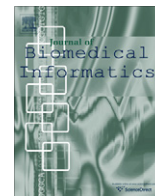




Contents lists available at ScienceDirect

Journal of Biomedical Informatics

journal homepage: www.elsevier.com/locate/yjbin

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

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ARTICLE INFO

Article history:

Received 31 July 2010

Available online xxxxx

Keywords:

Personal health record
Electronic Health Record
Information Collection
Data Integration
Taiwan
Hospital Information System

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.

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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 be 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

the PHR system. The criteria used for selection was based on what data would be most relevant to patients in terms of understanding and managing their health, and their encounters with the health-care system. Based on their suggestions the PHR template contains 12 of 70 templates contained in TMT. The individual PHR templates are referred to as “sheets” for the rest of this paper and are listed in the first column of Table 1.

Copying the data from a hospital EHR system into a PHR requires a mapping to be created that describes the relationship between the EHR data and fields in tables of the PHR sheets. Defining a mapping can be a fairly labor intensive process since a decision for the correct mapping needs to be made for each field. We thus developed a mapping tool in order to make the work process more efficient. A screen shot of this tool is shown in Fig. 1.

The tool allows a user to browse through the fields defined in TMT tables and EHR tables concurrently, to define relationships between these fields, and also allows the user to save profiles of a mapping. Our experience indicates that it takes about a week for a hospital to define a mapping from its EHR system to the first PHR sheet, and about a day for each additional sheet. Some additional work will also be necessary over time in order to keep the mapping up to date based on changes in the hospital EHR system.

Before creating the mappings it was not possible to know which portions of the PHR template the participating hospitals would actually use. Table 1 lists the total number of available fields in each PHR sheet, along with the actual number of fields used by each participating hospital. The 10 hospitals do not use the majority of the available data fields. Although a formal analysis has not been conducted there also seems to be a fairly strong overlap between the mappings from each hospital into the PHR template. It is thus likely that additional hospitals should be able to be added to the system without the PHR template needing to be expanded significantly to accommodate them.

3.2. Software architecture

The overall system architecture that is used for creating a PHR instance is based on two components installed on a server at each participating hospital. The components installed on the server are a TMT-gateway that provides an interface to the Hospital Information System (HIS), and a Mini-server that provides a user interface for hospital workers, and that performs functions related to packaging the PHR data into a format that can be provided to the patient. The relationship of these components is visualized in Fig. 2 and the process for creating a record works as follows:

- (1) A hospital employee inputs the necessary parameters, such as the identification number for the patient, into the Mini-server.

- (2) The Mini-server feeds these parameters to the TMT-gateway.
- (3) The TMT-gateway interacts with the HIS using various parameters.
- (4) The HIS returns data to the TMT-gateway based on these parameters. The previously defined mapping profile is used in order to place the data into the correct tables in a temporary database (temp DB) on the TMT-gateway.
- (5) The TMT-gateway generates XML files based on the data in the temp DB and passes the files to the Mini-server.
- (6) The Mini-server packages the XML files into secure zip files. More details about these security mechanisms are described in the next sub section.

The hospital worker then copies and pastes the zip file into a memory stick and also includes a version of a viewing application called the TMT-viewer onto the stick. The memory stick is provided to the patient in order to complete a transaction of the PHR data.

This can occur using a number of different workflow strategies which may vary from hospital to hospital. Currently the hospitals that participated in this project have a hospital employee create the PHR and physically hand the USB stick to the patient. In the future it could be possible to reduce the workflow at the hospitals further by, for example, developing a vending machine that would create the USB stick and distribute it to patients. The hospitals that participated in the project however did not find the workflow needed to support the creation and distribution of USB sticks that contain PHR data to be a significant issue at this time.

3.3. Data Security

The PHR data is kept secure by having the zip files encrypted using a 256 bit Advanced Encryption Standard key [28,29]. The patient is given an initial password that allows them to access the files from the TMT-viewer and is prompted to change the password during the first login. In addition to being password protected the zip file also contains a digital signature from the hospital and a checksum. This guarantees that the TMT-viewer will only view files that have been provided by a hospital and that have not been altered or corrupted.

3.4. Presentation of the PHR data

The data is presented to the patient using an application called the TMT-viewer. It also supports browsing functionality and allows the user to export the XML files containing their health data.

