

An Ontology-Driven Information Model for Interoperability of Personal and Electronic Health Records

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Abstract—Personal Health Records allow patients to maintain their own health information and are viewed as an important tool for patient self-management. However, uptake of these systems has been hindered by the large burden placed on patients to record information or to arrange for information to be transferred from other clinical systems. The favored option of transferring information from other systems is hindered by a lack of semantic and syntactic interoperability between Personal and Electronic Health Record systems. In this position paper, we describe the ongoing development of an information model that uses an ontology to ensure semantic integrity between concepts recorded by both types of record systems, and HL7 standards to maintain equivalent structure and function. The information model acts as a middle layer between record systems and thus is not tied to any specific Personal and Electronic Health Record implementation.

Keywords - Personal Health Records; Electronic Health Records; Information Model; HL7; Ontology; Interoperability.

I. INTRODUCTION

Personal Health Records (PHRs) provide a summary of an individual's medical history and allow patients to view and edit their own medical data [1]. The aim of PHRs is to encourage patients to become more involved and informed as equal partners in their care, making positive choices to improve or maintain their health. Further, due to the increasing prevalence of long term conditions, patients' involvement in their care is viewed as potentially cost saving, and as such PHRs have become a strategic priority. For example, in the USA most Americans will have access to a PHR by 2014 if present Federal goals are accomplished [3], and Australia's 2011 budget mandated PHRs for all Australians to be achieved within 2 years [4]. However, despite much investment, adoption rates for PHRs remain low with causes such as lack of awareness, interoperability, and privacy and security concerns widely cited [5]. Although these are all important concerns, in particular, interoperability has been identified as a major barrier and in this research we focus on proposing a novel solution for PHR interoperability.

There are two prevailing models of PHR - "tethered" systems, which are sponsored by an organization and where the record is automatically populated without the patient needing to enter information, and "untethered" standalone systems which are entirely under the control of the patient who must enter their own information or arrange for it to be transferred from another system. As the majority of PHRs

are untethered, the success of these systems is determined by a person's willingness to maintain their PHR information or on their health providers' willingness to share data from the patient's Electronic Health Record (EHR) so that it can be transferred to the PHR.

Although the tethered approach places fewer burdens on the patient it presents challenges for healthcare providers. The development of tethered PHRs usually involves the costly process of exposing selected parts of an organization's EHR to the patient by reprogramming or 'retrofitting' proprietary EHRs for purposes they were not originally intended [6]. As a result many tethered PHRs focus on providing simpler data to patients, for example, hospital visits or prescription drugs dispensed, rather than clinical data which requires gathering fragmentary information from multiple resources but which is necessary if patients are to be encouraged to self-manage in a meaningful way.

The aim of our research is to develop a framework to enable seamless interoperability between PHRs and EHRs in order to allow meaningful exchange of clinical data from providers to patients and vice versa in order to better encourage PHR use and patient self-management. The solution is equally applicable to tethered and untethered systems as it abstracts away from the specific PHR and EHR using an ontology-driven Information Model (IM) based on the HL7 Reference Information Model (RIM) that acts as a middleware layer between PHR and EHR systems. In this position paper we provide a description of the proposed IM for transferring information in a standardized way between EHR and PHR systems. In the next section we provide describe recent work on PHR interoperability. Section III describes the methods used to develop the middleware layer between EHR and PHR. Section IV presents a discussion and finally in Section V we outline some future work.

II. BACKGROUND

Our research proposes the use of an ontology-driven IM to address issues of semantic and syntactic interoperability between PHR and EHR systems. An IM is a representation of concepts and the relationships, constraints, rules, and operations that might be applied to these concepts for a particular problem space [7]. "An ontology is an explicit specification of a conceptualization" [8] and used to formally represent domain knowledge. Syntactic interoperability refers to the capability of communicating and exchanging data whereas semantic interoperability is the ability of systems to meaningfully interpret information exchanged.

Recent work by Puustjärvi [9] focused on achieving semantic interoperability by developing a specific ontology for active PHRs. We borrow from this work but extend it to include syntactic interoperability using Health Level 7 (HL7) standards for data and document exchange [10]. Other research using HL7 standards for PHR interoperability has focused on messaging rather than full document exchange [11, 12]. In order to facilitate full document exchange, we have developed a general ontology-driven IM derived directly from common PHR data and functions. In addition, the proposed general framework provides a blueprint for developing new PHRs interoperable with EHRs.

