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The Taiwanese method for providing patients data from multiple hospital EHR systems

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ABSTRACT

Personal Health Record (PHR) systems are growing in popularity and are receiving increased attention from the Biomedical Informatics research community. *Information Collection* is one PHR research topic and includes system functionality that helps patients retrieve their data from external sources. One of the most potentially useful external sources of information is the data stored in patients' EHRs at medical institutions. PHR systems that support *Information Collection* from EHR systems are thus interesting to investigate. In this paper we present PHR system that allows patients to receive data from 10 participating hospitals in Taiwan via a USB flash memory device. The overall design goals and architecture for the system are presented. Based on our experiences in designing and implementing the system we propose a three step method for accomplishing Information Collection from EHR systems at medical institutions for similar PHR systems in the future.

1. Introduction

Healthcare systems are being increasingly burdened by aging populations [1]. It has been suggested that the only way to meet future demand will be to empower patients so they may meet their own health needs more independently from existing structures [2–4]. The WHO for example has noted that " better access to technology, such as computers and internet, may help to improve understanding and management of specific conditions and enable patients to engage more in self-care" [5–8]. At the same time, patients are becoming more autonomous and often desire more personal health information [9,10]. Access to personal health information is also viewed as a mechanism that can promote patient-centered care [11], and health care that combines integrated information from Electronic Health Records (EHRs) and Personal Health Records (PHRs) is considered one of the biggest challenges in the field of medical technology [12,13]. For these reasons there has been increased interest in PHR over the past several years.

This interest has lead two of the largest software companies, Google and Microsoft, to develop PHR systems. It also has increased focus on PHR system research among the MIS community. A "PHR research agenda" has been created for example that provides an analytical framework for guiding PHR research. It also seeks to help develop "important insights that would increase the likelihood that PHR implementation will lead to better, more efficient healthcare, and improve patient outcomes" [14].

One of the key research issues in the PHR research agenda is *Information Collection,* which refers to functionality that supports the ability for patients to input their own health information and/or to retrieve it from external sources. One of the external sources with a large amount of potentially useful information is the electronic record systems at patients' medical institutions. As PHRs become more popular one consequence is thus that patients will increasingly desire access to their EHR data stored at hospitals [15–17]. This can provided to them with a number of advantages over other methods they may use for PHR data creation. It may save them time in comparison to manual entry for example, and can also help avoid errors that are created when patients enter data manually into a PHR [18].

Although a large number of studies have been published on shared medical records [19–22], no existing solutions have been published on how to support PHR Information Collection from multiple hospital EHR systems. With a PHR patients may, for example, use their data independently of medical institutions. They also may not be able to edit the data in the EHR system.

This paper describes a PHR system in Taiwan that supports Information Collection from EHR systems at 10 participating hospitals. The design goals, system architecture and features of the system

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are presented. The PHR system has been developed as part of a larger 5 year project to develop portable health records that includes EHR data exchange between hospitals, creation of data banks and the PHR system. The PHR system has been designed developed and implemented over this 5 year period and has already been used to provide 1844 patients with electronic versions of their health data from the participating hospitals. We use the experience to contribute to Biomedical Informatics methodology by proposing a generalized three step method for approaching PHR Information Collection from EHR systems at medical institutions. The design goals developed as part of the project can also be of value as they provide a set of design goals that have been validated through the development and implementation of a system in practice.

2. Design goals

There are a number of issues must be overcome in order to provide EHR data effectively to patients [13,23]. The overlying goal when designing this PHR system was to provide the EHR data from multiple hospitals to patients in a way that was satisfactory to both the participating hospitals and patients that would receive the data. Ten participating hospitals were recruited as part of a larger project on portable EHR systems. One of the primary interests the hospitals expressed in participating was that providing patients with their EHR data would help to improve patient relationships in a competitive market where patients can choose which hospital they want to visit.