The browsing functionality of the TMT-viewer, is shown on the left of Fig. 3. It provides view navigation using a link-node diagram, similar to that commonly used for exploring file structures. The

Table 1

Number of database fields used by each hospital.

	Temporary tables fields	Number of database fields used by each hospital									
		1	2	3	4	5	6	7	8	9	10
Face sheet	431	52	48	72	32	62	42	33	43	48	31
Medical encounter	942	102	120	111	98	71	81	99	101	136	99
Prescription	201	34	41	20	33	41	26	37	31	21	36
Admission note	429	42	57	66	62	47	41	40	39	44	30
Progress note	331	33	43	48	31	41	20	33	41	35	44
Discharge summary	411	33	41	26	37	31	52	48	72	32	46
Exam report	323	41	26	37	31	21	36	42	33	43	48
Lab report	458	41	20	33	41	35	33	43	48	31	41
Referral sheet	352	37	31	21	36	42	33	41	26	37	31
Emergency note	453	47	41	40	39	44	30	41	26	37	31
Emergency order	345	48	31	41	20	33	42	33	43	48	56
Emergency triage note	234	20	33	41	35	44	34	41	20	33	41

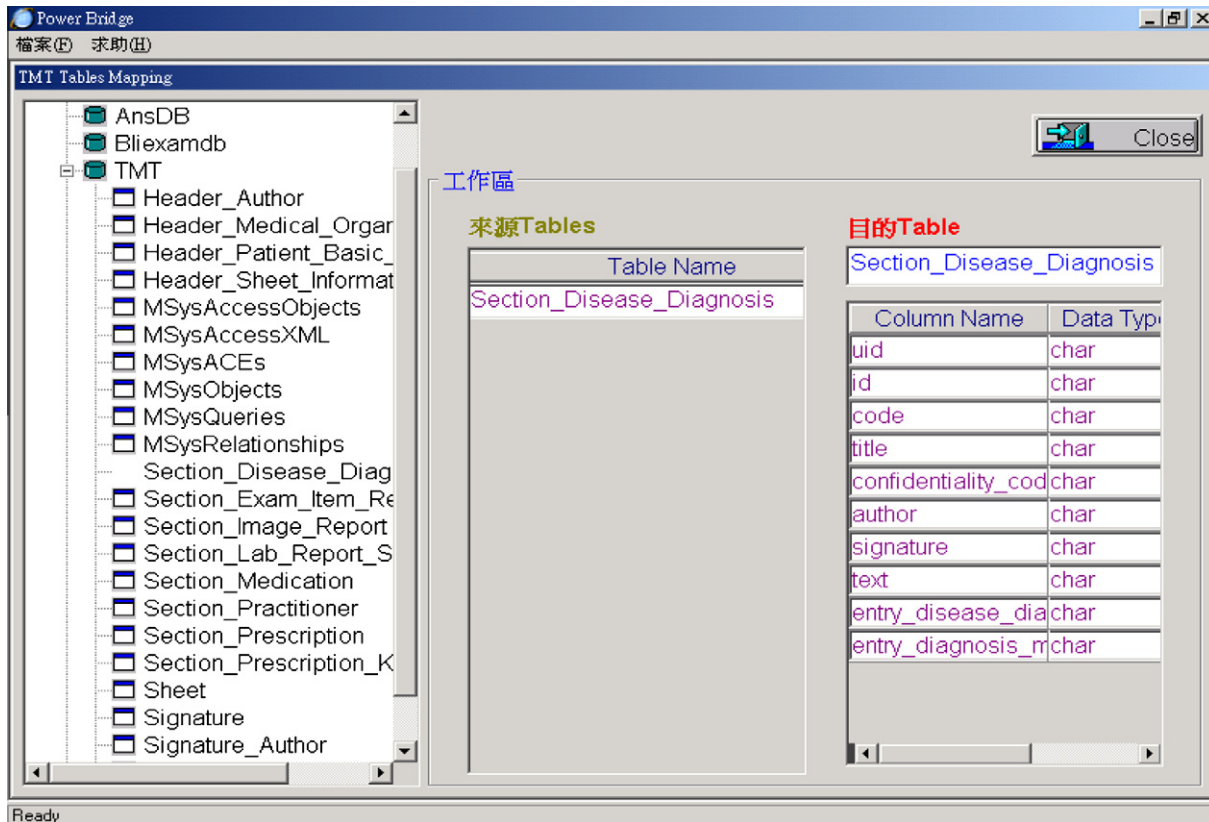


Fig. 1. A screen shot of the mapping tool for specifying relationships between EHR data and TMT tables.