III. METHODS

The process of developing the IM involved a number of distinct stages including an analysis of data and functionality available via common PHRs to determine information to be exchanged between PHRs and EHRs, a review of EHR and PHR standards, and designing and developing a middleware architecture for clinical document exchange. These steps are outlined in the following subsections.

A. Analysis of common PHR functionality

Initially 81 PHRs were accessed via myPHR web portal [13] and another 19 were selected based on a review by Carrión Señor et al [14]. By deciding to focus only on easily accessible free and web-based systems, 45 PHRs were selected. We applied a scoring system developed by [14] which assigns a utility score to PHRs based on data and access management, privacy and security settings and use of recognized standards. This resulted in the following 5 systems that scored >70% and thus were selected for detailed review:

- 1) Microsoft Health Vault
- 2) Telemedical
- 3) NoMoreClipboard
- 4) Health Spek
- 5) Health Companion

Due to the large variation among PHR systems, a template including a free text notes section was used to manually summarize functionality rather than a formal information extraction method. Table 1 summarizes extracted PHR information. Functionality has been separated into 6 categories which represent natural groupings of functionality: i) Patient Demographics and Other Family Members, ii) Care Provider Roles, iii) Clinical Record, iv) Interoperability, v) Social Aspects, and vi) Other Functionality. The last column (“Score”) assigns a score reflecting the number of features available in each of the outlined categories and the last row of the table summarizes the total number of available features for each PHR.

TABLE I. ANALYSIS OF PHR DATA AND FUNCTIONALTY

Features	Health Vault	Telemedical	NoMore Clipboard	Health Spek	Health Companion	Score
<i>Patient Demographics and Other Family Members</i>						
Personal Information	Y	Y	Y	Y	Y	5/5
Emergency Contact	Y	Y		Y		3/5
Emergency Card	Y		Y	Y		3/5

Em. Print-outs	Y	Y	Y			3/5
Add Other Family Members	Y	Y	Y	Y	Y	5/5
Friends					Y	1/5
<i>Care Providers Roles</i>						
Doctor	Y	Y	Y	Y	Y	5/5
Guarantor		Y				1/5
Insurance	Y	Y	Y	Y	Y	5/5
Pharmacy		Y	Y		Y	3/5
Provider	Y	Y	Y		Y	4/5
<i>Clinical Record</i>						
Allergies	Y	Y	Y	Y	Y	5/5
Condition	Y	Y	Y	Y	Y	5/5
Device	Y				Y	2/5
Diet	Y	Y	Y	Y	Y	5/5
Exercise	Y	Y	Y	Y	Y	5/5
Family History	Y	Y	Y	Y	Y	5/5
Imaging	Y			Y	Y	3/5
Immunization	Y	Y	Y	Y	Y	5/5
Labs	Y			Y	Y	3/5
Medication	Y	Y	Y	Y	Y	5/5
Procedures	Y	Y	Y	Y	Y	5/5
Social history		Y	Y	Y	Y	4/5
Supplement				Y		1/5
Surgery		Y				1/5
Vitals	Y	Y	Y	Y	Y	5/5
Wellbeing Considerations		Y			Y	2/5
<i>Interoperability</i>						
Import	Y	Y			Y	3/5
Export	Y	Y			Y	3/5
Import Documents	Y	Y	Y		Y	4/5
Connectivity with Devices	Y					1/5
<i>Social Aspects</i>						
Access Control	Y		Y			2/5
Groups					Y	1/5
Posts					Y	1/5
Share Medical Record	Y	Y	Y		Y	4/5
<i>Other Functionality</i>						
Appointment request		Y				1/5
Appointments	Y					1/5
Educational Information					Y	1/5
Health Goals	Y					1/5
Lab/Test Results		Y				1/5
Manage Expenses					Y	1/5
Messaging		Y				1/5
Notifications & Reminders				Y	Y	2/5
Prescription		Y				1/5
Referral Request		Y				1/5
Refill Request		Y				1/5
Refills	Y			Y		2/5
Renews Request		Y				1/5
Risk Assessment					Y	1/5
Sent Payments		Y			Y	2/5
Visible Clinical Codes	Y					1/5
Emergency profile				Y		1/5
Web Visit		Y				1/5
Score	30/53	34/53	21/53	23/53	31/53	139

Considering the “Other Functionality” category in Table 1, the majority of components have a score of 1/5. Many of the functions associated with specific PHRs in this section are either slightly different to common functionality grouped in other categories or represents the same functionality from other categories only labelled in a different way. For example, the function of requesting lab results is additional functionality in Telemedical that allows users to request lab results from third party applications but not to register results in the same way as in the other system (i.e. as part of the clinical record). This is an example of how similar functionality is implemented (lack of syntactic interoperability) as well as in nomenclature of similar concepts (lack of semantic interoperability) among PHRs.

