

Consent-based Access to Core EHR Information

Collaborative Approaches in Norway

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Keywords

Consent, core EHR, EHR, patient summary, medication, information systems, socio-technical approaches, information infrastructure

Summary

Objective: Lack of access to updated drug information is a challenge for healthcare providers in Norway. Drug charts are updated in separate EHR systems but exchange of drug information between them is lacking. In order to provide ready access to updated medication information, a project for consent-based access to a core EHR has been established.

Methods: End users have developed requirements for additions to the medication modules in the EHR systems in cooperation with vendors, researchers and standardization workers. The modules are then implemented by the vendors, tested in the usability lab, and finally tested by the national testing and approval service before implementation. An ethnographic study, with focus on future users and their interaction with other actors regarding medicines and medication, has included

semi-/unstructured interviews with the involved organizational units.

Results: The core EHR uses the EHR kept by the patient's regular GP as the main source of information. A server-based solution has been chosen in order to keep the core EHR accessible outside the GP's regular work hours. The core EHR is being tested, and the EHR-vendors are implementing additions to their systems in order to facilitate communication with the core EHR. All major EHR-system vendors in Norway participate in the project.

Conclusions: The core EHR provides a generic basis that may be used as a pilot for a national patient summary. Examples of a wider use of the core EHR can be: shared individual plans to support continuity of care, summary of the patient's contacts with health providers in different organizations, and core EHR information such as important diagnoses, allergies and contact information. Extensive electronic cooperation and communication requires that all partners adjust their documentation practices to fit with other actors' needs. The implementation effects on future work practices will be followed by researchers.

cases where the municipality administrates a patient's medication, there were discrepancies in the information about medication between the home nursing care and the patient's GP [2]. A study has indicated that 35% of such errors could be prevented [3]. It is assumed that a considerable number of these medication-related errors are due to faulty or inaccessible drug information.

An increasing number of elderly people live at home and municipal authorities seek to provide them with integrated care. This implies securing both safety, medical treatment, pastimes, bolstering of independence and self-respect, as well as sustenance and cleanliness. Medication, which involves both ordination information, distribution of medication, evaluation and sampling as well as documentation and its coordinative communication, is a significant but yet only a part of employees' daily concerns. The work practices of home care nurses, and those of the other involved parties, are characterized by a hectic pace and the arrival of eventualities that fragment the flow of orderly processes [4].

In terms of keeping their drug charts updated, the clients who live mainly in their own homes pose a large challenge due to the need for collaboration between many actors. While securing consistent information on a patient's medication is in the interest of all parties involved, the sheer number of actors also complicates the issue. As well as involving a variety of units and employees within the municipality's own organization, other actors include private doctors, the county hospital in case of emergencies or planned treatments, pharmacies, the multidose supplier, social security's medication refunding systems, various rehabilitation and specialist facilities, nurses for hire and alarm-call services. Not to discount the efforts of family and friends who

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Introduction

Professor Anders Grimsmo at the Norwegian EHR Research Centre has estimated that medication-related errors cause 190 deaths/

year in Norway (population 4.5 M) and that 160,000 unintended incidents occur outside hospitals every year. The estimates are based on results from [1]. A study in Trondheim municipality revealed that in 50–90% of the

also figure as part of the picture. This plethora of private vs. public and semi-public organizations ensures that electronically based communication and collaboration is a complex challenge and currently virtually non-existent due to both lacking technological solutions as well as suitable regimes of collaboration that may satisfy juridical and privacy concerns. Initiatives to achieve more electronically based communication now appear near fruition, after some 20 years of diverse efforts, in the shape of a core EHR.

Objectives

In order to reduce the number of drug-related unintended incidents, Trondheim municipality initiated a drug chart project based on a core EHR. The project focuses on a group of mostly elderly people (age 80+) living at home but with an extensive need for healthcare services.

The project was launched as a joint initiative between the municipality of Trondheim, the Norwegian Centre for Informatics in Health and Social Care (KITH), the Norwegian EHR Research Centre (NSEP), and the regional ICT unit of the Regional Health Authority of Mid-Norway (HEMIT). KITH has a national responsibility for standardization of electronic cooperation in the health and social sector in Norway. The project is linked to the Norwegian government's national strategy for e-Health, Teamwork 2007 [5].