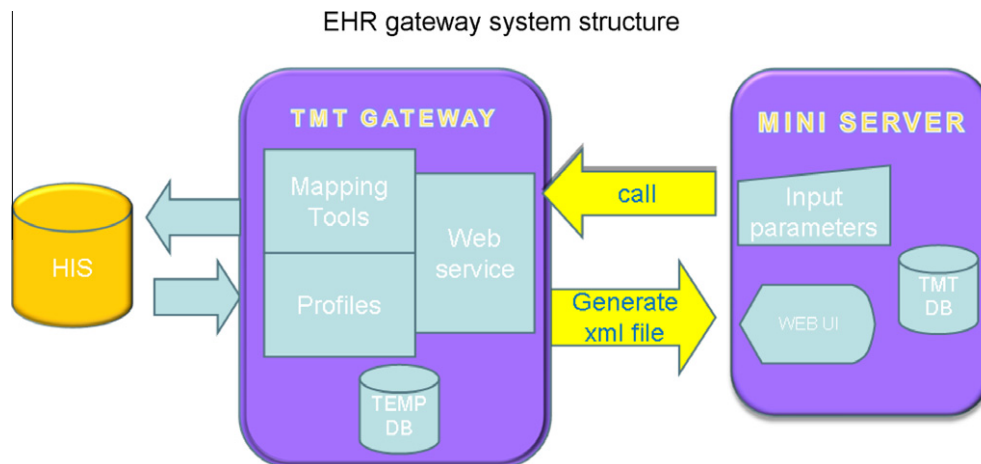


Fig. 2. The software architecture used to create PHRs.

data is organized so that a folder represents the data connected to a specific hospital and the individual files represent each data sheet. When clicking on a file its contents are displayed in an XML compatible web browser.

Each hospital was given the possibility of customizing the view that is with respect to providing a logo and other identifying marks that show up on the header of the page. This helps to ensure that the data they provide is used in a way that promotes an improved relationship between the hospital and patient.

In 2008 the project distributed 1844 USB devices to patients that contained over 6000 sheets with PHR data. When distributing the PHRs to the patients a user survey was provided to the patients in order to see if they felt the overall functionality of the system

was satisfactory (Wen-Shan J, et al. Patients' Usage Intention and Adoption Behavior of Personal Health Records Submitted). This survey revealed that 91% of the patients had a positive view towards the use of the system.

4. Discussion

Information Collection is a key research area for PHRs [14]. In this paper we focused on how to support *Information Collection* for a PHR system from multiple hospital EHR systems that do not support any open standards such as CDA or HL7. We have developed and implemented a PHR that supports such collection from 10

