Disease Control and Prevention (CDC) estimated that roughly 1 in 6 Americans or 48 million people fell ill, 128,000 were hospitalized and 3,000 died of food-borne diseases each year [1]. Many countries have setup special government agencies that monitor and act on complaints related to food safety, which includes complaints received from citizens with regard to food hygiene, food poisoning incidents. These government agencies actively seek inputs/feedback from citizens using traditional channels such as call centers, e-mails etc. Once sufficient or severe violations are reported against an establishment (supermarket, public or private canteens, restaurants etc.), the government agency acts on these complaints by carrying out a physical inspection of the facility followed by punitive actions that include fine, closure or license revocation of the establishment. The current process of gathering such feedback from citizens has its own limitations. Due to the formal nature of the process not many citizens report such incidents. Also the incidents that are reported through the traditional channels are not current i.e. reports/complaints are filed days or weeks after the actual incident took place. These facts severely restrict the amount and recency of information available with the government agency with respect to food safety violations.

To address the above limitation we propose a solution that sifts through several internet forums (user forums, citizen journalism websites, blogs etc.) looking for "up-to-date'' information related to food safety violations as reported by citizens on such websites. Our work is similar in spirit to recent work on using citizen' updates on social media to characterize electoral debates [2], detect real time events such as natural calamities [3] etc. Considering the fact that these forums also contains discussion threads and posts on other topics such as politics, entertainment, technology etc automatically detecting posts that are relevant to food safety violations requires the use of text mining methods. Our proposed approach, which was deployed for a real world government agency, employs state of art machine learning/text mining techniques to automatically *detect* and *process* citizen posts that mention food safety violations.

1. Methods

The first task is to (periodically) crawl internet forums that are of interest. As mentioned earlier, an internet forum receives thousands of user posts daily of which only a few mention food safety violations (food safety violation posts could include posts that mention food hygiene lapses in food establishments, supermarkets or shops selling expired food, or food poisoning incidents after consuming food etc.). Identifying such user posts automatically is done using the *text classification* module as part of the *Text Analytics* layer. Once such a post has been identified the next step is to (automatically) process this post by extracting relevant nuggets of information from the post such as the name of the food establishment, the address/location etc. This is done using the *Entity detection and extraction* module which is part of the *Text Analytics* layer. Due to space constraints this paper provides details of only the *text classification* module.

2. Text Analytics Component Description

Any popular internet forum usually receives a few thousand new user posts every day. Not all of these postings mention food safety violations. A key challenge, which is addressed by the *text classification* system, is to automatically identify which user post mentions food safety violations. To be able to do this automatically requires domain specific feature engineering and deciding which classification model to use. We discuss these two topics in Section 2.1 and 2.2 respectively.

2.1. Feature Engineering

Feature engineering is the step of identifying textual features which will help a classification model differentiate food safety violation reports from posts on other topics. It is a critical step that affects performance of a classification model. For our setting, we experimented with a combination of features described below:

1. *Features derived from training data:* Lexical features such as unigrams (single words) and bigrams (pairs of words). We use TF-IDF scores on these after removal of stop-words.

2. *Features capturing sentiments:* Complaints often use words that express negative sentiments such as “bad", “disgusting" etc. Adding a manually crafted dictionary of negative words as features showed improvement in the classification accuracy. One could also use any of the state of the art sentiment analysis techniques to classify a post into one of (positive, negative, neutral) classes and then use this label as a feature. However, such a label would not capture the severity of occurrence of the negative words which we intend to capture using the dictionary. We also observed that complaint articles were relatively short compared to other types of discussions (personal experiences detailing a story, political discussions, discussions and stories about celebrities etc). Using the length of an article as a feature further improved the classification performance.
3. *Domain specific features:* We also observed that using domain specific annotations such as food names, food center names as features improved classification accuracy.

Through our experiments we observe that different feature types contribute differently to the overall classification performance. A weighted combination of these three feature types was used for our classification task. A grid search with 5-fold cross validation on the test data set as described in the results section was used to find the optimum weights (according to F1 score) for the three types of features. The final weights we use are (2, 5, 5) for the three feature types described above in that order.

2.2. Text Classification Models

Text classification is the process of building a model that distinguishes posts that report food safety violation from posts on other topics. This distinction is learnt from a training data set that contains posts reporting food safety violations as well as posts on other topics. This fits into a binary classification task where the class labels are *Food_Safety* and *Non-Food_Safety*. We experimented with different state of the art classification algorithms including Multinomial Naive Bayes, k-NN and Support Vector Machine (SVM) with different parameters. For our setting, linear SVM gave the best performance and hence we report results with that method. A practical problem encountered in learning a classifier for the food safety domain is the class distribution skew. Most of the posts are crawled from citizen web forums where articles on other topics (e.g. entertainment, tourism) outnumber food safety articles approximately by 1:40. The problem of learning from imbalanced data is a relatively new challenge that has attracted growing attention from both academia and industry [5]. To address this challenge, we experiment with sampling (over-sampling and under-sampling) for imbalanced learning and report our results.

3. Results

Our system was deployed for the environment health department of a real world government agency. In Section 3.1 we provide an overview of the data sets and methods used to obtain those data sets. We report the performance of the classification model with different feature sets in Section 3.2.

3.1. Dataset

The system was used to detect food safety related complaints from a popular citizen journalism website in the country. The website has news stories on a variety of topics including movie gossips, science news, local events, food safety complaints, experiences with public transport etc. A total of 14722 user posts were collected by crawling this website. Subset of the training data for the classification task was obtained by hand labeling 1000 web-pages, where 20 belong to the *Food_Safety* class and the rest to the *Non-Food_Safety* class. We obtained additional training data by following two approaches*: (i) With the help of Wikipedia category tree:* We used Wikipedia category tree as described in [4] to obtain 407 samples of *Food_Safety* class and 13335 samples of *Non-Food_Safety* class. The training data obtained in this manner is referred to as "*gen-data"* in the discussion of results (ii) *From the agency's call center data:* The government agency we worked with also has a dedicated call center which logs citizen's food safety related complaints (citizens can call this call center to inform the government body about any food safety related observations/complaints). These calls are transcribed by call center agents and serve as training data for our classifier after some. We added randomly selected 407 complaints as examples to the *Food_Safety* class. The training data obtained in this manner is referred to as "*call-center-data"* in the discussion of results. The test set contains 52 posts from the *Food_Safety* class and 824 posts from the *Non-Food_Safety* class. These posts were hand labeled for the experiments.

3.2. Evaluation

Table 1 summarizes the results of classification. We report the standard information retrieval metrics precision, recall and F1 score only for the positive i.e. *Food_Safety* class since this is the class of interest.

Effect of training data generation: The first set of results, as indicated by the "*gen-data"* columns of Table 1 is obtained by using the training data set generated using the approach described in 3.1. The F1 score (using plain TF-IDF scores on unigram and bigram as features) for the *"call-center-data"* setup is higher than "*gen-data"* as shown in the first row of Table 1. This is expected since the call center training data is more "on-topic" as compared to the generated training dataset. It should be observed that the recall is significantly affected because the class distribution is highly imbalanced in the *"gen-data"* data set. However, as we add more informative features, it can be seen that the performance of the classifier improves, demonstrating the effectiveness of feature engineering.

Performance with different feature sets: The different rows in table 1 show the effect of using different types of features as discussed. The baseline TF-IDF scores on unigrams and bigrams, TF-IDF scores along with domain features, TF-IDF scores in conjunction with negative-words and a weighted combination of all these features together. It can be observed that adding informative features improves the overall performance, especially for model built using the generated training data. The improvement in performance is not very significant when the training data is obtained from the call center, and the distribution of classes is not very skewed.

Performance of methods to handle class imbalance: Under-sampling was performed by choosing random samples from the *Non-Food_Safety* class for creating a training set with more balanced distribution of the two classes. We performed experiments with

different values for the number of *Non-Food_Safety* samples and observed that the precision increases as we increase the number of *Non-Food_Safety* samples, while the recall drops. This behavior is expected as with a more balanced training set, more articles in the test set tend to be labeled as *Food_Safety* complaints, resulting in higher recall and lower precision. We report a precision of 0.75, recall of 0.71 and F1 score of 0.73 for this setup. Over-sampling was performed by repeating samples of the *Food_Safety* class, we observed that different class distributions achieved by this method did not change the performance much and we report the best results. We report a precision of 0.76, recall of 0.69 and F1 score of 0.72 for this setup. We also experimented with the misclassification cost parameters of SVM, and all the results reported in the table are with optimum misclassification costs.

Table 1. Classification performance with different feature sets and training datasets

Feature Types	**gen-data**			**call-center-data**		
	Precision	**Recall**	**F1**	**Precision**	**Recall**	**F1**
TF-IDF	0.875	0.2692	0.4117	0.7872	0.7115	0.7474
TF-IDF+ Domain	0.7441	0.6153	0.6736	0.7959	0.75	0.7722
TF-IDF + Neg	0.7777	0.6730	0.7216	0.78	0.75	0.7647
All	0.7608	0.6730	0.7142	0.7959	0.75	0.7722

4. Discussion

In this paper, we presented a platform that allows a real world government agency to detect and analyze food safety related complaints posted by citizens on internet forums. The output of this system serves as an additional source of information related to the state of food safety which is not captured through the traditional process. We believe that our system is a valuable tool to monitor such content and to use it for improving food safety practices and standards. We employ text mining techniques to identify user posts related to food safety violations. We also demonstrate that by using creative ways of generating training data and feature engineering we are able to obtain a satisfactory performance. Currently, our system focuses on internet forums as the source of such information. One challenge in applying the system to micro-blogs was the length of each post. The short posts often do not contain enough information about the location of violation and hence the government agency cannot take any action on such reports. We are working on other ways of using information from micro-blogs.

References

[1] Estimates of foodborne illness in the United States, US centers for disease control and prevention. 2011. Last accessed on 30 Jan 2014, Available at: http://www.cdc.gov/foodborneburden/index.html

[2] Diakopoulos NA, Shamma DA. Characterizing debate performance via aggregated twitter sentiment. Proceedings on Human factors in computing systems (CHI’10). 2010 April.

[3] Sakaki T, Okazaki M, Matsuo Y. Earthquake shakes Twitter users: real-time event detection by social sensors.WWW '10 Proceedings of the 19th international conference on World Wide Web. 2010 April.

[4] Chenthamarakshan V, Melville P, Sindhwani V, Lawrence R. Concept labeling: Building text classifiers with minimal supervision. IJCAI'11 Proceedings of the Twenty-Second international joint conference on Artificial Intelligence. 2011.

[5] He H. and Garcia E.A. Learning from imbalanced data. IEEE Transcations on Knowledge and Data Engineering, 21(9):1263–1284, Sept. 2009

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Pediatric Emergency Department Crowding: Survival Tree Clustering for Length of Patient Stay

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Abstract. The objective of this study is to analyse the length of patient stay in Pediatric emergency department according to diagnosis and the number of patients over a 3 year-period. A survival tree was used, to explore the underlying construct of overcrowding depending of the length of patient stay. The tree was used to cluster 55.183 patients with respect to length of stay where partitioning is based on covariates such as the number of patients, the diagnosis and existence of complementary exams. The hazard ratio test was used to determine optimal partition. The approach is illustrated using Electronic Medical Record Software database available at the Pediatric Emergency Department of Lille University Hospital.

Keywords. Crowding, Length of Stay, Emergency, Pediatric.

Introduction

The Emergency Department (ED) crowding *is one* of the crucial problems facing emergency physicians, nurses and their patients [1]. The ED crowding has been associated with increasing risks of healthcare system disruption, patients leaving without being seen [2], and increasing caregivers' stress.

Among all those problems, the Length of Stay (LOS) is an important measure of quality of healthcare in the emergency departments [3, 4]. Several studies found that crowding is associated with increased ED LOS [4, 5]. LOS is also considered as a key for clinical improvement and operational efficiency. From the patient's perspective, the LOS and the long waiting times to see a physician or to obtain the test results create the sense that the ED is busy and always crowded.

Rathlev et al. [3] considered the LOS as a measure of crowding and measured the association between the LOS and factors that potentially contribute to the LOS over consecutive shifts in the ED. They observed that daily ED LOS was positively associated with the hospital occupancy rate and number of emergency admissions at their institution. Asaro et al. [4] qualified the impact of input and output factors on ED and found that ED crowding factors increased waiting time and boarding time but not treatment time. Schull et al. [5] studied the effect of low-complexity ED patients on the waiting time of other patients, and showed that low-complexity ED patients was associated with a negligible increase in ED LOS and time to first physician contact.

Reducing the number of low-complexity ED patients was unlikely to reduce waiting times for other patients or lessen crowding.

Our work falls within the scope of the HOST Project (Hospital: Optimization, Simulation and Tension) whose aim is to solve the Pediatric Emergency Department (PED) crowding problem by analysing, modelling and developing the base of decision support system to anticipate the stress in the care process at the PED.

Our main objective is to quantify the notion of "crowding" using the hospital data and to be able to measure at any time the crowding level in the PED. We use the LOS of patients as a significant crowding indicator. Our contribution is, by using computer science and database analysis, to define methods and techniques to discover in large medical data bases the determinants having an impact on the LOS.

1. Methods

1.1. Material

The first step of this work was to create a system for collecting useful data for this study. We performed an extraction using Oracle SQL requests from Electronic Medical Record (EMR) data warehouse and built a new database where we integrated all necessary elements for our study. This database was cleaned, anonymized and formatted for an optimal use. The analyzed data were over a 3-year period from January 1, 2011 to November 30, 2013, in the Pediatric Emergency Department (PED) at the University Hospital of Lille-France for all 55.183 children visits.

The EMR records for each patient age, gender, principal diagnosis, existence of complementary medical exams and LOS. The number of patients present at the time of the entry was calculated as follows: for each new patient arrival, we identified the number of patients who were present at that moment.

1.2. Data analysis

A descriptive analysis was performed for all variables including the distribution of the dependent variable LOS. An individual patient LOS was the interval between registration at the PED and leaving the PED.

Then, a survival analysis was performed to identify determinants that affect the LOS: in this case, all patients have left the PED (they leave the PED after few hours) so the variable to be modeled is the delay it takes for a patient to leave this medical department. Such survival analysis is more robust that linear analysis to identify the determinants of the length of stay, as its distribution is often a gamma (or log-normal) distribution.

We decided to use a method based on survival tree in order to cluster patients into clinically meaningful patient groups. The variables used to identify clusters of LOS were age, gender, existence of laboratory tests, ultrasonography, scanner and radiology, kind of diagnosis and the number of patients present in the PED at the entry.

Survival tree is a kind of classification and regression tree [6] splitting on log-rank test. It is a powerful non-parametric method of clustering survival data for prognostication, i.e. to determine the importance and effect of various covariates (such as patients' characteristics) and their interrelation with patients' survival, treatment outcome, disease risk, and disease progress or hospital LOS.

We used a learning sample (including 70% of our population) and a test sample (including 30% of our population) to appreciate the robustness of our model. The main interest of this supervised data-mining method is to allow a simple interpretation by a physician or an expert of the factors retained by the algorithm in contrast to a method such as neural networks that return a black box. The packages "rpart" and "Survival" were used on R software [8] for this analysis. The main parameters used in rpart were the value 0.01 for the complexity parameter and the value 20 for the minsplit.

2. Results

A total of 55.183 records were analysed. The mean of age in months is 60.12 +/-53.48 (mean +/-SD) and the sex ratio (male/female) is 1.22. The results show that 4% of the patients have an ultrasonography exam, 0.1% have scanner exam, 21% have a conventional radiography and10% have a laboratory exam. In our study, we focus on the LOS analysis. The Figure 1 shows the LOS distribution in the PDE. The mean of LOS is 2.56 +/- 1.518 hours and the median is 2.2 hours.

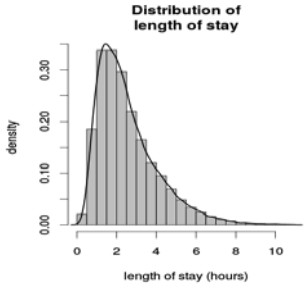


Figure 1. Distribution and density curve of LOS.

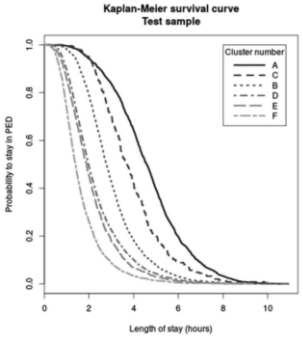


Figure 2. The Kaplan Meier Survival Curves.

Figure 3 shows the survival tree construction. Five significant determinants covariates were identified to affect the LOS. There are 3 discrete covariates representing the presence of complementary exams, a continuous covariate representing the number of patients and a qualitative covariate representing the diagnosis. The survival tree identified six clusters (A, B, C, D, E, F) determined by the hazard ratio (the hazard ratio reflects the analysis of time survived to an event). The event in our study represents the output of patients from the PED.

The first covariate that has the most significant impact on LOS is laboratory test which corresponds to the first split of the tree, 10% of the population has a hazard ratio of 0.42 representing the most significant probability (Figure 2) to stay at PED (median of LOS is equal to 4.5 hours) (Figure 3). The second variable that has an impact on the LOS is presence of radiology; we also note that the cluster generated by the tree indicates a hazard ratio of 0.79 meaning that 19% of the population has a high probability (Figure 2) to stay in the PED, about 3.7 hour. At the third split, there are qualitative covariates represented by two diagnosis groups, long group (Cold, Brain commotion, Gastroenteritis, Fiever, Abdominal pain....) and short group (Wound of head, Contusion of hand and wrist, Skin rash and eruption...). Among people with a diagnosis of the long group, those without presence of ultrasonography corresponds to 47% of the population with a hazard ratio of 1.2 corresponding to a LOS median of

1.98 hours. However, those who need ultrasonography (2% of population) have a hazard ratio less than 1, therefore a high probability (Figure 2) to stay more than 3 hours at the PED. For the short group, the split is based on the number of patients. When the number of patients present at the same time in the PED is greater or equal than 9.5, we obtain a hazard ratio of 1.4 corresponding to 9% of the population that has a probability to stay within 1.88 hours, when fewer than the threshold of 9.5 patients present concerns 13% of population with a probability of spending less time possible at the PED.

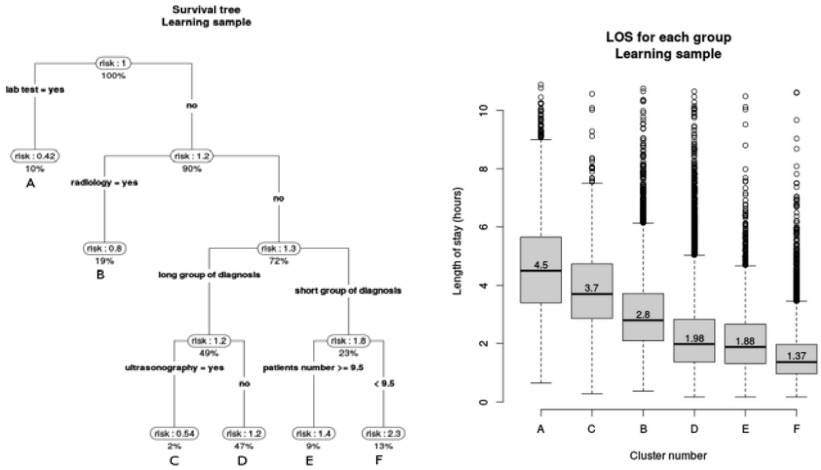


Figure 3. "Survival" Tree (construction in learning sample) and LOS distribution for all clusters. Median values of LOS (for each leaves) are shown in each boxplot

Five covariates identified to clustering the population: the existence of complementary exams 1) laboratory test, 2) radiology, 3) ultrasonography, 4) the patient diagnosis and 5) the number of patients present in the PED.

3. Discussion

A number of studies have attempted to measure associations between input, throughput, and output variables and ED LOS. For example, Asaro et al. [4] used autoregressive integrated moving average time series analysis to retrospectively measure the association between LOS and the covariates.

In our study, we choose a tree-based survival analysis because it is an effective tool for determining the relationship between input covariates and outcome measures and their interrelations. From this model, it is possible to estimate the LOS of a patient based on his/her characteristics available at the time of admission.

The results of our study demonstrate that the tree-based survival analysis led to divide the population into several clusters of patients with different LOS probabilities.

The covariates identified for clustering the population thanks to the tree-based analysis are: the existence of complementary exams, the patient diagnosis and the number of patient present in the PED. The major factors of discrimination turned out to be the presence of complementary exams, such as a laboratory test and radiology. These findings have been reported in other studies [7].

One of the explanations that we can have is that caregivers faced to a great amount of patient arrival tend to hurry and shorten care duration, so that overall LOS remains stable. We suppose that this adaptation can be efficient to a certain extent, and may depend on patient severity. Our results show that patients concerned by the influence of the number of patients seems to be low severity patients. Also, complementary exams of concern need a lot of time to be performed, and this time may be a stronger factor of LOS increase than additional time due to crowding.

A major limitation of this study is related to the available data. In order to study the covariates influencing the length of stay, we were limited to integrate only few covariates. It would be more interesting to use this analysis with other various covariates such as intermediate times of patient care (waiting time before the first care, waiting time for medical or complementary exams, bed occupancy …).

Concerning our analysis, even if the survival tree-based method is robust, all the results are not clinically relevant, such as the two groups of diagnosis which need further analysis to bring out the most important diagnosis.

Conclusion and Perspectives

Our approach allowed constructing a prediction model for the LOS. Data are simple to collect and can be registered at any time during the patient care period, so that it allows real time calculations for daily life in the ED.

Nevertheless, this model needs to be more precisely defined by using more data. Interesting fields for further researches could be time-series analysis and more complex assessment models by using more care-related data but also external data (seasons, popular events, weather …). To reach this goal, we also have to improve our work on data management.

Also, once the identification of covariates influencing the LOS is finished, we aim to implement a clinical decision support system that predicts and help to avoid ED crowding and optimizes patient LOS.

References

[1] Guinet A., Marcon E., Tahon C. Gestion et performance des systèmes hospitaliers, Hermès: 2008.
[2] Haradan C., Nolan T., Resar R. Optimizing Patient Row: Moving Patients Smoothly through Acute Care Setting. Cambridge, MA: Institute for Healthcare Improvement, IHI Innovation Series White Paper (2003).
[3] Rathlev N.K., Chessare J., Olshaker J. Time series analysis of variables associated with daily mean emergency department length of stay. Ann Emerg Med 49 (2007): 265-271.
[4] Asaro P.V., Lewis L.M, Boxerman S.B. The impact of input and output factors on emergency department throughput. Acad Emerg Med 14 (2007): 235-242.
[5] Schull M.J., Kiss A., Szalal J.P. The effect of low complexity patients on emergency department throughput. Acad Emerg Med 49 (2007): 257-264.
[6] Garg L., McClean S., Meenan B.J, Millard P. Phase-Type Survival Trees and Mixed Distribution Survival Trees for Clustering Patients'Hospital Length of Stay. Informatica 22 (2011) : 57-72.
[7] Yoon P., Steiner I., Reinhardt G., Analysis of factors influencing length of stay in the emergency department. Can J Emerg Med 2003 5(3):155-161.
[8] [8] R Development Core Team, R: A language and environment for statistical computing. 2013, R Foundation for Statistical Computing, Vienna, Austria. URL: http://www.R-project.org.

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Predicting the Operations Alert Levels for Dengue Surveillance and Control

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Abstract. Operations alert level is a discrete measure that quantifies the severity of epidemic outbreak with respect to operational measures. The alert levels are ordered based on the amount of response operations required. In this paper, we develop multi-class classification models based on ordinal multinomial logistic regression for predicting the alert levels for dengue at twenty weeks in advance. The regression uses the dynamic lag non-linear models to account for the non-linearity of the dengue incidence, along with its lagged values. The performance of the models is tested for the dengue case count data of Singapore.

Keywords. Dengue control, alert level, ordinal logistic regression, dynamic lag non-linear models

Introduction

Dengue poses a major threat to more than 100 countries worldwide. The number of dengue cases continues to rise globally, despite the improvements in diagnostics, vector control, and clinical management. Public health departments often define *severity* or *alert levels* that help in mobilizing the resources for containment of the transmission and the treatment of the infected. The focus of this work is on predicting such operations alert levels up to twenty weeks in advance. We use the dengue incidence data of Singapore for motivating the problem, building the models, and testing the performance.

Singapore has seen a resurgence of dengue cases since the late 1980s, after two decades of successful control, primarily due to integrated vector-control program. The recent epidemic cycle of dengue in Singapore is characterized by 6-7 year quasi periodicity. The incidence rates increase with each cycle. The 2005 outbreak in Singapore reported a total of 14,006 cases, with 27 deaths. After a lull period of 2006, there was another outbreak in 2007. The worst outbreak so far in the history of Singapore was in 2013, with 22,318 cases along with 8 deaths. Following the 2005 outbreak, the National Environmental Agency (NEA) of Singapore developed a formal trigger point system based on the number of weekly dengue cases.[2] Associated with a trigger point is an operations alert level. The operations alert level defines different action plans based on the level of severity in order to effectively utilize the limited resources. Once the trigger point is breached (which activates the associated operations alert level), relevant agencies and parties would be notified and necessary actions

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Table 1. Trigger points and the associated operations alert levels

Trigger Points (Cases/Week)*	Operations Alert Level
<= 120	0
> 120	1
> 150	2
> 200	3
> 300	4
> 400	5

* For consecutive two weeks, except for Levels 0 and 5

would be pursued. Table 1 shows the trigger points and the associated operations alert levels. In this work, we model the problem of predicting the operations alert level up to twenty weeks in advance, using the observed weekly dengue case counts.

1. Methods

The weekly dengue case counts data of Singapore from 2000 to 2013 is obtained from the *Weekly Infectious Diseases Bulletin*, published by the Ministry of Health, Singapore.[3] Operations alert levels is a *categorical* time series derived from the time series of weekly case counts. In order to predict the operations alert level for week $j+k$ at week j, the natural predictor to use is the observed cases of dengue till week j. Let d_j, $j=1, 2, \ldots, n$ denote the weekly dengue incidence time series and let o_j denote the corresponding operations alert levels categorical time series. The dengue count time series d_j is *auto-regressive* as the incidence count observed in week j depends on the incidence count observed in the recent past (infectious individuals infect the mosquitoes, which in turn infect susceptible individuals). The dependence between subsequent operations alert level observations in o_j is much stronger than auto-regression. By definition and construction of the operations alert level, observation at week j defines the operations alert levels o_j and o_{j+1}. Such dependency would cause spurious regressions, thereby resulting in poor model fitting and predictions. In order to remove the dependency, the weekly data is aggregated to biweekly data, defined as follows.

$$x_i = d_{2i-1} + d_{2i},\ i=1, 2, \ldots, n/2$$
$$Y_i = o_{2i},\ i=1, 2, \ldots, n/2$$

The biweekly incidence x_i has half the number of data points of d_j. Note that the biweekly incidence is aligned with the even weeks. Accordingly the alert levels are also defined only for the *even* weeks. One can similarly define for *odd* weeks, which would have a very similar structure. For our discussion henceforth, we will only focus on the above series that is aligned with the even weeks.

The aim is to predict the operations alert level at h time periods in advance. We consider the ten look ahead periods $h=2, 4, \ldots, 20$, each built with a separate model. The predictor variable for each model is the biweekly incidence data, with lagged values. Thus given the biweekly incidence data from week $i-L, i-L+1, \ldots, i$, the ten

[3] http://www.moh.gov.sg/content/moh_web/home/statistics/infectiousDiseasesStatistics/weekly_infectiousdiseasesbulletin.html

models would predict respectively the operations alert level for weeks i+2, i+4, …, i+20.

Given that the response variables are alert levels that are discrete and ordered, we use *ordinal multinomial logistic regression* for modeling the prediction models [1]. The basic assumption of logistic models is that the observations are independent. But both the incidence (predictor) and the alert levels (response) are time series data with autoregressive dependency. The *distributed lag* models are the general choice for modeling lagged values of predictors in regression. In this work, we use the *dynamic lag non-linear modeling* framework that captures simultaneously the effects of *exposure* and *lags* of dengue incidence [2]. A general model representation to describe time series of outcomes Y_i with i=1, 2, ..., N is given by a *generalized linear model*:

$$g(\mu_i)=\alpha+ \text{SUM}(j=1 \text{ to } J)\ s_j(x_{ij}; \beta_j) + \text{SUM}(k=1 \text{ to } K)\ \gamma_k u_{ik}$$

where μ=E(Y) is the expectation of Y, g is a monotonic link function, and Y is assumed to arise from a distribution belonging to the exponential family [3]. The function s_j denotes smoothed relationship with respect to the predictors x_j defined by the parameter vectors β_j. The variables u_k include the other predictors with linear effects specified by the related coefficients γ_k. In the context of our work, Y_i is the operations alert level that is assumed to arise from a *multinomial* distribution. The link function g is an ordinal multinomial logistic function. The relationship between x and $g(\mu)$ is represented by $s(x)$, which is included in the linear predictor of the generalized linear model as a sum of linear terms. This is usually done through the choice of a *basis*, a space of functions of which s is an element [4]. One can define several different basis functions – *linear*, *polynomial*, and *splines,* with varying degrees of non-linearity.

In addition to above, one can include the lagged values of x_i, say up to L time units, which would have different *lagged* effects on the outcome. The lagged effects can also be captured in terms of basis functions using *cross-basis* that simultaneously captures the non-linear effects of the exposure of the predictors along with the lagged values [2]. We use the above framework where the predictors are the cross-basis of the exposure and lagged values of dengue incidence, and the month of incidence (categorical variable) as a linear predictor.

2. Results

The weekly dengue incidence data of Singapore from 2000 to 2013 is first transformed into biweekly incidence data. The biweekly data from 2000 to 2011 is used for training, and the data from 2012 and 2013 is used for testing. The incidence in 2012 is non-epidemic and in 2013 is epidemic. Hence the test data would be useful for testing the models during both epidemic and non-epidemic periods.

A suite of models were created by varying the biweekly dengue incidence data along the following dimensions: 1) Degrees 1 to 3 of polynomial for exposure, 2) Degrees 1 to 3 of polynomial for lag, and 3) With and without log transformation. For all the above models, the categorical variable *Month* was added as the linear predictor. All the models were developed in R. The cross-basis for each of the model was developed using the *dlnm* package [5] and the ordinal logistic regression models were fit using the *bayespolr* function of package *arm* [6] The model with 2 degrees of polynomial for both the exposure and the lag, and with log transformation, showed

Table 2. Performance measures

Measure	Evaluation Focus
Avg. Accuracy	The average per-class effectiveness
Error Rate	The average per-class classification error
Precision	Agreement of the data class labels with those of the classifier, calculated from sums of per-class decisions
Recall	Effectiveness of a classifier to identify class labels, calculated from sums of per-class decisions
Fscore	Relations between data's positive labels and those given by the classifier on sums of per-class decisions.
$Precision_M$	An average per-class agreement of the data class labels with those of the classifier
$Recall_M$	An average per-class effectiveness of a classifier to identify class labels
$Fscore_M$	Relations between data's positive labels and those given by a classifier based on a per-class average.

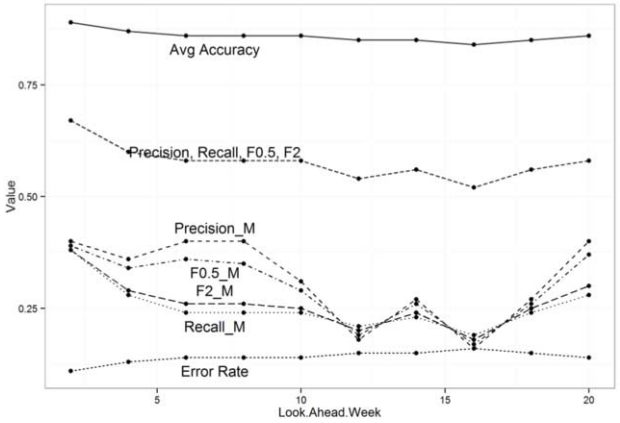


Figure 1. Performance measures for look ahead weeks from 2 to 20

better performance among all models. We show here the results for the above model for the incidence data of 2012 and 2013. The prediction of operations alert level is a *multi-class classification* problem and we use the performance measures in Table 2 to evaluate the models [7]. The scores with index *M* are macro-averages calculated across the classes. Figure 1 shows the performance of the models with look ahead of 10 time units (from 2 to 20 weeks in original data). The 0.5 and 2 refer to the commonly used β values in *Fscore* to give different weights to *Precision* and *Recall*. The *Average Accuracy* varied from 0.84 to 0.89 and the *Error Rate* was contained within 0.11 to 0.16, showing the applicability of the models from 2 to 20 weeks ahead in prediction.

3. Discussion

As the alert levels are defined based on the two week aggregates of the dengue incidence cases, it might be useful to directly predict the incidence instead of the alert levels. However, predicting the alert levels has its own advantages. The output of a multinomial logistic model is a probability distribution over the classes, which is then

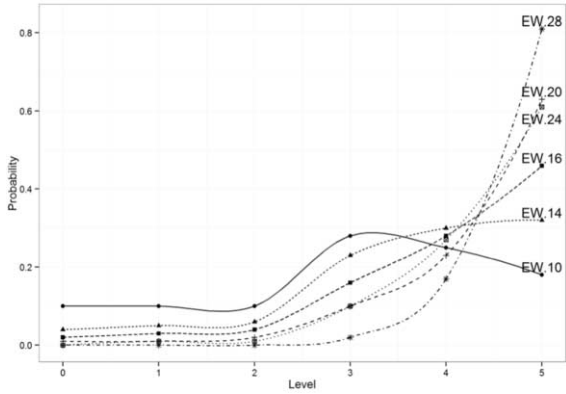


Figure 2. Predictions in probabilities for EW 30 of 2013

converted into a single class classification output using some thresholds. Figure 2 shows the prediction for EW (*epidemiology week*) 30 in 2013 from EW 10 onwards, in terms of probability distribution. At EW 10, level 3, 4, 5 had higher probabilities, with level 3 at peak. From EW 14 onwards, level 5 starts dominating, where level 5 is the observed alert level. Our experience in working with public health officials showed us that the officials are more comfortable working with probability distributions over the classes (sometimes complemented verbally as *less likely, more likely,* etc) than that of the confidence or prediction intervals of count data. Hence, we view the prediction of alert levels as complementary to count predictions, which could provide additional information in planning for epidemic contingencies.

Acknowledgements

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References

[1] Agresti A. An Introduction to Categorical Data Analysis. John Wiley & Sons; 2007.
[2] Gasparrini A, Armstrong B, Kenward M G. Distributed lag non-linear models. Statistics in Medicine. 2010; 29:2224 - 34.
[3] Dobson A, Barnett A. An Introduction to Generalized Linear Models. CRC Press/Chapman & Hall: Boca Raton/London; 2008.
[4] Wood S. Generalized Additive Models: An Introduction with R. Chapman & Hall/CRC Press: London/Boca Raton; 2006.
[5] Gasparrini A. Distributed lag linear and non-linear models in R: the package dlnm. Journal of Statistical Software 2011; 43(8):1–20.
[6] Gelman A, Su Y S, Hill M Y J, Pittau M G, Kerman J, Zheng T. arm: data analysis using regression and multilevel/hierarchical models. 2010.
[7] Sokolova M, Lapalme G. A systematic analysis of performance measures for classification tasks. Information Processing and Management. 2009; 45:427 - 37.

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Dengue Disease Outbreak Detection

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Abstract. Early detection of outbreak of a disease may help in timely and effective public health interventions. Our motivation for this work is to assist EHD planning officer to analyze the incidence data and based on it declare whether there is an outbreak or not. In this paper, we develop ensemble of multiple techniques for detecting dengue disease outbreak. These techniques are applied to dengue incidence data from Singapore and results are summarized.

Keywords. Dengue Disease, Epidemic, Outbreak Detection

Introduction

Singapore is a high urbanized and densely populated island nation with a land size of about 700 sq km. We briefly outline here the dengue epidemics in Singapore. For more details, refer to Koh *et al* [3] and references therein. All four serotype dengue viruses are endemic in Singapore with cases of DF and DHF reported year round. Since 1960, large epidemics occurred almost annually from 1961 to 1964 and 1966 to 1968. Nationwide implementation of Aedes control programme was initiated in 1969 focusing on intensive source reduction, health education, and law enforcement. Following the programme, the disease incidence rate decreased from 42.2 per 100,000 in 1969 to between 3 and 10 per 100,000 for the period 1969 to 1972.

The source control mechanism resulted in sustained suppression of the Aedes mosquitoes as reflected by the *premises index* (percentage of premises found breeding Aedes mosquitoes) which decreased from over 50% to less than 1%. However, successive epidemics occurred in 1986, 1989, 1992, 1998 and 2004 with the dengue incidence increasing more than 10 fold from 16.7 per 100,000 in 1987 to 223.1 per 100,000 in 2004. One of the possible reasons for sustained epidemics is the lowering of herd immunity (among the humans). Figure 1 shows the weekly dengue incidence notified since 2000. The data was obtained from the weekly infectious diseases bulletins of Communicable Diseases Division, Ministry of Health (MOH), Singapore [9].

Early detection of outbreak is helpful in taking timely measures to reduce the impact. Various statistical techniques can be used for early detection purpose. One of the popular techniques is based on statistical control chart. Traditionally these techniques are very popular in flagging anomalies in production processes. It assumes that readings obtained from the observed process are independent and identically distributed. But disease incidence series behaves very differently. The series exhibits seasonal variation, trend and serial correlation. In this paper, one of the techniques we

[1] Corresponding Author.

propose is a robust version of control charts which can be applied to such a dengue time-series.

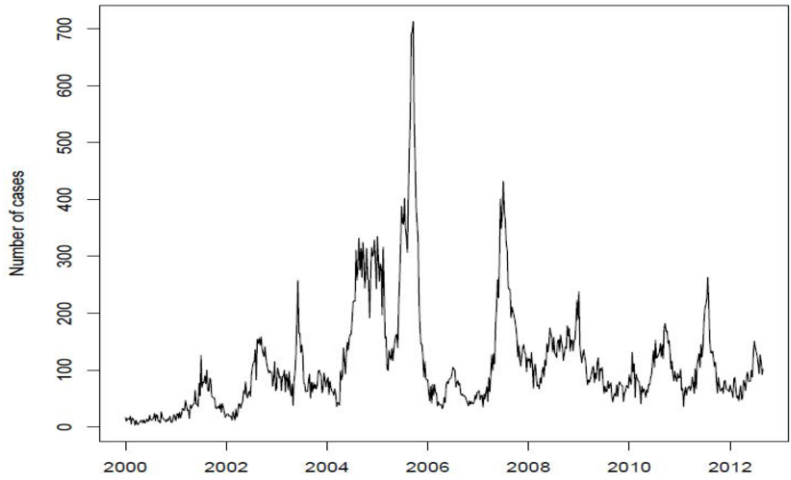


Figure 1. Weekly notified dengue incidence in Singapore

1. Methods

1.1. Existing Approach:

EHD as well as Ministry of Health (MoH) Singapore use the following definition for flagging a week as epidemic [9]. For any given year, they compute two threshold values: (1) warning threshold and (2) epidemic threshold. These are based on past 5 years moving average and standard deviation of dengue incidence. Hence they change every year but remain constant throughout the year. Warning threshold is set to (mean + 1sd) and epidemic threshold is set to (mean + 2sd). A sample plot for year 2012 is shown in Figure 2. Here the two threshold values computed based on past 5 years data are 155 and 200. Based on these thresholds, weeks 27 through 31 get flagged as epidemic.

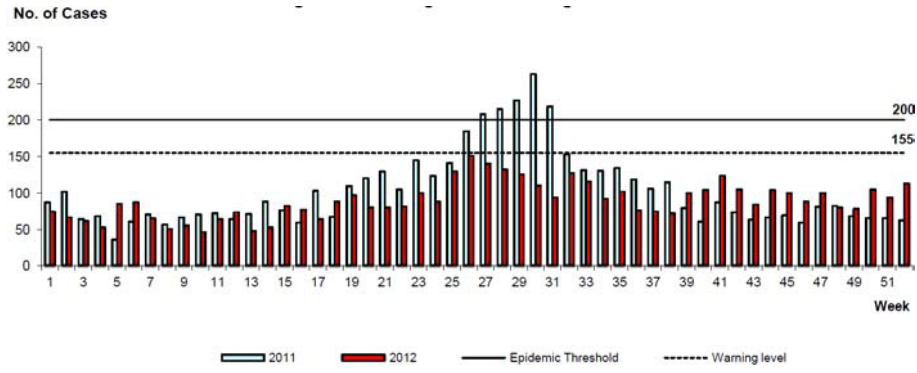


Figure 2. Dengue Epidemic Threshold based for year 2012 (Source: ref [9])

We observe at least two issues with the existing approach:

- Seasonal fluctuation of dengue incidence is not considered while deciding the threshold value for a given week of the year. Correlation in the dengue series is also ignored.
- It does not account for inherent limitation of accurately capturing of dengue incidence cases as there may be delay in reporting such cases.

