

The eFOSTr PROJECT: Design, Implementation and Evaluation of a Web-based Personal Health Record to Support Health Professionals and Families of Children Undergoing Transplants

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Abstract. We describe the eFOSTr PROJECT, which has involved the design, implementation and testing of a unique Internet-based Personal Health Record (PHR) to support the families of transplant children and their healthcare providers. There are many gaps in the way that information is stored for children undergoing or about to undergo transplants. This group of children presents the most challenging exercise in information support between geographic and institutionally separated medical teams. They are, however, supported by highly motivated parents and families in life-threatening circumstances. A PHR was designed that allows for secure data entry, data storage, and easy controlled data access by the children's guardians or parents. The record includes contact and team member names, and medical data such as growth charts, immunizations, allergies, medications, lab values and scanned or digitized medical reports. Families can record the progress of their child as they would with a paper binder and customize their child's record with a photograph gallery and Internet link section for personal and general interest. Extensive computer-based testing of the PHR is complete. The system is being evaluated to determine the extent to which it meets the information needs of families and health providers in differing situations across Canada. The effectiveness of the system as a means for providing continuity of information and education is also being assessed. To conduct these evaluations, new users are being interviewed and tracked in a qualitative longitudinal study. Characteristics of the transplant families known to the David Foster Foundation (DFF) in Canada are described so that comparisons can be made to other patient groups who could benefit from their own adapted and specialized PHRs.

Keywords. PHR, EHR, childhood transplants, information needs, longitudinal study

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Introduction

Currently there are many gaps in the way that health information is stored about children undergoing or about to undergo transplants. Paper patient records may be hard or impossible to access by family members and time delays and distance between physician teams as well as incompatible electronic records in differing offices, laboratories, hospitals and pharmacies can frustrate timely care. By adding a personal health record (PHR) as an adjunct to traditional data collection and storage, the possibility exists for the family (i.e., guardians and parents) to better understand their child's condition [1,2]. It is hypothesized that having some "ownership" of their child's health information may lead to better understanding, care and compliance with physician's recommendations for care of the child [3,4]. In addition maintaining an up-to-date record of the child's health information from various sources could be of value to physicians as an adjunct to current record keeping and information flow [2]. We are not aware of any similar specialized PHR system and anticipate that experience with this highly motivated group of families will provide useful insights into its adaptation to other user groups.

In this paper, the design, implementation and testing of a PHR to address the above issues will be described (the eFOSTr PROJECT). The record, which was developed with the support of the David Foster Foundation (DFF), is designed for several classes of users, specifically: a) parents and guardians of children undergoing or about to undergo transplants, b) the child's physician and health professionals at the "home" location as well as at remote locations where operations may take place, and c) in the case of older children (teenagers) access by the patient themselves. The user interface is organized around a "calendar" metaphor, with key events in the child's progress used to enter and retrieve data. The main functionality of the system (which was designed to be accessed over the WWW) includes the following: a) basic patient information and quick access to information about all relevant health professionals dealing with the case, b) full information about all growth, medications, allergies, immunizations and lab results, c) links to educational and family support material, and d) a section where electronically scanned in reports and documentation about the patient can be stored. In addition, the user interface allows for personalization of the system (e.g., including a photo gallery of pictures documenting the child's progress).

Over the past six months extensive black-box and white-box computer-centered testing of the system and its user interface has been undertaken, with rapid cycles of feedback in the refinement and customization of the system in an iterative development approach. In addition, in response to a strong expression of interest in the project, we are also currently undertaking a study of the use and usability of the initial working version of the system from the perspective of potential end users. In phase I, a telephone based survey questionnaire is being conducted using available families known to the David Foster Foundation across Canada experiencing pediatric organ transplantation. In phase II, subjects (parents/guardians of transplant children as well as health professionals) will be interviewed about their information needs and their initial reaction to the system. Subjects will also be asked to enter data from reports they have collected (e.g., immunization reports, or lab reports) into the system and comment on ("think aloud") their impressions of the usability (i.e., ease of use). Lastly, a smaller select group will be remotely tracked over time as they interact with the initial version of the system over several months.