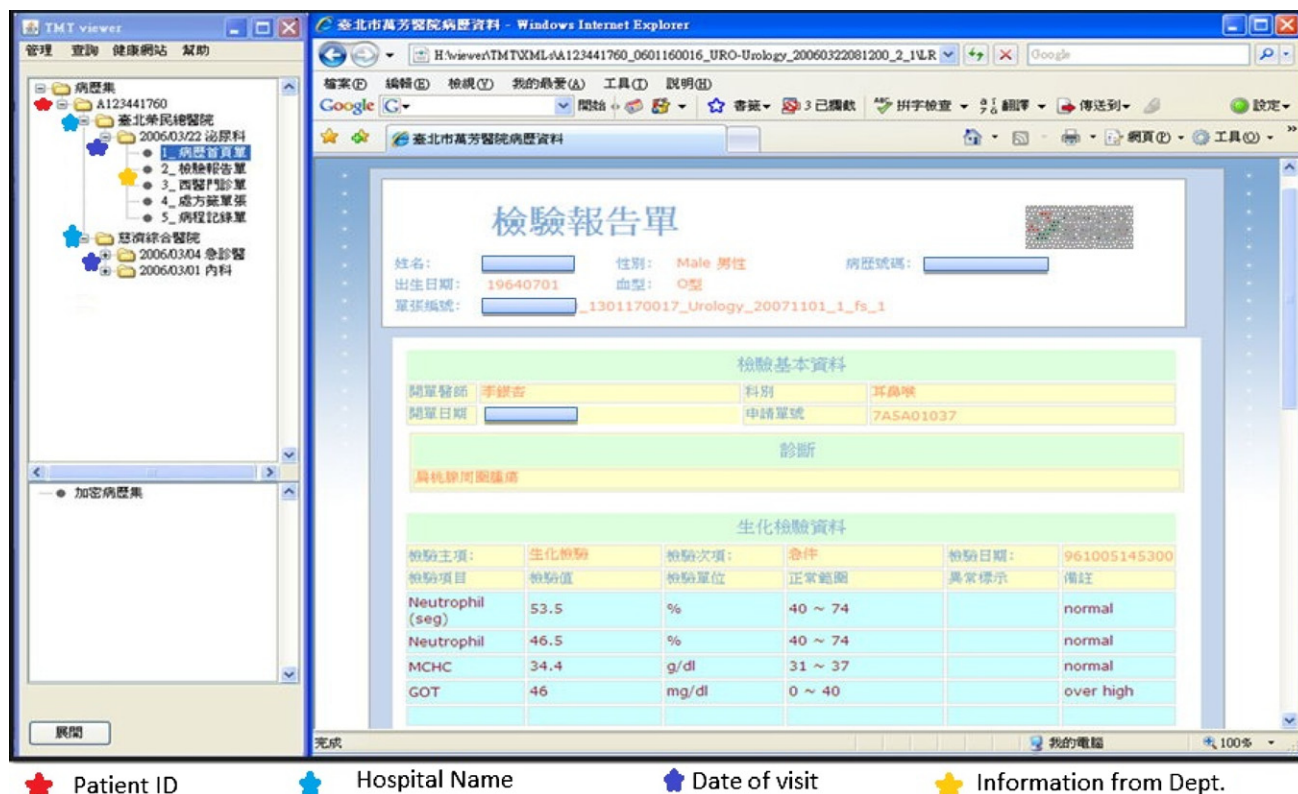


Fig. 3. User Interface of PHR displaying laboratory results.

hospitals in Taiwan, and that has been used to provide EHR data to 1844 patients.

The success of any PHR system based on EHR data will ultimately be based on acceptance by patients and medical institutions. In order to gain this acceptance for our PHR we identified a number of design goals that were used to guide the development of the system. These design goals can be used as a general guideline when seeking to develop a methodological approach for the development of similar systems in a different context. The specifics of achieving these goals may vary considerably from project to project. In Taiwan for example unskilled labor is relatively inexpensive. Having hospital employees generate and distribute USB sticks is not a significant burgeon on hospital workflow. In other countries where labor costs are high it may be necessary to use a different approach that, for example, reduces labor costs through the use of vending machines.

These design goals, and the eventual solution that was implemented, also help to illustrate how some of the topics from the PHR research agenda are interconnected and may create engineering tradeoffs. Two of the design goals for the system for example, were insuring that the patient could trust the data provided, and that they also were given a certain degree of flexibility in using the data.

This can create somewhat of a paradox since giving the patient the option of editing the data creates the possibility of confusion by the patient when they try to understand any edits they have made in relation to the data in the PHR that was provided by the hospital. In order to avoid this problem we thus decided on a middle ground solution where patients can export the PHR data as XML files, but cannot view edited files using the viewer application provided to them. This allows the patient to use XML-related tools to convert the data into various document formats such as Microsoft Word, Adobe PDF, and Microsoft Excel, and to directly import the data into any PHR system that supports XML. They can then choose to

edit this data through another PHR system while being reassured that the data they view with TMT-viewer is the actual data that was provided to them by the hospital.

4.1. Primary challenges

The fact that we were able to implement the system successfully at 10 hospitals using a relatively “simple” technical solution suggests that the main barriers to development of systems of this type are in fact not technological but rather are related to organizational collaboration. Patients likely do not need to be provided with sophisticated solutions that merge data elegantly from multiple hospitals, and extensive technical system development should not be required to export data from heterogeneous hospital EMR systems.