The collaboration between diverse types of end users, various providers, standardizing and funding bodies along with actors who hold supplementing competence in areas like medicine, ICT and research related to socio-technical studies on information infrastructures has been assumed to provide an arena for creative processes whose results may be reused by the more than 400 other municipalities in Norway. In addition to reuse of results at a national level, the project is also linked to international standardization and research with basis in the European Commission's eHealth action plan [6]. Actors from KITH and NSEP have ongoing collaboration with European research and standardization initiatives related to patient summary, allowing for mutual exchange of information in a wider context. Development of national stan-

dards has been limited to areas where international standards did not cover the project's requirements.

Although the initial objective was to reduce the number of drug-related incidents at a local level, work so far, including the study on work practices, has indicated that there is a need for a core-EHR solution which could be used for more purposes than drug information alone. A wider objective is to provide a basis for a more generic Norwegian core EHR.

Methods

"Action research aims to contribute both to the practical concerns of people in an immediate problematic situation and to the goals of social science by joint *collaboration within a mutually acceptable ethical framework*" ([7], p 7). The described strategy for establishing both technology and suitable collaboration, for securing updated information for the municipality's clients, may be seen as an example of action research. While the government's and other actors' motivation might espousedly be one of pragmatics based on lessons learned, the resulting project and its wider interaction fits the theoretical definition of action research. Additionally, the wide participation aiming to bridge and negotiate the differences and requirements of a wide range of diverse actors represents a socio-technical approach to systems building characteristic of insight from research on information infrastructures and their establishment [8].

The main author has followed the project as a case from the initiation. The project has used a development method which has been applied with success by several cooperative projects within the health sector in Norway in recent years. End users develop requirements for additions to the EHR systems that can facilitate the collection of the information necessary for work practices. This is done in cooperation with developing providers and vendors, researchers and standardization workers. New standards, or extensions to existing ones, are developed by KITH based on the users input. Vendors subsequently develop new EHR modules based on the requirement specifications. The modules are then tested in the usability lab at NSEP, and

the vendors' implementation of the communication standards are tested by the national testing and approval service at KITH. The vendors are refunded only 30–50% of their development costs via public funding. The remaining development costs are meant to be covered by customer licenses when the project is spread to new users.

The cooperation with NSEP and the University of Technology and Science in Trondheim (NTNU) has also provided opportunity for the second author to follow the project as a participant of an ethnographically inspired study to gain insights into the future users' daily work practices, routines and challenges. In particular, focus was on their interaction with others in regard to medicines and medication. The study included semi-/unstructured interviews with nine organizational units collaborating on medication of the client, several of which will participate directly in the pilot project. The other units will be implicated indirectly.

Results

The Core EHR Drug Chart

The core EHR uses the EHR kept by the patient's regular GP as the main source of information. All Norwegian healthcare providers are obliged to forward any relevant health information to the patient's regular GP unless the patient explicitly refuses. Drug information is automatically copied from the GP's EHR to the core EHR on a separate server that handles the requests. A server-based solution has been chosen in order keep the core EHR accessible outside the GP's regular work hours.

The core EHR will be updated automatically when pharmacists, hospitals and other healthcare providers send information to the GP. Information about medication that is changed or new will be transferred from the hospital to the GP when the patient leaves the hospital. Information about cures and medication used only at the hospital will not be considered part of the core EHR, and will not be sent. The patient's GP is responsible for the core EHR and will check all information received from other healthcare providers in order to detect any medication inconsistencies before it is accepted as part of the core EHR.