Meeting the needs of the patients and hospitals required a number of real world issues to be considered. Implementing such a system proposed several interesting research questions such as "What are the critical features that determine the success of the system?" and "How should we approach the development of a system that will contain such features?" A committee of five software engineers with extensive experience in Biomedical Informatics met at the beginning of the project in order to identify design goals thought critical to the success of the system. Because our goal was to develop a system that would be implemented in practice, the goals were highly related to creating a system that would gain overall acceptance and satisfaction from hospitals and patients. Such acceptance was viewed as the overall measure of success for the project. These design goals are listed below.

(a) Minimize the impact of the system on the workflow at participating hospitals.
(b) One issue creating skepticism towards PHR systems among healthcare professionals is "concerns about whether adoption of PHRs will create additional work that is not reimbursed" [14]. Minimizing the impact on workflow meant that the system needed to be compatible with the existing EHR systems at the hospitals without requiring them to make extensive changes. Use and maintenance of the system also should require minimal effort on the part of the hospitals. Since overall success was defined by the creation of a system that was acceptable to the hospitals, the project did not set a quantitative goal regarding changes in workflow. Instead we took a pragmatic approach based on achieving acceptability for the system by the hospitals by, for example, developing the system so that it could function with the existing EHR systems at the hospitals regardless if they supported CDA [24,25] or any other standards. In the end if the hospitals accepted the system we viewed this design goal to be achieved.
(c) Make the system secure and trustworthy.
(d) Persons unauthorized by the patient should not be able to view the data. The patient should be able to trust that the data they view in the PHR has been provided by their medical institutions.
(e) Present the data in a satisfactory way to the patients and hospitals.
(f) This does not mean that the system should necessarily explain all medical terminology patients are interested in understanding. While this may be advantageous for patients, we viewed it as something that would not be necessary for the patients to view the system as satisfactory. Patients normally do not have a way to obtain data for their PHR systems from hospital EHRs. We thus felt that providing this data to them in a well structured way would be a great improvement on current practice, and thus something they would appreciate. This goal thus clarified that presentation of the data should be in an organized and attractive way that allows patients to easily find the information that they are looking for. Each hospital should also be satisfied with the overall way the data obtained from its EHR is presented to its patient's.
(g) Support flexible handling of the data for patients.
(h) Ultimately the goal of the PHR system is to provide data to patients so they may use it in the way they see fit. Similar to design goal c, this design goal thus focused on making sure the system would provide the patients with data that they deemed to be useful.

3. System architecture

Meeting the design goals required a number of problems to be solved. In this section we describe the basic architectural components of the PHR system. These include the PHR document format and data mapping from EHR systems, the overall software architecture, data security, and data presentation. The section does not provide a detailed overview of the system architecture but rather presents the architecture on a level of detail to familiarize the reader with the basic functionality of the system and some of the key features of the system that helped meet the design goals in Section 2. It also helps to ground the method for approaching the development of similar systems that presented later in the discussion in the experience in developing this particular system.

3.1. Document format and data mapping

One of the key challenges in obtaining the data from the hospital EHR systems is that none of the participating hospitals use systems that are based on open standards such as CDA [24,25]. It was thus not possible to obtain data for the PHR through using HL7 messages [26] or some other standardized data transfer mechanism. Since one of the design goals was to minimize the impact of the system on the workflow at the hospitals, it was not deemed realistic to expect them to update their EHR systems to support open standards.

Instead the PHR system was constructed by creating a document template that was derived from a subset of the Taiwan electronic Medical records Template (TMT) [27]. TMT is an XML based document format that is designed to contain data templates and fields that correspond to the wide range of information that is expected to be contained in the record systems of Taiwan's hospitals and clinics. It was developed through a process that included collecting, examining and classifying over 20,000 electronic and paper forms from 200 medical institutions in Taiwan into 70 templates based on their similarities. The advantage of using TMT is that it was a locally produced solution that was large enough to be able to support the vast majority of data contained in the hospital EHR systems.

The Taiwan Department of Health participated by helping to identify which of the TMT-templates would be most relevant for