We propose a new approach, which tries to address these shortcomings.

1.2. Proposed Approach:

In our proposed approach, we aggregate results from three techniques given below. First two techniques handle seasonal fluctuation. The third technique is more advanced and it handles both seasonal variation and serial correlation in the dengue incidence (DI) data. We analyse three different ways of aggregation for a given week:

- Majority Voting: Outbreak if at least two techniques flag an outbreak
- Unanimity: Outbreak if all three techniques flag an outbreak
- Atleast One: Outbreak even if one of the techniques flags an outbreak

1.2.1. Generalized Shewart Chart

The dengue incidence in control state is assumed to be normally distributed. But in order to capture inherent seasonality in the dengue incidence series an independent normal distribution is estimated for each week. For a given week *t*, we track the deviation of dengue incidence count from the estimated mean for that week. As we are interested in detecting outbreak only upper control limit is of interest. Week *t* is marked as an outbreak week if the incidence value is more than Mσ away from the mean where M is a pre-specified value.

1.2.2. Percentile Based Threshold

This is a non-parametric technique. We set the baseline value for each week in the yearly cycle to be the median based on historical data. A threshold is obtained by computing M percentile for dengue incidence for a given week. The procedure declares an outbreak as soon as observation exceeds this threshold.

1.2.3. Robust Control Charts

The exploratory analysis of DI series showed that the data is non-stationary and serially correlated, with trend and seasonality. We use a two-step detection method: a time series filtering procedure followed by a statistical surveillance method. Forecast errors (residuals) of a time-series prediction method are subject to control chart based technique. A large residual value i.e. large deviation between actual and predicted value of dengue incidence will increase the likelihood of outbreak.

We use seasonal autoregressive integrated moving average (SARIMA) model for prediction. SARIMA models are widely used to forecast correlated non-stationary time series with seasonality. Using the Box-Jenkins modeling approach, we select the best fit SARIMA model based on lowest Akaike's Information Criterion (AIC). We verify if the model is a good fit by ensuring that the residual series is white-noise.

The residual series is analyzed using two control chart techniques, namely the CUSUM control chart and Exponential Weighted Moving Average (EWMA) control

chart and we finally selected EWMA as it gave better results. The EWMA technique relies on exponential smoothing of observations. Given a smoothing constant, a weighted average of all the observations in the past is computed and compared against an upper control limit. Control limit is set based on estimated mean and standard deviation of residual series.

2. Results

We have dengue incidence data for Singapore from 2000 to 2014. Also, it is known that there was outbreak in the year 2004, 2005 and 2013. With this as input we compare the performance of existing and proposed ensemble approach at two different instants. (1) Training data from 2000-2004 and use it for predicting outbreaks in 2005-2006. (2) Training data from 2000-2010 and use it for predicting outbreaks in 2011-2013. We compare the predictive capability of the fitted models using the following three measures:

1. Sensitivity: Measures the proportion of actual positives which are correctly predicted
2. Specificity: Measures the proportion of actual negatives which are correctly identified
3. Accuracy: Measures the proportion of weeks which are correctly predicted

We take the historical dengue data and carry out smoothening to account for inherent limitation of accurately capturing of dengue incidence cases as there may be delay in reporting such cases.

In case of *Robust Control Chart* technique, we validate the time-series model by ensuring that the residual series is independent and identically distributed. The ACF plot for residual series from the time-series model fitted is shown in Figure 3.

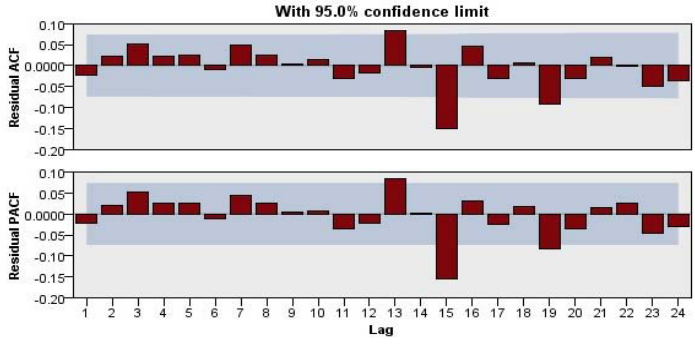


Figure 3. ACF and PACF plots of residual from fitted time series model

The comparison of results for the proposed and existing techniques using two different datasets is given in Table 1 and 2. Table 1 clearly shows that proposed approach with majority voting performs better than existing approach. On dataset 2 the majority voting approach is better in terms of specificity and accuracy.

Table 1. Outbreak Prediction Performance for 2005-2006 (using data till 2004)

Approach	Sensitivity	Specificity	Accuracy
Existing	0.51	1	0.75
Proposed(Majority)	0.90	1	0.95
Proposed(Unanimity)	0.36	1	0.68
Proposed(Atleast One)	1	0.86	0.93

Table 2. Outbreak Prediction Performance for 2011-2013 (using data till 2010)

Approach	Sensitivity	Specificity	Accuracy
Existing	0.97	0.95	0.96
Proposed(Majority)	0.91	1	0.97
Proposed(Unanimity)	0.65	1	0.89
Proposed(Atleast One)	0.93	1	0.98

3. Discussion

The proposed method provides a statistical approach for generating better predictions of dengue outbreaks. Aggregation of signal from various methods will be helpful in improving prediction performance and thus timely planning of control efforts. The parameters of the models can be tuned to improve the performance further. The models are developed using IBM SPSS Modeler 15.0 product and the SPSS stream has been deployed on NEA EHD server for further evaluation in real-time setting. In future, we would like to explore batch learning techniques such as weighted majority where weights update is based on recent prediction performance of the techniques.

References

[1] Que, Jialan, and Fu-Chiang Tsui. "Rank-based spatial clustering: an algorithm for rapid outbreak detection." *Journal of the American Medical Informatics Association* 18.3 (2011): 218-224.
[2] Unkel, Steffen, et al. "Statistical methods for the prospective detection of infectious disease outbreaks: a review." *Journal of the Royal Statistical Society: Series A (Statistics in Society)* 175.1 (2012): 49-82.
[3] Koh BK, Ng LC, Kita Y, Tang CS, Ang LW, Wong KY, James L, Goh KT. The 2005 dengue epidemic in Singapore: epidemiology, prevention and control. Ann Acad Med Singapore. 2008:37(7):538-45.
[4] Martinez EZ, Silva EA. Predicting the number of cases of dengue infection in Ribeirão Preto, São Paulo State, Brazil, using a SARIMA model. Cad Saude Publica. 2011:27(9):1809-18.
[5] MOH (Singapore). Weekly Infectious Diseases Bulletin. Singapore: Ministry of Health.
[6] Chatfield C. The Analysis of Time-Series: An Introduction. Chapman & Hall/CRC Press. London. 2004.
[7] Chatfield C. Time-Series Forecasting. Chapman & Hall/CRC Press. London. 2000.
[8] Egger JR, Ooi EE, Kelly DW, Woolhouse ME, Davies CR, Coleman PG. Reconstructing historical changes in the force of infection of dengue fever in Singapore: implications for surveillance and control. Bull World Health Organ. 2008:86(3):187-96.
[9] MOH (Singapore). Weekly Infectious Diseases Bulletin. Singapore: Ministry of Health. Url: http://www.moh.gov.sg/content/moh_web/home/statistics/infectiousDiseasesStatistics/weekly_infectiousdiseasesbulletin.html

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Cause-of-death Certification in Africa: Analysis of a Model Implemented at the Teaching Hospital of Souro Sanou of Bobo-Dioulasso (Burkina Faso)

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Abstract: Introduction: In Africa, mortality statistics are not reliable due to the low performance of the death registering systems. Our aim is to implement an efficient system. In this article we make a comparison between the existing system model and the new system that will be set up. **Method**: UML has been used as the modeling language based on the 2TUP analysis methods. **Results**: the new system for registering deaths and their causes was conceived and represented through activities, utilization cases and data model diagrams. **Discussion**: We have developed a tool for death registration taking into account African hospitals characteristics. The progressive deployment of this system at the CHUSS of Bobo-Dioulasso enables users and actors to appropriate it.

Keywords. Death causes, death certificate, mortality statistics

Introduction

Nowadays, in Burkina Faso, as in most African countries, there is no effective and reliable registration system for civil status acts (births, deaths) [1,2]. Statistics are mainly gathered through population sample surveys. Physicians do not systematically certify deaths. The WHO guidelines for determining and coding the main causes of death are not applied [3].The "Global Health Observatory" estimates the world-wide mortality rate to 7,9 p 1000 compared to 11,8 p 1000 in Africa and 12,4 p 1000 in Burkina Faso [4]. More than 25% of the population data are not available when needed in developing countries, particularly in Africa [4,5]. This situation is mainly due to the low performance of the systems and tools implemented for data collection [6]. Hospitals in Burkina Faso have no information system and processes able to produce reliable mortality information [8].

This paper analyses the different steps to move from the current paper-based system to a future one whose target is to meet the requirements of good practice for gathering death events, coding and certifying cause-of-death [9].

1. Methods

The civil registration service covers two closely linked processes: on the one hand individual official documents (births and deaths) and on the other hand population statistics of births and deaths. In this study, we have focused on the deaths and their causes.

The 2TUP (Two Tracks Unified Process) has been used to analyze the existing system in order to study both the functional and the technical branches [10]. We have used UML rules to describe the different aspects of the system [11].

2. Results

2.1. Current system analysis results

The sequence diagram of the current system (Figure 1), states that the documents and information related to births are essentially managed by the health worker and the civil registration officer. As for deaths, the observation can be made by any health worker present at the time of death (physician, intern, nurse, …). A death certificate document is issued only at the request of the family. As for statistics purposes, data are collected by the health worker (who is rarely a physician), from the hand written admission register and transmitted to the medical informations service (MIS), which processes and forwards the data to the Ministry of Health.

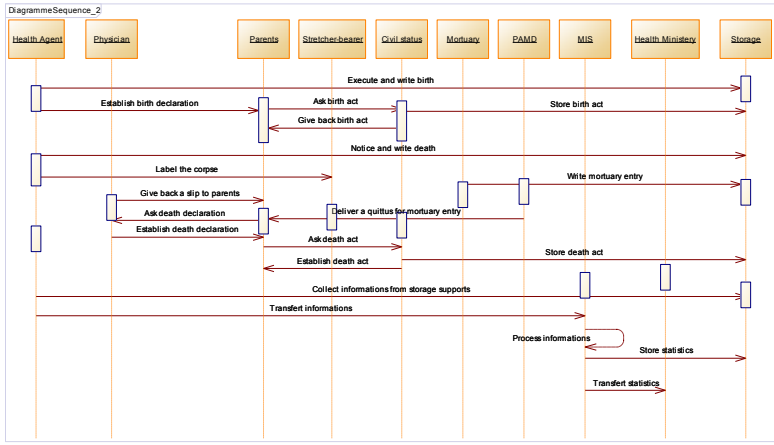


Figure 1: Diagram of current system sequence

2.2. Diagnosis and critical analysis of the current system

The analysis of the existing system points out the following situations: the death certificate is not exclusively written by the physician, and the declaration of death is not systematic; the deaths documents are not managed by the Civil registration department of the hospital; the causes of death are not certified by a physician, and the WHO rules on death certification and causes coding are not applied; information management is manual with a high risk of redundancy and poor quality of data.

2.3. Implementation of the new system

2.3.1. Certification and causes of death coding

The WHO recommends that each death must be stated and certified by a physician who reports on the civil certificate the civil status information and the sequence of morbid conditions that led to the death. Moreover the determination of the underlying cause of death must be done according to mortality statistics rules [3]. This is only possible, consistently, with the use of the certificate of death model recommended by the WHO [11]. The issuing of the medical certificate of death facilitates the choice of the underlying cause of death when two causes or more are recorded. Part I of the certificate with the lines "a", "b", "c", "d" is for recording diseases related to the chain of events that led directly to the death, and Part II is reserved for conditions with no relation to the cause of death but which have contributed to it. The causes of death listed on the certificate are coded according to the rules defined in Volume 2 of the ICD-10 [3].

The analyses of current systems used abroad and the identifying of their deficiencies have led to the development of the new system we propose.

2.3.2. Causes of death certification model within the new system

The workflow of the future system (Figure2) describes the flow of documents and information related to the death. Filling the death certificate is systematic and the corpse exit authorization can only be delivered with the administrative certificate.

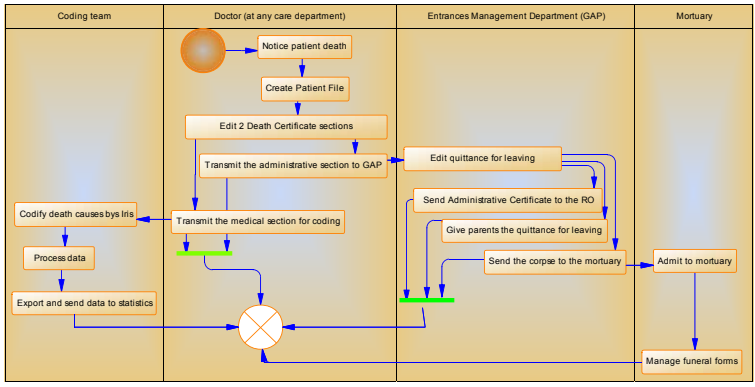


Figure 2 : Activities diagram

The physician and the coder are the two main actors. The physician can consult the (electronic) medical records of the deceased patient and use a dedicated application module in order to fill and sign the medical and the administrative forms of the death certificate. The coder records the certificate, codes the causes of death and produces death statistics based on the initial causes previously determined.

2.3.3. Set up of the new system

Our system is designed to be used in all hospitals of Burkina Faso. It has been built by coupling the two following applications. On the one hand, we have developed an application named “MIMIR” which collects information. It is a modular and scalable

web application. It is provided with a synchronizer module to receive information from different sources. On the other hand, we have used a proprietary software called "IRIS" for coding causes of death [12]. IRIS is a desktop application. It is an add-on of MMDS (Mortality Medical Data System) developed by the CDC for the automatic coding of death causes [13]. IRIS has been created to overcome the problem of natural language that MMDS could not solve. It is an expert system based on conventional algorithms, able to determine the underlying causes of death. Its general principle is: "*When more than one condition is entered on the certificate, the disease chosen as the initial cause of the death is the one that could generate all the other conditions health status in the other lines*". For example, in a written certificate: (a) coma, (b) generalized metastases, (c) lung cancer, the selected underlying causes of death will be " lung cancer " provoking metastasis which, in their turn have led to the coma, in which state the patient died [14].

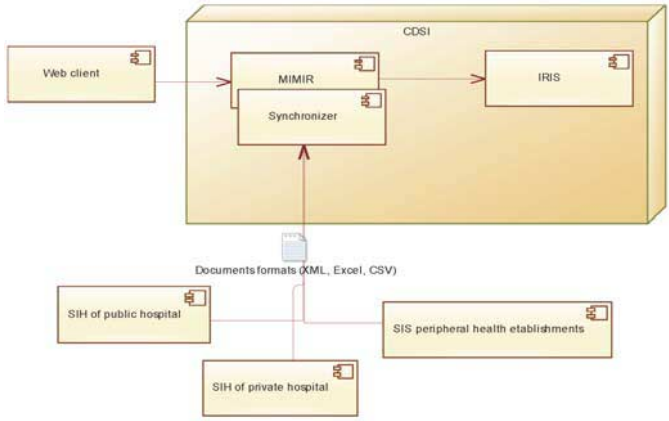


Figure 3: Diagram for the deployment of the new system

So far the system has been validated by the board of the CHUSS and the Ministry of Health. The Ministry has agreed and provided a resource person for monitoring the implementation of the system. Physicians have been trained to use the software and to produce death certificates. The launch of the project was formalized by an administrative letter sent by the General Director of CHUSS. Currently, the system operates under two types of records: 1) electronic-based records integrated in the electronic patient record (implemented in an intensive care unit); 2) paper-based records (for other services) by filling a paper-based form which is sent to the MIS for coding the causes of deaths.

3. Discussion

More than the half of deaths occurring in countries with low to middle incomes are due to 10 main causes most of which could be prevented [6]. Data provided by countries help to identify the causes of death against which it is possible to act in order to reduce mortality. In Africa and particularly in Burkina Faso, an evaluation of the national health information system in 2008 indicates the lack of an effective process of births and deaths registration [7]. Several studies show the relationship between data quality and decision making. For example, Mathers et al. have pointed out in 2003 that the

WHO had completed data on deaths registration for only 64 of 194 countries [15]. We chose to implement a "collector and coder-producer" of death data system based on the current information flow with the introduction of electronic certification. The studies of Dr. Bagayoko in Mali shows that many IT projects fail because of the boundaries have not been properly defined. It is therefore essential to determine the functional scope of the system for the HIS setup because the aim is not to cover the entire information system from the beginning, but we want to consider the possibility of interoperability with other programs. We therefore intend to gradually set up this system (both electronic and paper based) to facilitate its appropriation and extension. This is a first level of sustainability. The implementation of a training plan for new agents, the support of the Ministry of Health, of the West African Health Organization and of the General Directorate of Modernization Civil State are elements that suggest that term, our system will be an reference in Burkina and Africa. Recording of deaths occurring outside hospitals is another challenge for our system.

References

[1] Navarro V. Assessment of the world health report 2000. The Lancet. 2000;356(9241):1598–601.
[2] Organization WH. The world health report 2000: health systems: improving performance. World Health Organization; 2000.
[3] Organisation mondiale de la santé. Classification statistique internationale des maladies et des problèmes de santé connexes. Genève: Organisation mondiale de la santé; 2009.
[4] Mortality and global health estimates [Internet]. WHO. [cited 2014 Feb 3]. Available from: http://www.who.int/gho/mortality_burden_disease/en/index.html
[5] Organization WH. Statistiques sanitaires mondiales 2007 [Internet]. 2008 [cited 2014 Feb 6]. Available from: http://apps.who.int/iris/handle/10665/43829?locale=fr
[6] Sibai AM. Mortality certification and cause-of-death reporting in developing countries. Bull World Health Organ. 2004 Feb;82(2):83–83.
[7] Boussari L, Somé R. Evalutation du système national d'information sanitaire du Burkina Faso [Internet]. Ministère de la santé, Burkina Faso; 2008 p. 57. Available from: http://fullnulled.com/doc/pdf/download/www__who__int--healthmetrics--library--countries--HMN_BFA_Assess_Draft_2008_12_fr.pdf
[8] Organisation mondiale de la santé. Classification statistique internationale des maladies et des problèmes de santé connexes. Genève: Organisation mondiale de la santé; 2009.
[9] Belangour A, Bézivin J, Fredj M. M2T: Une amélioration du processus 2TUP dans le contexte du MDA. Rev AMADEIA À Par En. 2007;
[10] Muller P-A, Gaertner N. Modélisation objet avec UML [Internet]. Eyrolles Paris; 2000 [cited 2014 Jan 14]. Available from: http://ftp.sliim-projects.eu/docs/Dev/Methodologie/UML/coursUML.pdf
[11] DIMDI - Iris Institute [Internet]. [cited 2014 Feb 4]. Available from: http://www.dimdi.de/static/en/klassi/koop/irisinstitute/index.htm
[12] NVSS - Mortalité médicale Data System [Internet]. [cited 2014 Feb 4]. Available from: http://www.cdc.gov/nchs/nvss/mmds.htm
[13] Lu TH. Using ACME (Automatic Classification of Medical Entry) software to monitor and improve the quality of cause of death statistics. J Epidemiol Community Health. 2003;57(6):470–1.
[14] Mathers CD, Ma Fat D, Inoue M, Rao C, Lopez AD. Counting the dead and what they died from: an assessment of the global status of cause of death data. Bull World Health Organ. 2005;83(3):171–177c.
[15] Bagayoko C-O. Mise en place d'un système d'information hospitalier en Afrique francophone: cinz@ n, étude et validation du modèle au Mali [Internet]. Aix Marseille 2; 2010 [cited 2014 Feb 6]. Available from: http://www.theses.fr/2010AIX20680

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A Comprehensive Clinical Research Database based on CDISC ODM and i2b2

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Abstract. We present a working approach for a clinical research database as part of an archival information system. The CDISC ODM standard is target for clinical study and research relevant routine data, thus decoupling the data ingest process from the access layer. The presented research database is comprehensive as it covers annotating, mapping and curation of poorly annotated source data. Besides a conventional relational database the medical data warehouse i2b2 serves as main frontend for end-users. The system we developed is suitable to support patient recruitment, cohort identification and quality assurance in daily routine.

Keywords. Medical Informatics, Health Information Systems, Information Storage and Retrieval, Clinical Trials, Hospital Information Systems, CDISC ODM

Introduction

Clinical informatics provides information technology (IT) and services for health care and research. The data centre project of the Integrated Research and Treatment Center Adiposity Diseases (IFB) [1] develops methods which supports clinical research projects in the phases of planning (including cohort identification, feasibility, data reports for hypothesis generation), implementation (e.g. data-entry-systems, recruitment management) quality assurance (e.g. data monitoring, benchmarking) and information translation back into clinical routine.

To do so, we have built up a clinical research database (RDB) which integrates as many relevant data sources from the hospital information system (HIS) as possible (laboratory, biobank registry, health record, secondary sources) and data from clinical trials of the IFB, held in the clinical data management system (CDMS). When the IFB started in 2010 and the outpatient clinic opened, no structured obesity-specific documentation existed. Even weight and height of a patient, needed to calculate the Body Mass Index – the single most important measure for obesity diagnosis – were missing. A detailed entry form (PMD, parameterized medical document) for structured obesity anamnesis and documentation for the clinical workplace SAP/Siemens i.s.h.med was devised and implemented. Every patient of the obesity outpatient clinic was documented, although the database behind was a black box for physicians and researchers.

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We decided to develop an easy to use system based on standard technologies and open source software to establish a RDB at the University Medical Center Leipzig.

1. Methods

1.1. Clinical Research Database (RDB) – an Archival Storage Information System

The RDB presented here is not a single perfectly trimmed database, but is instead the core of an Archival Information System (AIS) in the sense of OAIS [2]. The methods we describe can be interpreted as part of the functional entities (or layers), ingest (ETL with ODM target), archival storage (ODM based) and access (i2b2 [3], SQL database). We conceived the RDB knowing that the most time consuming challenge is not setting up an appropriate, secure IT research infrastructure, but to support the early steps of the data lifecycle from conceptualisation to the ingest-phase [4]. To be of practical use, a comprehensive RDB has to cover storage and access functionalities and at least in a modest way aspects of data curation, normalization and standardization.

Instead of using transformations from every proprietary data source to an evolving proprietary RDB and then implement transformations to all potential access systems, we use a standardized format for medical data representation as stable target for all data transformations from external source to the access layer, thus completely decoupling ingest and access layer. Only transformations to and from this standard are necessary. Changes at the producing or consuming systems do not affect the middle, storage tier.

1.2. CDISC ODM

"The Operational Data Model (ODM) is designed to facilitate the archive and interchange of the metadata and data for clinical research" [5]. Various CDMS can write, some statistical software can read ODM. An ODM file contains metadata (<Study>) and a data part (<ClinicalData>). The metadata defines the structure of a study in terms of events, forms, item groups and items with data types and code lists. The clinical data section refers to these definitions and contains the actual data for each subject (patient / proband). This structure is oriented toward clinical trials [6], but as we discuss here, it can be mapped to represent hospital data as well.

1.3. Access Layer

Typical users of a RDB are biostatisticians and physicians or PIs (principal investigator of a clinical trial), often with very different needs and qualifications.

We built up a classical relational database for the first group: a scheme for each data source, tables for every group of items, tables for code-lists and so on. Access rights can be given in very fine granularity. This database is suited for statistical analysis of data with well-known endpoints, but not for ad hoc queries since scheme overarching queries grow complex especially as multiple joins and patient-id mapping tables become too large.

In contrast, the medical data warehouse i2b2 uses a user friendly web-based query tool to search for specific patient groups in heaps of data coming from different sources [7]. It operates on a star-scheme, holding facts in a single EAV (Entity-Attribute-

Value) table. Queries are assembled in groups by drag and drop and refined by operators (e.g. and, or, exclude) or constraints (data range, occurrence counts, same encounter).

2. Results

We installed the RDB inside the clinic as part of the HIS. In Saxony, clinical data may be used freely for research within the institution. However, to contact an outpatient patient at home, e.g. because he/she qualifies for a clinical trial, or to use data outside the clinic, written consent is obligatory. More than 50% of our patients gave informed consents to do both.

2.1. Data Integration – Ingest Layer

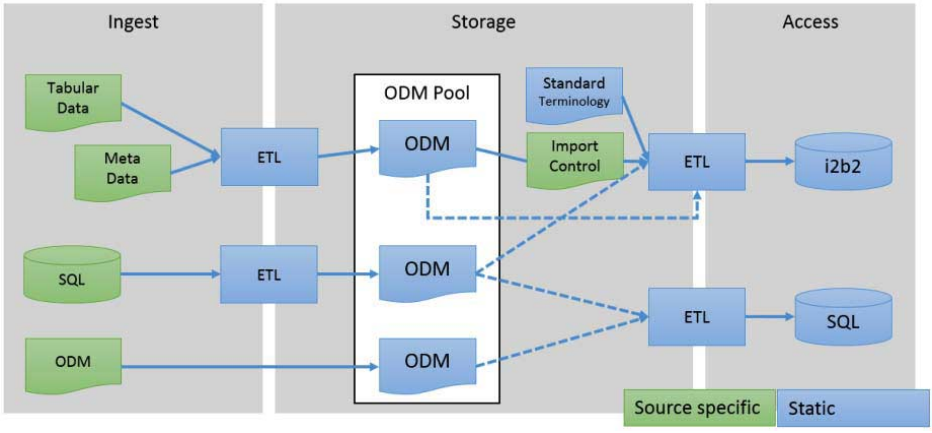


Figure 1. Data integration pipeline

Data coming in tabular format is transformed to ODM by a generic, highly customizable job written in a dedicated data integration tool in three steps:

- de-identification of data (e.g. names, addresses, free text)
- curation (e.g. remove test cases, respect special missing codes, correct known data-entry errors and so on)
- annotating (e.g. comments, grouping labels) and normalization (e.g. use of UCUM (Unified Code for Units of Measure) from a separate metadata definition file

The metadata description is derived from structural data analysis, interviews and existing documentation. This applies to all data coming from HIS. For non-tabular sources, namely CDMS systems, the above steps are not necessary as data is already quality assured. If the CDMS cannot provide ODM on its own, the data is transformed directly from the source database.

All ODM files are archived in a pool. Data subsets are assigned to user group specific projects, e.g. for the paediatric or adult departments. The process pipeline from storage to i2b2 is controlled and configured by a source specific control file, defining superfluous structure levels, mapping local to generics concept (e.g. gender, age), inserting standard terminology trees (ICD, OPS), mapping data items to i2b2-metadata

(e.g. subject key, timestamp of observation) and more. Other control elements manage database connections, define the destination ontology path or include nested import jobs. The import from ODM to SQL database is based on XSL Transformation.

2.2. Mapping hospital data to ODM

We started with two specific obesity documentation forms (PMD) used in the children and adult outpatient clinics and in bariatric surgery with about 300 / 200 defined items. A standardized dataset from the HIS (§21 KHEntgG [8], e.g. diagnoses and procedures), biobank registry data and trial structure data was added for testing. Record linkage is based on hospital patient-id. The definition of the metadata and data cleansing process is troublesome, as exports from the SAP system neither contain metadata nor inner structure. Table 1 shows the mapping used. The top level nodes of the i2b2 ontology are fixed as documents, diagnoses, studies etc.

Table 1. HIS to ODM to i2b2 Mapping

Source	ODM	I2b2
SAP encounter	StudyEvent	
SAP document	FormEvent	2nd level
Metadata module definition	ItemGroup	3rd level
SAP data columns + Metadata meas. units	Item	4th level
Metadata codes/labels	CodeList	5th level
ICD-10-GM / OPS/ICPM catalog		5th to nth level

Additional information (e.g. case-id, date of observation, patient age or sex) was retrieved by XPath expressions directly from corresponding ODM item values, entities or attributes – whatever is available. ODM itself does not determine these.

2.3. User Feedback and usage Scenarios

I2b2 kept its promise to be easy to use. Even people having only a vague knowledge of IT and database internals needed only 1-2 hours of training. We encountered two typical usage scenarios:

1. Immediate help in recruitment phase, e.g. *Find patient with BMI > 40 kg/m² without diabetes*. I2b2 exports patient-id, candidates are looked up and double checked against their health record, double checked for their written consent, and finally contacted.
2. Quality assurance for the outpatient clinics, e.g. check for patients not fulfilling outpatient inclusion criteria or concerning data quality.

In both cases help was appreciated as a true time and labour saving option; the alternative would have been to scan health records or to send unspecific invitations. However, temporal questions (e.g. X occurs not more than 3 weeks after Y) are still difficult. Usual queries took less than 10 seconds.

The system itself is not easy to setup. Data import and maintenance of the more elaborate features are not well supported, although some third party effort is currently developed [9], from which we used the installation and administration tool.

3. Discussion

Much care has been taken to make i2b2 usage as comfortable as possible by using an intuitive concise ontology and readable item labels, integrating clear labeled code lists and standard-terminologies. It took time and some persuasion to implement the system into research routine, but clinicians and researchers are beginning to appreciate the new possibilities. The black-box RDB became more transparent, especially physicians working in the clinic and for a clinical trial see the immediate benefit of the structured documentation. The possibility to explore their *own data by themselves* provides confidence, trust and fosters acceptance. We expect the RDB will be used for trial planning (estimate sample sizes, develop hypothesis) in the future.

Our ODM centric approach seemed like an artificial complication at first, but in fact reduced the complexity of the whole system by managing rather simple ETL jobs reading or writing ODM. ODM proved to be flexible enough to handle all data sources and could be easily processed and understood.

We are working on a more general approach outside the clinical context, which allows true trial and HIS data overarching queries. This solution demands additional components and processes, such as a pseudonymization service, trustee managed patient lists. Data exports for retrospective analysis will play a bigger role, making a second level of pseudonymization and elaborated reporting tools necessary. Finally this concept will lead to the establishment of an Archival Informations System.

Data quality of primary care is often criticized, analysts and physicians know this. Particular financially motivated coding is problematic in research. [10] Nevertheless this is not a big issue in the scenarios considered here, as the patient set is big enough to minimize the effect of a few false negatives. The best way to assure data quality is to work with it.

A**cknowledgement:** This work was supported by the Federal Ministry of Education and Research (BMBF), Germany, FKZ: 01EO1001 and 01KN1102

References

[1] IFB, "Integrated Research and Treatment Center AdiposityDiseases," [Online]. Available: http://www.ifb-adipositas.de/en. [Accessed 07 02 2014].
[2] OAIS, Reference Model for an Open Archival Information System (OAIS), ISO 14721:2012.
[3] i2b2, "Informatics for Integrating Biology and the Bedside," [Online]. Available: https://www.i2b2.org/. [Accessed 07 02 2014].
[4] S. Higgins, „The DCC Curation Lifecycle Model," The International Journal of Digital Curation, Bd. 3, Nr. 1, pp. 134-140, 2008.
[5] CDISC, "Operational Data Model," [Online]. Available: http://www.cdisc.org/odm. [Accessed 07 02 2014].
[6] M. Löbe, Einsatzmöglichkeiten von CDISC ODM in der klinischen Forschung, Proc. 57th GMDS Annual Meeting, Braunschweig 2012, 1294 – 1304.
[7] T. Ganslandt, Mate S, Helbing K, Sax U und H. U. Prokosch, „Unlocking Data for Clinical Research – The German i2b2 Experience," Applied Clinical Informatics, Bd. 2, Nr. 1, pp. 116-127, 2011.
[8] KHEntgG, §21 Transmission and use of data, German Hospital Financing Act, 1972/2013.
[9] T. Ganslandt, Integrated Data Repository Toolkit: Werkzeuge zur Nachnutzung medizinischer Daten für die Forschung, GI, Lecture Notes in Informatics, Bonn 2012, 1252 – 1259.
[10] T. Botsis, G. Hartvigsen, F. Chen und C. Weng, „Secondary Use of EHR: Data Quality Issues and Informatics Opportunities," AMIA Summits on Translational Science proceedings AMIA Summit on Translational Science, Bd. 2010, pp. 1-5, 2010.

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Using Geographic Information Systems to Simulate Patient Access Areas

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Abstract. We constructed a simulation model with a geographic information system (GIS) to predict the future shortage of beds in the Tokyo Metropolitan Area. With a grid square method, we calculated patient numbers for every 500 square meters of the Tokyo Metropolitan Area until 2040 and estimated whether those in need could be admitted to hospitals within an hour's drive from their homes. The simulation demonstrates that after 2025 many patients may not be able to find hospitals within this time framework. The situation will be especially serious in the center of Tokyo and along the railway lines, where many senior citizens reside. We can now apply this innovative GIS method in many fields and especially for the precise estimation of future demands for and supply of medical assistance.

Keywords. GIS, Health services needs and demand, Super-aged society, grid method

Introduction

Japan is rapidly becoming a super-aged society. In the Tokyo Metropolitan Area, with a population of 40 million, medical demand is predicted to rise dramatically because of the progressive increase of senior citizens [1]. However, the health care resources of Tokyo and its surrounding prefectures are quite poor in relation to the national average. Therefore, it is urgent to estimate accurately the future medical demand of each area in order to sustain an adequate health care system. Estimations have usually been made by the numbers of patients in large districts but not in small areas. However, to develop community medical policies more precisely, the local government needs such assessments for each community.

A geographic information system (GIS) is a computer system for capturing, storing, checking, and displaying data related to positions on a map. It is often applied, for example, in the field of medical informatics to evaluate the accessibility of primary health care services for a population [2] and to consider realistic measures to ensure that demand for them are properly provided by health service locations [3]. In this study, we constructed a simulation system with a GIS to predict shortages of beds in the Tokyo Metropolitan Area. We called the system the "Patient Access Area Model";

[1] Shunsuke DOI.

with it, we simulated patient access to hospitals in order to estimate the balance of medical supply and demand in the future.

1. Methods

We chose the Tokyo Metropolis and the surrounding three prefectures as an experimental region. There were three steps in the simulation:

1. An estimation of the population and the number of patients in the future
2. A simulation of patient access to hospitals with the Patient Access Area Model
3. An evaluation of supply and demand

First, by using the grid mesh method, we designed a patient map. The population of each five-year age group, from 0 to 85 years or older, and the number of inpatients of each 500 square meter area (called a mesh) were calculated, based on the cohort component method for every five years from 2010 to 2040. We estimated the future population with the data of the 2010 National Census Data on the live birth rate, the mortality rate, and the in-and outflow rate [1]. The number of patients admitted to hospitals for every five-year period was calculated with the rate of the treatment accepter [4].

Second, we set the accessible areas according to patient transit time to a hospital. All patients for the total area were numbered at random, and each patient was individually allocated to a hospital. As shown in Figure 1, the patients living in each mesh were only allowed to enter hospitals within an hour by train or car from their mesh. We investigated the accessible areas with the GIS and the "ACT Distance Calculation Service" provided by Advanced Core Technology Co. Ltd. [5].

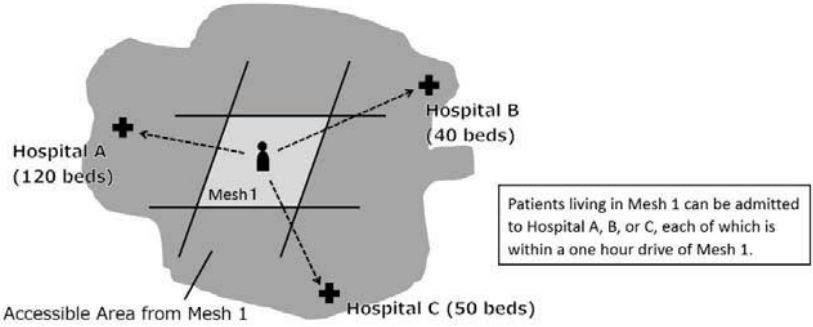


Figure 1. Overview of 'Patient Access Area Model

Algorithms permit the determination of a hospital. For example, a hospital can be chosen by 1) the stochastic model, 2) size (the largest), and 3) proximity (the nearest). We constructed an algorithm that imitated inpatient behavior, based on the concept that patients want to enter the largest and nearest hospital.

Figure 2 shows the algorithm. We classified all the hospitals into three groups according to the number of beds. Small, medium, and large hospitals were defined as those with fewer than 100 beds, fewer than 400 beds, and more than 400 beds, respectively. If there were no large hospitals in the area, we chose the nearest medium-

sized one; if the latter was missing, we selected the nearest small hospital. For example, in the case of Figure 1, a patient living in the Mesh 1 is admitted to Hospital A because it is the only medium size hospital.

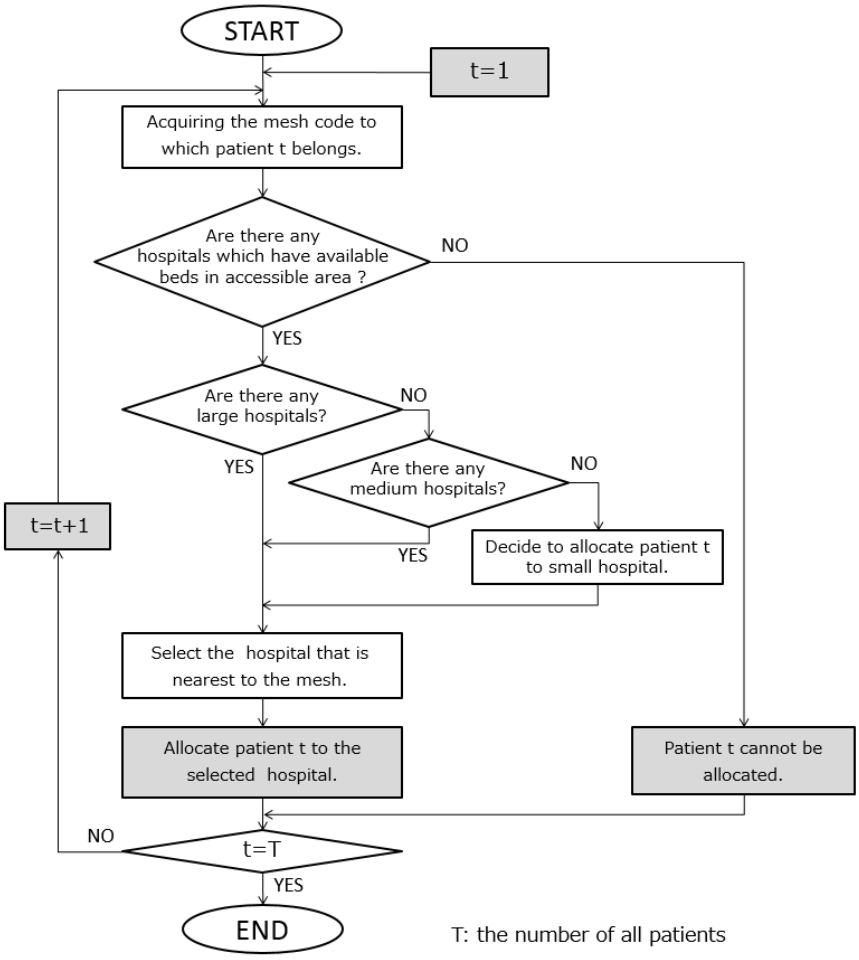


Figure 2. Flow of the selected algorithm

Because every hospital has a limited number of beds, some patients may have a problem finding a hospital within an hour. In the target field, there were 1,623 hospitals with 258,794 beds. For the evaluation of supply and demand, we defined the situation as one of "over-demand" when patients could not be admitted to hospitals within the accessible area. Similarly, a situation of "over-supply" was defined as the presence of unutilized beds in the hospitals.

We prepared some scenarios to perform a sensitivity analysis. We introduced two scenarios by changing the average number of hospitalization days and rate of the treatment accepter. In Scenario 1, we set both of them to the current values. In Scenario 2, we set them 10% lower. In each scenario, the simulation was repeated 100 times in random order for all patients choosing hospitals.

2. Results

We present the number of over-demand patients for each mesh. The results of the first scenario show that hospitals will be able to accommodate all inpatients until 2020. However, the number of patients will increase dramatically after 2025 because of the rapid aging of the baby boomer generation. As shown in Table 1, in the five-year periods from 2025 to 2040, the number of patients who cannot find a hospital will be about 17,000, 25,000, 27,000, and 33,000, respectively. However, the over-supply—the number of unutilized beds—will decrease immediately and hardly exist after 2025.