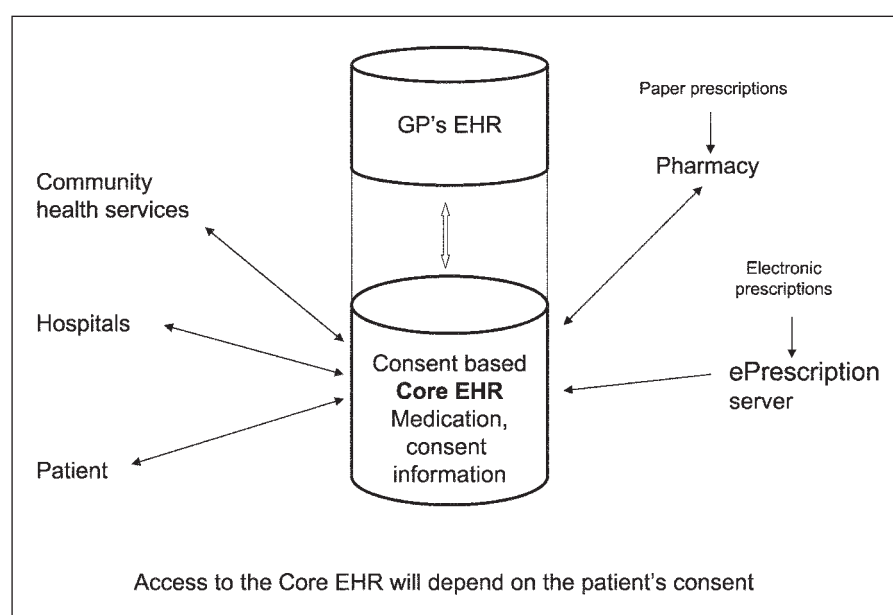


Fig. 1 Core EHR^a

Actors will receive updated drug-information based on requests sent to the core EHR system. Each request is automatically checked against the set of distribution rules and if the request is covered by one of these rules, a message containing the requested information is automatically returned. Medication messages that have not yet been handled by the GP will also be visible, but will be clearly marked as unread.

The patient and his/her GP jointly decide the distribution rules to be followed:

- distribution rules are partly based upon ENV13606-3;
- who may receive healthcare information;
- explicitly named healthcare professionals to be included or excluded;
- healthcare professionals having a specific role;
- why they need to receive healthcare information.
- A set of standardized request options is used to specify why the requesters need the information.
- The patient's consent is either given for a specified period of time or for a specific period of care.

When the GP registers the patient's consent, the patient will also be provided with a document that shows the actors that are given access to his/her drug chart. The patients may at any time change or withdraw their consent, or change the distribution rules.

To comply with Norwegian legislation, the core EHR is updated by messaging. Standardized messages will be implemented by the vendors. Access to the core EHR can also be provided by web-services.

Discussion

All EHR-Systems Need to Communicate with the Core EHR

To achieve an up-to-date drug chart, it is also necessary to involve all the EHR-system vendors related to all the actors that contribute input to the chart. This means that vendors of all the communicating EHR systems had to be included in the development project, ranging from hospitals to GPs and home care nursing facilities. The inclusion of the pharmacies was also attempted, but although positive their participation has been delayed.

All the hospitals in Regional Health Authority (RHA) Mid-Norway are using the same EHR system from Siemens. The EHR systems in the region are all operated from the

same location, but the hospitals' databases are kept separate due to Norwegian legislation. Doosselaere et. al. [9] give an overview of issues related to legal and regulatory barriers or gaps that may exist between current EU-regulations and the need for sharing information in eHealth applications. Norway also has challenges with legislation within its own borders. Although it would be technically possible to share EHR information between the hospitals, this cannot be done without the patient's consent.

The municipality of Trondheim uses an EHR system in community care from the vendor TietoEnator. This system is in use at both nursing homes and homecare by both administrative workers and healthcare providers.

The GPs in Trondheim have been using EHR systems for more than a decade. They do not keep paper records any more, and rely solely on the electronic record. The GPs use their EHR system actively while the patient is in the office. Thus their systems need to be easy to use, and new functionality must only be added in a way that does not force changes in work routines without also providing identifiable benefits. There are currently EHR systems from two vendors, Profdoc and Hove Medical in use by the municipality's GPs.

The project involves many actors and also covers the development of new standards. This adds to the complexity of the project, but the project would on the other hand also not be possible to sustain as an isolated pilot. Ideally one would like to develop a small standalone pilot as a starting point, but drug charts are already in use as a module in all the vendors' EHR systems. The issue is not lack of drug charts, but rather the lack of coordination between them. The existing drug charts may be regarded as pilots that demonstrate a need for better integration by involving all the implicated actors from the set out.

From Local Project in Trondheim to SUMO

Stavanger and Tromsø municipalities also initiated local drug chart projects at the same time as Trondheim. Tighter cooperation between the projects was considered to be beneficial in the long run, although this would also to some extent cause delays. De-

^a Based on a model by Torbjørn Nystadnes, Norwegian Centre for Informatics in Health and Social Care (KITH).

velopment of common standards and implementation of the same standards for all EHR vendors would be highly advisable, both from the vendors', users' and the authorities' perspectives. The project in Trondheim municipality only counted for one third of the EHR-vendors in Norway, but with a joint project between Stavanger, Tromsø and Trondheim all major vendors would be covered. The three projects thus decided on cooperation, and the projects in Trondheim and Tromsø are now using the same core-EHR system. All three projects plan to use the same set of message standards. To comply with Norwegian legislation, the core EHR is updated by messaging. Access to the core EHR can alternatively also be provided by web-services.