Although a large amount of technical complexity was not encountered in developing the system, defining the correct data templates and mapping the data from the EHR system to the PHR template did involve several challenges however. It was labor intensive and required some central decision making that was acceptable to all the hospitals that would support the system. Our experience suggests that this is a key issue that will be faced in the development of similar systems. Some level of collaboration or centralized decision making will be needed in order to create a common format for exported data. We thus propose the following 3 step method that can be applied by others looking to collect data from multiple hospital EHR systems.

- (1) *Develop a large inclusive data template* This template should consist of all types of data likely to be contained in EHR systems grouped into general categories. Conducting a broad investigation of the record systems at many hospitals is fairly resource intensive and this must be considered in project planning. The creation of a large template however

reduces the need for customizations later on for each hospital that wishes to contribute to the PHR system and thus is a fairly scalable solution. In order to make this aspect of our work compatible and transformable with international standards, the project team has also created XSLT transforming program. This program transforms TMT format to a HL7 CDA standard XML file. Future projects can thus acquire the information encoded in an international format, and potentially save considerable time and costs when creating a data template.

- (2) *Determine which of the general categories is relevant for the PHR system* This step can present a risk to projects since it may require centralized decision making that is satisfactory to all of the participating institutions. In some situations an existing body may be able to perform this work (in our case the Taiwan Department of Health) and in other cases it may require the formation of a decision making committee. Since knowledge of existing systems that have been used in practice may aid the decision making process we have included a list of the categories and data fields that were deemed relevant for our PHR-template downloadable on the Internet[30]. Since the majority of the hospitals that participated in the project had a similar profile with respect to how their data mapped to the PHR-template it may be the case that in the future it will be possible to create a standardized template that will be fairly inclusive so that future projects that seek to create similar PHR systems do not need to complete these first two steps.
- (3) *Define mappings* between the hospital EHR systems and data fields in the relevant categories. This will create some initial start up cost and the need to maintain the mappings over time suggests that a smaller amount of stable funding over time will also be required in order to maintain the system.

5. Future work

The PHR system was created as part of an overall effort to create a portable EHR system for Taiwan that includes an integrated PHR system, support for transfer of data between hospitals, and the establishment of an information data bank that can be used for research. The architecture described in this paper provides a basis for investigating these issues on the basis of patient consent to use their data for these purposes. Once a zip file is created on the mini-server it may be used in a number of additional ways when authorization is provided by the patient, for example to support transfer of records between hospitals.

The project team will also continue developing and defining more medical record forms for Taiwan's medical community. We are also considering establishing a standing agency or organization to specialize in defining EHR templates for the medical community while continuing to monitor international developments in the area. The team will therefore continue support continued revisions and definitions of TMT standards so that Taiwan's development on medical informatics can continue to be compatible with the newest standards in the world.

6. Conclusions

Creating a PHR system that supports Information Collection from multiple hospital EHR systems presents a number of challenges. Our approach focused on providing patients with a USB stick that contains their patient data in a secure, viewable, and exportable format. The overall system design also had minimum impact on the workflow at the participating hospitals since they

did not need to update their EHR systems extensively to support the system.

A three step approach was used in order to define a standardized template for the PHR data, and mappings from the HIS to the template. Using this strategy we created a PHR system that gives patients access to their medical information from 10 participating medical institutions. The results of our efforts demonstrate that a fairly strait forward approach can be used to provide PHR systems to patients that contain data from a variety of hospitals that would be interested in supporting the system. These hospitals do not need to have EHR systems that support open standards such as CDA. The key challenges in creating such a system are the man hours needed for defining templates and mappings between EHR and PHR data. Future projects however may be able to benefit from standardized PHR data templates, and thus may only need to define the mappings between the HIS from the participating hospitals and the PHR template. We conclude that if future projects can successfully complete the three steps required to export data from the hospital EMR systems that we proposed in the discussion, and accomplish the design goals we described in Section 2, that similar positive results should be possible in other contexts.

Acknowledgments

We are thankful for the staff and Managers of the 10 participating hospitals in this project. This study was funded by Taipei Medical University under Grant 95TMU-WFH-17, PMP: NSC 98-2218-E-038-001, CER: DOH99-TD-C-111-008 and partly funded by The Research Council of Norway Specialist Exchange Program and Grant 176852/S10.

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