Table 1. Over-demand (number of patients) and over-supply (number of unutilized beds) in Scenario 1

	2010	2015	2020	2025	2030	2035	2040
over-demand	0	0	0	17,000	25,000	27,000	33,000
over-supply	56,000	29,000	5,000	800	600	700	900

We mapped the over-demand patients for each mesh (Figure 3). Most of the over-demand was concentrated in densely populated regions, mainly in the center of the Tokyo Metropolis and along the major traffic lines.

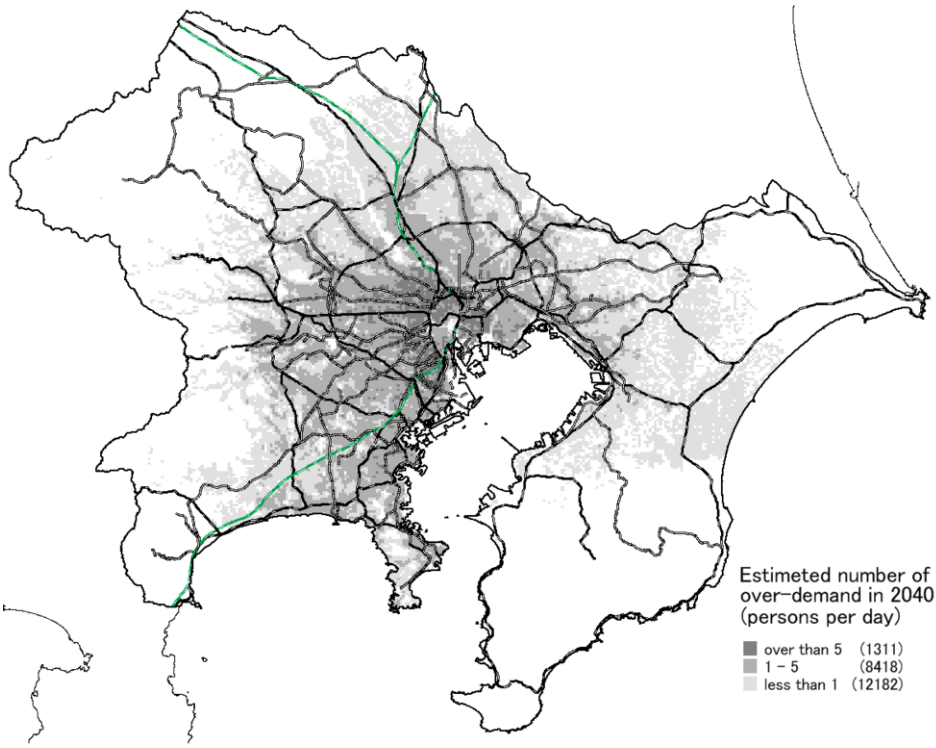


Figure 3. Over-demand in the Tokyo Metropolitan Area in 2040

This shortage can be minimized through the target term in Scenario 2. The over-demand appeared only in isolated islands or mountainous regions. However, it seems very hard to implement a 10% decrease in the average number of hospitalization days

and the rate of treatment accepter because the target area lacks sufficient medical resources.

3. Discussion

This study developed an innovative method, the Patient Access Area Model, to estimate the demand for health care by integrating geographic information. Using this method, we geographically visualized the demand for health care. Through repeated simulations of our model, we demonstrated not only the shortage of hospital beds in the Tokyo Metropolitan Area after 2025 but also indicated which areas face the most serious shortfalls. In addition, we conducted simulations by changing the parameters and predicted the best scenario for the future.

In this paper, we chose the Greater Tokyo Area as an example. However, the Patient Access Area Model can estimate supply and demand in other urban areas as well. Because GIS systems are falling in price, local governments and researchers can easily apply this method to large data. In this paper, we conducted the calculation mainly with the rate of the treatment accepter. In the near future, we will consider other aspects of medical care, including emergency medicine and acute and recovery phase medicine in order to evaluate situations with greater realism and more precision, although knowing the average number of hospitalization days of all hospitals is a difficult task.

4. Conclusion

We developed the Patient Access Area Model to evaluate the balance of supply and demand for medical care in small areas in the future. We predicted that the Tokyo Metropolitan Area would lack hospital beds after 2025. Using this model, we obtained a clearer understanding of the demand for local health resources. This method will be very useful in planning adequate resource allocation for medical services.

References

[1] National Institute of Population and Social Security Research [internet]. Population Projections for Japan (January 2012). IPSS; [updated 2012 Jan 30; cited 2014 Jan 31]. Available from: http://www.ipss.go.jp/site-ad/index_english/esuikei/gh2401e.asp.

[2] Lovett A, Haynes R, Sünnenberg G, Gale S. Car travel time and accessibility by bus to general practitioner services: a study using patient registers and GIS. Social Science & Medicine. 2002;55(1):97-111.

[3] Martin D, Wrigley H, Barnett S, Roderick P. Increasing the sophistication of access measurement in a rural healthcare study. Health Place. 2002;8(1):3-13.

[4] Ministry of Health, Labour and Welfare of Japan [internet]. Summary of Patient Survey in 2011: Trends in the Estimated Number of Patients (Per Day) by Type of Medical Institution and Inpatients / Outpatients. MHLW; [updated 2012 Nov 27, cited 2014 Jan 31]. Available from: http://www.mhlw.go.jp/english/database/db-hss/sps_2011.html.

[5] Advanced Core Technology Co. Ltd. [internet] ACT Distance Calculation Service. ACT; [updated ; cited 2014 Jan 31]. Available from: http://www.act-inc.jp/contents/package/product/std.html

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Addressing the Challenge of Encoding Causal Epidemiological Knowledge in Formal Ontologies: A Practical Perspective

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Abstract. The paper presents an overview of approaches to encoding uncertain causal knowledge in formal ontologies and demonstrates how these approaches can be used in a semantic-driven application for public health using the Population Health Record (PopHR) platform as an example.

Keywords. formal ontologies, causality, uncertainty, public health

Introduction

The Population Health Record (PopHR) [1] is a web-based software infrastructure that automates the retrieval and integration of heterogeneous data from multiple sources, and supports intelligent analysis of these data to create a coherent portrait of population health. Focused on facilitating the planning and evaluation of population health interventions, the PopHR addresses common limitations of existing web portals for population health information, such as: outdated indicators computed at low spatial resolution, limited transparency of algorithms and data sources, unintuitive graphical interfaces, and presentation of indicators that ignores the relationships between them.

To address these limitations, PopHR relies on a suite of OWL ontologies that encode relevant domain knowledge and constitute a semantic framework for organizing indicators supported by the system, understanding user queries, and providing query-specific analytical tools. The ontologies also incorporate a body of epidemiological knowledge about causal links between health issues, their determinants and outcomes. The PopHR uses this knowledge to present data for multiple population health indicators in the context of known relationships between these indicators, thus enabling a knowledge-based analysis of the information derived from multiple data sources.

Encoding of causal epidemiological knowledge in formal logic is essential in many medical informatics applications, but it presents a challenge in ontology engineering, due to the way epidemiology considers causality. In particular, the causal relationships are non-deterministic; there are multiple alternative causes for the same phenomena; and causal links established from the analysis of populations cannot be assumed to hold for all individuals. Ontology languages with rigid semantic structure, such as OWL, cannot accommodate these features. The problem has been recognized in the literature, and a number of solutions have been proposed ranging in quality and applicability [2, 3]. In this paper, we provide a practical perspective on the problem, drawn from our experience in encoding causal epidemiological knowledge in the PopHR ontologies.

1. Methods

A vast amount of knowledge in the biomedical domain, particularly causal knowledge in epidemiology come in the form of uncertain statements, i.e. these statements are neither implied nor expected to be true in all cases, and the conditions under which they are true or false cannot be fully specified. The examples of such statements are assertions of the link between a risk factor and a disease or a disease and a symptom. In the PopHR, a user monitoring prevalence of type II diabetes in a certain region may need to retrieve data about health determinants that affect the risk of this disease in the same region. To achieve this, a query to the ontology shall return risk factors of diabetes, including obesity. Note that the link between obesity and diabetes is not always observed in individuals, but the association at the population level is undisputed.

In general, it is important to be able to capture the notion of possible, typical or default in medical ontologies, but the languages and tools for ontology development cannot represent this notion naturally. In a standard ontology language OWL, as in any formalism based on description logics (DLs), any statement must be either true or false, and any statement about a class must hold for all instances of that class. So if *obesity* and *diabetes* are classes, and we want to make a general statement about causal relationship between their instances, this statement would have to be true either for all instances of *obesity*, or for all instances of *diabetes*, neither of which is the case.

Several research groups have been developing extensions to DLs for probabilistic modelling, incorporating formalisms like fuzzy logic [4] or Bayesian probability [5] to overcome the limited expressivity of DLs. Unfortunately, most of the proposed formalisms are impractical due to their computational complexity. Efforts to improve reasoning in probabilistic DLs constitute an area of active research, but there are still no tools available for practical use by ontology developers. Luckily, in many medical applications including PopHR, the need to formalize probability is not critical. Our focus is on encoding the optional nature of causation in a way that is logically and ontologically sound and supports querying and logical inference.

In the absence of the standard semantics for uncertainty in OWL, ontology developers have come up with a number of "work arounds" [2]. For example, instead of using an incorrect statement involving existential quantifier "A *causes* **some** B", one would use a universal restriction in a form: "A *causes* **only** B", or invert the property: "B *is_caused_by* **some** A". Neither option correctly captures our previous example of obesity and diabetes. Another solution is to use the minimum cardinality restriction in a form: "A *causes* **min 0** B". Although formally correct, it has little practical value, since reasoners effectively ignore statements like that. With the similar effect, uncertain causal links can be encoded in annotation properties, where they can be accessed by human readers or retrieved through API, but do not add knowledge for logical inference. This approach may be justified for some applications, where ontologies are used for the mere purpose of knowledge representation. However in these cases the use of less formal conceptualization (e.g. SKOS) may be more appropriate [3].

Another popular solution is to express uncertainty using a predicate that sounds less deterministic, e.g. *may_cause*, *possibly_causes*, etc. While seemingly correct, the statement "obesity *may_cause* **some** diabetes" would be refuted by a case of obesity without diabetes in the same way as "obesity *causes* **some** diabetes" would be refuted, because it affirms that for every instance of obesity, there must exist an instance of diabetes, which that instance of obesity *may have caused*. For a logical reasoner, "may cause" still denotes an association, which, as we know, is not always present between

instances of obesity and diabetes. What is always present is a *possibility of association*, so to correctly encode the relationship between obesity and diabetes we need a concept denoting possibility. Schultz [3] has suggested using a concept of disposition defined as a property that may or may not be *realized in* some observed process (e.g. salt bears a disposition to dissolve in water). The relationship between a cause and effect is split in two parts resulting in the statement: "A *causes* **some** (Disposition **and** *has_realization* **only** B)". This dispositional clause is obviously more complex than a relation expressed by a single predicate, so it may be difficult to define an inverse relation or to specify the transitive nature of causal links. It is, however, the only solution within the expressivity of OWL-DL that is ontologically correct and suitable for logical reasoning.

2. Results

2.1. Overview of the PopHR Ontology Suite

The PopHR semantic framework includes an application ontology and three domain ontologies (one developed externally) briefly described below.

Public Health Indicators Ontology (PHIO) is an application ontology designed to support the specific needs of the PopHR software, such as presenting health indicators to the user in an organized way, computing and visualizing the results, etc. [6] PHIO includes a taxonomy of health indicators by the Canadian Institute for Health Information (e.g. disease indicators vs. health system performance indicators), and properties allowing classification of health indicators according to other criteria (e.g. rates vs. proportions). PHIO also encodes concepts necessary for data specification and manipulation, and a limited set of relevant statistical methods and temporal concepts.

To contextualize health indicators by public health knowledge, we have developed a *Public Health Ontology (PHOnt)* incorporating more general concepts and relations, which can be reused by other applications and ontologies. PHOnt is based on the Australian Classification of Public Health Activity [7], and covers a broad domain of issues and methods relevant to public health. PHOnt defines many associative relations, in particular, causal pathways from upstream health determinants to diseases. PHOnt imports an existing *Disease Ontology* [8] and a simple *Geography Ontology* that we developed to cover a small part of the geospatial domain essential for PopHR.

2.2. Characteristics of the Encoded Causal Relations

Causal links among diseases and health determinants used by PopHR to contextualize health indicators are quite diverse: in some cases a change in the level of factor can hasten onset of a disease, in other cases one event triggers another, and in yet other cases, a factor has an effect on the severity of disease rather than on its probability of occurence. There are, however, several common properties of all causal links captured in PHOnt: a) they are probabilistic; b) they cannot be quantitatively compared or summed up; c) the beneficial and adverse effects of the same determinant on a health issue are not mutually exclusive, and d) they represent causality at the individual level, which may or may not be observed as a statistical association at the population level (due to ecological bias). These characteristics influenced our formal encoding of causal relations and they should be considered during the interpretation.

2.3. Encoding Examples

Let us encode our example of the causal link from obesity to diabetes using a dispositional clause. We define the risk of a disease as a disposition to developing a disease, which may or may not be realized in a particular individual, and a property *has_effect_on* with two sub-properties for positive and negative effects:

Obesity *has_positive_effect_on* **some** RiskOfDiabetes
RiskOfDiabetes ≡ Disposition **and** *is_realized_in* **only** OnsetOfDiabetes
OnsetOfDiabetes ≡ Process and *results_in* **some** DiabetesMellitus

Here, the risk of diabetes is a personal characteristic (disposition), and it is asserted that for any instance of Obesity, there is an instance of RiskOfDiabetes, which is affected. In the second line, we assert that if the RiskOfDiabetes is realized, then it is realized in the OnsetOfDiabetes and nothing else; however it is not mandatory for the risk to be realized. The intermediate concepts RiskOfDiabetes and OnsetOfDiabetes do not have to be encoded in the ontology as named classes. In PHOnt, we combine the three expressions, expanding intermediate concepts with their definitions, and therefore avoiding the problem of proliferation of classes.

In the example above, the consequent is an event. To represent the links, in which the consequent is a change in some measurable property (e.g. amount of physical activity, disease severity), we introduce a class ChangeInLevel – a process that realizes a matching disposition – with subclasses IncreaseInLevel and DecreaseInLevel. The next example shows how PHOnt encodes the link between caloric intake and BMI:

CaloricIntake *has_positive_effect_on* **some** (Disposition **and** *is_realized_in* **only** (IncreaseInLevel **and** *is_change_in_level_of* **some** BMI))

The properties *has_positive_effect* and *has_negative_effect* can only be applied to monotonically increasing or decreasing functions, but not to complex relationships. Although we do not intend to encode the exact functional form of causal links in PHOnt, it is valuable to be able to deal with those cases where the sign of an effect changes for different value ranges of a cause. Consider for example a U-shaped relation between BMI and mortality. To encode a non-linear effect like this, we partition the value range of a cause into two intervals, over which the relationship is monotonically increasing or decreasing. These intervals can be represented as subclasses of the cause:

BMI_<20 *subclassOf* BMI; BMI_ 20+ *subclassOf* BMI
BMI_ 20+ *has_positive_effect_on* **some** (Disposition **and** *realized_in* only Death)
BMI_<20 *has_negative_effect_on* **some** (Disposition **and** *realized_in* only Death)

The same approach can be used to deal with some simple cases of factor interaction. For example, if the effect of some health determinant changes for different age/sex/ethnic groups, we can define subclasses of that determinant similarly to the above example with BMI value intervals.

There may be additional information to characterize the causal relationships, e.g. the source of established association (reference to a study) or the strength of the association. In PopHR, this information is not used for logical inference; therefore, it can be encoded in the form of annotations to the axioms defining each relationship.

3. Discussion

In this work, we have demonstrated how existing knowledge modelling approaches can be used to encode in OWL the notion of probabilistic causation in epidemiology and public health. While developers of medical ontologies encounter this challenge in many settings, the preferred solutions will vary depending on the intended use of a particular ontology. For instance, the lack of ontological realism may be acceptable in an application ontology tailored for a specific system, but is problematic in a domain ontology meant to be reused. Our modelling choices were driven by the semantic needs of the PopHR application and the nature of the encoded knowledge.

All causal links encoded in PHOnt reflect *consensus knowledge*, which has vast support from epidemiological research and is generally undisputed. A key implication of this fact is that the encoded relationships are often simplified in some way due to a lack of empirical data that could fully specify more complex relationships. One such simplification is asserting a relationship for the entire range of a risk factor, while in reality it may hold only for a sub-range. For example, although the risk of diabetes likely starts growing only after a certain threshold in BMI is reached, we assume a linear relationship over the entire range of BMI, since there is insufficient knowledge about the threshold. Another simplification is accepting imperfect measurement. For example, although it is visceral fat that increases the risk of diabetes and not the person's weight, the amount of fat is difficult to measure, so most of the available empirical data links the risk of diabetes to BMI instead. Assuming independence of multiple risk factors contributing to the same condition is yet another simplification. It is important to understand that PHOnt represents a shared conceptualization of causal epidemiological knowledge, rather than "the truth", which is not fully known. It is thus impossible to assess it in respect to ontological realism.

The causal knowledge we have encoded so far is not complete. As we continue to extend this body of knowledge, we will need to develop a formal approach to knowledge extraction and validation to ensure that the facts encoded in PHOnt continue to reflect a consensus in an epidemiologic and public health communities.

References

[1] Buckeridge DL, Izadi MT, Shaban-Nejad A, Mondor L, Jauvin C, Dube L, Jang Y, and Tamblyn R. An infrastructure for real-time population health assessment and monitoring. IBM Journal of Research and Development, 2012, 56(5): 2 2.

[2] Rector A., Stevens R., Drummond N. What Causes Pneumonia ? The Case for a Standard Semantics for " may " in OWL. Proceedings of the OWLED 2008

[3] Schulz S, Schober D, Tudose I, Stenzhorn H. The Pitfalls of Thesaurus Ontologization - the Case of the NCI Thesaurus. AMIA Annual Symposium proceedings, 2010, 727-731

[4] Lukasiewicz T, Straccia U. Description logic programs under probabilistic uncertainty and fuzzy vagueness. Int. J. Approx. Reasoning 2009, 50(6): 837-853

[5] Da Costa PC, Laskey KB, Laskey KJ. PR-OWL: A Bayesian Ontology Language for the Semantic Web. Uncertainty Reasoning for the Semantic Web I. Lecture Notes in Computer Science 2008, 5327, 88-107

[6] Shaban-Nejad A, Okhmatovskaia A, Izadi M, Naderi N, Mondor L, JauvinC, BuckeridgeDL. PHIO: A Knowledge Base for Interpretation and Calculation of Public Health Indicators. MedInfo 2013: 1207

[7] Jorm, L., Gruszin, S., Churches, T. 2009. A multidimensional classification of public health activity in australia. Australia and New Zealand Health Policy 6(1):9

[8] Schriml LM, Arze C, Nadendla S, Chang YW, Mazaitis M, Felix V, Feng G, Kibbe WA. Disease Ontology: a backbone for disease semantic integration. Nucleic Acids Res. 2012 Jan.

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13. Visualization

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Semi-Automatic Segmentation Methods for 3-D Visualization and Analysis of the Liver

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Abstract. Pre-evaluation of donors prior to surgery of living donated liver transplantation is one of the challenging applications that computer aided systems are needed. The precise measurement of liver volume requires effective segmentation procedures, while three dimensional rendering of the segmented data provides demonstrative information to radiologists and surgeons before surgery. The Insight Toolkit provides effective algorithms for segmentation, which are also optimized for high computational performance and processing time. Furthermore, An ITK pipeline can be combined with a VTK pipeline, so that the result of segmentation can be represented directly in 3-D using VTK. Therefore, there is an on-going trend for developing ITK/VTK based systems. This study presents quantitative and qualitative performance evaluation of two effective ITK algorithms on segmentation of liver from CTA data sets.

Keywords. Liver segmentation, Computed Tomography, Fast Marching, Connected Threshold, Insight Toolkit

Introduction

Liver is one of the most important and complicated organs in the human body. Therefore, analysis of liver using radiographic images is necessary in several occasions including but not limited to diagnosis, planning surgical procedures and treatment follow-ups. One of these procedures is the evaluation of the liver volume of the transplantation donors prior to the hepatic surgery using the images acquired by Computed Tomography Angiography (CTA) [1]. This requires delineation of liver border in each slice image, which is a tedious and expert dependent task if it is done manually. Unfortunately, automatizing this task with computer aided techniques is a very challenging task due to Hounsfield Unit (HU) inhomogeneity after injection of contrast media, partial volume effects, overlapping HU ranges of adjacent organs (i.e. right kidney, spleen, hearth, muscles and fat tissues). Thus, effective segmentation and visualization techniques should be employed for robust segmentation of liver, calculation of its volume and 3-D rendering for further evaluations.

ITK (The Insight Toolkit) [2] is a free toolkit for processing, segmentation and registration of image data. ITK is being developed by three commercial facilities

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(including GE Corporate R&D and Kitware) and three academic institutions (including the University of Utah). Visualization Toolkit (VTK) [3] and ITK is implemented in C++ and they are available for many platforms and has interfaces to Java, Tcl and Python. All algorithms implemented in ITK for processing and segmentation work with two, three, and multi-dimensional data. The algorithms also include linear and non-linear smoothing filter, edge detectors and various regional growth and level-set methods.

Furthermore, an ITK pipeline can be combined with a VTK pipeline, so that the result of segmentation can be represented directly in 3-D using VTK [4]. According to the rapid developments in processors and graphics cards, 3-D visualization of the volume data provides very high additional terms to evaluations in clinical use. As a result, the implementations that are based on ITK and VTK become very popular among medical image research community [5].

This study shows the results of the application of two important ITK segmentation techniques (i.e. Connected Threshold [6] and Fast Marching [7]) to segmentation of liver from CTA data sets. These segmentation algorithms are used with proper pre-processing and post-processing operation through a software developed for medical image analysis research [8]. Then, the results are evaluated quantitatively by performance metrics and qualitatively by expert radiologists.

1. Methods

The segmentation procedure is structured as a three-step procedure. First, pre-processing of the volume data, with the aim to improve the segmentation process (i.e. data reduction, noise suppression) is carried out. In the second step, the actual segmentation is performed to extract one or more objects. In the subsequent post-processing, segmentation results are further processed for pruning. Taking into account the three criteria mentioned above, two methods were selected as segmentation method for parameterization: region growing and active contours (level set method). For both groups, a variety of specific algorithms have been established [2], among which Connected Threshold (see 1.1) and Fast Marching (see 1.2) are used.

1.1. Connected Threshold (CT) Method

The Connected Threshold (CT) method is universally applicable; there is no restriction on certain medical application areas or certain topologies. It can be used to segment both compact objects (such as the kidney), or long, narrow objects (such as blood vessels). The prerequisite is there should be a difference that distinguishes the object to be segmented from the environment through its HU values. Segmentation for the setting of one or more seed points [6] within the searched object is required. The positioning of the seed points can be arbitrary, which makes the method robust against misplacement. However, the CT method is susceptible to noise. Any noise present should therefore be reduced in a pre-processing by a smoothing filter. The CT algorithm has three free parameters (i.e. lower and upper HU limit and the position of the seed points), which can be determined by a physician without theoretical knowledge about the algorithm. Due to its simple operation, the running time of the algorithm is low even for large volumetric data sets. The CT method works very successfully with objects that have a homogeneous HU value distribution and with

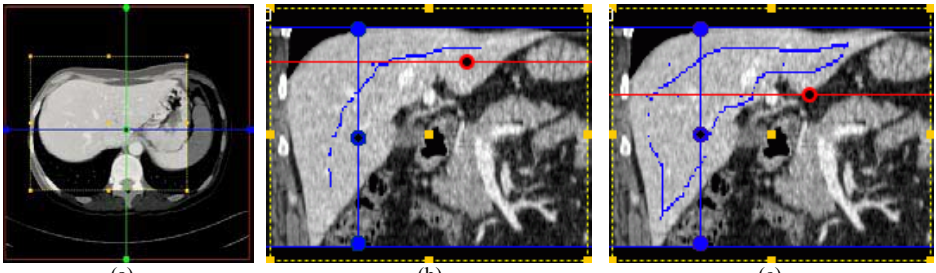
contrast-filled vessels. However, depending on the HU value distribution of the object and its environment, leaking may happen. For this case, the Fast Marching method provides more control through additional parameters to control the segmentation result.

1.2. Fast Marching (FM) Method

The Fast Marching (FM) method [7] was chosen because it is supplemented in some way with the CT method. The risk of leakage is significantly lower, but the application is not as wide as CT method: Long, narrow objects - in particular vascular trees - cause problems. Similar to CT method, the set of one or more seed points are required within the object to be segmented. From each seed point, a front propagation launches. The seed points should be placed in the center of the object (Fig. 1.b) to prevent too early slowdown of the uniformly propagating front (i.e. due to high HU value gradients). If two successive fronts overlap, the corresponding regions are merged. In addition to the position of the seed points, the actual FM method has only one additional parameter: the number of iterations. However, it should be noted that although the implementation of the algorithm does not expect the HU value range as the input data, a so-called "velocity field", which contains the velocity of propagation for each voxel position, should be specified. This field is calculated from the HU value gradients in a pre-processing step. The complexity of FM is higher than the CT method, but it can be significantly reduced, if the number of the seed points is increased. Due to the geometric description of the surface, FM method always returns a closed and smooth surface of the segmented object. A spill in the region can only occur when the seed points are placed too close to object boundary (low HU value gradients).

1.3. Application of the Segmentation Methods

Both methods are based on HU values and their gradients. Through interference (such as contrast media) in the volume data, there can be high local HU value fluctuations that negatively affect the segmentation process. It is therefore useful to perform a smoothing in a pre-processing step, which affects the edge steepness as little as possible. Some alternatives are anisotropic diffusion, Gaussian and median filters.



(a) (b) (c)

Figure 1. (a) 2D slice of a VOI determined for reducing data to process. Possible position of the seed points for liver segmentation using the Fast Marching Method: (b) in the center of the liver (more appropriate due to high HU value gradients), (c) close to the border of the liver (low HU value gradients).

In order to reduce memory requirements and to reduce the segmentation time, a volume of interest (VOI, Fig. 1.a) is defined. A further reduction in the memory

requirement and the time segmentation can be achieved by subsampling. For the post-processing of the segmentation result, the same filters used for the pre-processing can be employed. It has already been mentioned that the FM method always produce a smooth surface. For the CT method, this is not true, so that a subsequent Gaussian smoothing should be applied to produce a smoother surface.

2. Results

The methods are evaluated on 24 CTA data sets obtained from Dokuz Eylül University Hospital, Radiology Department, Izmir, Turkey. The liver volumes obtained by application of the segmentation methods are quantitatively compared to the manual segmentation, which are delineated by the software tool that is currently used for calculation of the liver volumes of transplantation donor candidates (Fig. 2). The segmentation algorithms (i.e. CT and FM), together with necessary user interaction mechanisms (i.e. insertion of the seed points, VOI selection tools) and necessary pre-processing and post-processing operations (i.e. smoothing filters such as anisotropic diffusion, median, Gaussian etc.) are realized through a software developed for medical image analysis research [8]. Fig. 2 presents three boxplots representing median values for reference, CT and FM volumes. This corresponds to a visual hypothesis test that is analogous to the t test used for means. The line in the middle of each box is the sample median. If the median is not centered in the box, it shows sample skewness.

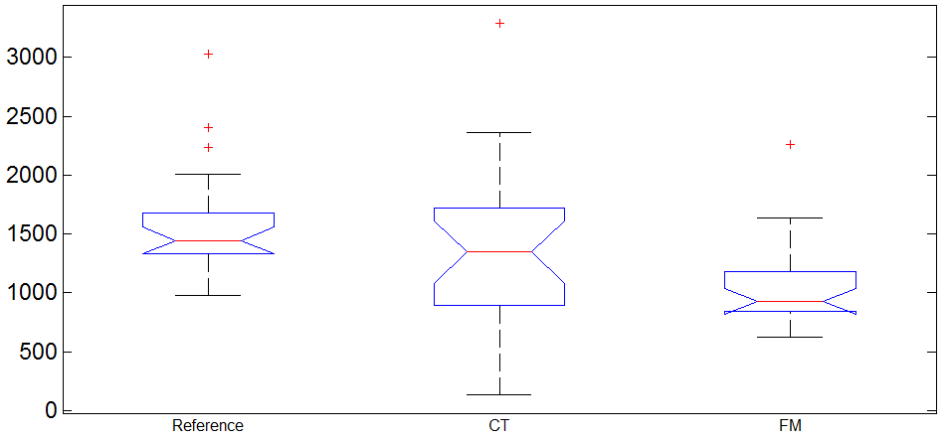
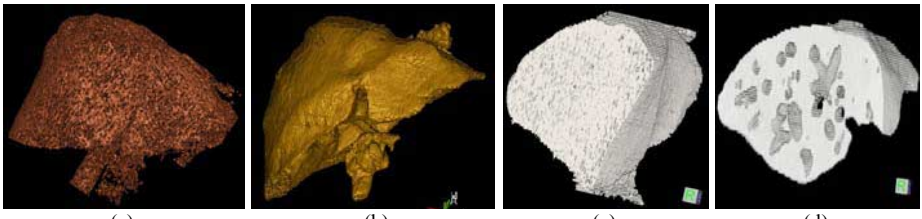


Figure 2. Comparison of the relative deviations from the reference volume for CT and FM methods

There exist significant differences between the results produced by the two segmentation methods. The maximum deviation from the reference volume in the CT method is at 87.52%, while it is 45.18% at the FM method. Thus, it can be concluded that the FM method works more stable than CT. Moreover, the deviation from the reference volume is between 22.39% and 45.18% (difference in percentage: 22.79) for FM method. In comparison, the variation in the CT method is between 0.69% and 87.52% (difference in percentage: 86.83).

The qualitative results show that the segmented data obtained by FM can be visualized for qualitative 3-D visualization of the liver (Fig 3.b), while CT result

require significant amount of post-processing (Fig. 3.a). However, these techniques cannot provide enough precision for quantitative analysis. For instance, vessels within the liver are not included in the segmented data when FM is used (Compare Fig 3.c and Fig. 3.d). For this reason, the volume values for the liver cannot be compared with the manually determined values. To be able to use the segmentation results for diagnostic (quantitative) purposes, segmentation process must be extended accordingly (for instance, a morphological post-processing to fill excluded vessels inside the liver parenchyma). It would also be helpful to have additional manual segmentation tools. For instance, if the liver is successfully segmented with some minor mistakes (such as inclusion of the vessels that are too far outside the liver, but collected in the segmentation result), a fast correction can be done using the manual tools. So, there will be no need to re-run the time consuming segmentation procedure including insertion of the seed points, adjustment of the parameters etc.



(a) (b) (c) (d)

Figure 3. Segmentation result using (a) Connected Threshold method, (b) Fast Marching method. Inside of the segmented liver, (c) Manual segmentation, (d) segmentation with the Fast Marching method.

3. Discussion

Based on the results, it can be concluded that the FM method provides more stable results compared to the CT technique, while the results obtained by CT algorithm have higher accuracy. To be able to use the liver segmentation results for diagnostic purposes (i.e. volume measurements), both algorithms need careful selection of pre- and post-processing operations prior to their application.

References

[1] Selver MA, Kocaoğlu A, Demir G, Doğan H, Dicle O, and Güzeliş C, "Patient oriented and robust automatic liver segmentation for pre-evaluation of liver transplantation", *Computers in Biology and Medicine*, **38(7)** (2008), 765-784.

[2] Ibanez L, Schroeder W, The ITK software guide. Kitware, Inc., (2003) ISBN 1-930934-10-6.

[3] Schroeder W et al. The Visualization Toolkit, 4th Edition. Kitware, Inc., (2007).

[4] Martin K, Ibanez L, Avila L, Barre S, and Kaspersen JH, Integrating segmentation methods from the Insight Toolkit into a visualization application, *Medical Image Analysis*, **9** (2005), 579–593.

[5] Bitter I, Van Uitert R, Wolf I, Ibanez L, and Kuhnigk JM, "Comparison of Four Freely Available Frameworks for Image Processing and Visualization That Use ITK", *IEEE Transactions on Visualization and Computer Graphics*, **13(3)** (2007), 483-493.

[6] Adams R, Bischof L, "Seeded Region Growing," *IEEE Transactions on PAMI*, **16** (1994), 641-647.

[7] Sethian J, "Level set methods and fast marching methods," Cambridge Uni. Press, Cambridge, 2002.

[8] Fischer F, Selver MA, Hillen W, and Güzeliş C, Integrating Segmentation Methods from Different Tools into a Visualization Program Using an Object Based Plug-In Interface, *IEEE Transactions on Information Technology in Biomedicine*, **14(4)** (2010), 923-934.

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Performance Comparison of Compression Algorithms for Archiving Segmented Volumetric Binary Medical Data

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Abstract. Archiving result of a segmentation task allows the representation of the segmented volume at a later time. The segmented volume can be stored in a binary format, which can be restored by a simple combination of the original data with this binary information. Since, the sizes of the segmented binary data have high memory requirements; a lossless compression method should be employed for efficient archiving. Thus, this study examines different approaches for compression and their suitability for restoring binary segmentation results. To evaluate the compressive properties, multiple test cases with diverse spatial structures and acquired with different modalities from clinical practice have been used. The results show that best performance is achieved with JBIG2 method both in terms of compression ratio and processing time.

Keywords. Medical Image, Segmentation, Compression, DICOM, Visualization.

Introduction

Tomographic medical imaging systems (i.e. CT, MR etc.) produce two-dimensional cross-sectional images (i.e. slices) of the human body in DICOM format. The number of these slices may vary from hundreds to thousands based on the acquisition parameters. Mostly, diagnoses are preformed based on these individual slices, which require the physician to interpret the spatial context between slices. This task is very difficult, especially when the amount of data (i.e. number of slices) increases. Since, three-dimensional (3-D) analysis can overcome this difficulty; they are becoming a more frequent tool in parallel to the developments in 3-D technology.

Segmentation is a fundamental step of 3-D analysis that delineates the anatomical structure of interest (i.e. organ, tissue, tumor, vascular tree etc.). A binarized form of segmented volume can be defined as a set of voxels, whose values are 1 if they belong to the object and 0 otherwise. Once the binarized form is obtained; the segmentation result can be restored by a simple combination of the original data with the binary data. This makes the binary data an ideal tool for saving segmentation information, efficiently. Since, the sizes of the segmented binary data have high memory

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requirements; they must be compressed with a lossless technique. Thus, this study examines different approaches for compression and their suitability.

To accomplish this task, several compression methods, which exploit the special structure of the (binary) segmentation results, are compared. It must be noted that there must be a lossless compression so that the original data can be fully restored. The following compression methods have been studied:

- Run-Length Encoding [3]
- Entropy Encoding: CCITT T.4/T.6 [4], JBIG2 [5], JPEG 2000 [7]
- Phrase Encoding: ZIP, LZW [4]
- Octree Encoding [8]

To evaluate the compressive properties multiple test cases from clinical practice have been collected. During the selection of datasets, special care was given to select anatomical objects with diverse spatial structure and acquisitions with different modalities. This ensures that the presented compression results are representative of a wide range of applications. Based on the application results, the most suitable method is determined for the compression of binary medical volumetric data sets.

1. Methods

Considering that a 3-D anatomical structure located in a volume of interest (VOI), we can define a segmented object as the set of voxels, whose values are equal to 1 inside the VOI, while all other (background) voxels are equal to 0. The VOI can be used to reduce the complete data set to a partial volume by specifying a rectangular area in all dimensions. Thus, in this study a VOI is defined for each object of interest prior to its segmentation and compression.

The tested compression methods - with the exception of the octree - work on two-dimensional images. Therefore, the data is first stored slice by slice in a series of single images in uncompressed bitmap (BMP) format. As a second step, the BMP image was converted in a Portable Bitmap image (PBM). In the PBM format, the pixels are stored bitwise (i.e. without compression); thus, it does not reduce the size of the original data. Since the volume data exists as a series of two-dimensional images in PBM format, they can be opened in graphics programs without problems and stored in other formats such as PNG or TIFF with additional compression options.

As mentioned above, the octree coding is a special case since, unlike the other methods, the segmented data is considered as a volume (i.e. not as series of slice images). The storage was carried out in two separate files: The values of the voxels are consecutively written to one file. In a second file, the dimensions of the VOI can be stored. With the help of these two files, it is possible to restore the binarized segmentation result as a volume.

The following paragraphs introduce further details of the compression methods used in this study and corresponding software programs to implement them:

Run-length encoding (RLE): The run-length encoding has been performed with the freely available Java software Birle [3], where the PBM image was used as the input file. However, this program is not designed specifically for the encoding of binary data. Although, run-length coding can be applied to PWM files, the data is processed byte by byte. This result with eight voxel values that are combined into one byte and this byte is encoded as a symbol. The result of the compression is stored in a raw file.

CCITT T.4/T.6: With the freely available graphics program IrfanView 3.98 [4] the images of different formats can be opened, viewed and converted into other graphics formats. By storing the PBM image in TIFF format, the test cases with the CCITT T.4 procedure and CCITT T.6 were compressed directly by the saving process, when the compression CCITT Fax 3 and CCITT Fax 4 were selected.

JBIG2: The encoding of the PBM image with the JBIG2 method was performed using the C + + program jbig2enc [5]. The compression obtained this way was written to the standard output and redirected to a file in JBIG2 format. With the C program jbig2dec -0.9 [6], the JBIG2 file was decoded again.

JPEG 2000: The free command-line program GeoJasper [7] allows the conversion of common graphic formats to JPEG 2000 (JP2) format and therefore, was used for the JPEG 2000 encoding. However, it only accepts image formats in which a pixel has at least one byte. For this reason, BMP image was used as the input file.

ZIP: The ZIP code was also carried out with IrfanView [4]. Through a lossless conversion of the PBM file in the graphic format PNG data, images were automatically compressed using the ZIP method. Also the run-length encoding of eight bits are grouped into a byte and then compressed in this case.

LZW: CCITT T.4 and CCITT T.6 encoding was chosen for the application of LZW under IrfanView under TIFF format, but with the compression option LZW. Again, the data processed byte by byte similar to the run-length encoding and the ZIP method.

Octree: Because there was no program available for the octree encoding, this was implemented independently according to an algorithm from [8], and then optimized for speed using the user manual of [9]. Input of the octree coding requires the two files containing the voxel values and the dimensions of the VOI.

2. Data sets

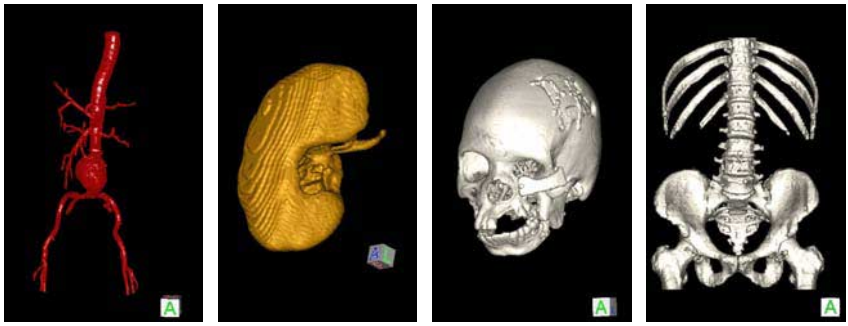
The data sets for testing compression methods are selected from acquisitions of different modalities and diverse anatomical objects with diverse spatial structure so that actual performance of the techniques can be evaluated for a wide range.

The first data set is called aorta, which is acquired with contrast medium (288 slices, slice thickness (ST): 1.5 mm), by a CT and segmented with the Connected Threshold method used in [2]. With a VOI of 139x322x288 voxels, "aorta" has the greatest dimensions and file size among all test objects (Figure 1.a).

The kidney was segmented from two different data sets (i.e. CT, MR), which provided different segmentation results for the interior of the kidney. The first data set is a coronal MRI image series with 72 slices with a slice thickness of 1.4 mm. The segmentation of the (right) kidney was performed using the Fast Marching method [2]. The selected VOI has the dimensions 121x52x205 voxels. The second kidney data set is a CT series with 238 slices with a slice thickness of 1 mm. Again, the Fast Marching method was used to segment kidney and the size of the VOI is 114x101x112 voxels.

The skull CT data set consists of 361 slices with a thickness of 0.7 mm. For the segmentation of the skull, the Connected Threshold method was chosen. For the skull, a VOI size 175x214x302 voxels was set (Figure 1.c).

Skeleton data set includes the ribs and the hip of a CT dataset (288 slices, slice thickness: 1.5 mm) and it was segmented with the Connected Threshold method (Figure 1.d). The corresponding VOI has a size of 239x146x288 voxels.



(a) (b) (c) (d)

Figure 1. Volume rendering based illustrations of selected medical data sets used for testing the compression algorithms, (s) aorta, (b) MR kidney, (c) skull, (d) skeleton.