An application for funding the EHR-system vendors' development of client modules for interaction with the core EHR was sent to Innovation Norway, and was approved late 2006. The funding was limited up to 50% of the vendors' own cost estimates. The requirements from Innovation Norway were that the implementations should be based on standards and use of the Norwegian Cooperation Architecture [10]. KITH has developed the national cooperation architecture in cooperation with the RHAs, the Directorate of Health and the Norwegian Medical Association. Basic requirements for this architecture are:

- All messaging traffic should use the national broadband infrastructure, The Norwegian Health Net.
- Only standardized messages should be used.
- The vendor's message implementations should be approved by the Norwegian Testing and Approval Service at KITH.
- ebXML framework should be used.
- Application receipts should be sent for all messages.

A project to coordinate the vendors' work, called SUMO, was established in early 2007. The SUMO project has been running a number of workshops with vendors and users throughout 2007. Messaging standards for administration of the core EHR, and exchange of EHR information, have been developed by KITH based upon requirements from users and vendors in the SUMO project. The new messaging standard for communi-

cation between the EHR systems is based on reusable components [11], and will probably prove to be a useful basis for development of future communication standards in Norway. Requirement specifications for the client modules in the vendors' EHR systems have also been developed. The vendors are in September 2008 at a stage where they are implementing the standards and the client-modules in the EHR systems. The project is due to finish in 2009, and the first pilots will be up and running during 2008. The core EHR is already developed, and is scheduled to be tested by Trondheim and Tromsø municipalities.

Implications of the Development Strategy

The project works closely together with the national ePrescription project and other national projects initiated by KS^b, the Norwegian Nursing Association and the Norwegian Medical Association. These projects are strategic and also linked to [5].

It is crucial for the vendors that larger national projects are coordinated and that the same set of standards can be shared and reused. The Norwegian vendors do not want to develop non-standard solutions. The vendors want new modules as part of a standard package, and even if the development of a new module was fully compensated, the maintenance cost would still be high for both vendor and customer if the module did not comply with the installed base.

From the start of the project in Trondheim municipality, the initial project's expected completion date has been delayed with at least a year. This is mainly due to the need for coordination with other projects and national initiatives. The fact that the vendors have a limited number of software releases per year, including that release dates do not match across vendors, has also been a challenge. This has caused individual delays of up to five or six months.

The above illustrates an apparent need for the existence and cultivation of large net-

works of action which coincides with research insights from the development efforts on health information systems through action research in South Africa [12].

Context and Future Work Practices

Other issues to be evaluated are the overall effects of the new systems for the work practices of the various healthcare providers. The core EHR effectively provides a gateway for secure electronic communication on client medication between diverse parties and technological platforms. While this ensures a common location of documentation, it remains to be seen how the various actors will need to adjust their documentation practices in terms of timing their activities as well as tailoring their information in order to ensure usability for the various end users. The standard ensures structured information, but end users, with the help of their own EHR, will still need to 'translate' the information to a form suitable for their own uses. For instance, what the doctor ordines may be substituted by the pharmacy with the synonym-drug they have available, which may result in two pills with another name instead of the original one. The home care nurse may need to alter the timing of dispensing, compared to the doctor's ordination, in order to accommodate their own or a client's timetable. Lessons from the research within CSCW (Computer Supported Cooperative Work) indicates that work processes will need to be continually revised when new technology provides new functionality in interactive contexts. Collaborators will need to develop new patterns of interaction through the new media [13]. The implementation effects for future work practices will be followed by researchers.

Conclusions

The work so far, including the ethnographic study, has indicated that there is a need for core-EHR solutions that can be used for wider purposes than drug information. This is also in line with other European initiatives. Bernd Blobel [14] concludes that establishment of shared care must be supported by distributed, interoperable information systems. New information infrastructures which have grown from regional networks into national net-

^b The Norwegian Association of Local and Regional Authorities (KS) is a national organization for municipalities, counties and public enterprises under municipal or county ownership.

works, like the Norwegian Health Net, provide possibilities for better and more secure communication than few years ago. The health-care providers at different levels do have access to EHR systems, but still the possibilities for exchange and sharing of health information is limited, as also addressed in [9].

The core EHR and the model from the SUMO project can provide a good basis for a more general Norwegian core EHR. The RHA's ICT organization, NIKT, and the Directorate of Health have now initiated projects to evaluate how a core EHR can be established in the years to come. Examples of a wider use of the core EHR can be: shared individual plans to support continuity of care, summary of the patient's contacts with health providers in different organizations, and core-EHR information as important diagnoses, allergies and contact information.

More extensive electronic cooperation and communication, requires that all part-

ners adjust their documentation practices to fit with other actors' needs. The implementations effects on future work practices will be followed by researchers.

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