B. PHR and EHR standards in use

HL7 RIM, HL7 CDA (Clinical Document Architecture), and messaging standards (e.g., HL7 v2.x and v3.0) form the backbone of EHR systems. RIM expresses the data content needed in a specific clinical context and provides an explicit

representation of the semantic and lexical connections that exist between the information carried in the fields of HL7 messages. CDA is an XML-based standard that specifies the encoding, structure and semantics of clinical documents for exchange. The v3 messaging standard defines a series of electronic messages to support all healthcare workflows [10].

The most common standards used for PHRs include the Continuity of Care Record (CCR) which specifies the encoding, structure, and semantics of a patient summary document. Furthermore, HL7 Continuity of Care Document (CCD) provides a template for representing vital signs, family history and plan of care [10]. In the case of the selected PHRs, CCD, CCR, and XML are used to import and export medical data. In most cases the imported documents are not fully embodied or merged with the patient’s medical record; rather they can be seen as separate documents using Extensible Stylesheet Language Transformations (XSLT).

C. Representing PHR data and relationships

Our proposed IM, shown in Figure 1, consists of four classes to represent PHR data and relationships, namely: i) Role (participants), ii) Entity (roles are played by Entities), iii) Act (happenings) and iv) Element (data corresponding to Acts). The classes Role, Entity and Act have been preserved from the HL7 RIM foundation classes, however, both the use of each class and their relations have been altered. In RIM the class Role is related to the class Act through another class named Participation, and to the class Entity. In our IM, class Role is related to class Entity and the latter is then related directly to class Act. This is due to the fact that Roles in PHRs are more limited than in EHRs and thus Entities participate directly in Acts. The class Element has two subclasses named “Data” and “Unit” to manipulate represented data. These subclasses characterize data input or saved by a user as part of an Act. Sub classing data into its constituent Elements allows for finer-grained representation of patient data thus allowing the IM to capture variations among data stored by various PHR, as well as to adequately capture the greater number of data and data types stored by PHR when compared to EHR.

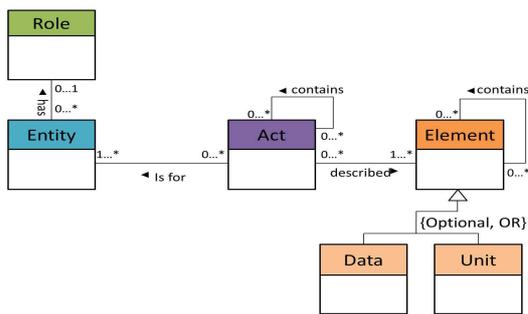


Figure 1. Information Model Classes

Figure 2 provides a sample scenario representing a patient monitoring their vital signs. A person (Entity) who is the patient (Role), monitors (Act) his vital signs (Element). Monitor is a composite Act that involves the measurement of different Elements. Moreover, a simple Element may consist

of Data Elements or/and Units Elements). Data Element contains the actual value of a measurement (e.g. 120) and Unit Element contains the unit of measurement (mmHg).

Three of the proposed IM classes are used by HL7 RIM which is developed to accommodate any possible act in healthcare. Moreover the attributes of each class and the class themselves are flexible. Hence, it is expected that the proposed four classes can accommodate all relevant information for PHRs.

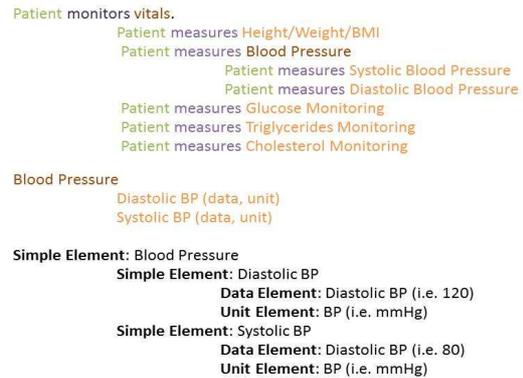


Figure 2. Sample scenario

D. PHR – EHR semantic interoperability

PHRs and EHRs may use different terminology to describe the same concept and thus obstruct data exchange between applications. To circumvent this obstacle the proposed IM uses an ontology developed using Protégé [15] and instantiated using Ontology Web Language (OWL) [16] as shown in Figure 3. The Ontology defines all classes described in the previous subsection along with their attributes, data properties (including cardinality and multiplicity) and relationships among them. This generic ontology may be instantiated for various PHRs.