3. Applications and Results

Tables 1 and 2 show the results of the compression in terms of the compression capacity. Since the size of PBM data correspond to uncompressed size of the original data ([width x height x depth of the VOI] x 1 bit + header of the PBM Data), it has the smallest possible compression ratio. Thus, these values are used as the benchmark for comparing the compression results (see first row of Table 1).

Table 1 shows the sizes of the original/PBM files and compressed files in kilobytes (kB). According to the VOI dimensions of the individual test cases, the size of the original files are relatively small for kidney data (i.e. 166 kB and 167 kB), while the files of the aorta, cranial and skeleton are significantly larger (i.e. over 1000 kB).

Table 2 is based on the data of Table 1 and shows the compression ratio (i.e. the ratio between the compressed file and the original file in percentage) for each of the algorithms. The procedures are arranged in descending order according to their average efficiency over all test cases.

In Table 3, the compression time of each method is given. The test cases are grouped into two categories: 1) test cases, whose PBM file is smaller than 1000 kB (i.e. kidney CT and kidney MRI) and 2) test cases, whose PBM file is larger than 1000 kB (i.e. aorta, skull and skeleton).

The compression of the test cases was carried out with the help of various software programs (described in section 2) using a computer with Intel Pentium 4 Processor (3.40 GHz), 2 GB of RAM and the Windows XP operating system.

4. Discussion

With a reduction of the VOI of the original data below 5% for all test cases even for very large volume data, the application of JBIG2 method performs the best among all other compression techniques used in this study. Moreover, the compression ratio of the JBIG2 method reduces the segmented binary volume data to acceptable file sizes. Another important advantage is that the compression time of JBIG2 is negligible with less than one second. Therefore, the JBIG2 method can be used effectively for compressing the binary segmentation result of volumetric data.

Table 1. File sizes of compressed test cases of all tested methods (in kilobytes (kB))

	Aorta	Kidney CT	Kidney MR	skull	skeleton
Original/PBM	1631	166	167	1389	1232
RLE	73	51	42	477	208
CCITT T.4	467	67	65	496	208
CCITT T.6	36	10	14	90	70
JBIG2	10	5	8	59	44
JPEG 2000	234	148	186	1442	882
ZIP	24	12	15	121	92
LZW	59	20	21	212	131
Octree	160	99	150	1393	825

Table 2. Compression ratios for all test cases (from top to bottom: high). The compression ratio is the ratio between the compressed file and the original file (PBM) in percent.

	Compression ratio in %				
	Aorta	**Kidney CT**	**Kidney MR**	**skull**	**skeleton**
JBIG2	0,61	3,01	4,79	4,25	3,57
CCITT T.6	2,21	6,02	8,38	6,48	5,68
ZIP	1,47	7,23	8,98	8,71	7,47
LZW	3,62	12,05	12,57	15,26	10,63
RLE	4,48	30,72	25,15	34,34	16,88
CCITT T.4	28,63	40,36	38,92	35,71	26,46
Octree	9,81	59,64	89,82	100,29	66,96
JPEG 2000	14,59	89,16	111,38	103,82	71,59

Table 3. Compression duration of each process in seconds.

	RLE	**CCIT T T.4**	**CCITT T.6**	**JBIG2**	**JPEG 2000**	**ZIP**	**LZW**	**Octree**
File<1000 kB	2-3	<1	<1	<1	<1	<1	<1	30
File> 1000kB	5-6	<1	<1	<1	6-7	<1	<1	35-700

References

[1] Salomon D, Data Compression: The Complete Reference, Springer-Verlag, New York, Inc., 1998

[2] Fischer F, Selver MA, Hillen W, Güzeliş C, Integrating Segmentation Methods from Different Tools into a Visualization Program Using an Object Based Plug-In Interface, *IEEE Transactions on Information Technology in Biomedicine*, **14(4)** (2010), 923-934.

[3] Tyler T, BIRLE – Bijective Run Length Encoding (RLE) compressor, http://mandala.co.uk/birle/, Last checked: 30.10.2008

[4] Skiljan I, IrfanView 4.20g, http://www.irfanview.de, Last checked: 30.10.2008

[5] Langley A, JBIG2 Encoder 0.27, http://www. imperialviolet.org/jbig2.html, Last checked: 30.10.2008

[6] Giles R, Levien R, jbig2dec 0.9, http://sourceforge.net/projects/jbig2dec, Last checked: 30.10.2008

[7] Levit D, Fedorov V, GeoJasper, http://www.dimin.net/software/geojasper/, Last checked: 09.09.2008

[8] Gargantini I, Linear Octrees for Fast Processing of Three-Dimensional Objects, *In Proceedings of Computer Graphics and Image Processing (CGIP)* **20** (1982), 365–374.

[9] Samet H, Applications of Spatial Data Structures, Addison Wesley, 1990.

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A Context-Sensitive Image Annotation Recommendation Engine for Radiology

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Abstract. In the typical radiology reading workflow, a radiologist would go through an imaging study and annotate specific regions of interest. The radiologist has the option to select a suitable description (e.g., "calcification") from a list of predefined descriptions, or input the description directly as free-text. However, this process is time-consuming and the descriptions are not standardized over time, even for the same patient or the same general finding. In this paper, we describe an approach that presents finding descriptions based on textual information extracted from a patient's prior reports. Using 133 finding descriptions obtained in routine oncology workflow, we demonstrate how the system can be used to reduce keystrokes by up to 86% in about 38% of the instances. We have integrated our solution into a PACS and discuss how the system can be used in a clinical setting to improve the image annotation workflow efficiency and promote standardization of finding descriptions.

MeSH/keywords. natural language processing, pacs radiology, radiology information system, radiology finding descriptions, image markup, autocompletion, context-driven autocompletion, typing assistant.

Introduction

In the day-to-day imaging workflow, radiologists interpret Digital Imaging and Communications in Medicine (DICOM)-compliant [1] images stored within the picture archiving and communication system (PACS) and generate a radiology report describing main findings and diagnostics. Radiology reports are typically free-text documents, which are difficult to structure and interpret automatically. Recently, informatics languages (e.g., Annotation Image Markup initiative [2]) and solutions [3, 4] have been proposed that integrate imaging data (e.g., pixels and measurements) with finding and diagnostic information in a structured manner. These efforts enable enhanced reporting functionality and also provide structured information to automated consumers, such as data mining applications.

During the image interpretation process, the radiologist would typically annotate specific regions of interest directly on the image. Figure 1 shows an instance where a lesion is observed on the right heart border, and annotated accordingly. Descriptive labels can be selected from a predefined pick list, but such a user interface is inherently restrictive and can be inconvenient, especially if it contains a long list of items with multiple layers (e.g., organ based structuring). Typing narrative finding descriptions is

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time consuming, error-prone (e.g., misspelling) and does not promote standardized terminology (e.g., *liver mass* vs. *mass in the liver*). To mitigate these drawbacks, in this paper we propose a method to show a patient-specific auto-completion suggestion list by utilizing context information available within the patient history.

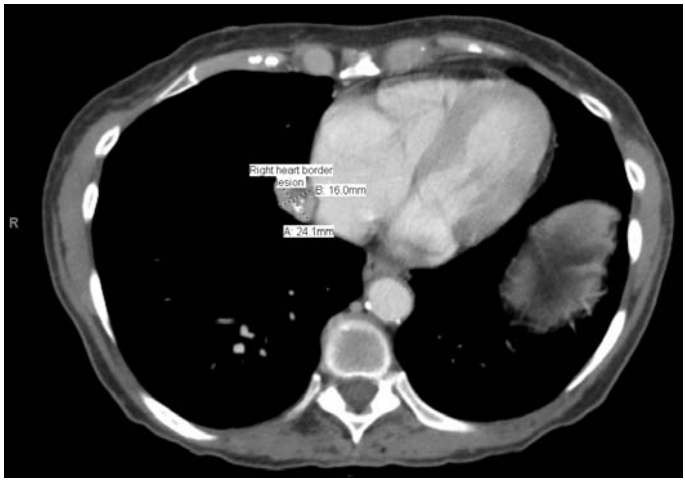


Figure 1: An image annotated with an oncological finding description ("Right heart border lesion")

1. Methods

We describe a system that uses contextual information from the patient's prior reports to filter a master list of finding descriptions. We evaluate the hypothesis that this system reduces keystrokes when integrated with an autocompletion algorithm.

1.1. Datasets

We obtained a corpus of radiology reports from an academic hospital in the Midwest containing over 100,000 radiology reports dictated by over 50 radiologists for over 15,000 patients across ten different modalities. Dates were shifted with respect to a patient-specific random offset; other electronic protected health information items were automatically removed per HIPAA requirements.

We also obtained a list of 133 finding descriptions describing measurable oncologic lesion of 41 patients. These labels were entered by a board-certified radiologist in a longitudinal lesion tracking tool in the course of another study conducted at the institute from which the corpus was obtained. The methods discussed in this paper can be integrated with longitudinal lesion tracking tools (such as LesionViewer [5]) and the list is therefore representative of this use case.

1.2. Algorithm development

The proposed algorithm attempts to suggest a list of most likely finding descriptions with minimal number of keystrokes. For instance, in Figure 1, the output of the

algorithm should include "Right heart border" with minimal input, ideally after the user types "r". This functionality is enabled by various engines that are described below.

Master finding list creation: A master list was constructed to have a representative list of normalized finding descriptions. All reports in our corpus were indexed with MetaMap [6]. All phrases detected by MetaMap containing "index" or "reference" were selected as these are typically used to describe oncological index lesions. This resulted in 9,495 phrases. This list was semi-automatically cleaned and normalized (e.g., "Right upper lobe reference nodule", "Right upper lobe reference nodules" and "Upper right lobe index nodule" all normalized to "Right upper lobe reference nodule"), resulting in 634 unique descriptions. Although the corpus contained the radiology reports of the 41 patients, the 133 labels were not necessarily contained in master list.

Sentence boundary and noun phrase detector: We developed a sentence boundary detection algorithm that recognizes sections, paragraphs and sentences in narrative radiology reports. Section headers are normalized with respect to a list of known headers, such as *Procedure Description*, *Clinical Information* (used to provide a brief description of reason for study), *Comparison* (relevant prior study details), *Findings* (details observed in the images) and *Impression* (diagnostic and follow-up recommendations). SharpNLP [7] was used to extract noun phrases from sentences. We favored SharpNLP to MetaMap as it had superior response time on our corpus.

Relevant prior report extractor: Typically, radiologists use the most recent, relevant prior report to understand the patient's current status, especially about existing findings. We decided to use two relevant, distinct prior reports to establish context – first, the most recent prior report having the same modality and body part (e.g., *CT chest*); second, the most recent prior report having the same body part (e.g., *chest*). Procedure Description section of the report contains modality and body part information, and given a set of reports, this module determines the two relevant priors for a given study.

Description recommendation module: Based on user input (e.g., "r" or "ri"), this module returns a filtered, sorted list of candidate descriptions from the master list at run time. We decided to implement this module to match user input only at the beginning of any word in the finding description. For instance, typing "h" would include "Right heart border lesion" as one of the matched candidates after filtering. Similarly, if needed, the user can also type multiple characters separated by a space to match multiple words in any order; for instance, "Right heart border lesion" will be a match for "h l". Algorithms were developed to evaluate the amount of common information (by calculating the proportion between the number of common stemmed words to number of words in description) contained in each of the finding descriptions in the filtered candidate list and sentences from relevant prior reports. The list is then sorted giving preference to the candidates having the most information in common with the sentences.

Module integrator: This module integrates the different modules so that the system can show a list of candidate descriptions to the user. When the user opens an imaging study, this module uses the study's DICOM header to determine the modality and body part information. It then uses the Relevant prior report extractor module to determine the relevant prior reports. The reports are then parsed using the sentence detection module to extract sentences from the *Findings* section. The master finding list is then sorted using the sorting module and displayed to the user. List is filtered using the user input if needed.

2. Results

We simulated the user-system interaction by programmatically entering the 133 finding descriptions into the system, character by character. For each character input we evaluated if the top 5 recommendations by the algorithm contains the target description. For a successful match, we required the candidate description string to contain over 75% of the words of the target string, and all words in the candidate finding description had to be present in the target description. Table 1 shows the results of this evaluation.

Table 1: Evaluation of keystroke reduction by using prior report context

		Partial Matching (target contains all suggestion words & [suggestion words / target words ≥ 75%])		
	Instances	Saved keystrokes	Total keystrokes in target	Saved keystrokes as % of target
No suggestions	73 (55%)	0	1770	0
With auto completion	60 (45%)	1209	1406	86%
Overall keystroke reduction	133 (100%)	1209	3176	38%

In 45% of cases, the system can recommend the target string as one of the values in the top 5 candidates. Whenever the system finds such a candidate, it saves around 86% of the keystrokes the user would otherwise have to type. For instance, to enter "Right heart border lesion", the user had to type only "r" and the system found this as one of the candidate values. We integrated this recommendation module into the PACS reading environment with the list (number of candidates to display is a configurable parameter in the system) showing the top seven candidates in this instance (Figure 2).

In 55% of cases there was no match and therefore the user had to type the entire description resulting in no key stroke reduction. The average length of a finding description was 23 characters and on average, when the user typed 5 keystrokes the system was able to make a successful recommendation. The overall keystroke reduction of the system was 38%.

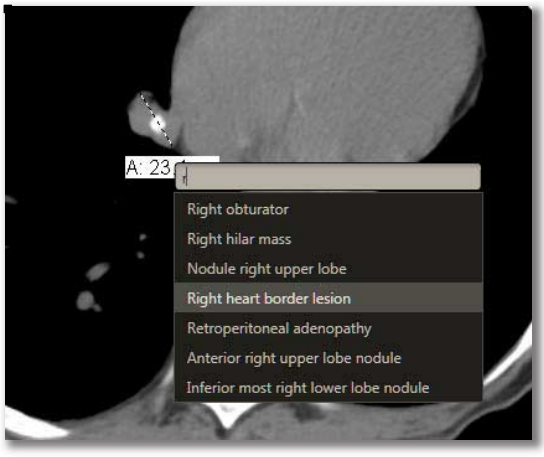


Figure 2: Finding recommendation module integrated into the PACS reading environment.

3. Discussion

In this paper we presented a workflow enhancement technology that can be used to recommend a list of most likely finding descriptions by taking the patient context into account. We demonstrated how the system can be integrated into the clinical workflow to assist clinicians to minimize the number of keystrokes required to arrive at the desired description. Further, we used a master finding list created using a large corpus of reports to support auto-completion of findings and a key advantage of this is that it promotes standardization of descriptions instead of radiologist-specific ones. The master list can be modified, for instance by a department administrator, to create an institution-specific list of finding descriptions if needed.

We used a data-driven approach to create the master list of finding descriptions. As such, these descriptions were narrative by nature. Alternatively, a tool such as iPad [3] can be used to capture annotation information in a more structured manner. Although any list of finding descriptions could be used (e.g., from RadLex), we used a dedicated master list for suggesting oncological findings descriptions.

Our study has several limitations. The most notable one is that we used data from one institution and therefore the master list may not be complete despite using a large corpus. This limitation can be mitigated using a standardized dictionary. A second is that we had only 133 production finding descriptions which is not sufficient to make a claim on the generalizability of the approach. A third is that we used the number of reduced characters to evaluate performance which may not always happen in human testing. For instance, in our example, we required only "r" to arrive at "Right heart border lesion", but due to various human factors a user may type more characters. Lastly, in our evaluation we did not give any weight to the position of the desired description as long as it appeared within the first five candidates. We didn't include extra keystrokes that are required to select the correct finding description in the list.

Despite the limitations, the system shows potential to improve the efficiency and standardization of creating finding descriptions on images and we are currently exploring how the system can be evaluated in a production clinical environment. Our approach, though evaluated in the context of the specific imaging annotation task in radiology, can be applied to patient data entry in other clinical workflows where standardized terms need to be entered into the patient record.

References

[1] *DICOM Homepage*. [cited 2013 Dec 28]; Available from: http://medical.nema.org/.

[2] Channin, D.S., Mongkolwat, P., Kleper, V., et al., *The caBIG annotation and image Markup project.* J Digit Imaging, 2010. **23**(2): p. 217-25.

[3] Rubin, D.L., Rodriguez, C., Shah, P., et al., *iPad: Semantic annotation and markup of radiological images.* AMIA Annu Symp Proc, 2008: p. 626-30.

[4] Pathak, S., Kim, W., Munasinghe, I., et al. *Linking DICOM pixel data with radiology reports using automatic semantic annotation*. in *Medical Imaging: Advanced PACS-based Imaging Informatics and Therapeutic Applications*. 2012. San Diego.

[5] Levy, M.A., Garg, A., Tam, A., et al., *LesionViewer: a tool for tracking cancer lesions over time.* AMIA Annu Symp Proc, 2007: p. 443-7.

[6] Aronson, A.R. and Lang, F.M., *An overview of MetaMap: historical perspective and recent advances.* J Am Med Inform Assoc, 2010. **17**(3): p. 229-36.

[7] *SharpNLP - open source natural language processing tools*. [cited 2014 Jan 22]; Available from: http://sharpnlp.codeplex.com/.

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Two-dimensional Signal Analysis Reduced from Three-Dimensional Nystagmus Eye Movements

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Abstract. Earlier we developed signal analysis for nystagmus measured from otoneurological patients suffering from vertigo and dizziness. It was based on three rotation directions of the eye: horizontal, vertical and torsional. However, nystagmus frequently appears only in two of the former directions. In order to enable two-dimensional analysis approach on the basis of various pairs from the original three, we designed and implemented an advanced method from our earlier one. These signals can be used to investigate and model the dysfunction of semicircular canals in the inner ear. Nystagmus has to be stimulated for healthy subjects, but in patients it can also be spontaneous. The method developed was tested with the signals of 30 otoneurological patients.

Keywords. Eye movements, nystagmus, otoneurology, two-dimensional and three-dimensional signals

Introduction

Signal analysis has been applied to nystagmus investigations since the 1970s [1-5]. Nystagmus (Figure 1) is a reflexive eye movement of the "saw-tooth" form which can be stimulated in a caloric way by injecting cool or warm air or water to a subject's ear canal. However, otoneurological patients may have spontaneous nystagmus incurred by a disorder of a semicircular canal. It may also be brought about after shaking the head of a patient. Nystagmus investigations are important for patient diagnostics as well as for research.

Video-oculography of two small videocameras directed at the eyes has become a promising way to measure eye movements. In three-dimensional (3D) measurements torsional eye movements are recorded in addition to horizontal and vertical movements. In our earlier studies [6,7], we developed a signal analysis method for 3D nystagmus of all three directions: horizontal, vertical and torsional. There are patients for whom nystagmus only occurs in two directions, as in Figure 1. In most unilateral vestibular deficits except those rare occasions affecting only one of the vertical semicircular canals, the resulting nystagmus is dominant in horizontal and torsional components.

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Therefore these components are usually most important in the analysis of nystagmus and in clinical diagnostics.

It was necessary to develop a technique to discard the influence of one of three directions. Earlier 2D systems have not contained the torsional direction at all. Nevertheless, the torsional direction is needed and very useful in the analysis of nystagmus since there are three pairs of the antagonist muscles that rotate an eye in the orbit of a subject and such rotations do also include the torsional direction. The choice from three pairs of the directions can be made by leaving out that 1D signal the average nystagmus amplitude of which is the smallest such as in Figure 1.

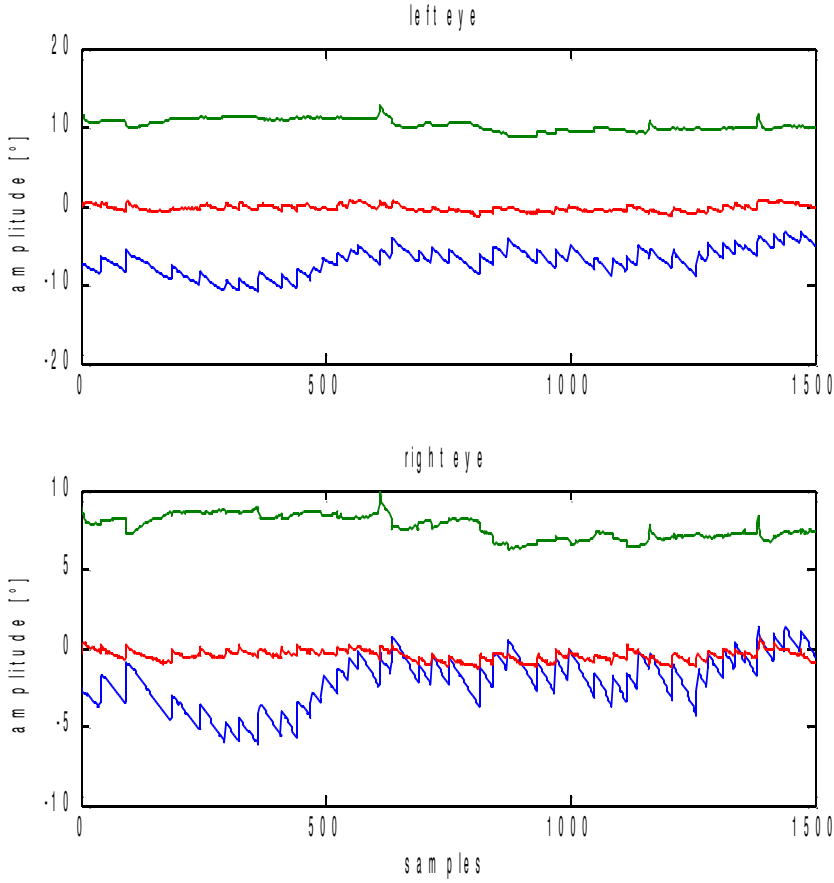


Figure 1. 3D signals represented as three 1D signals for both eyes of a patient having spontaneous nystagmus. The lowest curve of each subplot is the horizontal signal, the middle curves are the torsional signals, and the uppermost curves are the vertical signals to be left out. The duration of the signals was 30 s.

A nystagmus beat includes a slow phase (down in Figure 1) followed by the fast phase in the opposite direction. The vertical nystagmus was virtually non-existent. The reduction from 3D to 2D was reasonable for the present measurement. The average slow phase velocities were small in these signals: 2.6°/s for the horizontal and 1.1°/s for

torsional movements. The vertical signals did not include actual nystagmus beats, but random eye movements represented by peaks or drifting. The signals of the right eye with slightly larger amplitudes and velocities than those of the left eye were chosen for the final analysis.

1. Signals

We used nystagmus recorded from 30 patients with a mean age of around 50 years. The majority of patients suffered from acute, unilateral loss of vestibular function. Figure 1 presents 3D nystagmus of a subject. Horizontal eye movements are from left to right or vice versa, vertical eye movements up or down and torsional movements are clockwise or counterclockwise round the axis in the forward direction. (These are seen from the view of a subject, not from that of a spectator.) A subject was sitting relaxed, alert and did not move the head.

First, calibration was performed by making a subject to alternately look at nine points located symmetrically on the wall. Recordings were made with two small eye movement cameras embedded in a mask (3D VOG Video-Oculography, Sensomotoric Instruments, Germany) in a dark room. The sampling frequency was 50 Hz. The horizontal and vertical amplitude resolutions were 0.05° and the torsional resolution 0.1°. We estimated the resolution to be better than 0.5° after calibration.

2. Methods

The following procedure was programmed with Matlab.

1. Angular velocity of each of the components of a three-dimensional signal was approximated with slope values of linear regression. The better from the signals of two eyes were taken based on less noise and higher amplitudes estimated from the amplitude distributions of the signal samples. (In Figure 1, the signals of the right eye including larger amplitudes were selected.)
2. The directions defined by fast phases of nystagmus are also determined with the amplitude distributions: the majority of the distribution indicates whether slow phases of nystagmus of each 1D signal are to the right or left (horizontal), up or down (vertical), or clockwise or counterclockwise (torsional).
3. Nystagmus beats are detected according to velocity. A minimum or maximum is found when absolute velocity values drop below 10°/s.
4. Noise peaks or other non-nystagmic phenomena are left out by detecting them on the basis of rules of upper bounds computed with earlier data for maximum velocities, amplitudes and durations of slow and fast phases of nystagmus.
5. Average angular velocities of all accepted nystagmus beats are computed as slopes of linear regression.
6. On the basis of the velocities, the direction including the smallest average velocity is removed from the horizontal, vertical and torsional directions. Alternatively, this choice can also be made by the user.
7. A unit circle is formed so that from the 3D unit sphere of three directions the component of the removed direction is deleted. Six normal vectors (from [8]) corresponding to three semicircular canals in each ear are projected from the unit

sphere onto the unit circle (Figure 2). The accepted unit velocity vectors are mapped as dots on the circle and their mean vector is mapped as a line from the origin through the circle.

8. (8) The results are computed. First, the angles from the normal vectors to the preceding mean vector is computed. The closest normal vector predicts the probable origin (semicircular canal) of dysfunction. Average velocities of the two directions (vector components) and the number of the accepted nystagmus beats are computed (Table 1).

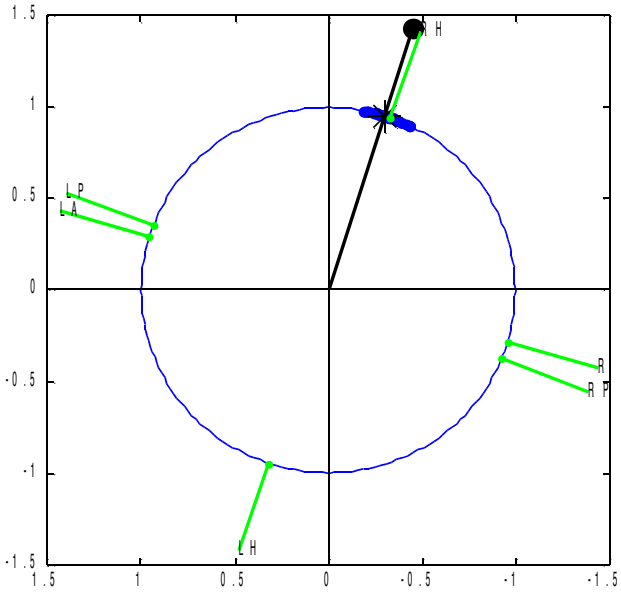


Figure 2. The unit circle model for nystagmus: positive horizontal axis (to the left) corresponds to clockwise torsional eye movements (negative is for counterclockwise) and positive vertical axis corresponds to horizontal eye movements to the right (negative to the left). Values equal slow phase velocity [°/s] as two-dimensional unit vectors. Semicircular canals are by their normal vectors. The angles were computed from the normals to the mean vector (near normal RH) of the dots of the velocity unit vectors. (L=left and R=right inner ear; A=anterior, P=posterior and H=horizontal semicircular canal).

Table 1. Means and standard deviations of the slow phases of the accepted nystagmus beats from 30 signals after discarding the vertical direction.

Number of nystagmus beats	Angle from mean velocity vector to closest normal [°]	Horizontal velocity [°/s]	Torsional velocity [°/s]
35.9±15.5	9.5±8.6	6.7±5.4	4.8±5.8

3. Results

We computed results of 30 signals measured from the patients for whom nystagmus in the vertical direction was virtually missing or was minor. Consequently, the vertical direction was the one left out in the 2D analysis. Figure 2 shows one of those signals. Note that if some other than the vertical direction had been left out, the axes of the unit circle would have been named partly differently and the six normal vectors been projected in different positions. The means of the velocities of the slow phases of nystagmus in Table 1 are greater than those in Figure 1. This can also be seen indirectly about small amplitudes in the horizontal and torsional signals (directions) in Figure 1.

4. Discussion

The method is especially useful because the torsional direction is here new since earlier 2D video-oculographic systems only registered along with the horizontal and vertical directions. Nevertheless, the torsional direction seems to be more impressive for frequent patients than the vertical direction. Moreover, the results obtained support the hypothesis called Ewald's first law [9] originated from the year 1892: the trajectory of nystagmus induced by a semicircular canal should reflect the anatomic orientation of that semicircular canal. Thus far, evidence for Ewald's first law has been studied very infrequently with patients, except in our present and two earlier studies [6,7].

References

[1] Baloh R.W., Honrubia, V., *Clinical Neurophysiology of the Vestibular System*, F.A Davis Company, Philadelphia, 1979.
[2] Carpenter R.H.S., *Movements of the Eye*, Pion Limited, London, 1977.
[3] Henriksson N.G., Hindfelt B., Pyykkö I., Scahlén L., Rapid eye movements reflecting neurological disorders, *Clinical Otolaryngology*, **6** (1981): 111-119.
[4] Wall III C., Black F.O., Algorithms for the clinical analysis of nystagmus eye movements, *IEEE Transactions on Biomedical Engineering*, **28**(9) (1981): 638-646.
[5] Zee D.Z., Mechanism of nystagmus, *The American Journal of Otology*, supplement issue (1985): 30-34.
[6] Juhola M., Aalto H., Hirvonen T., On signal analysis of three-dimensional nystagmus, Proc. of Medical Informatics in Europe 2009, K.P. Adlassnig et al. (Eds.), IOSPress, pp. 846-850.
[7] Juhola M., Aalto H., Jutila T., Hirvonen T.P., Signal analysis of three-dimensional nystagmus for otoneurological investigations, *Annals of Biomedical Engineering* **39**(3) (2011): 973-982.
[8] Della Santina C.C., Potyagaylo V., Migliaccio A.A., Minor L.B., Carey J.P., Orientation of human semicircular canals measured by three-dimensional multiplanar CT reconstruction, *Journal of the Association for Research in Otolaryngology* **6** (2005): 191–206.
[9] Cremer P.D., Migliaccio A.A., Pohl D.V., Curthoys I.S., Davies L., Yavor R.S., Halmagyi G.M., Posterior semicircular canal nystagmus is conjugate and its axis is parallel to that of the canal, *Neurology* **54** (2000): 2016-2020.

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Computer Aided Detection and Measurement of Peripheral Artery Disease

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Abstract. Computer-Aided Tomography Angiography (CTA) images are the standard for assessing Peripheral artery disease (PAD). This paper presents a Computer Aided Detection (CAD) and Computer Aided Measurement (CAM) system for PAD. The CAD stage detects the arterial network using a 3D region growing method and a fast 3D morphology operation. The CAM stage aims to accurately measure the artery diameters from the detected vessel centerline, compensating for the partial volume effect using Expectation Maximization (EM) and a Markov Random field (MRF). The system has been evaluated on phantom data and also applied to fifteen (15) CTA datasets, where the detection accuracy of stenosis was 88% and the measurement accuracy was with an 8% error.

Keywords. Computer aided detection, peripheral arterial disease, stenosis quantification, vessel detection.

Introduction

Peripheral artery disease (PAD), or peripheral vascular disease, is a severe ailment, with high mortality rates being experienced in recent times.

As a medical imaging investigation modality, Computed Tomography Angiography (CTA) is a reliable tool for the identification of arterial abnormalities. The 3D image analysis of CTA data is the basis for the diagnosis, quantification and surgical planning of vascular diseases [1].

The main arterial abnormalities in the peripheral artery are: stenosis (narrowing of the blood vessels), occlusion (total obstruction of a vessel) and calcification (accumulation of calcified atherosclerotic plaque). CTA images of the peripheral arteries also present a series of challenges associated with the partial volume effect (i.e. the mixture proportion of intensities of peripheral vessel boundary voxels and surrounding tissue), inhomogeneous bone tissue, image noise and the large number of image slices (up to 1000 per scan). Due to these factors a system that can automatically detect and quantify (CAD-CAM) PAD is highly desirable but has yet to be successfully developed.

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A wide range of segmentation techniques have been applied for PAD CAD. Felkel et al. [2] overviewed existing segmentation methods for peripheral vessels in CTA datasets, identifying issues such as the non-homogenous distribution of the contrast agent and the partial volume effect. However, most of these approaches require manual intervention. A system for vessel visualisation and analysis has been applied to MRI images [3] and the detection analysis was limited and not targeted at PAD or its particular challenges (e.g. the proximity of bone). The main achievement of the system was the automatic quantification of stenosis.

The CAM task has been explored in the literature but applied to the more general application of vascular measurement and was only assessed on a 3D synthetic phantom representing vessels with different structures [4].

This paper proposes an integrated CAD-CAM system for detecting PAD. The CAD system automatically detects the peripheral arteries using a sequence of image segmentation operations: optimal thresholding, 3D region growing and bone removal, a fast morphology operation, artery centerline detection and distortion correction. Accurate measurement of the artery diameters is performed orthogonal to the centreline and is combined with a method to compensate for the partial volume effect based on Expectation Maximization (EM) and Markov Random fields (MRF).

1. Methods

The following major algorithmic steps are used to extract and measure the dimensions of the peripheral vascular network.

Optimal thresholding – the high-contrast vessels in CTA images can be detected using intensity thresholding. The threshold value is estimated using an optimal selection algorithm.

3D region growing – a 3D region-growing algorithm is seeded at a location determined by automatically identifying the bifurcation of the aorta at the junction with the common iliac artery. The bifurcation of the aorta is identified using thresholding (a), labeling and removing other objects such as spinal cord by taking into account the anatomical information of abdominal region based on length, angle and location features.

Bone removal – bone detection is problematic in the upper (pelvic) and lower (popliteal) regions of the image data. A connected component analysis algorithm is used to label the image in 2D and 3D regions. For each of the problematic sub-volumes, the algorithm utilises anatomical and spatial information. For example, the hip bones are large in comparison with the iliac arteries, so this characteristic is used for identifying and removing the bone tissue in this region. A fast morphology operator is used to repair holes and lost connectivity in the vessel construction. The method uses efficient shift operations applied to packed bit arrays using the BigInteger data structure of the C# programming language. With this novel implementation, the maximum number of arithmetic operations is at most 27 for the entire image, independent the size of the morphological mask used.

Centerline detection - a thinning algorithm, proposed by Lee [6], was implemented and tested. The algorithm uses a fast, iterative, symmetrical erosion technique using topological information of the image. The algorithm is based on a decision tree method and finds all the deletable surface points. In order to create a smooth

centreline and correct distortions, an interpolation method based on Catmull Rom splines [5] was employed. This method is based on the general approach of spline curves where an interpolating curve is constructed from a given sequence of points and is constrained to pass through each point.

Orthogonal plane construction – image cross-sections normal to the peripheral vessel centreline are obtained from a sliced-based rendering technique (SBVR) [7] which uses texture for visualization of 3D data sets. The image data is represented as a 3D texture and a view-aligned bounding box is generated around the volume. The intersection between a plane and the bounding box is performed. The intersection slices are a series of polygons characterized by the intersection vertices between the plan and the bounding box, which can be at most 6 vertices. The polygons are then decomposed into a series of non overlapping triangles derived from the polygon centroid. These triangles are textured through linear interpolation using the intersection points and the volume data. Since the original data set is a lattice with values specified at certain points, an interpolation scheme is used to sample the values.

Vessel diameter measurement – the diameter of the peripheral vessel is measured directly from the orthogonal image cross-section extracted in (e) and computed as the diameter of the equivalent circle. To minimize the measurement error, especially for narrow vessels, an algorithm based on a maximum a posterior (MAP) expectation maximization (EM) algorithm is used to compensate for partial volume errors. For this, the mixture percentage (percentage of the mixture of peripheral vessel and surrounding tissue) for each voxel is determined, making use of the image as input and of the voxel's neighbours. The algorithm is iterative and the estimation of tissue mixtures is determined at each iteration by maximizing the conditional expectation.

Stenosis identification – finally, a stenosis is identified as a distinctive narrowing of the vessel diameter over a short length of vessel.

2. Results

The proposed CAD-CAM system has been validated using a vascular phantom and real patient data. For the CAD system validation, the real data was supported by ground-truth assessed by two experienced radiologists.

Vascular Phantom: The vascular phantom used for the CAD-CAM system assessment simulates the vessel's anatomy and can be used in conjunction with other imaging acquisition systems. The MAP-MRF method was evaluated on phantom data and compared with the threshold method for performance assessment. A threshold of 200 (HU) was used, corresponding to the simulated artery in the phantom. The results in table 1 show that the MAP-MRF method is superior to the threshold algorithm, resulting in significantly smaller errors for the estimation of the vessel diameters.

Table 1. The average diameter measurements obtained by applying threshold and MAP-MRF methods on 32 phantom samples of 18 slices each

Diameter true value (mm)	1	2	4	6
Threshold mean value (mm)	1.326	2.532	4.637	6.682
Threshold Percentage error	32%	26.6%	15.9%	11.3%
MAP-MRF mean value (mm)	1.108	2.136	4.284	6.341

MAP-MRF Percentage error	11%	6%	7%	6%

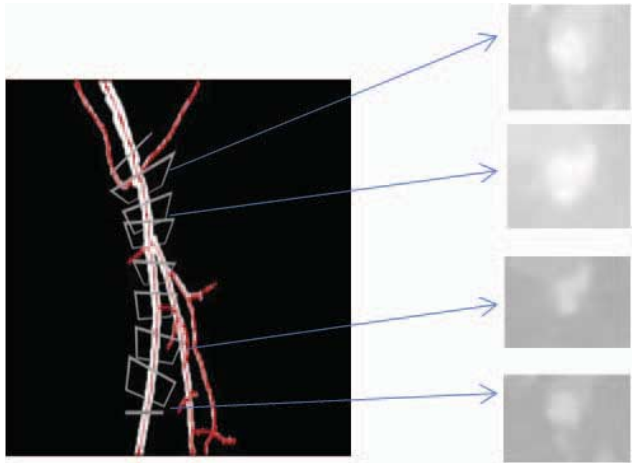


Figure 1. a. (left) Vessel centerline (in red) overdrawn onto the extracted artery; b. (right) vessel intensity cross-section orthogonal to the artery centreline;.

Real patient data: The CAD-CAM methodology was applied to fifteen (15) CTA scans of patients with PAD supplied by CHUV, Lausanne. The images were acquired with GE Multi-slice helical CT having the following parameters: 120kV, 749 mA, slice thickness 0.6 mm. Fig. 1a shows the extracted vascular network (in white), the centerline (in red) and a series of plane sections that orthogonally intersect the profile. Figure 1b shows examples of the image intensity cross-section through the planes. Fig. 2a shows the result of the optimal thresholding in a region near the head of the femur, which detects both vessel and adjacent bone tissue. Figure 2b shows the result after successful removal of the bone tissue. Figure 3 shows a profile of the vessel diameter in the slice and the corresponding slice number. The dashed lines indicate the stenotic region, characterized by a significant reduction in vessel diameter measured over two consecutive slices. From the 15 patient scans a total of 149 stenotic segments were identified by the radiologist's assessment ,for which the CAD stenosis detection resulted in a sensitivity was 0.88 (131 correctly detected) while the specificity was 0.96 (i.e. 3 false positives).



Figure. 2 a) Maximum intensity representation of vessel contiguous to femur bone; b) after bone removal

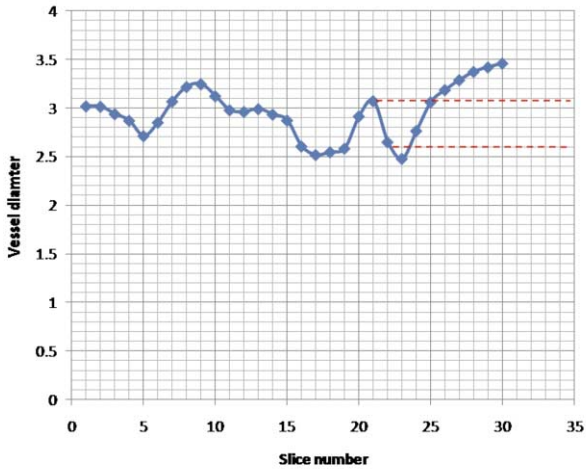


Figure. 3. Vessel profile for a short section of a CTA sample data.

3. Discussion

Quantitative results from a phantom target have been used to validate the accuracy of the vessel detection and diameter measurement. When applied to CTA patient scan data the system was able to detect 131 locations of stenosis compared to the 149 reported by the radiologist (i.e. sensitivity of 0.88), with a false positive rate of only 4%. These results are particularly promising as, according to the radiologists' assessment, 132 of the stenoses can be attributed to soft plaque deposits, which can be more challenging to detect than the hard plaque variety. The results demonstrate the potential application of CAD-CAM for PAD, which we believe can be further improved using more sophisticated algorithms for determining the degree of vessel narrowing in stenosis.

References

[1] D. Geoffrey and N. M. Rofsky, "CT and MR Angiography: Comprehensive Vascular Assessment", 1st Edition, Rubin, 2009

[2] P. Felkel, R. Wegenkittl, A. Kanitsar, Vessel Tracking in Peripheral CTA Datasets – An Overview, SCCG '01: Proceedings of the 17th Spring conference on Computer graphics, IEEE Computer Society, Washington, DC, USA, 2001, p. 232.

[3] Hernández-Hoyos M, Orkisz M, Puech P, Mansard-Desbleds C, Douek P, Magnin IE. "Computer-assisted analysis of three-dimensional angiograms". RadioGraphics 22 (2002), 421–436.