It is acknowledged that there will be a large variation in the degree to which different families will make use of the eFOSTr PHR just as some families keep extensive files in numerous binders and others have only limited information. No attempt was made purposely with this version of the system to allow automatic transfer of information from labs, pharmacies, and other EHR's due to incompatibilities in inter-organizational, inter-provincial and international software and security perceptions by families of information transfers. Although scanned-in documents such as consult letters are read-only in the record and therefore secure, data entered is the responsibility of the entering individual and cannot replace the EMR data at the source. The advantage, however, of a real time, family participating, and full medical team accessible record is obvious if it can be shown to result in better compliance and health of the child involved.

1. System Features and Functions

The overall approach of providing a Web-based access to personal health records requires that access not be limited by user operating system choice (PC, Apple, iPhone...) and that the child's record be accessible from any location. Arriving at the address of the server (with the starting information supplied by the DFF), security is assured by entering the correct e-mail address and the associated password. Correct response to a random one of three personal questions is required to identify the user. All entries and actions are logged for the user. The home page is illustrated in Figure 1.

As shown in Figure 1, the user's name appears in the upper right box above the patient name (i.e., the child's name). Users associated with more than one patient (e.g., a physician) have a pull down list to choose from. A photo, diagnosis, transplant type, and contact address are all chosen by the family. From the home page all other functions are accessible. The "How to get started" button links to a user manual searchable by word or section. Short tutorials are also available in audio-video format. Along the upper left hand side of Figure 1 the links to the main functional components are listed: Patient Information, Medications, Immunizations, View Lab Test Results, Gallery, etc.

Patient information includes a link to a page of names of contacts, health care team, birth date, phone numbers and e-mail addresses. Growth data in table and graphical display is presented for height, weight, head circumference, with calculated surface area and BMI in metric and imperial units. Contacts include addresses of connected users of the system as well as any additional relatives or friends granted limited access, for example, to photos only.

Allergies, medications, and immunizations are listed by date with appropriate details including a separate listing of disease related immunizations and antibody testing results for both before and after a transplant. Lab results are listed by date with normal range for specific labs noted. Graphing of blood levels and daily dose levels of selected drugs and lab results can be produced.

Documents scanned into the record from the user's computer in PDF format can be sorted by author, date, and other categories and can include photos, X-rays, videos, letters etc. The Gallery is a display of digital photos that can be transferred into the record from your computer with a description of contents, if desired. Links allow for easy transfer to Internet sites such as Web based education sites as well as personal