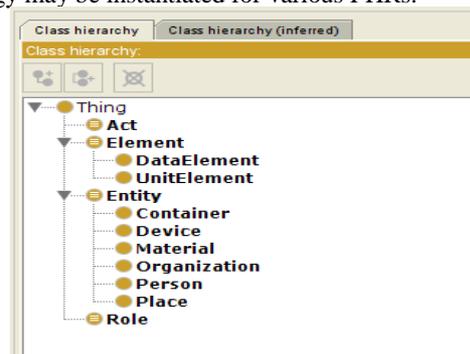


Figure 3. Information Model as an Ontology

By utilizing an ontology-based approach, semantic issues can be effectively addressed. For example, the declaration of equal features “Past Medical History” and “Previous Medication”. Moreover, the use of Data Properties that can replicate coding schemas is also possible. For instance, the SNOMED CT code for past medication is “394829006”. By assigning this code to Past Medical History, the meaning of these two individuals could also be interpreted as equal.

E. PHR – EHR data syntactic interoperability

Data exchanged between PHRs and EHRs must conform to relevant structure and syntactic rules. In our framework, information will be transformed to and transferred as a CDA document; therefore the syntactic rules are the actual rules of the HL7 CDA standard. The CDA is represented in XML and an XML schema has been developed which is responsible for encapsulating all relevant syntactic rules. A PHP script is used to verify the XML schema.

F. Proposed Architecture

Our proposed architecture is shown in Figure 4. Data may be either exported from a PHR to an EHR or vice versa with the ontology-based IM instantiated as a middle layer between the two systems. This is in contrast to the system developed in [9] where transformations for exchanging data were embedded within the specific PHR and thus any updates to the PHR (e.g. addition or deletion of a field) must also be propagated through PHR transformations. We decided against such a specific solution to ensure greater scalability. Our middle layer solution ensures that when modifications are made to either a PHR or an EHR, they can be encapsulated directly by altering only the middle layer. The other prevailing approach (e.g. as in [11, 12]) is to create a domain specific IM called a Refined Message Information Model (RMIM) using RIM classes. As demonstrated in II.C, RIM is composed of pre-defined attributes which are difficult to change and generally not flexible enough for the wide variety of PHR concepts and associated data. Moreover, the use of RMIM emphasizes message exchange rather than the exchange of full medical records.

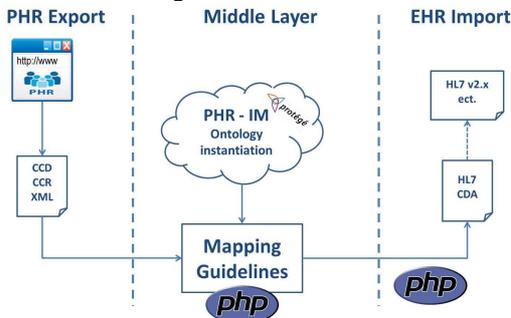


Figure 4. PHR- EHR architecture

IV. DISCUSSION

Interoperability between PHR and EHR is a major barrier to PHR adoption. In this paper we have described ongoing development of an ontology-based IM for PHR to EHR interoperability. The proposed IM has been derived directly by analyzing common features and functionality of current PHRs. It extends HL7 RIM beyond EHR requirements to cover essential PHR requirements. Furthermore the instantiation of the IM as a middle layer between PHR and EHR systems insures additional flexibility by not tying the solution to any specific system. As well as being applicable to existing solutions (both tethered and non-tethered), the framework could be used as a blueprint to develop new

EHR-interoperable PHR by allowing better flexibility both in the types and volume of information to be represented.

V. CONCLUSIONS AND FUTURE WORK

The next stage of our research is to develop a set of mapping guidelines for transforming information from the ontology-based IM to CDA format. XPath and xQuery will be used to parse data exported from PHRs and EHRs and PHP scripts will be used to apply the required transformations and create the final CDA document. The guidelines will be evaluated using scenarios representing transformation of PHR data exported from CCD and XML format to CDA and vice versa. Longer term we intend to analyze PHRs that are not web-based or free of charge - primarily tethered systems - and make the required alterations to our framework accordingly.

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