[4] D.-G. Kang , D. Suh and J. Ra "Three-dimensional blood vessel quantification via centerline deformation", IEEE Trans. Med. Imag., vol. 28, p.405 , 2009.

[5] G. Soulez and S.D Qanadli, "A multimodality vascular imaging phantom with fiducial markers visible in DSA, CTA, MRA and ultrasound", Medical Physics, vol. 31, pp 1424-1433, 2004.

[6] Lee TC, Kashyap RL,Chu C-N, "Building skeleton models via 3-D medial surface/axis thinning algorithms",Vision, Graphics, and Image Processing, 56(6):462–478, 1994.)

[7] Milan Ikits, Joe Kniss, Aaron Lefohn, and Charles Hansen. "Volume rendering techniques." In GPU Gems. Addison-Wesley, 2004.

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Visualizing Unstructured Patient Data for Assessing Diagnostic and Therapeutic History

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Abstract. Having access to relevant patient data is crucial for clinical decision making. The data is often documented in unstructured texts and collected in the electronic health record. In this paper, we evaluate an approach to visualize information extracted from clinical documents by means of tag cloud. Tag clouds will be generated using a bag of word approach and by exploiting part of speech tags. For a real word data set comprising radiological reports, pathological reports and surgical operation reports, tag clouds are generated and a questionnaire-based study is conducted as evaluation. Feedback from the physicians shows that the tag cloud visualization is an effective and rapid approach to represent relevant parts of unstructured patient data. To handle the different medical narratives, we have summarized several possible improvements according to the user feedback and evaluation results.

Keywords. Visualization, EHR, Text Mining, Tag Cloud

Introduction

The electronic health record consists of information captured in various data types, e.g. in radiological images, in textual documents, in structured values or graphs, etc. They confront physicians with complex data describing complex patient histories based on which they have to make treatment decisions [1]. In particular, information stored in clinical documents is difficult to assess since it requires more time to read and to bring together the information in a mental patient model that forms the basis for clinical decision making. When patients are monitored over a long period of time, at each appointment it is crucial for a physician to get an overview on the progress and changes in the patient status promptly. In this work, we address the question of representing the current status of a patient that is described in form of unstructured text to enable physicians to get an overview quickly.

For visualizing textual information several means are available. Relevant information, such as diagnoses, medications or medical procedures can be highlighted in the text. Charts and diagrams can be used to show relations between terms, categories or expressions [2]. Kopanitsa et al. [3] reviewed the state of the art of medical data visualization and defines requirements for a generic ISO 13606 based data visualization method. Existing visualization approaches base upon a structured EHR, i.e. diagnosis with information on length and date of hospital staying etc. The LifeLines

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Project [4, 5] visualizes temporal relationships between treatments, consultations, disorders etc. Similar events are organized into facets. Colors are used to indicate severity or type of a symptom or disease. This kind of visual representation requires availability of structured data. In contrast, our approach is to exploit and visualize the information available in unstructured documents.

We will introduce an approach that visualizes patient information extracted from the documents of the EHR in an easy understandable manner, namely by means of tag cloud visualization. Tag cloud is a common visualization method in the Web 2.0 community. Studies showed that they enhance the perception of (Web) documents [6] and they support an explorative search when it is difficult to specify a concrete query. These benefits perfectly address the challenges of accessing and monitoring patient data documented in unstructured documents. In this context, using tag cloud for information visualization is still relatively unexplored.

1. Methods

1.1. Tag Cloud Generation

Generally, a tag cloud is a visual representation of the bag of words model. The tag size reflects the occurrence frequency of the corresponding term in a text or set of texts. The more often a term appears in one document, the larger the size of the tag in the cloud. We used the OpenCloud [7] tool to generate the tag clouds from clinical documents. For our study, tags are selected from a text (1) just by frequency (Bag of words), or (2) based on their part of speech (POS). A first type of tags (Bag of words) is generated using all the words of a document except stop words. The 50 most frequent tokens are shown in the tag cloud with size depending on their frequency in the document. All the tags are rendered with same color. To generate the second type of tags, the tokens of a text are annotated with their part of speech labels. The lexical category of the remaining words of a document is after removal of stop words determined by the Stanford POS-tagger [8]. We intuitively highlight the nouns, verbs, and adjectives with three primary colors (red, yellow and blue) due to the decisive roles of these lexical categories in the meaning delivery. Their applicability and correctness of our intuition from meaning representation need to be analyzed in experiments.



Figure 1 Tag Cloud with Part of Speech

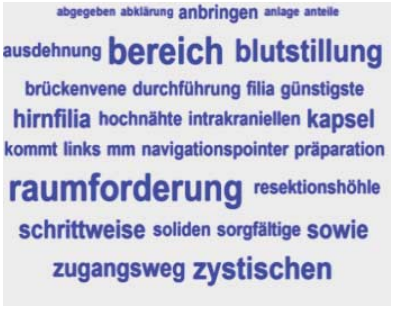


Figure 2 Tag Cloud with Bag of Words

1.2. Study Design

In order to figure out the effectiveness of the tag clouds, a user study has been performed in the neurosurgical department of a university hospital. Three residents were asked to assess the tag clouds generated for different texts and to judge whether (1) the **tag clouds are useful** to get an overview on the patient status, (2) shown **words are relevant** and (3) **visualization** of relevant aspects is **clear**. Six medical reports in German (three surgical operation reports, two pathological reports and one radiological report) were used to generate the tag clouds. Before starting to answer the questions, the physicians were introduced to imagine the following simulated task scenario:

In the outpatient department, facing a patient who has never seen before, but he/she was treated in the hospital already, you have the complete patient documentation in computer. You are expected to grasp the basic status of this patient and start the treatment in very short period of time.

Based on this scenario, all six medical reports visualized by the two types of tag cloud (generated through bag of words approach or POS tagger) were judged on a rating scale from 1 (bad) to 5 (excellent).

2. Results

Since the medical narratives have shown significant differences in format and writing styles, we decided to perform a comparison based on different data sources, namely, operation notes, pathological reports and radiological reports. In order to obtain the arithmetic mean for one narrative type, the sum of judgments' means (three evaluators) is divided by the amount of documents in this narrative type. In Figure 3, the mean of judgment for each type of narratives and the corresponding standard errors presents the attitude of three evaluators towards the tag clouds. The pathological report has achieved the best scores in the first question (Usefulness) with 3.33 of mean value, while the operation note reaches the highest mean value by the second question referring to the tag relevance. For the question three, the visualization of relevant aspects, the tag clouds have also provided moderate representation of details to the physicians, although only entity extraction approaches were applied to generate the clouds without considering the semantic meanings of terms. Generally, evaluators stated to have obtained an overview on the reports through the tag clouds, but desired to see some more details on the medical condition of a patient. For all three questions, different variances and deviations in the perceptions of the physicians have been analyzed. The main reason is their varying work experiences and knowledge background. For example, a surgeon with the specialty of cervical spine can understand the meaning of a radiological report with the topic of disc protrusion through tag clouds much easier than a surgeon with the specialty for neuro-oncology.

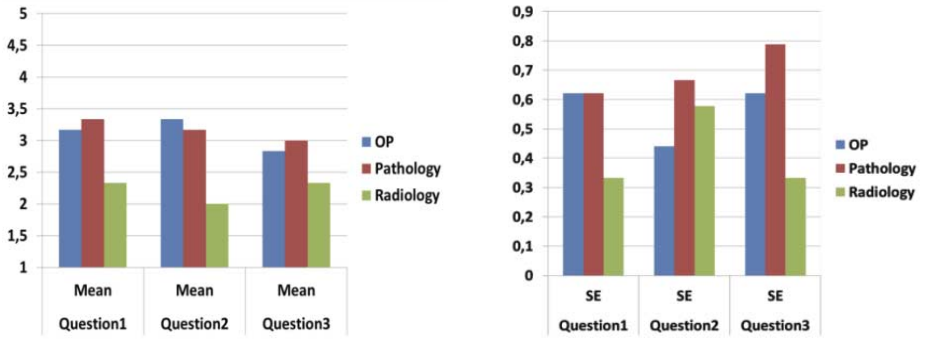


Figure 3 Result of the User Study (Mean = Arithmetic Mean, SE = Standard Error, Question 1: Usefulness of tag clouds, Question 2: Relevance of words, Question 3: Visualization of relevant aspects)

3. Discussion

From the feedback of the physicians, we learned the following: While the tag cloud representation in general is considered to be useful, however, the multicolored tag clouds (part of speech) are not well accepted. In particular, the red color is too dazzled. Future work should involve physicians in defining colors. As far as the content of tag cloud is concerned, only certain sections of the texts contain the most relevant aspects regarding patient status (e.g. judgment section, indication section). From other sections, only small amount of information is relevant: e.g. the surgical procedures described in operation reports are not that relevant for assessing the patient's status. Only the results of the surgery and whether complications occurred are of interest. Focusing on these sections and information within tag cloud generation could improve their usefulness and relevance significantly. To address that issue, focused extraction methods and proximity-based approaches should be applied to emphasis the relevant information and eliminate the information outliers. So far, we removed expressions with numbers from the texts before generating tag cloud. The feedback showed that expressions with numbers can be relevant for obtaining an overview and details representation, e.g. T1, T2, or the measurement of the tumor. This holds true especially for the pathological report and radiological report: the numeric information such as measurement and distance can play an essential role in transmitting meaning and information to the users. As limitation of the study, the following two points need to be mentioned: Our questionnaire did not well compare the differences between the two types of generated tag cloud (bag of words and part of speech). No specific questions were asked regarding that topic. However, we recognized from their feedback, that the physicians preferred to browse the single color tags, since the multicolor in tag clouds has disturbed the interpretation of part of speech due to the choosing of color. Furthermore, although only three physicians have been asked to conduct the aforementioned study, the acceptance and usefulness of tag cloud is already approved. For a further usability test, we will involve more physicians in the study to reduce the deviation of the result.

In conclusion, already with simple methods, perception of relevant aspects reported in clinical documents can be supported. Since the approach exploits only tokenization, part of speech tagging and stop word removal, texts of different languages can be easily processed using that method. Several improvements are possible and would increase user satisfaction. In future, we will study whether tags

generated using concept extraction will be a better option to identify most important aspects of a clinical document. Medical concepts could be extracted for example using the MetaMap [9] system that maps terms of a document to UMLS [10] concepts. Symptoms, diseases and anatomical concepts would be the most interesting information in the medical records and concepts belonging to those categories could be used for tag cloud generation. Moreover, the semantic relations between the concepts will also be presented to the users. Through clustering of tags, the potential topics will be detected and visualized.

References

[1] Smith R. What clinical information do doctors need? BMJ, 1996 Oct 26, 313(7064): 1062-69.
[2] Ballstaedt SP. Texte visualisieren (Visualizing texts). In: E.-M. Jakobs, D. Knorr, K-H. Pogner (Eds.):
[3] Textproduktion. HyperText, Text, Kontext. Peter Lang Verlag, Frankfurt/Main, 1999. P. 129-40.
[4] Kopanitsa G, Hildebrand C, Stausberg J, Englmeier KH. Visualization of Medical Data Based on EHR Standards. Methods Inf Medicine, 2012 Dec 7,52(1):43-50.
[5] Rind A, Wang TD, Aigner W, et al. Interactive Information Visualization to Explore and Query Electronic Health Records. In: Foundations and Trends in Human-Computer Interaction, 5(3), 2013: 207-98.
[6] Plaisant C, Shneiderman B, Mushlin R. An Information Architecture to Support the Visualization of Personal Histories, CS-TR-3855, UMIACS-TR-97-87. Revised version appeared in Information Management and Processing, 1998 Oct 15, 34(5): 581-597.
[7] Gottron T. Document Word Clouds: Visualising Web Documents as Tag Clouds to Aid Users in Relevance Decisions. In: Agosti M et al. (eds.). ECDL 2009, LNCS 5714. Berlin, Heidelberg: Springer, 2009 Sep 27- Oct 2:94 –105.
[8] OpenCloud Java Library [Internet]. Sourceforge MIT License. Mcavallo; [updated 2013 April 23; cited 2014 Jan 31]. Available from: http://opencloud.mcavallo.org/
[9] Stanford Part-Of-Speech Tagger [Internet]. Stanford University GNU License. NLP group; [updated 2014 Jan 04; cited 2014 Jan 28]. Available from: http://nlp.stanford.edu/downloads/tagger.shtml
[10] MetaMap [Internet]. NLM copyright. NLM; [updated 2013 Dec 24; cited 2014 Jan 31]. Available from: http://metamap.nlm.nih.gov/
[11] UMLS [Internet]. U.S. National Library of Medicine. NLM; [updated 2014 Jan 18; cited 2014 Jan 31]. Available from: http://www.nlm.nih.gov/research/umls/

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Big Data in Medical Informatics:Improving Education Through Visual Analytics

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Abstract. A continuous effort to improve healthcare education today is currently driven from the need to create competent health professionals able to meet healthcare demands. Limited research reporting how educational data manipulation can help in healthcare education improvement. The emerging research field of visual analytics has the advantage to combine big data analysis and manipulation techniques, information and knowledge representation, and human cognitive strength to perceive and recognise visual patterns. The aim of this study was therefore to explore novel ways of representing curriculum and educational data using visual analytics. Three approaches of visualization and representation of educational data were presented. Five competencies at undergraduate medical program level addressed in courses were identified to inaccurately correspond to higher education board competencies. Different visual representations seem to have a potential in impacting on the ability to perceive entities and connections in the curriculum data.

Keywords. Visual analytics, big data, medical education, data representation, medical informatics.

1. Introduction

There is a constant need to develop the competency of health workers through education, in order to match the demands of healthcare. One approach has been to react to observed deficiencies in healthcare that were linked to unsatisfactory required competencies [1]. An example was given by Cho et al. who highlighted the difficulties the physicians had to keep in pace with the growing medical literature, and therefore proposed to include a journal club in undergraduate medical education to acquire at an early stage the ability to critically review scientific literature, a skill needed as a future physician using evidence-based medicine [2]. While reviewing the literature, we've found limited research reporting on improvement of healthcare education based on educational data [3]. Hege et al. reported how non - previously perceived discrepancies between taught and the assessed curriculum were revealed using a web-based learning objectives database [4].

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Methods and techniques that can manipulate data in many different disciplines have been developed [5], [6]. Visual Analytics (VA) is a relatively new research field that combines two frequently used techniques, information visualization and data analysis, along with the ability of human perception. The main purpose of VA is to support the manipulation and exploitation of complicated big data, and a holistic view of the data, in order to positively impact on analytical reasoning and decision-making [7]. VA allows the disclosure of previously unknown hidden information and patterns within the data, the use of cognitive strengths like perception and visual pattern recognition, and finally, the presentation of the processed information using visualization techniques [8], [9]. In healthcare education Olmos & Corrin reported how a simple visualization of data, extracted from a healthcare education system, enabled involved stakeholders to instantly review and preview the effects of implemented and future changes [10].

Big data are regularly collected during the evaluation of healthcare education and could, contribute to the continuous improvement of the medical curriculum. However, there is still a lack of empirical data about the use and benefits of VA in healthcare education.

The aim of this study was therefore to explore novel ways of representing curriculum and educational data using visual analytics.

2. Methods

2.1. Collection and sense-making of the educational big data

Big educational data have been collected by the undergraduate medical program at Karolinska Institutet during the preparation for the curriculum review by the Swedish Higher Education Authority (higher education board). This study has access to these curriculum data. Major entities within the curriculum that play important role in healthcare education delivery and quality improvement were identified. Examples are competencies, intended/taught learning objectives and the relation between them. They are defined in three different levels within the curriculum. In first level (higher education board) are the three major competencies (knowledge, skills and attitude) and these are analysed and given to the medical program as sixteen sub-competencies (H1-H16) [11], the students should achieve to learn after graduating from the medical program. In second level, the medical program based on higher education board three and sixteen competencies, developed eight major competencies that should be realized through different learning objectives in the third level of the courses. An example of this structure of competencies and learning objectives is: One sub-competency (H5) that belongs to skills is described as "diagnosing and treating" from the higher education board. According to this, the medical program developed one competency (#4), "system of man in direct contact" and this is addressed in the course level as "patient history". Skills → diagnosing and treating → system of man in direct contact → patient history, correspond to (three major competencies → H1-H16 → eight major competencies → learning objectives).

2.2. Exploration of novel ways of representing curriculum using visual analytics

We performed a review of the literature and found no scientifically validated VA technique or reported appropriate tools for the analysis, visualization and representation of curriculum and educational data. We therefore, explored existing tools and techniques from a plethora of open-source and proprietary software already applied for similar purposes of data visualization. We then examined their appropriateness and ability to represent educational big data from healthcare education. We opted for Cytoscape [11] in our study as a suitable tool because that allows for building a network of different entities and relations between them as they exist within the curriculum and enter it to cytoscape. This is automatically recognized as network with nodes and edges and we could easily rearrange them to preferable representations of shapes and formations. Thereby we built three different visual representations of a part of the curriculum with a focus on previously perceived and non-perceived connections existing in the curriculum. Three approaches were used; competencies mapping, competencies clustering and gap analysis.

3. Results

3.1. Competencies mapping

In Fig. 1 the three major competencies (Grundmål1-3) at the top are depicted with dark green colour and sub-competencies (H1-16) with light green. At the bottom are the eight major competencies of the program level (KI_mål1-8) in dark red and in the middle the learning objectives of the courses level in light red. We represent here how the learning objectives from course level relate to competencies of the program level and to competencies of the higher education board level.

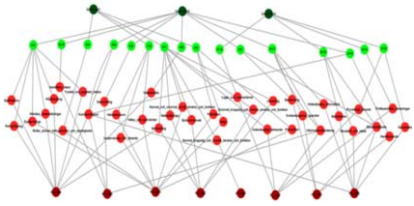


Figure 1 – Map of competencies and learning objectives of all levels. (larger competencies map)

3.2. Competencies clustering

In Fig. 2, entities have the same colours as in Fig.1 aiming to represent what learning objectives are used to address clusters of competencies connecting competencies from both program and higher education board level in the curriculum. Competencies are independent to each other within the clusters. Clusters with light blue background represent competencies from high education board and the cluster with light grey background represents the eight major competencies from medical program.

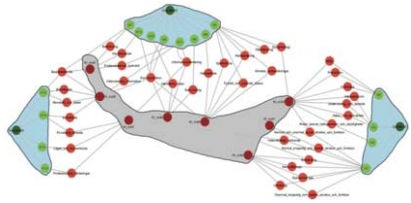


Figure 2 – Clusters of competencies and learning objectives. (larger competencies clustering).

3.3. Competencies gap analysis

In Fig. 3 the eight major competencies are depicted with red colour and have two different names so they can be processed as entities that represent the same information in two different places (KIMål1-8 on the left and KI_mål1-8 on the right). H1-H16 sub-competencies are with dark grey and three indicatively picked courses with light pink, light green and blue colours. We represent here mistakenly connected competencies between KIMål1-8 and H1-H16 as they are addressed in the courses. For example bold light pink line from KIMål3 should be connected to H5 according to intended connections between KI_mål1-8 and H1-H16 and instead is connected to H15. In total, five program level competencies were identified to mistakenly correspond to H1-H16 competencies (three bold blue lines, one light pink and one light green).

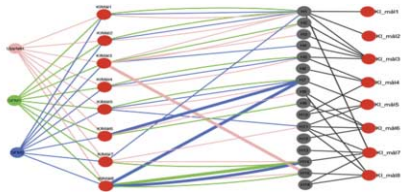


Figure 3. Gaps between higher education board and program's competencies. (larger gap analysis).

4. Discussion

This study reveals that visual analytics has the potential to impact quality improvement decision making. The techniques however were only applied to a snapshot of the curriculum data. The complexity of the curriculum indicates that more analysis must be undertaken to lower levels of learning outcomes and activities, and expand the analysis to represent the curriculum as it is evolved from previous years to today to create a holistic view. VA can be used to explore curriculum and educational data. The five competencies at medical program identified to mistakenly correspond to H1-H16 competencies reveal non-previously perceived discrepancies in competencies connections within the curriculum. The impact of different visual representations on the ability to perceive entities and connections was evaluated with semi-structured interviews with teachers from undergraduate medical education. The figures for relationship perception indicate that the ability to perceive connections between entities within curriculum data increased. The degree of analytical reasoning and data cognition of the curriculum data was also improved but to a lesser extent. Our findings are in line with a study by Corrin & Olmos that used a similar approach to help medical faculties enhance the alignment between clinical experiences and the curriculum [13].

This study therefore opens a new promising direction for medical educational informatics research, with possible implications for quality improvement and decision making in healthcare education.

5. Conclusion

VA can be used to explore and provide novel ways to represent curriculum and educational data. Moreover, different visual representations seem to have a potential in impacting on the ability to perceive entities and connections in the curriculum data thus enhance data perception and cognition. The new direction VA opened in this study for medical educational informatics research, requires further investigation towards both curriculum's structure complexity and ways to represent it, and the role that plays on impacting quality improvement and decision making in medical education.

References

[1] Frenk J, Chen L, Bhutta Z., Cohen J., Crisp N., Evans T., et al. Health professionals for a new century: transforming education to strengthen health systems in an interdependent world. Lancet [Internet]. 2010 Dec 4 [cited 2014 Jan 12];376(9756):1923–58.doi:10.1016/S0140-6736(10)61854-5

[2] Cho N., Gilchrist C., Costain G.Rosenblum N., (2013). Incorporating Evidence-based Medicine in the Undergraduate Medical Curriculum: Early Exposure to a Journal Club may be a Viable Solution, 88(3), 154–155. Available from: http://utmj.org/utmjupload/journals/2/articles/1344/public/1344-1938-1-PB.pdf

[3] Gathright M.M., Thrush C., Jarvis R., Hicks E., Cargile C., Clardy J., O'Sullivan, P. (2009). Identifying areas for curricular program improvement based on perceptions of skills, competencies, and performance. Academic psychiatry: the journal of the American Association of Directors of Psychiatric Residency Training and the Association for Academic Psychiatry, 33(1), 37–42. doi:10.1176/appi.ap.33.1.37

[4] Hege I., Nowak D., Kolb S., Fischer M.R., Radon K. (2010). Developing and analyzing a curriculum map in occupational- and environmental medicine. BMC medical education, 10, 60. doi:10.1186/1472-6920-10-60

[5] Steele J, Iliinsky N, editors. Beautiful visualization. Looking at data through the eyes of experts. O'Reilly Media; 2010. Chapter 10, Finding beautiful insights in the chaos of social network visualizations; p.157-73.

[6] Witten I., Frank E.H., Hall M.A. Data Mining. Practical machine learning tools and techniques. 3rd ed. Morgan Kaufmann series in data management systems; 2011. Chapter 9, Moving on: applications and beyond. p. 375-97.

[7] Keim D.A., Mansmann F., Thomas J., (2009). Visual Analytics: How Much Visualization and How Much Analytics?, 11(2), 5–8. Available from: http://www.hiit.fi/vakd09/vakdsi09keim_final.pdf

[8] Steed C.A., Goodall J.R., Potok T.E., Maness C., Patton R.M., Senter J. Interactive Visual Analysis of High Throughput Text Streams. 2012;1–4.Available from:http://research.microsoft.com/en-us/um/people/shliu/tasmc/paper/Interactive-Visual-Analysis.pdf

[9] Keim D.A., Mansmann F., StoffelA., Ziegler H. Visual analytics. Encyclopedia of Database Systems. Springer, 2009. 3341-3346.

[10] Olmos M, Corrin L. Academic analytics in a medical curriculum: Enabling educational excellence Academic analytics: A timely new field. 2012;28(1):1–15.Available from:http://www.leishman-associates.com.au/ascilite2011/downloads/papers/Olmos-full.pdf

[11] Swedish Higher Education Authority (English version), http://english.uk-ambetet.se

[12] Cytoscape, http://www.cytoscape.org/ (17.12.2013)

[13] Corrin, L. Olmos, M. (2010). Capturing clinical experiences: Supporting medical education through the implementation of an online Clinical Log. In Steel C. H., Keppell M.J., Gerbic P., Housego S.(Eds.) Curriculum ,technology& transformation for an unknown future. Proceedings ascilite Sydney 2010 (pp.231-235). Available from: http://ascilite.org.au/conferences/sydney10/procs/Corrin-concise.pdf.

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Globalising Health Informatics: The Role of GIScience

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Abstract. Health systems globally are undergoing significant changes. New systems are emerging in developing countries where there were previously limited healthcare options, existing systems in emerging and developed economies are under significant resource pressures and population dynamics are creating significant pressures for change. As health systems expand and intensify, information quality and timeliness will be central to their sustainability and continuity. Information collection and transfer across diverse systems and international borders already presents a significant challenge for health system operations and logistics. Geographic information science (giscience) has the potential to support and enhance health informatics in the coming decades as health information transfers become increasingly important. In this article we propose a spatially enabled approach to support and increasingly globalised health informatics environment. In a world where populations are ageing and urbanising and health systems are linked to economic and social policy shifts, knowing where patients, diseases, health care workers and facilities are located becomes central to those systems operational capacities. In this globalising environment, health informatics needs to be spatially enabled informatics.

Keywords. Gobal, ageing, modelling, giscience, spatial, visualisation

Introduction

The developing economies of Asia, South America and, to a lesser extent, Africa are all seeing significant changes to their established health care systems. These changes include the emergence of rapidly expanding public and private healthcare systems, medical insurance schemes, long term care systems and a massive expansion in aged care as well as skilled migration internally and internationally. Population ageing is driving major changes in the healthcare systems of the developed world and in many emerging economies because it is increasingly a global demographic trend [1]. This means that health information systems are in a phase of expansion, diversification and interconnection [2]. The globalisation of health information systems has important implications for the quality, safety and effectiveness of health services in this dynamic and rapidly changing environment.

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In this paper we briefly explore how the integration of spatial concepts, methods and technologies has the capacity to enhance and support a globalising health informatics paradigm. The broad interdisciplinary field of the spatial sciences is highly information focused. A major issue for those sciences over the past few decades has been the issue of revising and integrating their information paradigms as the context of their theories and practices became increasingly interconnected and internationalised. This form of globalisation has had a significant impact on the way in which important information management concepts and practices have developed. Firstly, data collection is increasingly collected with geospatial indexing attached (georeferencing) which contextualises that data at both a local (collection site) and a global level (e.g. latitude, longitude and altitude). Secondly, significant metadata issues have undergone a process of inquiry, revision and restructuring in order to ensure that data interchange practices facilitate this local to global transformation and to support the complex research issues we are dealing with at a local-global level (e.g. climate change phenomena). Thirdly, the type and variety of user interfaces has expanded enormously and in ways that increasingly permit non-expert use and application of georeferenced data (e.g. Google Maps and Google Earth). Lastly, this drive towards a broadly accessible spatial informatics paradigm is producing its own innovation drivers that increasingly seek to connect those older data paradigms with these new theories and methods [3].

1. Methods

The scenarios presented here are case studies developed by the authors as part of their research programmes in the fields of spatial science and health informatics. They only illustrate the potential of the premise we are exploring – that is, the integration of a giscience perspective to a globalising health informatics environment. As such they are developmental studies and not the endpoints of a defined or funded research programme.

In the first instance we applied this kind of approach to Australia where population ageing is seen as a presenting a major challenge to the way health and social care systems are currently designed, funded and managed. A major concern of many observers of this process is the likely impact that age-related cognitive impairments will have on those systems as population ageing progresses and if current epidemiological patterns of ageing persist. Currently there are no population-level studies of the dementias or Alzheimer's disease in Australia, an affluent country with a developed economy and significant investments in national and sub-national health information systems [4]. Yet it is already clear from Census and related analyses that the impact of population ageing in Australia is likely to vary significantly by time and location, with some states experiencing ageing sooner and at higher rates than others.

The second example, arising from our experiences with the first, is predicated on what can this application of giscience do for environments in which even national-level data sources are limited – if indeed any such resources even exist? And where health information systems themselves are also extremely finite as well as other issues confront treatment and care, such as a lack of health infrastructure and resources to address age-related issues directly. In this case, we chose Africa as a continental-level scenario where older people confront may health and social support issues and where societal and economic changes. The focus on infectious diseases along with poverty,

conflict and development issues has limited the attention given to population ageing in much of the health research conducted in African countries [5]. Yet even as Africa's estimated population rises to double its current level by the year 2050, growth in cohorts of older people will expand at equal or greater rates [6].

In this scenario, we took a population estimation model for the continent of Africa and applied estimates of dementia prevalence for the whole continent from Alzheimer's Disease International. The prevalence data was sub-divided for the continent by World Health Organisation region to take into account those areas most affected by factors such as HIV/Aids and life expectancy variations [7]. The application of the regionalised prevalence rates, by age cohort, to the population data have us an estimation of *likely* prevalence for the whole continent. This model was then driven down to the sub-national level to include the major administrative geography for each country (states/provinces). Finally, we graphed the resulting data in GE Grapher to produce a Keyhole Markup Language (KML) file that could be opened by anyone with access to Google Earth™.

2. Results

The results for the continent of Africa show how spatial methods can expand on existing knowledge and visualise the results at varying scales. In a situation where we currently have very little reliable scientific data and even censuses can be problematic, this provides us with an enhanced understanding of what patterns *may* be prevalent at the both the continental, national and sub-national level concurrently. The process of taking a consistent population data set, combining it with current epidemiological understanding and geographic methods builds our understanding of what may be occurring at different scales across Africa. Even if the results are subsequently shown to be wrong, especially as new and better data becomes available, the spatial scientific paradigm informs questions about what is happening where and what we might expect to see when better data is finally produced.

The results for Australia follow a similar pattern in that while available data for population as well as dementia prevalence and incidence are much better than for most African countries, the prevalence data for dementia and sub-types are still basically estimates because no population-level research studies exist. The added dimension of spatial visualisation contributes to our understanding of what potential impact population ageing and dementia are likely to be having on local communities including those in rural and remote regions where specialist service access and provision can vary considerably to those available in urban areas.

The logic of this approach includes providing the capacity for various types of health information (e.g. prevalence and/or incidence data for chronic conditions) to be accessed in a highly visual, multi-scalar environment. Like conventional maps, KML files permit the representation of data about multiple entities in spatial relation to each other. Added benefits are that (1) we can utilise the 'what-if' characteristics of modelling temporal prevalence data against existing healthcare facilities to explore the implications for the future and (2) better understand the dynamic relationships that may exist between data sets of varying quality (e.g. prevalence estimates versus incidence data).

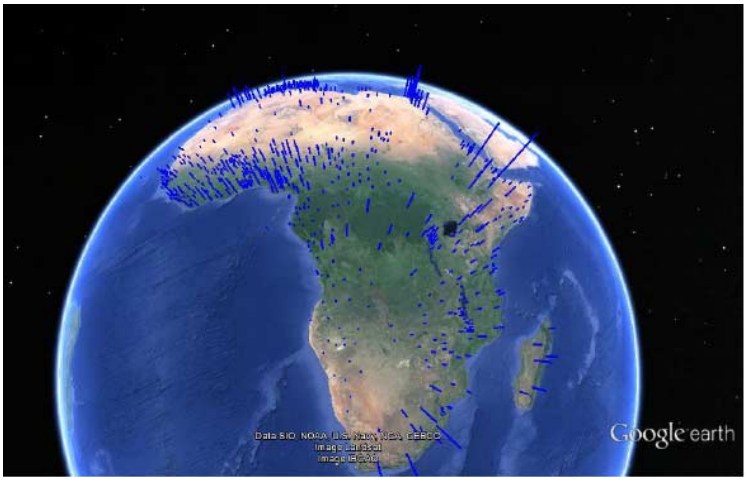


Figure 1. Alzheimer's Disease in Africa

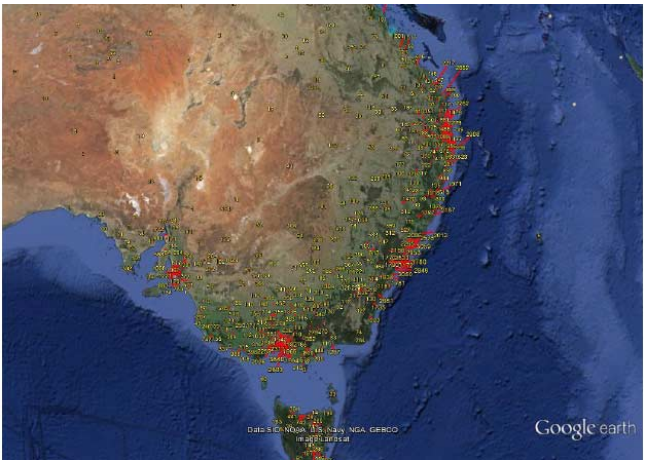


Figure 2. Dementia in Australia

3. Discussion

This paper illustrates two important aspects of the role of giscience for the wider, global health informatics environment. Firstly, we can take data known at one order of scale, such as the nation-state, and apply that to a larger scale (i.e. finer geographic detail) in order to explore and examine what we might expect to be happening at much more local levels – even when data is currently lacking, poorly collected or presently not integrated. Secondly, we can use known health information where data quantity and quality are high to help us model environments where data quantity and quality remain low. Thus, applying projected scenarios of disease expression or time-dependent incidence to explore what we would expect to see if our data systems were at the standard necessary for informed interventions, since a key aspect of the role of health

informatics is not only to track what is currently happening but to provide a supporting evidence base for various interventions in complex health environments.

We have briefly examined the potential contribution that giscience offers to the field of health informatics. More specifically our focus is on the advantages of adding giscience concepts, methods and technologies to a globalizing health information environment. Our position is that giscience has already been through many of the changes necessary to make the various spatial sciences able to actively engage with each other and to develop a future spatial environment in which local, national, cultural and semantic/linguistic issues are adequately incorporated into a genuinely global giscience environment. Health informatics is at the beginning this change process and has yet to become spatially integrated. The convergence of many information science approaches in an age of 'big data' offers an opportunity to address these outstanding issues. The outcome of this unfolding process will, we believe, lead to a genuinely *spatial* health informatics paradigm. Given the rising complexity of health systems globally and their multiple scales of interaction, it is our contention that health informatics needs to be spatial in order to meet these emerging challenges.

References

[1] UNFPA. Ageing in the Twenty-First Century: A Celebration and A Challenge. New York and London. United Nations Population Fund (UNFPA) and HelpAge International; 2012

[2] Adebesin F, Foster R, Kotze P, van Greunen D. A review of interoperability standards in e-Health and imperatives for their adoption in Africa. S Afr Comp J. 2013; 50:55-72

[3] Richardson D. Real-time space-time integration in GIScience and geography. Ann Assoc Am Geogr. 2013; 103:1062–1071

[4] AIHW. Dementia in Australia. Canberra. Australian Institute of Health and Welfare. 2012; Cat no. AGE 70.

[5] Mavrodaris A, Powell J, Thorogood M. Prevalences of dementia and cognitive impairment among older people in sub-Saharan Africa: a systematic review. Bull World Health Organ. 91. 2013;10:773-83.

[6] Pillay NK, Maharaj P, Population Ageing in Africa. In P. Maharaj (ed). Aging and Health in Africa: International Perspectives on Aging. 2013. New York. Springer.

[7] World Health Organization. Atlas of Health Statistics of the African Region. 2011. Regional Office for Africa

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Spatio-temporal information and knowledge representation of disease incidence and respective intervention strategies

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Abstract. The supplementation of medical data with environmental data offers rich new insights that can improve decision-making within health systems and the healthcare profession. In this study, we simulate disease incidence for various scenarios using a mathematical model. We subsequently visualise the infectious disease spread in human populations over time and geographies. We demonstrate this for malaria, which is one of the top three causes of mortality for children under the age of 5 years in sub-Saharan Africa, and its associated interventions within Kenya. We demonstrate how information can be collected, analysed, and presented in new ways to inform key decision makers in understanding the prevalence of disease and the response to interventions.

Keywords. Healthcare and health systems, visualisation, mathematical modelling

Introduction

The ability to predict outcomes of healthcare programs and interventions can help guide policies and allocate resources; all the while improving population health outcomes. A major challenge, however, is the availability of accurate healthcare and disease incidence data, with spatio-temporal attributes, to make such predictions. For example, despite the availability of effective intervention strategies, malaria, pneumonia and diarrhoeal disease continue to be the top three causes of mortality for children under 5 years of age in Africa [1]. Data from mathematical models and simulations greatly assist in understanding the transmission dynamics and spread of the diseases representing the top causes of childhood mortality. Integrating the effects of public health interventions into the mathematical models further enhances the insights provided by these data. The development of intuitive visualisations then allows the information and knowledge to be visualised in ways that provide meaningful insight. As examples, 3D visualisations have been used in epidemiology to clearly represent

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and understand complex data from genetics and population analyses [2], environmental epidemiology [3], and generally rendering spatio-temporal data in geographic context [4].

In this study, we develop a visualisation portal, which displays selected and mathematically simulated data sources of disease burden, as well as the potential impact of available and relevant interventions. To demonstrate a proof-of-concept, we generated exemplary disease outbreak simulations for malaria incidence and intervention strategies within Kenya.

1. Methods

The underlying technology of this framework comprises a data storage and analysis component. The framework is designed to create a unified data view and implement a number of adapters that enables inputs from various data sources, including epidemiological simulations, GIS systems, and associated metadata. By further augmenting the input data with information representing other entities, such as points of interest (i.e. healthcare clinics, pharmacies etc.), we can obtain a deeper insight into the disease and appropriate resources available to the different regions. The visualisation portal facilitates relevant bodies with the ability to obtain and visualise data within the system. The portal provides a geospatial 3D environment enabling the user to view information from a country, region, sub-county, town to even house level overview, both spatially and temporally. The appropriate zoom level will depend on the resolution and relevance of data provided to the system.

1.1. Predictive analytics simulations of healthcare interventions

For the purposes of our study, we generated exemplary simulation data representing malaria transmission in Kenya. For this, we used the Spatiotemporal Epidemiological Modeler (STEM) [5], an open source application to model and simulate infectious disease spread in a population. We simulated four different malaria scenarios, a baseline and those demonstrating common public health interventions for malaria – distributing insecticide treated bed nets (ITN), residual indoor insecticide spraying (IRS), and one that combines both interventions. Each scenario was simulated for the entirety of Kenya at sub-county resolution on one-day intervals for one year. For each sub-county, the simulation calculated the vector burden (mosquito population), disease incidence, and disease states (susceptible, exposed, infectious, and recovered) for the human and mosquito populations. As malaria is endemic to Kenya and simulations quickly reach a steady state for much of the country, we chose to limit our simulated interventions to four sub-counties in Vihiga County, Western Province, Kenya. This region was chosen due to its higher elevation and tendency to display epidemic, not endemic, malaria characteristics in our base model. This would highlight how the framework could be used to predict disease outbreaks, where the population within the regions would less likely have the same levels of acquired-immunity compared with those living within the endemic regions.

To simulate the effects of our interventions, we applied changes to the underlying disease and population models at fixed intervals. To simulate the effects of the distribution of ITNs we lowered the effective mosquito bite rate by 50% after day twenty of the simulation. For IRS, the vector population was decreased by 10%. The

modulation of biting rate and vector population is intended to mirror the relative risk reduction of using ITNs and IRS [6]. The malaria disease model used to simulate disease transmission by region takes into account earth science and environmental data sources including temperature, elevation, precipitation, and vegetation coverage [7, 8]. Additional model parameters were derived from literature [7]. We performed several changes to the original model, denominator data, and STEM software to make the simulation for Kenya and the integration of intervention scenarios feasible.

1.2. Visualisation and Interaction

A geospatial 3D environment utilising a combination of D3 [9] and Cesium [10] is used to visualise the data and simulation results from a sub-county, to town to even house level. Simulation data is fed directly into the visualisation portal via a JSON data logger in the simulation engine. Depending on the selected interventions, data from a cached file is retrieved from the system, transformed, and displayed. We use Cesium's JavaScript application programming interface (API) to create the interactive 3D environment and present geographic data and simulation results spatially and temporally. The 3D environment provides a more interactive navigation experience as well as an additional dimension on which to represent data versus a 2D canvas. Geographic features can include national, county, and sub-county borders, county and sub-county names, points of interest etc. Simulation results are displayed by shading the individual sub-county polygons based on the estimated relative infectiousness of the disease for that region at the current time. The relative scale of both human (yellow bars) and mosquito (blue bar) populations for each sub-county is also drawn. Cesium also provides time and animation control APIs, allowing a user to navigate the 3D environment, play/pause/step the simulation animation, and clearly see the spatial and temporal impact on disease burden by changes to polygon shading. We use the D3 API to create an interactive time series plot to compare simulation results. By selecting a sub-county on the map, users can both view disease impact over time and compare the impact of intervention strategies. A menu of options (blue arrows) represents different classes of selectable interventions.