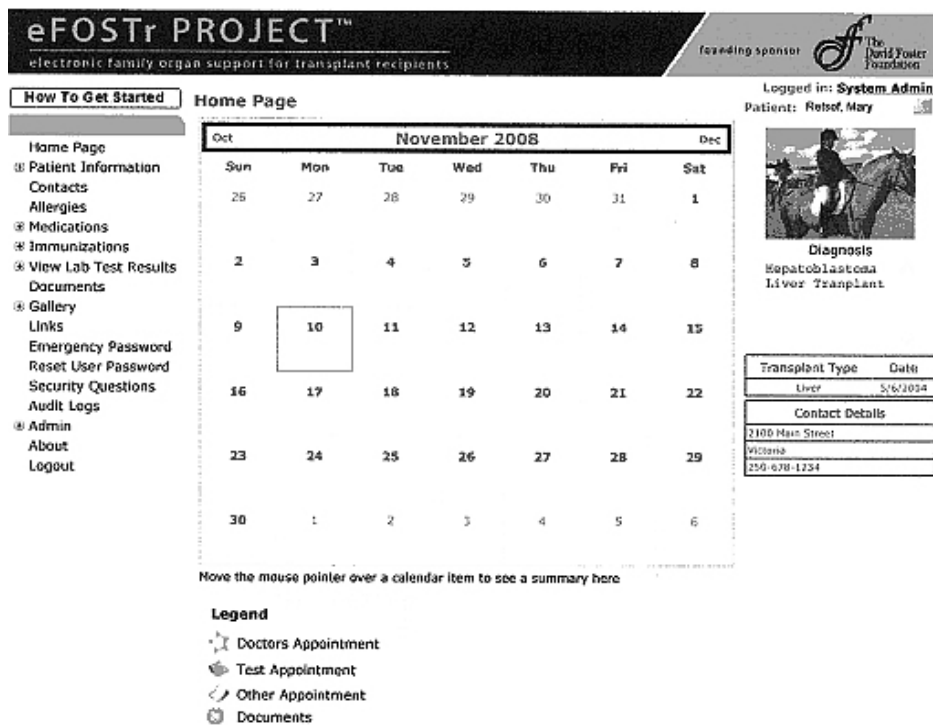


Figure 1. Main screen from the eFOSTr personal health record.

sites on you-tube etc. from a general list produced by DFF or from a customizable personal listing.

Emergency password generation is randomized and incorporated into a wallet sized card that can be printed out for selected use by the family and patient if emergency access (read only) to the PHR is necessary. Notification of emergency use of this card is indicated on the home page as a reminder to reset the password to protect access to the record (and generate another emergency card). Calendar dates can be flagged with icons reminding of appointment dates and written descriptions of the appointment appear under the calendar within one week of the appointment.

1.1. Technical Considerations

To allow widespread but restricted access to the information contained in the PHR, a web server in a licensed commercial site in Canada was set up to host the application (after a server was used at OA Solutions in Victoria BC during development). Duplication offsite is a standard requirement for back-up. Adherence to Canadian PIPEDA guidelines for the storage and confidentiality of personal health information is a fundamental priority for the project. Neither personal nor group patient information is used for commercial or product promotion in this project. The software for the eFOSTr PROJECT was developed at OA Solutions Victoria, BC under the project management

of Scott Peterson, Ian Gallagher and Mark Langton. Web browsers supported include Microsoft Explorer, Firefox, and Safari.

2. Evaluation

A two phase evaluation has been planned and is currently underway. In Phase I a telephone survey is being conducted to assess the information needs of families of children about to or having undergone transplants. In addition a questionnaire is being distributed to the families associated with the DFF. The questions included in the interview and questionnaire are designed to assess the following: the number of families traveling outside local hospitals for transplant care, the number of families traveling outside their home province and Canada, whether the family has access to a computer or the Internet at home, whether they have ever had experience with a PHR before and, the number of physicians they interact with. They are also being asked if they would share information with their child's health care team and if they would use a PHR and feel comfortable with use of an Internet based PHR for their child. In Phase II a subset of the families will be invited to participate in usability testing of the PHR and will be observed as they interact with the system to enter and access information about their child while "thinking aloud" [5]. Criteria for inclusion as patients included registration with the DFF, under age 19 years, preparing for or having received a solid organ transplant and living in Canada. In future work we will also be examining physicians' and other health providers' use and reaction to the PHR.

3. Conclusions

In this paper we have described a novel approach to providing web-based access to personal health records for families of children who have had or are about to have a life saving organ transplant. In response to requests for improved access to personal health information and a system to organize it for these families over the years, the David Foster Foundation has responded by funding the first prototype of a specialized PHR. Dramatic expansion and almost universal access to home computers and the Internet as well as the rewardingly successful results of organ transplant technology and transportation possibilities has lead to the eFOSTr PROJECT. It is hoped that the experiences from this project will help other patient groups from the complex chronic care patient to the healthy child dealing with multiple immunizations in different locations. More research is needed in this field to understand the acceptance and resistance to PHR's and the features that make them work securely and successfully.

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possible from often distant locations performing miracles and are appreciated. We also thank David Foster and the David Foster Foundation for the 22 years of fund raising and the amazing success that has allowed the expansion of financial help for over 400 families from across Canada and led to the need for this project. Elements of the program were contributed by Chris Holt, Lorenzo Oss-Cech, Simon Dabbs, Mike Han, and Sade Ashby.

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