2. Results & Discussion

The simulation results of two different scenarios for malaria incidence in Sabatia sub-county, Vihiga County, Kenya are shown. The first (Figure 1) is our base model with no intervention applied. In this scenario, we see peak periods of malaria incidence, represented by deeper shades of red. In Vihiga County, climate conditions do not favour insect vector larval development throughout the year [11]. As a consequence, malarial transmission in these regions does not exhibit steady state dynamics. It is worth noting the incidence levels displayed do not necessarily represent the true disease incidence in Kenya, where intervention programs have been successfully implemented in some regions. Rather these data provide a baseline for comparing the effect of different intervention strategies using our mathematical models.

When we adjust model parameters to simulate distribution of ITNs and IRS (Figure 2), our data suggests a reduction of disease infectiousness from 18% to 5% at the initial peak after 90 days. This can be seen in the inset time series chart, where the bold red line indicates the infectious rate under the combined intervention strategy and

the thinner red lines top downwards indicate, respectively, the baseline and a single intervention strategy distributing ITNs only. The inset time series chart also shows a reduction in vector population size (bold blue line) relative to the baseline and ITN-only scenarios (thin blue line), reflecting the model parameter modifications relevant to insecticide spraying.

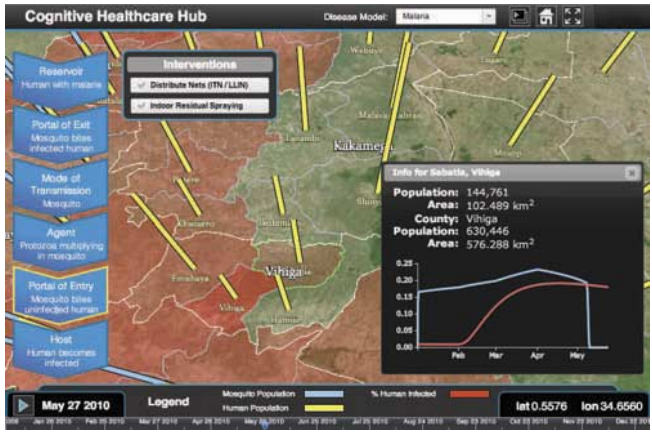


Figure 1. Screenshots of the visualisation portal at malaria simulation day 146 for the Sabatia sub-county. The yellow and blue bars on the map represent human and mosquito populations, respectively. The disease state with no interventions is shown. The inset graph (right) indicates predicted mosquito population size (blue line) and percentage of infectious humans (red line) through time. The blue chevron menu (left) shows the chain of causation for the simulated disease (malaria) and allows selection of intervention simulations for visualisation.

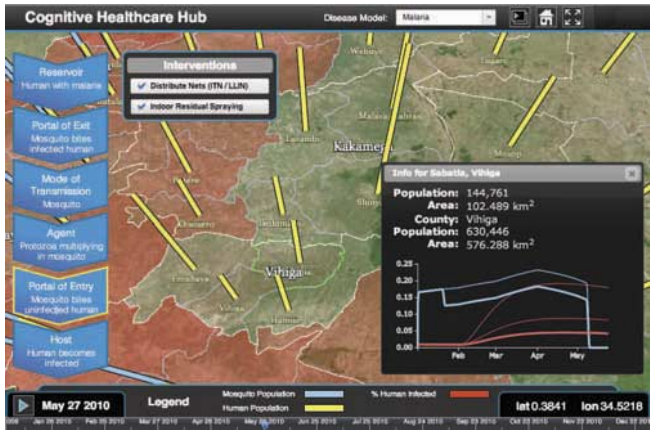


Figure 2. Screenshot of the visualisation portal at malaria simulation day 146 for the Sabatia sub-county as in Figure 1. The disease state with both intervention strategies applied is shown. The inset graph indicates predicted mosquito population size with (thick blue line) and without (thin blue line) intervention application. Predicted percentage of infectious humans is also shown; without intervention (upper thin red line); with net distribution only (lower thin red line); with both net distribution and indoor residual spraying (thick red line).

Thus, we can see that the visual representation of simulated data described here, can provide clear insight, by way of information and knowledge, to the potential impact

of intervention strategies, and allows comparison of the long and short-term efficacy of strategies within and/or between geographical regions.

The final observation is in comparing malaria incidence for all of Vihiga County relative to adjacent regions in the Western Province using the map and relative to non-intervention scenarios in the time series chart. The effectiveness of the intervention strategies targeted to a specific region becomes apparent due to the marked decrease in the shading brightness. While this geospatial representation of simulation data may have limited quantitative value, it can help quickly identify and understand at-risk regions and to design and test effective intervention strategies.

3. Conclusion

We demonstrate the use of mathematical simulations and advanced visualisation techniques for investigation of malaria disease incidence and intervention strategies in Kenya. Such visualisation allows more intuitive access to information and knowledge essential for those interested in understanding transmission dynamics or planning disease control strategies. Future versions could also link directly to the simulation engine, allowing scientists to modify rate parameters real time to the simulation and actively test alternate hypotheses. Such comparisons will greatly inform public health policy-makers to improve health population-wide.

References

[1] World Health Organization, Health Statistics and Informatics Department. Summary: Deaths by cause, in WHO Regions, estimates for 2008, 2011.
[2] Loh AM, Wiltshire S, Emery J, Carter KW, Palmer LJ, Celestial 3D: a novel method for 3D visualization of familial data, Bioinformatics 2008, 4(9):1210-1211.
[3] Meliker JR, Slotnick MJ, AvRuskin GA, Kaufmann A, Jacquez GM, Nriagu JO, Improving exposure assessment in environmental epidemiology: Application of spatio-temporal visualization tools, Journal of Geographic Systems, 2005, 7:49-66.
[4] AvRuskin GA, Jacquez GM, Meliker JR, Slotnick MJ, Kaufmann AM, Nriagu JO. Visualization and exploratory analysis of epidemiologic data using novel space time information system, International Journal of Health Geopgraphics, 2004, 3:26.
[5] STEM [Internet]. 2014. Available from: http://www.eclipse.org/stem
[6] Lim SS, Fullman N, Stokes A, Ravishankar N, Masiye F, et al., (2011) Net Benefits: A Multicountry Analysis of Observational Data Examining Associations between Insecticide-Treated Mosquito Nets and Health Outcomes, PLoS Med, 8(9): e1001091.
[7] Edlund S, Davis M, Douglas JV, Kershenbaum A, Waraporn N, Lessler J, Kaufman JH, A global model of malaria climate sensitivity: comparing malaria response to historic climate data based on simulation and officially reported malaria incidence, Malaria Journal, 2012, 11:331.
[8] G. Macdonald. The Epidemiology and Control of Malaria, Oxford University Press, London, 1957.
[9] Bostock, M. D3, Data Driven Documents [Internet]. 2014. Available from: http://d3js.org/
[10] Cesium [Internet]. 2014. Available from: http://cesiumjs.org/
[11] Anderson RM, May RM, Anderson B, Infectious Diseases of Humans: Dynamics and Control. New York. Oxford Science, New York, 1991.

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Novel Algorithms for Improved Pattern Recognition Using the US FDA Adverse Event Network Analyzer

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Abstract. The medical review of adverse event reports for medical products requires the processing of "big data" stored in spontaneous reporting systems, such as the US Vaccine Adverse Event Reporting System (VAERS). VAERS data are not well suited to traditional statistical analyses so we developed the FDA Adverse Event Network Analyzer (AENA) and three novel network analysis approaches to extract information from these data. Our new approaches include a weighting scheme based on co-occurring triplets in reports, a visualization layout inspired by the islands algorithm, and a network growth methodology for the detection of outliers. We explored and verified these approaches by analysing the historical signal of Intussusception (IS) after the administration of RotaShield vaccine (RV) in 1999. We believe that our study supports the use of AENA for pattern recognition in medical product safety and other clinical data.

Keywords. Network Analysis, Safety Surveillance, Pattern Recognition, Big Data.

Introduction

The Vaccine Adverse Event Reporting System (VAERS) is the repository of adverse events (AEs) reported following immunizations by health care providers, vaccine recipients, and other interested parties [1]. Specialized personnel assign AE codes from the Medical Dictionary for Regulatory Activities (MedDRA) to each report to represent the key medical information included in the narratives. Medical experts at the US Food and Drug Administration (FDA) review VAERS reports by following two approaches. They use statistical data mining algorithms (DMAs) to assess whether an AE is reported disproportionately for one product compared to others [2]. They also conduct manual review of reports to identify unusual patterns in demographics, exposures, medical history, and clinical characteristics that might suggest a safety issue.

The current process has two main limitations: DMAs do not evaluate the interactions among co-administered vaccines and multiple AEs in the VAERS database, and manual review is time intensive and the consistency of human pattern recognition is unknown. Previously, we proposed representing VAERS as a network of AEs and

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vaccines to expose their interactions [3]. We developed the Adverse Event Network Analyzer (AENA) because the existing network tools cannot handle our 3-mode data (reports, vaccines, AEs) that must be presented in a dynamic environment. AENA incorporates the traditional network analysis techniques as well as some new functionalities and algorithms. Here, we mainly focus on the novel network analysis aspects of AENA through a particular example of a safety surveillance signal.

1. Methods

1.1. Novel Network Analysis Algorithmic Approaches

The medical experts at the FDA run ad-hoc queries on the VAERS database to select the reports of interest and launch AENA. AENA supports the creation of 1- and 2-mode networks by treating the vaccines and AEs as the same or different type of objects, respectively; the 1-mode network is created at the initial launch of the tool. As we have previously shown, the report elements (vaccines and AEs) and their co-occurrence in the same report(s) are best represented as the nodes and edges, respectively, in a network [3, 4]. The edges are initially weighted based on the number of reports in which two elements co-occur. The weighted networks support the application of our novel algorithms and facilitate the identification of clusters and safety patterns. Pattern identification often involves "reducing" a network by systematically eliminating "noisy" nodes and edges. AENA uses several approaches to network reduction, including those based on traditional measures of node connectivity, as well as novel alternative edge weighting, outlier detection based on a preferential attachment model of network formation, and application of the "islands" algorithm.

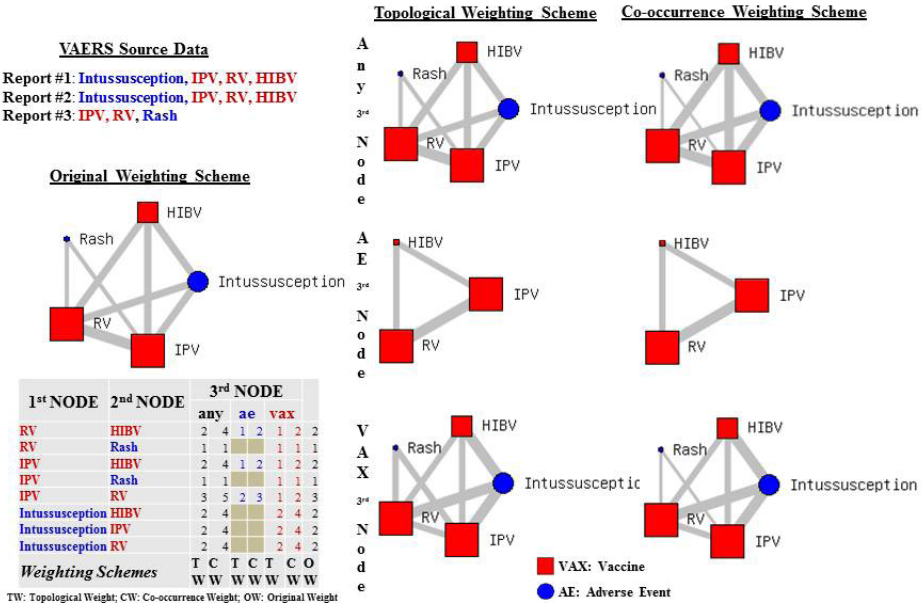


Figure 1. Three edge weighting schemes (original, topological, co-occurrence) on three types of networks (any pairing, only AE pairings, only vaccine pairings) in AENA.

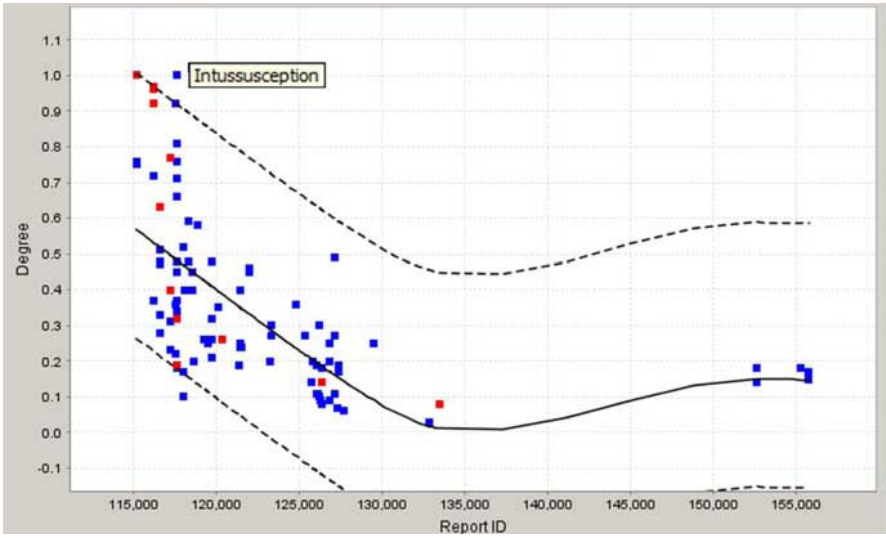


Figure 2. The nodes above the upper band are related to the 1999 signal of Intussusception.

Apart from the report-based weighting (RW), AENA supports two more weighting schemes. The first is supported by an algorithm that looks at each edge and counts the triangles in which the edge is included (topological weighting - TW). For the same edge, the second scheme focuses on the report level and counts all the report triplets in which the corresponding pair participates (co-occurrence weighting - CW). Either scheme returns three types of weights based on whether the "third node" in the triangle is a vaccine, an AE, or either. The new weights may potentially change the network topology, e.g. "RV" and "Rash" participate in one topological or co-occurrence triangle only, so their edge disappears in either case when the "third node" is an AE (Figure 1).

An additional novel functionality allows the identification of nodes with extreme attributes. The "Tolerance Band View" (TBV) was based on the idea of looking at the VAERS network growth over time [5] and displays a scatterplot of vaccines and AEs (Figure 2). The x-axis represents report ID; nodes receive an x-value based on the first report ID in which they appear. The x-value is a proxy for the time at which the node first appears in the network because IDs are assigned sequentially. It is important to account for time of appearance, because earlier appearing nodes have greater chance of connecting with other nodes, and are more likely to have higher connectivity as measured by network metrics (e.g., node degree). The y-axis represents the node metric score (degree, Figure 2) and nodes receive a y-value based on their metric value within the entire network.

AENA can visualize the networks using multiple layouts: the force-directed, circle, self-organizing map, and principal components layouts. It is also equipped with a novel layout option inspired by the "islands algorithm" and calculates an island height for the nodes based on their edge weights and their connections to other nodes [6]. Our islands layout places the two most strongly connected nodes at the very top of the visualization, and arranges all other nodes beneath according to their strength of connection with other nodes (i.e., island height). When two nodes are tightly connected to each other, they will appear at the same horizontal level (Figure 3). This layout also supports the selection of "network slices" to include nodes located at the same level(s).

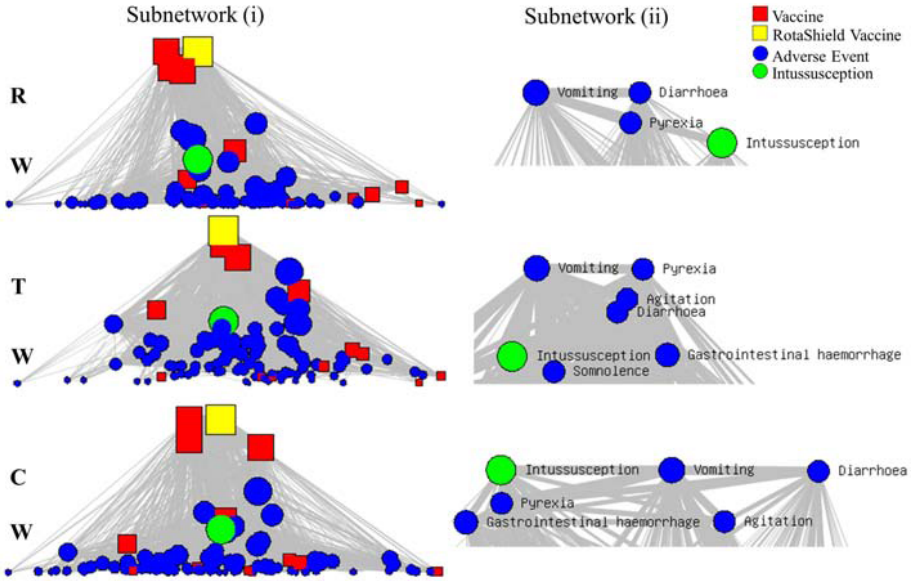


Figure 3. The representation of the IS signal in subnetworks (i) and (ii); the islands layout is used here. RW: Report-based Weighting; TW: Topological Weighting; CW: Co-occurrence Weighting.

In addition to the above novel algorithmic approaches, AeNA supports common NA techniques, such as the node and edge removal, the calculation of node centrality metrics and the network export to an edge list or Pajek format for further analysis.

1.2. Analysis of RotaShield Reports

We explored the known signal of intussusception (IS) that followed the administration of RotaShield Vaccine (RV) in 1999 [7]. We created the network in AENA using all the RV reports submitted to VAERS from the licensure to the withdrawal date of RV. The edges were initially weighted based on the number of reports a pair of elements co-occurred (i.e., RW network). We also applied our topological and co-occurrence triangular weighting scheme by defining the AE as the "third node" of the triangle and assigned the new weights to the edges (i.e., TW and CW network, respectively). To evaluate the AENA's ability to identify the pattern, we applied two reduction steps to all networks: (i) we selected the "IS" nodes and nodes directly connected to IS, and created the corresponding subnetwork; (ii) we created a subnetwork of AE nodes. We then ran the TBV for subnetworks (i) and identified the nodes above the upper tolerance band. We visually evaluated the differences between the RW, TW and CW subnetworks (ii) using the island layout.

2. Results

The TBV for the subnetworks (i) was the same, irrespective of the weighting scheme used when degree, betweenness or closeness metrics of network connectivity were selected. Intussusception was the only node that fell outside the confidence bounds for degree centrality for high parameters values (Figure 2). The visualizations of the three

subnetworks (i) (Figure 3) showed that RV and IS did appear in the same reports (they were both on the same vertical axis). However, the visualizations were dominated by the vaccine elements and the IS pattern was noisy. The subsequent creation of the AE networks removed the noise and revealed the presence of IS and other gastrointestinal AEs. Figure 3 shows subnetworks (i) and (ii) for the 3 schemes; the top layers of the island layout are shown for the subnetworks (ii). Our novel CW scheme best supported the pattern identification by placing the IS on the top of the topology, whereas RW and TW schemes hid its significant role by assigning more island height to other AEs.

3. Discussion

This study demonstrates the potential use of AENA for the pattern identification in safety surveillance data. We used the example of a known historical signal to explore the multiple interactions between the elements of reports and fill the gap of the existing DMAs. Guided by our previous studies in the area [3-5], we pursued the calculation of CWs that look at the triangular clusters formed at the report level and assign more value to the pairwise connections that participate in many triangles. This is of value when the triangles are related to a pattern in the full set of reports. The use of any AE as the "third node" assisted us in focusing on the AE patterns. Our approach performed best when compared to the traditional RW and TW schemes. This was nicely illustrated by the islands layout that incorporates various topological and weighting parameters.

Our study has certain limitations. First, we did not perform an exhaustive analysis of patterns with different characteristics and it is not possible to draw firm conclusions for the generalizability of our work. Second, we did not conduct a statistical analysis of the results, but visually compared the network representations. Third, we explored the novel functionalities of the tool only, while other options are available.

To our knowledge, this is the first network analysis tool developed for safety surveillance (or any medical) purposes. The edge weighting based on the information that is included at the document level has not been presented before. Future research should focus on the contribution of such weighting to the creation of document-based networks and their application to spontaneous reporting systems for safety surveillance.

References

[1] F. Varricchio, J. Iskander, F. Destefano, et al. Understanding vaccine safety information from the vaccine adverse event reporting system, *The Pediatric Infectious Disease Journal*, **23** (2004), 287-294.

[2] W.P. Stephenson, M. Hauben. Data mining for signals in spontaneous reporting databases: proceed with caution, *Pharmacoepidemiology and Drug Safety*, **16** (2007), 359-365.

[3] R. Ball, T. Botsis. Can network analysis improve pattern recognition among adverse events following immunization reported to VAERS? *Clinical Pharmacology & Therapeutics*, **90(2)** (2011), 271-278.

[4] T. Botsis, R. Ball. Network analysis of possible anaphylaxis cases reported to the US Vaccine Adverse Event Reporting System after H1N1 influenza vaccine, *Studies in Health Technology and Informatics*, **169** (2011), 564-568.

[5] J. Scott, T. Botsis, R. Ball. Simulating adverse event spontaneous reporting systems as preferential attachment networks: Application to the Vaccine Adverse Event Reporting System. *Applied Clinical Informatics* **5(1)** (2014), 206-218.

[6] V. Batagelj, M. Zaversnik, Islands, COSIN Meeting at the University of Karlsruhe, 2004.

[7] P. Haber, R.T. Chen, L.R. Zanardi, G.T. Mootrey, R. English, M.M. Braun, VAERS Working Group. An analysis of rotavirus vaccine reports to the vaccine adverse event reporting system: more than intussusception alone? *Pediatrics* **113** (2004), e353–e359.

14. Posters A

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Analysis of Forum Posts Written by Patients and Health Professionals

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Keywords. Text categorization, text mining, online health fora.

Introduction

For information retrieval purposes, it may be interesting to categorize posts produced by patients and those produced by health professionals on online health fora.

In this work, we evaluated a supervised approach based on n-grams (vocabulary), emotion markers, uncertainty markers and misspellings to distinguish the two categories of posts on the French health forum AlloDocteurs.fr[1].

1. Methods

First, external resources were used to annotate medical words, emotion markers and uncertainty markers on two cleaned corpus which where balanced between the two roles: a train corpus of 4000 posts and a test corpus of 450 posts. Then, a linguistic preprocessing step was applied to replace slangs, users' tags, emails, hypertext links, etc. and to correct and count misspellings. Finally, a feature selection step was applied to select the most discriminant n-grams.

2. Results

Different combinations of the following features: uni-grams, bi-grams, emotions, uncertainty markers and misspellings have been tested with four data mining algorithms (SVM SMO, RandomForest, NaïveBayes and JRip) to distinguish the two categories of posts.

3. Discussion

The results obtained by uni-grams and bi-grams have shown very high F-scores (up to 0.94), while the results obtained by considering only emotions, uncertainty markers and misspellings have shown low F-scores (from 0.52 to 0.76) comparing to chance (0.50). Finally, conducted experiments by grouping all the features have slightly improved the classification performance (F-scores up to 0.95).

1. www.allodocteurs.fr/forum-rubrique.asp [data collected on: 19-11-2013]

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A Randomized Online Health Experiment for a Safer Youth Sexual Behaviour

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Keywords. Gamification, Sexual health

Introduction

Gamification websites and apps are considered a good way to promote a safer sexual life. This abstract presents the study and the prototype of a novel game-based appointment system in www.sjekkdeg.no, an educative Norwegian gamified web app focused on sexual health, which had 3670 of visitors in 2013.

1. Methods

The online booking system is investigated from August 2014 – July 2015 in a pilot trial at a university venereology clinic. Half of the users will have access to the online booking system functionality (Group A), while there will be no access to this functionality to the other users (Group B). The use of each functionality by both groups of users (A/B) is tracked trough web analytics tools implemented to perform the study.

2. Results

The whole system, adapted to both, desktop and mobile technologies will be ready in August 2014. Data on the average time on site, and in every educative component, as well as the number of bookings using the online appointment system, will be assessed (A vs B), through the web analytics tools after one year.

3. Discussion

The A/B testing methodology will help to know if a game-based appointment system can facilitate the access to health services for youth, in sensitive topics, and in general; and it also will help to analyze its potential impact on clinical service settings.

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Play as a prevention strategy: Using a web app to teach youth about STDs

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Keywords. Gamification, Sexual health, STDs, Apps

Introduction

Chlamydia is the most common sexually transmitted disease (STD) in Norway; and 85,7% of reported chlamydia cases are found in persons below 29 years of age.

1. Methods

The web app sjekkdeg.no aims at providing information for Norwegian secondary school students about the prevention of STDs. The development of the app was based on a constructivist learning theory using text, multimedia, and interactive game-like applications. We examined the use of the various sections of the web app by Google Analytics statistics. The web app was also evaluated by students using questionnaires and by interviewing nurses engaged in teaching secondary school students.

2. Results

The web app had 3670 visits (35% returning visitors) in 2013, with a mean of 20.6 pages/visit. 1140 users reached the web app by Facebook ads. Students and nurses appreciated the game-like interactive sections of the web app. The most visited section was an interactive program for disease symptoms.

3. Discussion

The interactive game-like sections of the app were frequently used. After the evaluation the teaching nurses continued to use the web app in their regular educative work. The combination of a web app and Facebook ads seems to be a promising way to encourage Norwegian youth to learn about the prevention of STDs.

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Instructional Video Reduces Errors in Home Blood Pressure Management

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Keywords: blood pressure, blood pressure measurement, patient education, video instruction.

Introduction

Detection of hypertension is traditionally a matter for the general practitioner, but an alternative detection scheme is home blood pressure measurement (HBPM) by patients. This is a pilot assessment of how an instructional video showing how blood pressure can reduce errors and increase the validity of measurements.

1. Methods

We performed a randomised controlled trial with 24 subjects, comparing measurement accuracy (patients vs. nurses) and adherence to correct measurement technique. The intervention group used video for self-instruction and the control group used the written manual for the automated digital blood pressure measurement device. Each subject measured his or her blood pressure (BP) after the self-instruction, and adherence to correct technique was observed. A nurse measured the BP for accuracy determination.

2. Results

Accuracy of diastolic blood pressure was impaired in the control group. Adherence to correct measurement technique was higher in the intervention group, who made fewer errors than the control group.

3. Discussion

The present study underlines the importance of instruction method for patients before assigning them to HBPM.

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Using Machine Learning to Predict the Smoking Cessation Success Plan in Taiwan

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Keywords. Smoking cessation, Artificial neural network, Prediction model, Machine learning

Introduction

Tobacco use is a major public health issue all over the world. It is one of the main risk factors for amount of chronic diseases such as cancer, lung diseases, and cardiovascular diseases. The government implemented the "Outpatient Smoking Cessation Services (OSCS) program" since 2002 We intended to use machine learning to develop a prediction model which can be used in providing appropriate strategy on smoking cessation.

1. Methods

The data collected from January 2009 to December 2010 in two teaching hospitals in different districts in Taipei, Taiwan. We used data from one hospital as the training set, and the other hospital dataset for validation. We collected 18 input variables from quitters' demographic information, Fagerstrom Test for Nicotine Dependence (FTND) scores, medical history, medication, smoking status and whether they have had withdrawal symptoms. Three models (A, B, C) were designated based on the use of different input variables. Each model was fitted to the data using ANN and Logistic Regression (LR). .

2. Result

The overall smoking cessation success rate was 20.38%. The AUROC of ANN for the three models were 0.86, 0.83, 0.77 (model A, B, C) and the AUROC of LR for the three models were 0.85, 0.84, 0.70 (model A, B, C) respectively Both ANN and LR can predict smoking cessation with good accuracy with an AUROC ranging from 0.86 to 0.70. The performance of ANN was slightly better than LR without statistical significance. We believe that this prediction model can be used for better management of national-level smoking cessation program.

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Sex, Gender and Drugs – a tool for Gender-aware Drug Prescribing

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Keywords. Gender, sex, drugs, knowledge database

Introduction

Sex, and in some cases gender, can affect effects, adverse effects, and pharmacokinetics of drugs and needs to be considered when choosing drug and doses to a patient. The knowledge database Sex, gender and drugs provides Swedish prescribers and others access to sex- and gender related information on how drug treatment might be adjusted taking the patient's sex into account.

1. Methods

Special trained pharmacists perform literature searches and write short summary texts based on individual substances. The texts and facts undergo a careful review by senior clinical experts and the Expert Groups of the Drug and Therapeutic Committee in Stockholm County Council. The information is entered into a structured database.

2. Results

The knowledge database *Sex, gender and drugs* is presented on the web site www.janusinfo.se/genus, available for all health personnel in Sweden. In January 2014 there is information about approximately 50 substances, and more are about to come.

3. Discussion

As far as we know this is the first initiative to collect evidence based information on sex and gender aspects on drug treatment into a searchable tool. The database aims to support physicians to a gender-aware prescribing, resulting in a better and more individualized drug treatment for the patients.

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What Information about Cardiovascular Diseases do People Search Online?

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Keywords. Health Information Seeking, Search Log analysis, UMLS Metamap

Introduction

In this work, we performed categorization of cardiovascular disease (CVD) related search queries into "consumer-oriented" health categories to study what health topics users search for CVD. This study provides useful insights for online health information seeking and information needs in chronic diseases and particularly in CVD.

1. Methods

We collected ten million CVD related anonymized search queries that direct users from Web search engines to the Mayo Clinic's consumer health information website. Using UMLS MetaMap, we semantically mapped the CVD queries to UMLS sematic types and concepts. Based on the semantic type/concepts, we developed a rule-based approach and categorized 94% of the 10 million queries into 17 health categories.

2. Results

Top health categories that users search for CVD are 'Vital Signs', 'Symptom', 'Treatment', 'Drugs and Medications', 'Diet' and 'Cause'. Many CVD search queries have reference to body parts (heart), medical devices (pacemaker), quantitative measures, temporal reference and age groups. Although CVD can be prevented with some lifestyle and diet changes, interestingly very few users search for 'Prevention'.

3. Discussion

This study identifies frequently searched health categories for CVD and demonstrates utility of UMLS MetaMap as well as UMLS semantic types/concepts for customized categorizations. This study extends our knowledge about online health information searching and provides useful insights for Web search engines and health websites.

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Enterprise Architecture-Continuing Educational Program

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Keywords. Enterprise architecture, continuing education, evaluation

Introduction

In Finland, IT Service Act 2011 requires public administration authorities, such as health care providers, to describe and design the overall architecture of their information systems by the end of 2011. Consequently, need for training Enterprise Architecture (EA) was identified and a continuing educational program (32 ECTS) was established. The program gives the students an in-depth understanding of EA to develop the service systems and informatics. The aim of this study is to explore the teaching and learning outcomes.

1. Methods

The evaluation method is a summative program evaluation, students' self-reflection and self-evaluation. The data of 15 subjects is analysed using a content analysis.

2. Results & Discussion

The feedback of participants has been positive. Particularly, the benefits of teamwork by university students and professionals of working life were highly appreciated.

The program accelerated the learning process. Especially, the program exercises effectively supported the goals important in IT Service Act activities of working life.
In social and health care, specialized knowledge and practical skills are needed to apply architecture principles in order to guide organizations for effective management of information systems. The first analysis suggest that the present continuing educational program can help in this challenge. *Funded by the European Union Social Fund (ESF)*

[1] Ritva Karjalainen-Jurvelin.

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PMIR: A Personal Medical Information Recommender[1]

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Introduction

Medicine is undergoing a revolution that is transforming the nature of healthcare from reactive to preventive. Major challenges in this revolution are the quality of information that can be found online and the difficulty for a patient to accurately judge the relevance of some information to his own case.

1. Method

The Personal Medical Information Recommender (PMIR), implemented as a module of the IndivoX PHR system, aims to improve the options that patients have to be informed in the internet about their disease and provide to them personalized recommendations.

2. Results and Discussion

The patient is able to use an advanced search engine to retrieve relevant, high quality information. The feedback presented to the patient considers the following databases to make the results of the query as personalized as possible: a) *Topics/Terms Database* which indexes all web documents that are being searched for relevant information. Those web documents are high quality web resources (web pages, pdfs, docs etc.) selected carefully by the appropriate experts. If no relevant document is retrieved by this database then the results from HONsearch are used instead. b) *Patient Preferences Database* which contains user preferences and rankings that are acquired as the patient browses the results presented to him. c) *Medical Conditions Database* which captures the medical conditions that the patient has in his PHR. d) *Rules Database* which includes rules that are used for filtering and ranking the results of the database and for automatic presenting recommendations to the patients. Those rules are being generated by a Data Mining Service by processing semantically annotated external documents.

To the best of our knowledge no other system providing medical information is able to be dynamically adapted and personalized in such a diverse environment.

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Usability Evaluation of a Cloud Computing Based Context-aware Healthcare System

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[c] School of Health Information Science, [d] School of Nursing, University of Victoria, BC, Canada

Keywords. Health care, Usability, Personal Health Records**,** Context-aware, Cloud-Computing

Introduction

The cloud computing based context-aware healthcare system includes three sub-systems: cloud service of health, network service of communication, and mobile healthcare. The system can provide many functions such as physiological measurement, life and style management for supporting young adult self-health management.

1. Methods

We built an usability questionnaire by reviewing literatures of the usability evaluation and the Health-ITUEM. It also has been tested and reached the threshold of reliability and content validity. There are 100 young adults participate the experiment.

2. Results

With regard to system usability, subjects consider the system is helpful for promoting the ability of self-health management. Subjects also considered the application of cloud computing and context-aware architecture to manage personal health is valuable and trustable.

3. Discussion

Results have shown that the subjects' attitude to the healthcare system is positive. We will expand populations to further study of the usability response of diverse age backgrounds on adoption of context-aware healthcare system in further studies.

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A Framework of Sharing Patient Profile Information among Medical Institutions

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Keywords. Patient profile, data sharing, electronic medical record

Introduction

The electronic medical record (EMR) system becomes popular in Japan. However, the exchange of digital patient data among the medical institutions is still rather limited.

1. Methods

Since most EMR systems in Japan have some kinds of patient profile information (PPI) to survey patient clinical characteristics, we investigated the common items of the PPI among the EMR systems and of the medical questionnaires for new patients.

2. Results

Based on the investigations of PPI, we proposed a framework enabling healthcare professionals to obtain reliable and up-to-date patient profile information at any time, developing a common database of PPI.

3. Discussion

The key point for success of the proposal system is that the access to and update of the data in a common database of PPI should be very easy or semi-automatically executed.

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Automatic Scanning of Free-Text Entries

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Keywords. Data cleaning, Anaesthesiology.

Introduction

Anaesthesia Information Management System (AIMS) store into a database data about patient and anaesthetic procedures. Many data are recorded manually through free-text fields, causing spelling mistakes. This study aimed to detect automatically pertinent informations in free-text entries.

1. Methods

Keywords, linked to a predefined terminology of anaesthesia, were defined and used to scan all free-text entries in AIMS anaesthetic records. The keywords take into account spelling errors and abbreviations. All detected associations were checked by experts for validation or in order to correct linking errors between free text and keywords.

2. Results

Forty-seven keywords were defined: e.g., "suf", "sufenta" and "sufentanil" were linked to the drug "sufentanil". Among 3565 scanned free-text entries, experts validated 416 associations over 454 proposals. The 38 associations' errors were generated by 12 keywords: e.g., "suf" was detected into "insuflation", and therefore "insufflation" was wrongly associated with "sufentanil".

3. Discussion

Automatic scanning of free text entries allowed us to improve automatic detection of relevant data in anaesthetic recordings. These items can now be used for statistical analysis. Error prone keywords should be made less equivocal to decrease wrong automatic association : e.g., introduce a blank space before "suf" will prevent it to be fired by "insufflation". As the detection algorithm is independent from the type of data recorded, it could be used for other systems.

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Toward an Ontology-Based system for the Automatic Detection of Biases and Weaknesses in Drug Clinical Trial Results

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Keywords. Controlled Clinical Trials as Topic, Bias (Epidemiology), Biological Ontologies, Computer Reasoning

Introduction

New drugs can improve patient health, but require careful evaluation and comparison with older drugs in clinical trials. Clinical trial results are used as the basis for prescription in evidence-based medicine (EBM), but such trials can be impaired by various biases. We present a system for automatically detecting some biases, design flaws and other weaknesses impairing the results of a clinical trial, to help physicians to come to their own conclusions about evaluations of new drugs.

1. Methods

We designed an ontology modeling the results of comparative clinical trials, using OWL (Ontology Web Language) and the Protégé editor. Then, we defined a list of weaknesses detectable from the literature and we implemented the detection of these weaknesses in OWL, SWRL rules or Python scripts. Finally, the system was evaluated on a new drug with 5 trials, and the detected weaknesses were presented to 4 experts.

2. Results and discussion

The ontology for comparative clinical trial results was represented in the OWL-DL language (67 classes, 62 properties, 49 individuals, 574 axioms and 7 rules, SHOIQ(D) DL family). The detection of 13 weaknesses has been implemented. All experts agreed on the weaknesses detected on the evaluation drug. We have shown that it was possible to automatically detect some biases and weaknesses in clinical trial results.

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Combining a Computer Skills Course and Psychoeducation Reduced Symptoms for People Suffering from Social Anxiety

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Keywords. Anxiety, computer skills, psychoeducation

Introduction

People who suffer from social anxiety typically find it difficult to interact with other people in social and educational settings, and some have not been able to acquire sufficient basic computer skills because they have not managed to participate in relevant courses.

1. Methods

A computer skills course was supplemented with psychoeducation sessions offered by an experienced clinical psychologist. This combined course was offered to people who had dropped out of employment or education and who suffered from social anxiety. 25 participants rated their symptoms on the Hopkins Symptom Checklist-90-Revised form, shortly before and after the course. Data were analysed with a paired t-test.

2. Results & Discussion

The mean score of the participants was 131.28 before the course and 100.36 after. The difference in means was clinically significant (30.92, SD=30.92). This was also a statistically significant reduction in symptoms ($t=3.962$, $p<0.001$, 95% CI=14.81-47.02).

The participants' symptoms were significantly reduced after the course, but as this was not a randomized controlled trial, we cannot be sure about how much of this improvement that can be ascribed to the course. Further studies are needed to validate these promising findings.

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Emergency Department Information Systems and Workflows – A Pilot Study

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Keywords. Health information systems, emergency department information systems (EDIS), workflows

Introduction

The aim of the study is to evaluate a well-established Emergency Department Information Systems (EDIS) in terms of how it is used to support Emergency Department workflows.

1. Methods

This study employs qualitative approaches, i.e., observation, interviews (semi-structured and opportunistic) and documentary artefacts analysis. Framework analysis was used to identify themes from the data.

2. Results

The EDIS consists of non-integrated computerised systems, non-electronic whiteboards and paper forms. The ED department workflow includes elements such as the tasks to be performed by the care team based on their roles, for example, doctors, nurses, clinical technicians and administrative staff. It also includes the sub-units patients are assigned to in which the emergency care treatment given is different. In addition there are also different queues or streams patients are assigned to during triage as well as the exceptions that might occur.

3. Discussion

The EDIS serves a crucial role in supporting the ED workflows. The workflows are tasks and process intensive that require information to be stored, retrieved and transmitted as needed. It serves as a tool to distribute work among the staff, as a repository for information, as a mechanism to submit investigation orders and to collect investigation results.

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Using concept co-occurrences for a biomedical facts acquisition

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Keywords. Information extraction, biomedical information, fact repository

Introduction

The massive generation of biomedical knowledge is reflected in the current evolution of the size of literature databases. PubMed/MEDLINE has more than 22M bibliographic records. We investigate how this content can be used for populating a repository for biomedical facts.

1. Methods

We use the MRCOC file from the UMLS, which contains co-occurrence information of MeSH descriptors in MEDLINE. From frequently co-occurring descriptor pairs, enhanced by their attributed subheadings we infer plausible predications and store the resulting Subject-Predicate-Object triples using linked data design principles. In order to enhance interoperability the MeSH descriptors are linked to SNOMED CT concepts, which also assign them to a small set of semantic types.

2. Results

Initial experiments have shown that the identification of MeSH Descriptor/Subheading patterns allows inferring predicates between Substance and Disorder pairs with a good accuracy, e.g. *treats*, *prevents*, *etc*. Like in *"Antiviral treatment"-treats-"Yellow fever"*.

3. Discussion

This methodology is promising but it has its limitations in the granularity of the MeSH thesaurus. This could be addressed by using, in addition, concepts extracted from titles and abstracts, using text mining. Another limitation which has to be studied with more detail is the potential bias caused by the fact that the modality of the statements or the research context in which they are produced remains hidden.

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A Community-Based Health Promotion Program Utilizing Web2.0

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Keywords. Health promotion, Diet record, Sense of change, ICT, Web2.0

Introduction

The "E-health community" is a community-based health promotion program combining Web2.0 diet recording and face-to-face meetings. The aim of this study is to clarify the factor needed to improve participants' "sense of change" in the program.

1. Methods

We conducted surveys with the participants of the program from 2009 to 2011. The survey consisted of questions about basic attributes, Internet usage, lifestyle habits, and social participation, in addition to the "sense of change" that measures the change of understanding and confidence to control calorie intake, nutrition balance, and physical activity between the beginning and the end of the program. The diet record data is extracted from the Web2.0 diet record system.

2. Results & Discussion

From the 92 cumulative total participants, we selected 36 participants as the subject of analysis who participated in this program for the first time and submitted all surveys. Only the Web2.0 diet record was identified as correlating with self-rated sense of change scores. The Mann-Whitney U test showed that self-rated sense of change regarding understanding and confidence to control calorie intake and nutrition balance significantly increased in a group that utilized the Web2.0 diet record system ($p<0.05$).

Our study suggests that frequent users of the Web2.0 diet record system have more understanding and confidence of control about calorie intake and nutrition balance. The impact of influence among factors of Web2.0 diet recording remains to be investigated.

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Pregnant Women´s Perception of Using the Same Knowledge-base on Medications as Health Care Professionals

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Keywords. Drug Therapy, Knowledge Bases, Professional-Patient Relations

Introduction

The knowledge base *Drugs and Birth defects* provides assessments of fetal risks of all drugs in Sweden and is available on www.janusinfo.se/fosterpaverkan. Although it is designed for health care workers, the public also uses it. The present study investigates how pregnant women perceive the information compared to physicians and midwives.

1. Methods

An electronic questionnaire survey (http://korta.nu/questions) was undertaken among pregnant women and health care professionals at 10 antenatal clinics.

2. Results

275 pregnant women and 68 physicians/midwives participated (total response rate 55%). 81% of the pregnant women and 71% of the health care workers stated that the information is valuable for pregnant women. 65% of the pregnant women would also fully recommend the database to other pregnant women compared to 24% of the staff.

3. Discussion

The majority of pregnant women perceive that they benefit from using this database intended for health care professionals. The health care workers are more hesitant towards the suitability for pregnant women. It is important that the women are able to discuss the content with the staff, if they are worried after having read the texts.

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Clinical Evaluation of Nursing Observation Model for the Patients with Ileus

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Keywords. Ileus, nursing observation, observation, case analysis

Introduction

The authors have been engaged in visualizing and structuring nursing's knowledge. This work has shown that there are three foci of nursing observation: i.e. "signs and symptoms of the diseases", "complications of the invasive medical/ surgical procedures" and "adverse effects of the pharmacotherapy". Now we have constructed a nursing observation model for the patients with ileus based on these foci and have developed a method to evaluate clinical nursing care actually delivered to the patients.

1. Methods

We made chart review of one patient and analysed the actual number of nursing observations based on the nursing observation model.

2. Results & Discussion

The patient's progress and the number of the observation items were as follows: mild (14) - moderate (insertion of gastric tubes) (21) - severe (insertion of ileus tube) (32) – surgery – post-operative (PO) high risk phase (32) – PO acute phase (32) – PO recovery phase (25) – discharge planning (22) – discharge. On the other hand, the number of standardized observations was 60 to 200 items for the phases mentioned above. As for the actual observation, there were those which were common to all the phases, those which were varied according to the patient's conditions and those which were questionable. For each phase, the observation rate (actual/ model) varied 15 to 40 %.

It was revealed that the clinical observations were made according to the model, though imperfectly. Our evaluation is that we need to improve the accuracy of the observations.

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Pregnant Women in Developing Countries Who Receive Free Cell Phones may Get Help Faster: A Literature Study

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Keywords. Pregnancy, health, cell-phones, delays, review

Introduction

Delay in getting help is a major cause of death of pregnant women and new-born children in developing countries. Modern communication technologies including cell phones may help reduce such delays.

1. Methods

We present a review of the literature on delays and their implications for the health of pregnant women and new-born children in developing countries. We discuss how free cell phones could help the women get help faster.

2. Results

Four types of delays can be identified in the literature: 1) Delay in making the decision to seek healthcare, 2) Delay in reaching a health facility, 3) Delay in receiving appropriate health care at the facility, and 4) Delay in referring to next level of care.

3. Discussion

Free cell phones could address all types of delays: 1) Improve access to information regarding when to seek help, 2) Help get transportation, 3) Help health facilities get advice, and 4) Help make arrangements for referrals. Cell phones are likely to become increasingly important in improving the health of pregnant women and new-borns in developing countries.

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Usibility Analysis of Two of the Biggest Turkish Public Training and Research Hospitals' Websites

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Keywords. Hospital websites, website usability, usability test, eye-tracking

Introduction

This research aimed to have a general idea on usability problems of Turkish public training and research hospital's websites.

1. Methods

There were 11 participants, 5 tasks and 2 websites, Ankara and Numune Training and Research Hospitals, in the eye-tracking usability analysis. Also pre and post-test questionnaires were conducted.

2. Results

The first task was to find laboratory results page. The link was on the main pages in both websites. However, mean of the fixation counts are much higher for 'Numune' webpage because of high rates of distracting objects. Task 2 was to find the polyclinics of the hospital. According to the think loud notes, it was more logical to put clinics information under a relevant title. Participants were asked to find the virtual tour of the hospital to complete 3rd task, and users were intended to check the menus and icons rather than the slider. The task 4 was to learn the phone number for an appointment. Despite the easy accessibility of the numbers, participants continued seeking due to lack of explanation. The last task was to reach the rules for hospital visitors. While testing, most of the people stated that the icon was not clear enough to notice.

3. Discussion

Considering usability problems detected in both pages, hospital websites should be prepared in a more user-friendly way at least for basic tasks (i.e., finding appointment phone number, places of polyclinics etc.), by bearing in mind the diversity of users.

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Increasing Semantic and Technological Interoperability in Electronic Patient Records

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Keywords. Electronic patient record, interoperability, integrated care, semantics

Introduction

There is a need for EPR systems to be organized in a more structured manner and for such systems to be more interoperable in order to communicate information between heterogeneous contributors.

1. Methods

The aim of this study, which is now in progress, is to follow, describe and contribute to increased semantic and technological interoperability in EPR systems in Norwegian healthcare, in order to obtain more integrated care. This research will use qualitative methods, interpretive, and ethnographically oriented, grounded in the action research tradition.

2. Results

The qualitative descriptive studies will contribute to the establishment and evaluation of the regional administration of archetypes and describe/evaluate the process and national Norwegian cooperation over a six year period.

3. Discussion

Structured data will make it possible for clinicians to categorize variables to build meaningful reports, to extract data for quality registers, and for clinical research. Structured data elements will also make it possible to organize information that supports process and decision support inside an integrated EPR portfolio.

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Context Management in Health Care Apps

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Keywords. Context-reasoning, Helath care apps, Decision support systems

Introduction

Monitoring health care mobile apps are useful to inform physicians regarding patients' status whilst providing recommendations to patients. Such recommendations are based on smart components (decision support system) that can take advantage of the mobile device to improve their outcome thanks to the management of contextual information

1. Methods

Three main types of context data should be considered: sensors-related, geo-temporal, and environmental. Contextual information can improve reasoning processes of health care apps by determining the relevance of the attributes considered; by selecting the kind of reasoning model to be followed; and, finally, to retrieve clinical histories of similar patients in similar environmental contexts.

2. Results

The methodology described in the previous section has been applied in a smart e-Health app for remote patient monitoring. Particularly, the application is intend for assisting parents in charge of premature babies through and smartphone application and a set of sensors. In such scenario, the application used sensor-related and environmental context information in order to improve the system outputs and to evaluate the quality of the data gathered.

3. Discussion

In order to improve the reasoning modules of health care mobile applications, context should be modelled according to three different dimensions: sensor, geo-temporal, and environmental data. This modeling has been illustrated in the development of a monitoring application for premature babies with positive results.

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Cutaneous Melanoma Surveillance by means of Process Mining

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Keywords. Healthcare Processes, Process Mining, Electronic health records

Introduction

The aim of this study is to evaluate the feasibility of process mining using health data collected during routine care to improve the follow-up care and surveillance of cutaneous melanoma (CM) patients. Sequences of events identified by process mining will be compared to existing treatment guidelines of different melanoma stages and show physicians when their treatment varies from the guideline process.

1. Methods

The Department of Dermatology at the Medical University of Vienna operates a melanoma registry, which currently covers 2.100 patients. In order to analyze the processes, information about transfer from patients between different clinics within the hospital as well as treatment information are extracted from the Hospital Information System (HIS) and combined with the melanoma registry.

2. Results

The created logs are analyzed in the ProM tool. Using HIS data results in more exhaustive models with 30% more events compared to only using the melanoma registry data. The higher the AJCC stage the better is the compliance to the guidelines.

3. Discussion

Unstructured health records are used to evaluate the detected processes. Pseudonymized patients data are used. Beside compliance to guidelines, the tumor progression depending on the compliance will be tested.

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User Creativity and Problem Solving in a User-composable Electronic Health Record

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Keywords. User-composable EHR, EHR, EMR, electronic health record, usability

Introduction

Giving clinical users control of information selection and interface design could allow them to leverage their medical expertise to create systems and tools which better fit their tasks, needs and preferences. We implemented this approach in a system, MedWISE, and evaluated this approach with respect to user creativity and problem solving.

1. Methods

Mixed methods included a think-aloud protocol and analysis of user interface creations and time sequences. 13 clinicians were recruited to use the system to obtain an overview of a patient's condition and state their assessment, diagnoses and plan. Their thinkaloud protocols and interface creations were analyzed according to diagnostic reasoning and HCI schemata. We also analysed user suggestions for innovations and new use cases.

2. Results

As predicted, user creations reflected externalization of user mental schemata (in 5 categories), tacit knowledge and new ways of creating clinical interfaces, reflecting user perceptions of their needs as well as existing problems which could now be solved.

3. Discussion

Users made astute suggestions for technical improvements, and new use cases or contexts. They also expressed enthusiasm for the approach, based on anticipated time savings, cognitive ease, and potential to fit their tasks.

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Evaluating Design and Usability of a CDSS for Kidney related Drug Prescribing

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Keywords. Clinical decision support system, renal failure, usability,

Introduction

SLL developed a renal CDSS integrated into an EHR system using the medical content of Renbase®. Results from a first pilot, evaluated with a questionnaire, logs and focus group discussions (FGD) showed that; some elements were used to a limited extent, users were sceptical to the eGFR formula (CKD-EPI) and unaware recommendations are general. This study reports findings from usability tests performed during a second pilot to gain deeper understanding of and verify reported problems.

1. Methods

Usability-tests with 7 end-users at healthcare stations and 4 physicians unfamiliar with the system were performed using a think-aloud protocol with clinical test cases, followed by an interview. The use was followed in a log.

2. Results

Users believed that the first view contained all necessary information. Background texts were perceived as difficult due to their structure, length and English language. Many users were unaware that the given recommendations were general and that the eGFR value may need to be recalculated. The formula was new to most users.

3. Discussion

To combine several methods (questionnaires, FGD, logs of use and usability tests) for evaluation of the user-interface showed to be more effective in revealing users' views and preferences. The FGDs indicated the same usability problems noted in the usability-tests, but takes longer to perform and analyse.

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Patterns in the Prescription of Drugs to Elderly Delirium Patients and the Impact of Psychiatric Intervention: a nationwide cohort study in Japan

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Keywords. Regression tree model, Delirium, Data mining

Introduction

Delirium is a strong independent predictor of high mortality high morbidity prolonged length of hospital stay re-intubation and high per-day hospital costs. The purpose of this study was to clarify the practical treatment of delirium through observed drug and psychiatric interventions, by using nationwide administrative data.

1. Methods

Data were collected from 1139 acute care hospitals in Japan from April 1, 2010 to March 31, 2013. Data on the use of medications for the management of delirium in relation to medical guidelines and consultations by psychiatrists were assessed. We used classification and regression trees to assess the medical interventions.

2. Results

Among 11,690,974 cases studied, 37,172 (0.3%) cases were registered coded delirium (ICD10) cases in the database. Compared to inpatients without delirium, those with delirium showed longer length of hospital stay. In addition, almost all inpatients with delirium received a combination of psychiatric drugs.

The results of this study showed that despite the fact that delirium has a major impact on the consumption of medical resources, that virtually no delirium codes are registered compared to previous studies on the delirium onset rate. It is possible that this low rate of registration can be linked to a lack of awareness among acute care medical staff about the importance of delirium.

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Consulting Forensic Pathologists: A Secure Public Web Application

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Keywords. Forensic Medicine, Expert Opinion, Referral and Consultation

Introduction

Sometimes general practitioners, police and welfare offices encounter patients with injuries indicating potential victims of abuse. Clarification usually requires knowledge of a medical forensics expert. After looking at the medical report and picture documentation, the medical forensic expert can confirm or reject the GPs presumption.

The picture documentation and medical reports are commonly sent over unencrypted public email networks to the medical forensic experts. Due to the sensitive nature of this information, this method of transfer both ethically questionable and in violation of German privacy laws.

To solve these problems, we devised and implemented a secure public web application to request medical forensics expert opinions.

1. Methods

A requirement analysis was done by the institute of forensic medicine and the medical informatics division. The requirements were then used to devise a software architecture which respects privacy laws and includes up-to-date cryptography.

2. Results

Anyone may access the public expert opinion request form and upload images. Submissions are immediately encrypted with public key cryptography and stored on shared media. Decryption can only be done on a second secure system without internet access, which is used by medical forensics experts to review submissions.

3. Discussion

The devised web application for forensics expert opinions allows anyone to transfer sensitive picture documentation securely to the forensics experts.

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Development and Implementation of Perioperative Nursing Processes through user Software "Syntegra"

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Keywords. Information system, Nursing informatics, Perioperative health care, Perioperative nursing processes, software

Introduction

Existing health information system (HIS) is missing a set of activities performed by nurses in surgical wards, thus losing the continuity of surgical care.

1. Methods

In 2010, a nursing team was formed with a task of development electronic nursing documentation in the largest medical facility of the Balkans. Clinical center of Serbia have 8000 employees, 44 departments and almost 90.000 patients per year, with 50.000 surgical interventions performed each year. Developed set of perioperative nursing activities was implemented by user software "Syntegra". The system was MySQL based, Windows platform, developed by Power buider 10.5 Sybase.

2. Results

Throughout this application, the existing HIS is upgraded for following minimal data set of perioperative nursing activities: nursing diagnosis, care plan, care goals, patient outcomes, nursing recipient list and discharge letter, pain list assessment, wound care list, awareness assessment list and record vital signs list.

3. Discussion

Nursing activities are implemented through electronic health record, thus continuing surgical care process that could be charged adequately in the future.

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Patient-Empowerment Services for Diabetes Self-Management

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Keywords. Patient empowerment; diabetes; self-management; eHealth

Introduction

Diabetes patients have the need for personal self-management to foster a step-wise change in their lifestyle. In this poster we present a system that integrates multiple services to guide patients through their self-management pathway (SMP), which has been developed in the FP7 project EMPOWER.

1. Methods

The SMP starts during a medical consultation, where the healthcare provider forwards patient-specific recommendations to the patients' PHRS. Based on these recommendations, the patient should be able to derive self-management goals and schedule concrete activities for the upcoming week. During the week, the patient may receive reminders to perform the activities and will collect "observations of daily living" (ODLs) using his smartphone or a web application. After that, the patient performs a weekly review to be used as basis for upcoming consultations.

2. Results

This poster presentation shows the implementation of the following EMPOWER services: recommender engine, SMP service, security and consent management, mobile and web-based user interaction.

3. Discussion

The EMPOWER SMP integrates services medical professionals and patients: A decision support service that provides treatment and self-management recommendations based on Electronic Health Record Data and personal health applications in various flavors like smartphone or web-application based on a Personal Health Record System.

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Integrated Management of Medical Records using DACS and the Effects on Document Browsing

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Keywords. electronic medical record, patient information, viewer, usability

Introduction

Physicians must collect patient information from medical records within a short period of time. Because medical records are dispersed across several electronic medical record (EMR) systems, doctors must activate multiple viewers in order to collect patient information. In our hospital, all medical records were integrated into the DACS (Document Archiving and Communication System), allowing them to be viewed using a single viewer. In this paper we evaluate whether browsing medical records using a single viewer shortens the time required to collect patient information.

1. Methods

We randomly selected 10 patients and measured the time required to display documents and the number of mouse clicks used with/without the DACS viewer when browsing the first visit records, hospitalization summary and inspection reports.

2. Results

As for the first visit information, it took 27.6 ± 2.9 sec and 7.8 ± 0.8 mouse clicks to display the documents without the DACS viewer, compared to 25.9 ± 4.4 sec (NS) and 8.7 ± 0.9 mouse clicks ($p<0.05$) using the DACS viewer. As for hospitalization information, it took 16.0 ± 2.2 sec and 4.6 ± 0.7 mouse clicks to display the summary sheet for hospitalization without the DACS viewer and 13.0 ± 1.1 sec ($p<0.01$) and 4 ± 0.0 mouse clicks ($p<0.05$) with the DACS viewer. As for inspection information, it took 92.2 ± 21.5 sec and 30.3 ± 7.6 mouse clicks to display these documents without the DACS viewer, compared to 70.6 ± 22.8 sec ($p<0.01$) and 22.8 ± 6.9 mouse clicks ($p<0.01$) using the DACS viewer.

3. Discussion

The DACS is effective for collecting and organizing patient information for physicians.

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An interactive graphic reporting system for venous ultrasonography

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Keywords. Diagnostic reporting, web techniques

Introduction

Ultrasonographic exams of the venous system of the leg are important in preparation for varicose vein surgery. To describe exam findings an anatomic sketch helps considerably. We have designed a web based system for diagnostic reporting where findings are both quantified and outlined in an anatomic image.

1. Methods

The system combines a Perl script generating a CGI form, with embedded SVG images, interaction between form input and elements in the image via Javascript functions, and form input is saved as an XML file, enabling later data aggregation.

2. Results

The system has been in constant routine use for over ten years and has been used in reporting of 11255 exams on 7787 patients. 40% of exams show severe venous insufficiency in the proximal great saphenous vein (in the groin), and these veins are often severely dilated.

3. Discussion

The system makes it easy to produce a clear report from venous exams, and is popular both among examiners and surgeons that get the report. The interactivity between form and anatomic image makes correct and complete reporting important, and this ensures good quality data for follow-up and epidemiology.

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Development of the Modes of Disease Management for Infants and Children

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Keywords. Mode, disease management, clinical knowledge, standardization

Introduction

For infants and children, the players involved in their disease management are such community resources as their home, schools, educational committees, healthcare centers, clinics and hospitals. While pediatricians implement professional decision making, it is important for all the players to share the process of disease management (DM) to better support the infants'/ children's growth. The authors have tried to standardize the modes of disease management to facilitate the understanding among the players.

1. Methods

We identified the modes of DM through developing PCAPS contents for children with upper respiratory tract infection, heart disease, food allergy and short stature. PCAPS (Patient Condition Adaptive Path System) is a tool for structuring knowledge in clinical process. PCAPS is composed of Clinical Process Chart and Unit Sheet.

2. Results & Discussion

We developed six modes of DM: (1) healthy or no awareness, (2) managed living without medical supervision, (3) managed living with medical supervision, (4) management by the GPs, (5) management by the specialists, and (6) specialty intervention.

We apply clinical guidelines to mode 4, 5 and 6 for quality assurance. It is expected that the players involved are able to have common understanding regarding the status of the infants/ children and that they can implement more adapted intervention. Now we are developing paediatric disease management system using ICT and Mobile device.

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A WSN-based Physical and Mental Health Monitoring system for Geriatric Facilities

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Keywords. Wireless sensor network, wireless audio, mental health monitoring

Introduction

It is essential for the elderly people with chronic physical or mental diseases to be monitored in a reliable and unobtrusive way. A WSN based physical and mental health monitoring system with an audio module in it would offer convenience and efficiency.

1. Methods

The monitoring system comprises of three key components: the end nodes, the sink node and the data monitoring centre. Each end node consists of a physical sensor module, a WSN module and an audio module. The sink node comprises a WSN module and a serial port interface module over RS232/USB connection to the data monitoring centre. A mental health management software will be developed. The telephone version mini mental status examination (T-MMSE) will be pre-recorded and sent from monitoring centre to certain end nodes according to practical needs.

2. Results

Data from physical sensors and audio module can be collected and relayed to and displayed at the monitoring centre at current stage.

3. Discussion

The future work will include the integration of the SpO2 sensor, a sophisticated GUI software especially for the audio monitoring management and a database. Finally, a user's evaluation will be carried out in geriatric facilities in UK and China.

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15. Posters B

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Mobile Technologies: Expectancy, Usage and Acceptance of Clinical Staff

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Keywords. Mobile devices, hospital, policy implementation

Introduction

If used adequately, smartphones and tablet PCs may support doctors in their daily routines. Often, they use privately owned mobile devices but many hospitals are ill prepared for these devices and lack appropriate official guidelines. Guidelines should respect the needs of potential users if they are to be implemented successfully.

1. Methods

Physicians and medical students (final year) at Hannover Medical School (MHH) were interviewed via an anonymized, open ended online questionnaire (developed at our institution). It consisted of 16 items, covering actual usage, device type, type of purchase (private/employer), as well as behavioural questions regarding current and planned future use. Socio-demographic information was also obtained to ascertain differences between groups (age, gender etc.) and matched that of overall values for MHH.

2. Results

Demographic data of participants who had answered (survey period: 4 weeks; return rate: 26%, n=322) matched values for the entire staff. More than 50% actively use mobile devices (most purchased privately) in the hospital (work related use: 20%) and expect use to increase significantly in the near future. Major concerns voiced by the participants were related to data protection, privacy and hygiene.

3. Discussion

Results underline the need for firm policies regarding use of mobile devices from both technological (data protection, privacy) as well as medical points (hygiene) of view; technical, administrative medical staff must collaborate to avoid harming patients.

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Investigating Physician's Perceptions about Patient Related Benefits of CPOE

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Keywords. Electronic prescribing, CPOE, Healthcare, medication errors, patient related benefits

Introduction

Electronic prescribing is also known as Computerized Physician Order Entry (CPOE). It is a computer-aided system which offers the health professionals a robust platform for entering the prescription electronically. In a developing country like Pakistan where patient to doctor ratio is very high there is a need to implement such systems which could help in minimizing the potential medication errors.

1. Methods

It is a survey study regarding patient related benefits of CPOE as perceived by the health professionals. Data was collected from four major cities of Punjab. Response rate was slight above 50%. Data was analyzed in MS Excel.

2. Results

The advantages of CPOE are summarized here in the form of multiple bar graphs. The graphs clearly indicate that the most of the participants are in favor of achieving these benefits by adopting CPOE.

3. Discussion

Ultimate goal of all this system is to improve the quality of health services and improve quality of life at large. Overall response is very convincing indicating strong motivation for the use of CPOE among the healthcare professionals. The results call for an action to implementation of CPOE. Lack of infrastructure as well as political will might be the major factors impeding the adoption and implementation of this system in Pakistan.

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Extracting Imaging Observation Entities in Mammography Reports

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Keywords. Information Extraction, Mammography Reports

Introduction

Since radiology reports are created as unstructured text reports, Natural language processing (NLP) techniques are needed to extract structured information from reports to provide the inputs to information systems.

The goal of this project is to develop NLP methods to extract the Imaging Observations and their modifiers from free-text mammography reports in order to provide structured data to reduce variability in mammography interpretations.

1. Methods

Using the BI-RADS ontology and 80 example reports, we created a pipeline, which uses the ontology as a knowledge source for automatic annotation of the entities and modifiers in mammography reports. The pipeline we built uses the GATE (General Architecture for Text Engineering) NLP toolkit and performs the sequential tasks such as tokenization, report section segmentation, named entity recognition and so on.

2. Results & Future work

In 28 cases, only our pipeline claims the presence of an Imaging Observation and two other cases were only claimed in extended gold standard. Compared to extended gold standard, overall, our algorithm achieved a recall (99%) and F1-score (0.95) for a similar precision (92%).

Our future work will be to develop rules to find location entities to extract relationships among imaging observations and locations. In addition, we are going to add a component to find negations and hypothetical concepts. We will also be conducting an evaluation in a larger corpus of reports.

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Bridging the gap: Improving Secondary Use of EHRs with i2b2

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Keywords. Secondary use, i2b2, personalized medicine, EHR

Introduction

In order to reuse EHRs for research (Secondary Use), researchers may have to apply for the permission of using EHR data for their research. This process is e.g. necessary in a German research project, called *Greifswald Approach to Individualized Medicine* (*GANI_MED*). There, it is unknown to a researcher at the time of a query, how many patients are available that fit the necessary inclusion and exclusion criteria for a certain study. Between a researcher and the research platform exists an informational gap, not allowing a preview of the available data. Also, results come with a significant delay.

1. Methods

A Java-based tool has been developed that imports generic metadata and observations into i2b2. The i2b2 webclient was customized. The solution was evaluated by four key users. A questionnaire was used to measure the usability and usefulness of the solution.

2. Results

Generic metadata and observations can be imported into i2b2. The imported data is coming from multiple source systems and medical devices. More source systems can be added to i2b2 in the future. In i2b2, a query can now be defined analogous to the application process. This query is then integrated into the application process.

3. Discussion

Researchers are able to get a preview of existing patient data, allowing them to query for large parts of EHR data. Inquiries by phone or e-Mail are replaced by i2b2. Key users consider the solution a significant improvement to their research planning.

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Transformations between CDISC ODM and openEHR Archetypes

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Keywords. Metadata, Interoperability, CDISC, Data Standards, Archetype

Introduction

Metadata standards like ISO 11179, openEHR archetypes, CDISC ODM, etc. promote interoperability by facilitating the definition, reuse and exchange of data elements. Due to different data models, the exchange of metadata between information systems is laborious. Interoperability between ISO 11179 and ODM has already been shown[2]. In this work we want to develop transformations between ODM and openEHR archetypes.

Methods

The specifications CDISC ODM 1.3.1 and the openEHR archetype definition language (ADL) 1.5 were reviewed. A XSLT was developed to transform ODM to ADL including terminological bindings such as concepts of the UMLS and SNOMED-CT.

Results

ODM-*ItemGroups* contain similar elements of a specific topic. So, an *ItemGroup* can be mapped to one archetype. An ODM-*FormDef* corresponds to an openEHR template. Apart from *Protocols* and *StudyEvents* the transformation of names, descriptions, different languages and value sets as well as terminology codes is achievable. Thirty ODM files with 100 *ItemGroups* from the portal of medical data models[3] were converted and reviewed by an expert using the openEHR editor.

Discussion

Overall, a conversion of ODM to ADL is feasible barring *Protocols* and *StudyEvents*. Future work will cover an in-depth evaluation and transformations from ADL to ODM.

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[2] Bruland P, Breil B, Fritz F, Dugas M. Interoperability in clinical research: from metadata registries to semantically annotated CDISC ODM. Stud Health Technol Inform. 2012;180:564-8.
[3] Portal of Medical Data Models: http://www.medical-data-models.org (Last accessed: January 2014)

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Evaluating technologies for a patient portal

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Keywords. patient portal, PEHR, LIFERAY

Introduction

The University Hospital Heidelberg is implementing a personal electronic health record (PEHR). One aspect is to provide access control, consent and content management to the patients. Thus a patient portal is required, which is usable by patients in every age and with different technical backgrounds in order to address this aspect.

1. Methods

A requirements catalogue for product reviews was developed and success factors were defined. One of the major aspects was the consent management by the patient. Second, a market analysis was performed and different technologies were compared. Based on the results a technology product was selected.

2. Results

The analysis of requirements and success factors from various viewpoints (e.g. from the user perspective, data security, development, and many others) has shown that factors such as usability, expandability, backend integration and others are crucial for the success of a patient portal technology. LIFERAY is selected to be used as patient portal.

3. Discussion

As the patient portal is under development at the moment, practice will show if the chosen criteria have been right. The patient portal acceptance and the capability of patients managing their consents have to be evaluated.

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Visualising topic networks in infection control using word vector analysis

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Keywords. Infection control, text mining, meta-analysis

Introduction

Keeping up with the latest topics in infection control requires a substantial investment of resources, which are not always available. To help infection control specialists uncover new and interesting topics in their field, we created a method to visualise topic networks in infection control using word vector analysis.

1. Methods

We gathered a collection of infection control-related abstracts and full-text resources using Pubmed and BMC open-access. We used the Google word2vec tool to calculate the word vectors, and created a workflow that iteratively builds a network of word associations with the Taverna workbench. Finally, we used GraphViz to visualize this network and connection strengths.

2. Results

Results uncovered the use of several novel electronic data sources for infection detection, e.g. biochemistry results and clinical patient data. Terms within topic clusters (e.g. hand hygiene, infection surveillance) are highly interconnected, while intercluster connections appear less often.

3. Discussion

Visualizing word associations in literature enables infection control specialist to easily find new topics of interest. Lack of intercluster connectivity of topics with computerized methods suggests that medical informatics can have more impact in this field.

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Group differences in sites of metastases after being diagnosed with breast cancer

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Keywords. SEER, breast cancer, Caucasian, Japanese-American

Introduction

One eighth of women in the United States were affected by breast cancer over a lifetime and one sixth of them develop metastases. An aim of this study is to investigate group differences between Caucasians and Japanese-Americans in sites of metastases after being diagnosed with breast cancer.

1. Methods

The Surveillance, Epidemiology, and End Results (SEER) database with 2,410,581 records registered between 2000 and 2010 was used in this study. Chi-square test was performed to investigate group differences between Caucasians and Japanese-Americans in sites of metastases after being diagnosed with breast cancer.

2. Results

Higher incidences of breast and lung were observed in Caucasian and Japanese-American females. In addition, a higher incidence of colon was observed in Japanese-American females. Higher incidences of lung and prostate were observed in the Caucasian and Japanese-American males. A higher incidence of bladder was observed in Japanese-American males. Sites of metastases showed significant differences between Caucasians and Japanese-American in males and females, respectively ($P<0.001$).

3. Discussion

Our results showed group differences between Caucasians and Japanese-Americans in sites of metastases after being diagnosed with breast cancer. Although genetic factors cannot be excluded, a pathological grade may influence the observed differences.

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Need for Preventing Incorrect Intravenous Bolus Orders in ePrescribing Systems

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Keywords. Electronic prescribing, medication errors, intravenous injections

Introduction

Computerized physician order entry (CPOE) has been reported to improve patient safety. However, unintended effects can occur. CPOE may shift responsibilities from nurses to physicians, e.g. when the order entry allows physicians to specify the administration duration of intravenous (iv) drugs, a task which was previously assigned to nurses (save for a few exceptions such as chemotherapy). The purpose of this quality assessment was to analyse frequency and reasons of incorrect iv bolus orders.

1. Methods

The orders concerning 40 drugs never to be administered as iv bolus were analysed over a 25 months period following CPOE adoption on all inpatient wards of the University Hospital Zurich. The prescribed administration durations were compared with the guidelines defined by the Swiss drug information repository.

2. Results

We analysed 258,902 iv orders and 797,692 iv administrations in 76,467 inpatients. Drugs never to be administered as iv bolus were ordered 27,247 times, resulting in 78,516 administrations. 35 of these orders (0.13%) were incorrectly ordered as bolus for a total of 112 administrations (0.14%).

3. Discussion

The rates of incorrectly ordered iv bolus injections were low. In addition, nurses review prescriptions before drug administration in order to reduce the risk of incidents. To increase safety, clinical decision support could further minimise hazards, e.g. by restricting input options for iv administration duration. CPOE introduction may modify the collaboration of physicians and nurses and should therefore be monitored and managed as an iterative process of business improvements.

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Quality assurance: automatic detection of inappropriate prescriptions in the elderly

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Keywords. Inappropriate prescribing, quality assurance, cholinergic antagonists, health information technology, data mining.

Introduction

Drugs with anticholinergic effects are considered as potentially inappropriate prescriptions (IPs) in the elderly aged over 75 years, because they have an unfavorable risk-benefit ratio particularly in case of dementia, falls, or chronic constipation. The prevalence of anticholinergic IPs in the hospitalized elderly has not been evaluated.

1. Methods

We adapted an innovative IT tool for automated data exploration to assess the frequency of anticholinergic IPs in the hospitalized elderly in different risky contexts (i.e. dementia, fall, constipation). We explored 77.614 computerized hospital stays extracted from a community hospital between 2008 and 2013.

2. Results

Anticholinergic potentially IPs concerned 12.2% of the hospitalized elderly in the study, and were mainly antihistaminic prescriptions. In the elderly with dementia, history of fall and constipation, the prescription rates were respectively 19.6%, 11.4% and 6.9%.

3. Discussion

In this work, an automated rules-based tool showed that anticholinergic IPs are of major concern in the hospitalized elderly. This tool could be used in a quality assurance process and may help physicians to better identify and reduce IPs in the elderly.

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Travellers' Health Mobile Applications

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Keywords. Traveller, health informatics, traveller's health, mobile

Introduction

The last few years, smartphones and mobile services have changed the way the information is distributed among travellers. m-health emerged as a new field of study and research due to recent healthcare-oriented applications development. The research aim of the current scoping review is to present the findings of an online search with regards to mobile applications related with traveller's health context. In addition, findings of a relevant literature review in this domain are also outlined and presented.

1. Methods

An online search was conducted in one month period. Specific keywords or phrases were used, referred to the current domain (ex. mobile application), in electronic scientific databases (ex. MEDLINE) and Web search engines. 22 mobile applications were found and classified in four major categories based on their functions.

2. Results

Travellers' health mobile applications categories include, applications providing information for first-aid issues, applications locating the nearest health services, applications giving a diagnosis based on a list of symptoms, and Electronic Health Record (EHR) mobile applications for travellers. No scientific studies were found either to evaluate, or referring to Travellers' Health Mobile Applications.

3. Discussion

Although a lot of travellers' health mobile applications exist, the international scientific community has not dealt with this field yet. Future work will include an empirical study in order to evaluate the travellers' opinion on health mobile applications, measuring the potential usability and usefulness of them.

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Documenting the Health Care Processes in the Intensive Care Unit

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Keywords. Nursing documentation, Intensive care unit, data mining

Introduction

The documenting of health care processes in the intensive care unit (ICU) is extremely important for patients and health personnel. The aim of this study was to investigate what are the attitudes of nurses on planning health care processes and keeping records, and how their age, work experience and their level of education affect to their attitudes.

1. Methods

Respondents were nurses working in ICU. The survey was done using a web-based questionnaire. Questions were about the nursing documentation in ICU, e.g.: *Do you plan nursing care for patients in the ICU?, If yes, how?, Have you had training prior to the introduction of nursing documentation?, Do you use nursing care plans for patients in the ICU?, Do you evaluate the objectives after making the intervention to the patient*?. General data were added: gender, age, years of work experience, level of professional education.

Data are processed using descriptive statistical methods and explored using data mining (DM).

2. Results & Discussion

The questionnaire was completed by 66 nurses. They had professional education at 3 levels: *assistant nurse, nurse, graduate nurse*. They were divided in 3 age groups: *20-30, 31-40, 41*-50 and in 3 groups according to years of the work experience: *0-10, 11-20, 21-30*. Results of DM showed that there are differences in the approach to nursing documentation in the ICU depending on work experience and level of education.

Results of this study indicate that nurses are inadequately prepared for conducting electronic nursing documentation in ICU and it will help to improve the curricula of Nursing Study.

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Participation and Mode Preferences in a Questionnaire Study

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Keywords. childhood cancer survivors, participation rates, questionnaires

Introduction

Questionnaires are widely used in patient cohort studies. To produce valid results, a study population should be representative of the population as a whole to limit the possibility of selection bias. In this study we investigated the effect of different questionnaire modes on preferences and participation rates.

1. Methods

We randomized 750 childhood cancer survivors (CCS) across 3 study arms, in which a paper-based questionnaire was offered at different contact moments (follow-up invitations). CCS always had the possibility to complete a web-based questionnaire.

2. Results

Overall 58% CCS participated, with no significant differences between study arms. CCS, particularly unemployed and low educated, often choose to complete the paper questionnaire over the web questionnaire.

3. Discussion

To optimize participation rates in questionnaire studies, invitation strategies should be tailored to subjects' characteristics and preferences.

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Computational Biology Approaches in a Research Laboratory for Understanding Complex Diseases

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Keywords. Bioinformatics, Computational Biology, Precision Medicine

Introduction

Recent technological advances for biomedical research (such as next-generation sequencers, microarrays, mass spectrometers, cell-based assay methods…), are increasingly being used in the study of complex diseases incrementing the amount and diversity of data. The need to manage, integrate and analyse these data is critical for the advance in the understanding of complex diseases leading to the practice of a more precise medicine.

1. Methods

Review of the needs and solutions to implement the storage of the omics data, collecting and analyzing gene expression datasets and evaluation of common genetic variations associated with common complex disease in the genome-wide scale to identify potentially actionable phenotype-to-biomarker relationships.

2. Results & Discussion

An example is in the research related to cancer genomes, an expanding field, where the challenge is to have the computational techniques to annotate somatic variants identifying mutations that contribute to oncogenesis, tumor maintenance or response to therapy.

Given the urgent need to understand how the growth of omics information contribute to disease, computational biology is likely to be increasingly important in all biomedical research laboratories.

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Developing a Model of the Care Management for the Elderly with Dementia

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Keywords. The elderly, dementia, care management, multidisciplinary approach

Introduction

As the society gets aged, we face many challenges in Japan regarding the care of the elderly with dementia. One of the biggest is that the multidisciplinary care teams do not share the methods to develop appropriate care plans. Thus, the authors have tried to identify the factors of a effective model of the care management, which aims at patients' stability.

1. Methods

We collected the cases where the patients' stability had been attained through the integration of the medical and long-term care was attained and analyzed them to visually and structurally describe the objectives of the care management, methods of recognizing the patients' conditions and decision on interventions.

2. Results

It was revealed that the stable state was established through three interventions: adequate medication, checking adherence to the pharmacotherapy and monitoring for early intervention into the behavioural and psychological symptoms of dementia (BPSD) and patients' behaviours disturbing to the others. The multidisciplinary care teams shared ideas about what the stable state for each individual patient meant.

3. Discussion

We have recognized the attention to patients' conditions and three interventions to attain/ retain the elderly with dementia stable. We are now making a integrated care management model these factors based on the, which may be shared among the multidisciplinary care team.

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Task Analysis for Patient-Oriented Medication Information Management

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Keywords. medication management, task analysis, eHealth, health information systems

Introduction

We present an initial functional reference model to support the design of operational models, tools and systems for *Medication Information Management* (MIM) in varying settings holistically from patient-oriented viewpoint. The model consists of tasks which are combined in the processes and activities related to the care of the patient.

1. Methods

Our study was performed in a regional project in Northern Savonia region in Finland in 2012-2013. We applied the *task level* of SOLEA6D framework for process and activity analysis and design. The material was collected through fifteen thematic interviews and four focus groups in a workshop of 42 participants from 19 organizations, representing many different roles in medication treatment and information management.

2. Results

The resulting functional reference model includes the identified and analysed tasks related to MIM. We identified 102 key tasks which were grouped under 12 categories based on the main phases of the medication process or main nature of the tasks.

3. Discussion

The model was successfully used to structure the development requirements. We are further applying and refining the model in the specification of operational models and ICT tools for MIM in home care and care transitions in a further project.

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Development of a Needle Insertion Manipulator using Lego Mindstorms

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Keywords. Manipulator, Lego Mindstorms, Robotic needle insertion, Thoracocentesis

Introduction

Pleural effusion is a build-up of fluids in the pleural space. In this paper, we present a pilot study of a needle insertion manipulator for Thoracocentesis, a conventional procedure for draining fluid from the chest cavity.

1. Methods

The manipulator was constructed using the Lego Mindstorms 8547 kit (Lego, Denmark) with several additional parts from the Lego Technic range. On the hardware side, a manipulator had an end-effector and a registration frame with four pins that must be aligned with the pins on the phantom for registration on ribs and a touch sensor for automating translational movement of the needle. For evaluating the operation of the manipulator, a simulation of the flesh (a phantom) on the ribcage was constructed using a medium thickness cellulose scrubber considering Lego Mindstorms limitations.

The manipulator was programmed using Microsoft Visual Programming Language (MVPL) in Microsoft's Robotics Developer Studio (MRDS).

2. Results

User feedback suggested that the manipulator may be useful for large pleural effusions, therapeutic pleural tapping and remote Thoracocentesis. A manipulator could also act as an aid to inexperienced clinical staff to perform the procedure.

3. Discussion

Lego Mindstorms was shown to be not suitable for developing the manipulator beyond an early stage demonstration tool for showing the concept to potential users. The main problems restricting further use were poor reproducibility, instability during operation, poor repeatability of the moving parts, poor robustness of the assembled structure, poor accuracy of the sensors, no user feedback and potential sterilization problems. The manipulator was able to provide potential users with a "solid" version on which they could comment and a concept to develop modular surgical robots.

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Dynamic Adaptation of EHR Structure for Automated Compliance Evaluation

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Keywords. Clinical Practice Guidelines (CPGs), Electronic Health Record (EHR) systems, Compliance evaluation support system.

Introduction

Integration of Clinical Practice Guidelines (CPGs) within Electronic Health Record (EHR) systems improves dissemination, implementation, and effective enactment of CPGs in the organizational workflow, but requires that some inherent contrasts be faced. On the one hand, tailoring the EHR structure so as to fit a restricted set of CPGs induces a bias towards specific pathologies. On the other hand, representation of all medical concepts that may become relevant for *any* applicable CPGs definitely impairs practical feasibility and usability.

1. Methods

We propose an approach to the integration of CPGs into an EHR system that combines bias avoidance, usability, and completeness through a two-step dynamic adaptation of the EHR structure. Clinical information is first collected within an unbiased general structure. After the formulation of a diagnostic hypothesis, CPGs applicable to the case are automatically identified and the EHR structure is adapted so as to focus on concepts relevant for clinician's compliance to CPGs recommendations.

To achieve this adaptability, CPGs data and logic are represented using a two-level modeling methodology and a production rule-based approach, respectively. The concept is concretely implemented by separating information and knowledge in a reflective SW architecture based on the *Observations & Measurements* pattern.

2. Results & Discussion

An implementation of the described EHR system, focused on CPGs for valvular heart disease management, is presently on trial in various Cardiology clinics at the Azienda Ospedaliero-Universitaria Careggi (AOUC), the main hospital in Florence.

Preliminary experimentation shows the feasibility of the proposed approach and the benefits of dynamic adaptation of the EHR structure according to diagnostic hypotheses so as to support clinician's compliance evaluation. Ongoing activity is directed to exploit the system in the automation of retrospective analyses of compliance.

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Hospital Alliance and Minimum EMR Data in Mobile Device for the Disaster

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Keywords. Electrical Medical Record, Black Out, Disaster

Introduction

Emergency preparedness of Electrical Medical Record in case of disaster, such as storm, snowfall and earthquake, is essential for the staff of hospitals and administration. Blackout needs emergency power supply fit for computer systems. We have extracted minimum data sets from EMR and stored in mobile device in hospitals, and made regional alliance between 6 hospitals.

1. Methods

Each hospital has extracted minimum data as SS-MIX from EMR and stored in mobile devices and data centre. In case of emergency, each hospital can use mobile device driven with battery as a browser or download their own or other hospital's data.

2. Results

Minimum data can be browsed in Windows PC or iPad, and used in drills for disaster.

3. Discussion

In emergency phase without electricity and/or website connections, these mobile devices can rescue many patients with accurate medical information. Hospital alliance can work for mutual data usage, and it is cost-effective for wide area disasters.

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Heuristics to support user-centered design research for e-health applications with older adults

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Keywords. User-centred design, older adults, heuristics, e-health

Introduction

The aim of the research work presented in this poster was to determine how changes that are considered to be a normal part of the aging process relate to UCD research with elderly people, and to provide heuristics for doing UCD research with elderly populations.

1. Methods

From amongst a wide variety of UCD methods, we selected five of the more commonly used methods that actively involve users in the product development life-cycle: contextual inquiry, focus group, card sorting, task analysis, and user questionnaires. By taking into account the target population's characteristics and capabilities, and target domain characteristics, we modified the five selected standard UCD methods for the target population (i.e. older adults), and the product domain (i.e. e-health).

2. Results

The research work has enabled us to provide 27 heuristics to support UCD research for e-health applications with older adults.

3. Discussion

Some of the heuristics are more general and some of them are more explicit. Nevertheless, despite of the explicitness of the heuristic it is always important to consider the specific UCD method and context in which a given heuristic will be applied.

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A Nationwide Remote EHR Backup Project in anticipation of Large-scale Disaster in Japan

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Keywords. Disaster Recovery, Medical Records, Information Security, HL7

Introduction

Immediate recovery of the reference to past medical records is critical for the care of the large-scale disaster victims. This paper describes the nationwide remote backup system developed for all 45 national university hospitals in Japan.

1. Methods

Core part of EHR including 36 clinical events is periodically exported in each hospital following a domestic HL7-v2 based standard. The exported data are copied to 2 far-remote data centers, where a developed web service is equipped. After certain administrative operations, the backup data of the damaged hospital could be accessed from evacuation centers as well as from other hospitals and clinics over the Internet.

2. Results

Formal operation of the system has started in Apr. 2014 with 600 terabytes of backup storages and a nationwide private network. Web-based reference to medical records of the patients would be available within a few days after a disaster without any recovery of damaged hospital information systems.

3. Discussion

This system has achieved a quick recovery in data reference, though core clinical data of participated hospitals are stored in one place, secondary use, epidemiological studies for example, would be expected if patient's consent is available in the future.

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Ethical Impacts of Tele-Nursing Applications on The Patient Care

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Introduction

Tele-nursing applications encompass the healthcare services provided at the houses of the patients through the use of cameras and computer technologies. Problems can occur between patient and nurse or nurse and institution due to the fact that telenurses cannot meet their patients face-to-face or institutional policies are diverse and restrictive. This lead to discrepancies between what the nurses can do and what should be done and the nurse can experience ethical dilemmas

1. Methods

This is a methodological review study carried out by screening the articles published on the basis of the key words of "telenursing" and "ethics" over Pub Med and EBSCO host in January 2014. 26 articles were reached when a literature review was made by using the key words in the database (Pub Med, EBSCO)

2. Results

International tele-nursing application limits can lead to ethical problems on the part of the tele-nurses. Besides, conflicts can occur due to economic reasons. Institutional policies and expectations can affect the decision making process of the nurse as well and ethical problems can occur. Besides talking through a third party, discussing personal and sensitive problems over the phone, insufficient resources and the organization of health care, balancing callers' information needs with professional responsibility, and differences in judging the caller's credibility are other ethical dilemmas in tele-nursing too. Also, right to confidentiality, right to privacy, providing a standard of care, making a decision for a patient are ethical conflicts comforting nurses Determining the ethical problems encountered in the tele-nursing applications, use of models in the ethical decision making process and development of clinical skills of nurses are important steps to be taken for the solution of the ethical problems.

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Visualizing the Illness Trajectories of the Elderly with Respiratory Diseases

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Keywords. Respiratory diseases, illness trajectory, the elderly, nursing care plans

Introduction

Respiratory diseases are one of the major threats to the health of the elderly. Thus we have developed a visual tool called "clinical process chart (CPC)" to describe the illness trajectory of the patients, which assists nurses in making decisions for care.

1. Methods

An expert committee of four nurses specializing in respiratory care, gerontology, rehabilitative care or nursing informatics developed the CPCs based on the empirical data and literature review, focusing on two infectious diseases (community acquired pneumonia and aspiration pneumonia) and two non-infectious ones (chronic obstructive pulmonary disease and lung cancer).

2. Results

For these diseases, the CPCs shared four phases in common: risk phase, onset of illness, medical/surgical interventions and end-of-life phase.

As the infectious diseases were often reversible, the CPCs showed the cycle of the first three phases above with a certain chance of recovery. In contrast, as the non-infectious diseases were irreversible except for some cases of lung cancer, there were repeated exacerbations and remissions finally reaching to the end-of-life phase.

3. Discussion

The CPCs are useful for showing the illness trajectories of the patients with four respiratory diseases. They may provide nurses with better overviews of the patients' needs and thus help them make better decisions in giving care. Since these CPCs are conceptual models at the moment, we need to test their validity in clinical settings.

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Nearly All Students and Patients Use the Internet to Search for Health Information: Results from a Scandinavian Study

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Keywords. Health information, Internet, patients, students

Introduction

The Internet has become an increasingly important source of information about health and illness. While more information is becoming freely available, we need to know whether patients and the public actually make use of this information.

1. Methods

A questionnaire was distributed to medical students, students of sports, and to patients suffering from eating disorders. Respondents were recruited from academic and health institutions in Norway and Sweden. They were asked whether or not they had used the Internet to find information about health or illness. Responses were analysed with a Chi-square test.

2. Results

Of the 360 (284 students and 78 patients) that answered the question, 339 (94.2%) had used the Internet to search for information about health or illness. There was no significant difference in use between the students and the patients (d.f.=1, p=0.157).

3. Discussion

The study shows that patients were as active as students in using the Internet to find health-related information. Health authorities should recognize the importance of the Internet also for patients currently in treatment and make active use of the Internet in giving appropriate health information to patients and the public.

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A Model for Data Integration into a Regional Research Platform

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Keywords. Research platform, architecture, PEHR, secondary use

Introduction

The University Hospital Heidelberg is implementing a regional research platform (RRP) to support public health researchers evaluating and analysing 38 cross-institutional quality indicators. This work describes the definition and implementation of patient controlled data flows from a regional cross-institutional personal electronic health record (PEHR) to the RRP.

1. Methods

First of all, relevant data sources were identified and analyzed concerning data quality, representation of data and interfaces. Second an integration concept was outlined.

2. Results

Two standardized data transfer options to the RRP were identified. Most data are transferred from the PEHR using triggers and a pseudonymization service during the ETL process. Other data sources can send data via the pseudonymization service manually. The architecture of the RRP is standardized and based on IHE Profiles.

3. Discussion

The concept is rigorous but the suitability of the triggers has to be still tested. Moreover it has to be evaluated which types of format could be used for a proper pseudonymization process.

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Nursing Students' Technology Use Behaviors and Innovativeness towards Mobile Learning

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Keywords. Nursing, Mobile learning, Personal innovativeness

Introduction

Studies have shown that personal innovativeness and students' readiness are important variables in the new learning environment involving information technology. It is important for researchers to investigate these variables before deciding to implement mobile technologies for learning purposes. The objective of this study is to assess nursing students' current mobile device use behaviors and personal innovativeness for m-learning.

1. Methods

A questionnaire survey distributed to 436 nursing students, a total of 387 questionnaires were returned, yielding 89% response rate. The questionnaire consists of questions related to students' demographic information, mobile phone features and usage, and personal innovativeness.

2. Results and Discussion

The device that most owned by respondents is mobile phone (75,4%), followed by laptop PC(48,2 %) and smartphone(35,0%). More than 80% of the respondents have internet connection in their mobile phones. Social networking and information searching are most common internet applications used in mobile phone. For educational purposes, respondents prefer laptop PC, smart phones and mobile phones respectively. Nursing students have moderate level personal innovativeness (3,70±0,86) and who have high innovativeness tend to have high computer skills and prefer smart phones for educational purposes($p<0,05$).

M-learning has a huge potential to transform and revolutionize the learning process. This study showed that nursing students have personal innovativeness and are ready adopt m-learning as an integral part of their learning process.

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An IT Platform for Systems Medicine

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Keywords. Systems Medicine, Personalised Medicine, Medical Informatics

Introduction

The development of many common diseases cannot be explained by single factors but has multiple and complex causes. Further, patients have individual aetiologies and (genetic) preconditions leading to a differentiation of disease development. Systems Medicine (SM) tries to cope with these multidimensional problems by providing personalised treatment based on an integrated view on patient and disease specific data. This complex data integration task needs support by dedicated Medical Informatics methods and tools. Thus, our aim is to develop a prototype IT platform for SM.

1. Methods

Multiple myeloma (MM), a rarely curable malignant disease of clonal plasma cells, was chosen as model disease for our development. We develop a data management concept on five layers: 1. original data (-omics, clinical, imaging), 2. aggregation and consolidation, 3. data mining, correlation and, exploration, 4. visualisation 5. long-term storage and archiving. These layers have to be established for two application areas: biomedical research and individualized therapy.

2. Results

We are developing an IT-system based on a model for MM derived from four genomic and 14 phenotypic data sets. The model is applied to data of new patients. Results are visualised to support clinicians deciding on best treatment with respect to anticipated side effects and response to treatment. A score for prognosis is under research.

3. Discussion

Our generically designed IT-architecture for SM can be transferred to diseases other than MM and could be used in clinical practice in future. When supported by adequate IT-systems, SM will have significant impact on the future of medicine as a whole.

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INTERACCT: Serious Game Performance as Medical Condition Indicator

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Keywords. Health Games, Exergaming, Health Monitoring, Gamification, EHR

Introduction

The goal of the project is to let medical experts derive changes in young leukemia patients' (in after-care phase) health status by measuring their performance in specially developed digital games, combined with data entered into an electronic health record. Different game concepts should address different complication patterns: concepts include concentration measured by puzzle games, agility and endurance measured using motion capture, and games to support behavioural change of activities like fluid intake or medication compliance. Game performance data as well as data entered into the *EHR* is joined in a comprehensible web-based data evaluation platform for medical experts.

1. Methods

The design process of *INTERACCT* is iterative and combines the approaches of explorative design and design thinking. The software development process is based on SCRUM and user-centered design (UXD). An understanding of the target demographic is supported by a quantitative survey and series of qualitative explorations.

2. Results & Discussion

Game prototypes are under development (a game to encourage fluid intake; a puzzle game; a physical exercise game using *Kinect*), a first EHR data evaluation platform prototype was already developed, tested and evaluated.

The scientific challenge is to successfully derive reliable health data from game scores, as well as finding game content and mechanics to address the heterogeneous (regarding social class, age, ethnicity and gender) target group.

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Exploration of novel data sources in electronic infection detection

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Keywords. Infection Control, Cross Infection/methods, Automatic Data Processing.

Introduction

In the last decade more electronic detection systems for healthcare-associated infections (HAIs) have used novel sources of electronic patient data, such as clinical patient data, biochemical test results, and electronically available physician reports..

1. Methods

We used the PubMed service to search literature describing electronic HAI detection systems published between January 1st, 2006 and December 31st, 2012 that used at least one of the aforementioned data sources. Titles and abstracts were evaluated independently by all authors and included by majority wins consensus. Systems were compared using sensitivity and specificity performance metrics.

2. Results

The search generated 440 electronic references. After initial exclusion (no electronic system, n=312, not using aforementioned data, n=118), eight were selected for this review. Reported sensitivities were 86-100%, while specificity ranged between 47-100%. Results also show that using more data elements improves both sensitivity and specificity.

3. Discussion

The use of novel data sources in infection control has led to electronic systems with high sensitivity in infection detection. Given that the use of more data elements increases both sensitivity and specificity, combination of old and new data sources is likely to increase the performance of electronic infection detection even more.

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Designing a competency-based MOOC to facilitate EMR usage

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Keywords. EMRs, MOOC, Mobile Learning, Competencies.

Introduction

Despite the significant benefits of electronic medical records (EMRs) there are healthcare organizations with low EMR acceptance rate by healthcare professionals. EMR adoption may be enhanced by providing appropriate training to healthcare professionals. MOOC technology can facilitate the creation, distribution and use of knowledge. This paper focuses on empowering EMRs adoption by healthcare professionals through a competency-based MOOC that defines desirable competencies of healthcare professionals and that can be embedded into an EMR.

1. Methods

The design stages of a competency-based MOOC embedded into an EMR are:

Stage	Task
1	Define the target audience and groups
2	Analyze learning needs and goals
3	Identify the abilities/skills needed of groups of healthcare professionals
4	Explicitly define the required competencies and their components
5	Develop instructional strategies, matching competencies of healthcare professionals and their components
6	Define milestones along a development plan for the competencies and the overall training program
7	Plan the instructional design for the groups of healthcare professionals and develop the courses
8	Select social media tools according the needs of healthcare professionals
9	Ensure that resources are mobile accessible
10	Design an outcomes evaluation of the MOOC

2. Results

The main benefit of the proposed approach is the ability to train many healthcare professionals simultaneously. The time needed from healthcare professionals to perform tasks is reduced and efficiency of healthcare delivery is improved.

3. Discussion

Currently, MOOC design is at an advanced level and its incorporation in a prototype EMR is imminent and will be evaluated in the real world by healthcare professionals.

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Systematic Ski Injury Registration using a Digital Platform

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Keywords. Digital Registration, Skiing accidents, digital tool

Introduction

Registration of accidents in alpine resorts is to our knowledge done in a paper format. This results in late submission and poor flow of patient related data between healthcare workers in the primary line of treatment. We aim to develop a digital registration system for skiing accidents used by all levels in the primary chain of acute treatment. It is an application for a mobile device to be used by the ski patrols and at the doctor office. It has bin discovered a need for better handling of ski injury data when doing research on ski injuries at a norwegian ski resort. The research showed a underreporting of potential severe injuries by approximately 50%, due to the limitations in a paper based system. To our knowledge, there are no digital registration systems that collects data and transfer the data in a secure way with inn the chain of acute treatment.

1. Methods

Thru review of existing approaches on indexing and retrieval of textual data and background communication systems we develop a pilot database and a user interface model (UI). Variables to be registered on the UI: Time and GPS location of injury, gender, age, nationality, equipmentproperties, injured bodypart(s), use of protective equipment, trauma-mechanisme details (slope, speed, collision) and self-estimated level of skills. In the end we will implement and test the integrated model measuring skipatrol registration time in comparison with the goldenstandard, paper and pen.

2. Results

Phase 1 is completed. Phase 2 with the development of a pilot database and a user interface is in progress and will be ready august 2014.
An automated and intelligent registration system that addresses the drawbacks of the current approach is needed in order to enhance flow of information and save time by the partners in the chain of treatment when accidents happen.

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Future Trends in Picture Archiving and Communication System (PACS)

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Keywords. 'picture archiving and communication system', PACS, Future trends, next generation, Organizational efficiency , productivity, clinical practice, evaluation, improvement, cloud computing, information storage and retrieval, ubiquitous .

Introduction

At present, Picture Archiving and Communication System (PACS) is used to replace hard copy based film with filmless environments by acquiring, storing, transmitting, and archiving medical images electronically. Current PACS has many limitations. Therefore, an investigation through a literature survey is required to determine traditional PACS limitations and how to overcome with the most modern technical solutions. The next generation of PACS must solve the existing problems of PACS and enhance its functionality to reach maximum potential.

1. Methods

The systematic search was carried out in January 2014. A total of five databases were searched including Science Direct, Springer Link, Scopus, CINAHL Plus, and Google Scholar. Out of 202 publications, 15 articles were duplicated, and 55 articles were included in the review. The data was analysed using thematic analysis.

2. Results and discussion

The literature search shows that first generation PACS has many limitations. Second generation PACS has proposed many advanced solutions. Current implementations of PACS tend to limit access to the hospital or office workstation, however with web based solutions; access may be opened to multiple hospital sites, home, or even mobile access.

It is widely recognised that PACS has limitations. We have identified themes that when incorporated will enhance the functionality of PACS.

This review provides insight into the developments of PACS that vendors and medical institutes should consider for future implementation and teaching needs.

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NLP-based Information Retrieval from Vigilance Reporting Databases

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Keywords: Vigilance, Natural Language Processing, Named Entities Recognition

Introduction

The EIPAS project aims at developing an innovative cross validation vigilance platform for medical devices, able to take into account direct and indirect information and initiate unsupervised alarms sent to medical staff. In this development phase, the EIPAS NLP (Natural Language Processing) engine is mainly focused on retrieving information from direct sources such as vigilance reporting databases (VRDs).

1. Methods

EIPAS NLP engine is constructed with the goal of providing structured data related to medical devices' adverse events, by extracting the appropriate information from un/semi-structured vigilance reports. The general architecture of our system is composed of the basic modules of Name Entity Recognition (NER) enhanced by an ontology. NER involves five sub-modules: English Tokeniser, Gazetteer, Sentence Segmentation, POS Tagger and Annotation Pattern Engine enhanced by the EIPAS ontology.

2. Results and Discussion

In order to test our NLP engine we examined its ability to extract the desired entities such as manufacturer, model and serials which is related to the Final phase of the EIPAS Engine (phase of *entity extraction*). The preliminary results show that EIPAS engine has high success rate in detecting and separating the interesting section of the vigilance report related to the medical devices. On the other hand the results indicate the increased complexity and diversity of the data particularly with regards to the manufacturer, the recalled models and serials. It is expected that the proposed project through the design, development and implementation of modern ICT tools, will create a prototype system, capable of providing critical, on time and customised information to health care institutions, in addition to the existing traditional Systems.

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An Algorithm Enhances Fasting Plasma Glucose based Diabetes Screening Using Simple Patient Information

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Keywords. Diabetes, Screening, Fasting blood glucose

Introduction

We recently showed how screening with HbA1c could be improved by systematically adding simple healthcare information.2 However, there are parts of the world where the costs of providing the HbA1c assay exclude its routine use and in these circumstances, the fasting plasma glucose (FPG) test is the cheap alternative to screen for diabetes. We present a novel and simple model to screen for type 2 diabetes using FPG and additional patient information.

1. Methods

We used data from multiple years of the National Health and Nutrition Examination Survey (NHANES) from 2005 to 2010 where FPG, oral glucose tolerance tests (OGTT) and additional healthcare data were available. Logistic regression classification was used to model and detect undiagnosed diabetes in the general population.

2. Results and Discussion

In all 5381 participants were included in this study. This cohort included 7.5% undiagnosed type 2 diabetes patients corresponding to 404 participants. The model increased performance of screening compared to screening only with FPG. At a specific cut-off point our model yielded a sensitivity of 0.81 (CI 95, 0.78-0.83) compared to 0.74 (CI 95, 0.72-0.75) of FPG, when both methods had a specificity of 0.84.

This proposed model could possible improve screening for type 2 diabetes using FPG in areas of the world where asses to the HbA1c assay is not available due to high costs.

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A Semantic Interoperability Framework for Facilitating Cross-Hospital Exchanges

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Keywords. Semantic interoperability, information model, health information systems, ontology, interface terminology, reference terminology.

Introduction

Health Information Systems (HIS) are complex, heterogeneous and not sufficiently communicating especially at the semantic level. We propose a semantic interoperability framework for clinical information exchange between heterogeneous HIS.

Methods

The semantic interoperability between intra/inter-organizations for exchanging clinical messages/documents consists in the transaction of HL7 messages/documents (orders, lab results) and is achieved via proposed semantic services based on reference clinical information templates and reference terminologies that can be processed by HIS.

Results and Discussion

We demonstrate our approach by implementing a prototype of a cross-hospital document exchange module, adapted to local health professional needs and able to maintain the usual usage of local HIS. As perspectives, the proposed framework will be evaluated beyond the telepathology pilot and used in other contexts to provide the capability to (i) electronically exchange any type of clinical information among disparate HIS while maintaining the meaning of the information, (ii) exploit the meaning of the information for providing customized decision support, (such as context-based image analysis in telepathology or teleradiology).

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An Extensive Database of the Correlations Between Early Life Events and Ageing Outcomes

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Keywords: Biomarkers, Genetic Factors, Environmental and Lifestyle Factors, Metabolomics' Databases, Association of Data, Integrated Platform

Introduction

There is growing evidence that developmental and biological disruptions during the early years of life can lead to age-related diseases. By focussing on molecular mechanisms involved in both early life events and ageing we will find genes, metabolic and lifecourse pathways that are relevant in both early development and adult life. We assess the impact of the identified biomarkers on health benefit and the feasibility of their use within the context of the ageing European.

1. Methods

First methodological step was to perform a round of interviews with the scientists of the project in order to define the "user needs" and type of data to handle. Second step was to perform an extensive research on existing bioinformatic databases in order to study the way corresponding data are being represented by other experts in the field. Next step, currently undergoing, is to design static and dynamic mockups and use this as the working document for a second round of interviewing the users.

2. Results and Discussion

We will implement an integrated platform that will make available to its users an extensive database of the correlations between early life events and ageing outcomes, linking datapoints to methylation, metabolomic, genetic and post-translational modification (PTM) results, allowing future comparison with data derived from other studies. This database will hold all of the *first level associations* that will be discovered and will serve as the projects' repository. By understanding the molecular and environmental factors that determine healthy ageing, we will contribute to EU citizens leading healthy, active and independent lives.

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The Need for Standardization of Allergy Information in Electronic Medical Record Among Japanese Hospitals

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Keywords. allergy, adverse drug event, medical safety

Introduction

Among potentially fatal adverse drug events (ADEs), 6%‑10% are due to allergies. Thus information of such events is critical.

1. Method

A Japan nationwide survey with a 43-item questionnaire about allergy was conducted in 213 hospitals with 600+ beds between Oct. 2012 and March 2013, including 50 public university, 40 private university, 59 public and 64 private hospitals.

2. Results and Discussion

Of the 213 hospitals, 76 (35.7%) responded: 29 public and 11 private universities, 18 public and 18 private hospitals. The mean (± standard deviation) number of beds was 796 ± 191. EMR was implemented in two-thirds hospitals. The others relied on CPOE with paper-based records. Allergy information was displayed as an icon with text in 50% of the cases and icons only in one fourth. The severity of ADE was not described in the database of 72% of the hospitals, while 12% ranked the severity in two categories, heavy or mild, and 16% in multiple categories. Around 25% of the hospitals had a system preventing doctors from ordering incorrect drugs, whereas the others had only an alert. The alert parameters were replaceable according to the severity of the allergy in only 6% of the responding hospitals.

We hope that this report will serve as a foundation on which a consensus can be established for standards on how to represent, code, handle and interact with such alerts.

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A Medical Intelligent Module as part of a Tele-monitoring and Diagnostic System Targeting Fall Prevention

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Keywords. Fall risk assessment, tele-monitoring, falls prevention, Medical Business Intelligence

Introduction

Fall prevention policies have often low impact due to their lack of usability and adaptability. KINOPTIM[2] delivers an innovative service-oriented architecture fall prevention service based on tele-monitoring (TM), Rehabilitation and Gaming (RG) and Medical Business Intelligent (MBI) subsystem.

1. Methods

MBI acts as the main repository, middleware and decision support system (DSS), embracing *rules and workflows*. MBI provides alerts and DSS utilizing data-driven techniques (artificial neural networks) as well as rule-based techniques (Bayes network). It assists physicians to design more efficient rehabilitation plans in terms of sets of game sessions and postures provided by RG, taking into account multiple inputs such as the current clinical status of the user and the TM subsystem output. Finally, MBI delivers data analysis modules to evaluate the information of game sessions.

2. Results and Discussion

The expected results of the system, is the continuous and efficient operation of the TM, RG and diagnostic subsystem for fall prevention, as well as the appropriate handling of the acquired user and context data. MBI is currently under development and remains to be integrated with the other KINOPTIM subsystems. It will be tested with a number of 50 end users (elderly people) and their physicians/carers.

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[1] Corresponding Author
[2] A 4-year Marie-Curie Project (FP7-PEOPLE-2012-IAPP) started on March 2013

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TrendMD: An academic content discovery platform

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Keywords. Informatics, bibliometrics, content marketing, content discovery

Introduction

With over 2,000 new publications added across 33,000 journals daily, it has become impossible for readers (e.g. physicians, scientists, etc.) to discover relevant peer-reviewed content. Similarly, for researchers, it has become equally as difficult to get their content discovered and cited.

1. Methods

TrendMD is built on two principles – filters and social ranking. Our filters consist of machine-learning based, specialty-specific algorithms. Applying filters allows us to organize and sort academic articles. Once filtered, TrendMD uses social analytics and collaborative filtering techniques to rank academic articles.

2. Results and Discussion

We use our methodology to power a content recommendation widget to be placed by publishers next to STM articles that generates related articles recommendations based on content similarity, click behavior, and social media buzz, to increase engagement, promote content from publishers' own new or lesser known journals, and generate additional revenue for publishers. Content producers (researchers, pharmaceutical companies, publishers), use TrendMD to promote their papers, and drive traffic to their peer-reviewed content.

So far, the widget has increased engagement on the Journal of Medical Internet Research (jmir.org) by 7% over a 4-week period. Going forward we will conduct randomized split testing of article pages; some article pages will contain our recommendation widget, others will not. This will allow us to determine to what extent our widget keeps readers reading on the Journal of Medical Internet Research. We will also conduct similar split testing for variables in the widget (i.e. to what extent different variables predict engagement with articles).

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Reduce Medication Errors by Applying a Probabilistic Model: A Pilot Study

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Keywords. Data mining, association rule mining, clinical decision support, patient safety, medication errors, probabilistic model.

Introduction

Medication errors are common, life threatening, costly but preventable. This study was implemented a probabilistic model that can reduce medication errors.

1. Methods

The association rules mining techniques are utilized for 9.6 million prescriptions from 2007 to 2011 of three hospital claimed database. The dataset included 68.6 million ICD9-CM diagnoses codes and 91.2 million ATC medications codes. Disease-Medication (DM) and Medication-Medication (MM) associations were computed with their associations' strength which being referred as Q values. By considering the number of DMQs and MMQs, we developed the Appropriateness of Prescription (AOP) model that can determine the appropriateness of a given prescription. The AOP model was implemented in CPOE system at TMUH from May 27 to Jun. 1, 2013 via a web-service. The uncommon prescribed medications was shown as a reminder message in CPOE system.

2. Results & Discussions

The web-service was successfully predictive for 856 patients with a total 1,056 prescriptions in CPOE system. Out of 1,056 prescriptions, the web-service triggered 8 reminders, in which 37.5% of prescriptions were considered correctly classified as "inappropriate".

The probabilistic model was developed in this study that is able to detect sensitively the inappropriate medications prescribed via web-service in CPOE system. The AOP model be able to improve patient safety and quality of care as well as to enable better decision support and quality measurement.

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Modeling Requirements for Cohort and Register IT with 3LGM²

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Keywords. IT-Requirements, Catalog of Requirements, Modeling, 3LGM², Cohort Studies, Register, IHE

Introduction

The project KoRegIT (funded by TMF e.V.) aims to develop a generic catalog of requirements for cohort studies and registers. The catalog supports such kind of research networks to build up and to manage their organizational and IT infrastructure. The poster shows how to handle the nearly 200 use cases from the given text catalog, which are partly connected to each other, to visualize and analyze them e.g. for better understanding and optimization. The goal of this effort is to make the requirements of 3 investigated research networks based on this catalog comparable, find simplifications and support the information manager in planning and development.

1. Methods

The catalog of requirements is transformed into a 3LGM²-model as a reference. The actual state of 3 research network is modeled, too and then analyzed.

2. Results and Discussion

On basis of the derived model it is possible to analyze and compare the 3 investigated research networks. The modeling approach helps to reduce the complexity of the initial text catalog and has furthermore advantages in managing the IT infrastructure.

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Adherence to Prescribed Cycling Speed in Remotely Controlled iBikE System

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Keywords. Personal health systems, telerehabilitation, self-management

Introduction

Deconditioned older adults or frail elderly may benefit from passive exercise mode which can be subsequently enhanced by an active exercise program. The goal of this project was to compare adherence to prescribed cycling speed in remotely controlled interactive Biking Exercise System (iBikE).

1. Methods

The functionality of speed adherence between the active mode and the passive mode guided by a remote server was compared by investigating differences between the target speed and the performed speed in 8 healthy volunteers.

2. Results

The passive mode resulted in higher adherence with cycling speed prescription.

Table 1. Coefficient of variation (CV) of cycling speed for active and passive modes (%)

Mode	Mean	SD	Mode	Mean	SD	Mode	Mean	SD	Mode	Mean	SD
A120	9.62	6.30	P120	3.34	0.66	A15	15.71	10.29	P15	5.51	2.34

A120=CV(S) of all 120 seconds data for all 8 volunteers in the active mode, P120=CV(S) of all 120 seconds data for all 8 volunteers in the passive mode, A15=CV(S) of initial 15 seconds data for all 8 volunteers in the active mode, P15=CV(S) of initial 15 seconds data for all 8 volunteers in the passive mode, SD=standard deviation

3. Discussion

Our results indicated that passive exercise may be particularly attractive option in individuals who may have safety concerns such as frail elderly, patients with cardiovascular conditions or people with other contraindications for excessive exertion during exercise. Older adults with cognitive deficits may also benefit from the passive exercise mode.

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Monitoring System of Disease Structure by Integrating HIS and "AEROS" in Japan

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Keywords. Secondary use of data, HIS, AEROS, Monitoring system

Introduction

The scope of the study is to construct monitoring system for disease structure of the specific regions in varying atmospheric environmental factors, and to confirm impacts of environmental change on humans, particularly exposure to pollution. Generally in Japan, not only the 'first hand' clinical data is prohibited, but also the secondary data is restricted. Furthermore, the secondary use of data is at low cost but includes statistical errors. Our monitoring system involves reducing these errors.

1. Methods

In the constructed system, clinical data in each HIS(Hospital Information System) and AEROS(Atmospheric Environmental Regional Observation System), are duly matched, integrated, and analysed as retrospective. In our case, HIS variables are ages, sex, and medications to asthma patients (n=8819). AEROS variables are SPM(small particulate material), PM2.5, SO_2, NO, NO_2, etc. Matching variable is the date of records. To check the validity of the system, the logistic regressions for reducing errors are applied for asthma incidence against air pollution data from AEROS.

2. Results

Our monitoring system shows the good agreement of prospective study result of the relationship between the environment data and asthma incidence.

3. Discussion

We have further prospect that, with the evaluation system to accumulate medical treatment information of a target population, one can duly evaluate risk factors under exposure to environmental variations.

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Evaluation of a Decision Support System for Selecting Appropriate Radiological Test

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Keywords. Evidence-based medicine, appropriateness, decision support, radiology

Introduction

Data about the excess and inappropriate use of radiological tests is alarming and triggered the systematic research to overcome the problem. Decision Support Systems (DSS) are considered to be one of the beneficial solutions for the issue.

1. Methods

An XML based DSS for assisting physicians on appropriate test selection is developed and evaluated. American College of Radiology appropriateness criteria (ACRAC) was used as the base. Before testing, scenarios were given to the physicians and radiological test decisions are collected. Then, the physicians were asked to evaluate another scenario sets and advised to use the system when necessary. Results were compared.

2. Results

Statistical analysis showed that the decisions with the system support significantly increased the level of appropriateness. Moreover, the system was evaluated in terms of usability and the evaluation showed that the system has high usability.

3. Discussion

Radiological order appropriateness is an important concept that needs to be improved in medical practice. DSSs, which are based on ACRAC or other evidence-based criteria, will be beneficial in terms of improving the rate of appropriate radiological test orders.

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Mobile Learning Readiness of Nursing Students

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Keywords. Mobile learning, nursing students, readiness

Introduction

Mobile learning (m-learning) creates completely new communication and interaction possibilities in teaching and learning. The purpose of this study was to determine the current usage of mobile devices, preferences of m-learning environments and examine the readiness of nursing students in a public university prior to embarking on m-learning.

1. Methods

The survey conducted in the first quarter of 2013 with 387 participants. The questionnaire includes questions related to the willingness to use mobile device, preferences of materials and devices for m-learning, perceptions about m-learning and readiness to be a mobile learner.

2. Results

According to the survey findings, the ownership rate of the devices of nursing students was mobile phone (75.4%), laptop (45.2%), smart phone (35.0%), respectively. The most demanding device was be found as laptop (42.4%) within six months and they would also prefer to mainly access online content using these devices (48.4%). It is also learned that higher class students more willing to use a smart phone for learning activities than lower class students (p=0.016). It is also concluded that female (female: 58.6% male: 45.5%; p=0,012) and higher level students (p=0.03), generally, viewed m-learning as more usable and beneficial.

Respondents also declared some of the issues currently faced as limitations smart phones, such as battery life (40.5%), the screen size (32.1%), and the cost of connection (28.8%). The study revealed that from the sampled potential learners, 67% of students are ready to learn through mobile devices, while one of every four students has concerns to use m-learning.

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In addition the factors related to readiness to use m-learning was examined via multivariate analysis techniques. Grade (4th grade readiness higher than 1st grade; p=0.04), perceived easiness of use (p=0.005), personal innovativeness (p=0.023) and self management of learning (p=0.008) are the factors which explain %35 of readiness (Logistic Regression Model χ^2: 89.36; degree of freedom: 16; n: 229; p<0.001; success rate: 78.6%).

3. Discussion

The study highlights the findings m-learning project at the nursing faculty. This research contributes to the body of knowledge in readiness to m-learning and provides a foundation for similar research in the future.

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Game Theory and Radiology

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Keywords. Game theory, radiology, decision-making

Introduction

The applications of Game Theory are common in many fields. However, it is often hard to model actual problems as proper game designs since the definitions of utility and rationality in medicine are highly debatable. The aim of this study is to apply game theory techniques in radiology and provide strategies for better understanding the "appropriateness of imaging" concept.

1. Methods

We defined the most common decision-making problems in radiology. Several crucial decision-making processes in radiology may need successful evaluation and strategy selection approaches in terms of Game Theory. We primarily focused on the concept of "appropriateness of the radiological diagnostic test" and proposed a model based on game theory methodology and strategies.

2. Results

Our approach assigns two players of the radiological diagnostic test appropriateness game as "payers" and "demanders". Payoff matrix model is the basic analysis tool of our model. We included the following factors to the model: clinical impacts, financial costs, harmful effects and demand.

3. Discussion

There are a few studies focus on the conceptual framework of the appropriateness of the tests. Currently, three elements of the conceptual framework for appropriateness are described. However, this framework still needs further research in terms of medical decision-making in order to adopt it to the global scale. In conclusion, game theory is a promising approach to match this aim, as well as the other decision-making problems in radiology.

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rs10739592 is a New Candidate Loci for Type 2 Diabetes Risk in Men

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Keywords. Type 2 diabetes, Plink, GWAS, rs10739592, Affymetrix

Introduction and Methods

Type 2 diabetes (T2D) is a major public health concern which the prevalence is increasing at an alarming rate worldwide. T2D has mostly genetic background. Approximately, 40 T2D susceptibly variants have been identified so far, but they only explain a small fraction of the overall heritable risk. Therefore, we used genotypic data obtained with Affymetrix Genome-wide Human SNP Array 6.0 from The Nurses' Health Study (NHS) and Health Professionals' Follow-up Study (HPFS) cohorts to analyse associated variants and candidate loci for T2D.

Plink software was used for association analysis. Study population included 3,248 (1,769 controls and 1,479 cases) for NHS and 2,391 (1,277 controls and 1,114 cases) for HPFS. SNPs that met any of the following criteria are excluded from the analysis: 1) minor allele frequencies (MAF) <0.05; 2) call rate <95%; 3) P for Hardy-Weinburg equilibrium (HWE) <0.001; and 4) missing rates 0.1. After applying the QC filter, 642,576 SNPs was used.

1. Results and Discussions

The rs10739592, located on chromosome 9, with the lowest P value (2.08E-14) was identified as a novel susceptibility loci for T2D. Its odds ratio was 1.34 and minor allele frequency (G) was 0.49. It yielded 2.84% net reclassification improvement by itself. Distribution density showed that rs10739592 only associated with diabetic males. We found P value of rs10739592 as 1.19E-33 in males. Even though rs10739592 is not mapped to any known gene, it is located between “RAB14: GTPase Rab14” gene and “GSN: Gelsolin isoform b” gene.

rs10739592 could be a new candidate loci for T2D risk in men. Further studies are needed to explore its function and role in the development of T2D.

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What User Characteristics Influence Privacy Expectations from Hospital Information System

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Keywords. User Expectations, Hospital Information System

Introduction

An important aspect of a Hospital Information System (HIS) is protecting patient privacy. The purpose of the study is determining the user characteristics effecting privacy expectation from HIS.

1. Methods

We worked on data from a previously performed user expectation questionnaire of 431 users of a hospital. Thirty percent (136) of the users were randomly assigned as validation group. Education, IS experience, age, attitude towards change, business title, sex and working unit of the hospital were analyzed using CRT (Classification and Regression Trees) growing method.

2. Results

Business title is only determinant of privacy expectation. Physicians and office workers have lower privacy expectation mean score (56.0) than other users such as nurses, biologists and laboratory technicians (62.4). Validation group has similar results.

3. Discussion

Low privacy expectation of physicians and office workers is an interesting finding. This finding may be a reflection of low awareness about consequences of privacy violation. Reasons and solution of this problem should be investigated.

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Evaluation of a mobile EPR system for a new Healthcare Professional in Germany

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Keywords. Electronic patient record, home-visiting nurses, delegation of medical care, field test, mobile application

Introduction

This work briefly introduces the evaluation of the agnes[zwei] app, a mobile electronic patient record system for Android tablets that has been developed as working appliance for agnes[zwei] nurses. Such nurses are a new form of healthcare professional, working as a doctor's right hand with a special training in case-management. The app has been evaluated during a three month field test with six participants comprising approximately 2000 working hours and treating 174 patients (mean = 29).

1. Methods

Beginning and end of the field tests were marked with workshops. During the field test, we performed phone and personal interviews. In the end, a guided group discussion was performed and a questionnaire was handed out to elevate the nurses' opinions.

2. Results

The results of the field test emphasize that (i) following a flexible, user-centred design process is beneficial when developing such specialized ICT tools and that (ii) the usage of tablets as a highly-mobile and light-weight platform is promising in the field of home-visiting medical practitioners.

3. Discussion

Establishing a closed-feedback loop during the implementation helps to identify/satisfy the majority of requirements of different stakeholders and avoids expensive subsequent work.[2]

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[2] For further information about the development process, the applied paradigms and the evaluation results and findings, the interested reader is referred to http://www.dai-labor.de/publikationen/899.

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