Personal Health Book: A Cloud-Based Tool for Patient Centered Healthcare

Juha Puustjärvi¹, Leena Puustjärvi²

Department of Computer Science, University of Helsinki P.O. Box 68, Helsinki, Finland
The Pharmacy of Käivopuisto Neitsytpolku 10, Helsinki, Finland
¹juha.puustjarvi@cs.helsinki.fi; ²leena.puustjarvi@kolumbus.fi

Abstract- Patient centered healthcare is based on the assumption that physicians, patients and their families have the ability to obtain and understand health information and services, and make appropriate health decisions. This in turn presumes that patient’s personal health information is presented according to individuals understanding and abilities. Based on this argument our research has focused on analysing whether the existing PHRs (Personal Health Records) support patient centered healthcare in an appropriate way. The analysis of these questions led to the introduction of the Personal Health Book (PHB). It is an extension of PHR in that all healthcare providers augment the PHB by links to relevant information entities. We can exploit cloud computing in accessing the PHB as anyone with a suitable Internet connection and a standard browser can access an application in a cloud. In this paper we consider two approaches for maintaining PHBs: one extends XML based PHRs while the other exploits semantic web technologies in PHBs’ implementation. In particular, we present the advantages that can be achieved in using cloud computing and semantic web technologies such as RDF and OWL.

Keywords- Patient Centered Healthcare; Personal Health Records; Information Therapy; Drug Therapy; Semantic Web; Ontologies, XML, RDF, OWL

I. INTRODUCTION

The introduction of new emerging healthcare models, such as patient centered care, is changing the way people think about health and patients. “Patient centered healthcare” is the term that is used to describe healthcare that is designed and practiced with the patient at the centre [1]. It is based on the assumption that physicians, patients and their families have the ability to obtain and understand health information and services, and make appropriate health decisions [2]. This in turn presumes that patient’s personal health information is presented according to individuals understanding and abilities.

Based on this argument our research has focused on analysing whether the existing PHRs (Personal Health Records) [3-6] provide the functionalities required in patient centered healthcare. As far as we know, this viewpoint is not addressed in scientific articles though patient centered healthcare is widely studied in literature, e.g., in [7-11].

In particular, we have analysed the following questions:

• What are the shortcomings of XML-based PHRs in supporting an individual’s understanding and abilities?
• What health information an ideal PHR should contain?
• What functionalities a PHR system should provide?

The analysis of these questions led to the introduction of the Personal Health Book (PHB). It is an extension of PHR in that all healthcare providers, who are involved in patient’s healthcare, provide appropriate content for the PHB. For example, the extra work required from physicians is just to augment their diagnosis by appropriate links to relevant medical information entities, e.g., on an information entity dealing with blood pressure. Correspondingly, in dispensing a drug a pharmacist augments the prescription by appropriate links, e.g., by a link to Diovan (a drug for reducing blood pressure).

In such a PHB-based healthcare model, patient’s physicians are responsible for the patient’s information about therapy and pharmacists who dispense drugs for patient are responsible for the patient’s information about drug therapy. Correspondingly all sources, such as a trainer in a patient’s gym, that are involved in a patient’s healthcare and generate data into PHB should also augment the PHB by appropriate information.

The PHB-based healthcare model presumes that the information entities that are used in the therapy are accessible in the web, i.e., each entity should be stored in the PHB or have a url (uniform resource locator) in the PHB. This, however, does not require the creation of new content as relevant information entities have already existed in digital form, which can be accessed by the systems used by the healthcare providers. For example, in most countries such medical information entities are maintained by medical authorities, and the entities are presented in a way that patients can understand.

Further, in order to ensure that linking does not overly burden healthcare personnel we assume that they use a tool, by which input is a term or phrase and output is a link or links to relevant medical information entities.

The PHB-based healthcare model presumes that PHBs are Internet based meaning that the PHBs are stored at a remote location.

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server, so that PHBs can be shared with healthcare providers who are authorized by the patient. They also have the capacity to import data from other information sources such as from a pharmacy, a hospital laboratory and physician office.

In particular, in implementing the PHB we exploit cloud computing as anyone with a suitable Internet connection and a standard browser can access an application in a cloud. In addition, cloud computing [12] allows for more efficient computing by centralizing storage, memory, processing and bandwidth.

In spite of the widespread adoption of cloud computing by most industries, the healthcare sector has been rather slow in adopting cloud-based solutions. Slow adoption in healthcare sector is partially due to concerns about data security and compliance with key regulations, which defines numerous offenses related to health care and sets civil and criminal penalties for them. Assuming that data security and compliance with key regulations are met, we assume that cloud computing will provide significant benefits to healthcare organizations and help them improve patient care.

In our earlier work [13] we have analysed the importance of PHRs. In this article, we discuss how modern ICT-technologies such as cloud computing can be exploited in implementing PHBs.

II. STANDARD PHR AND PATIENT CENTERED HEALTHCARE

A. Standard PHRs

PHRs allow individuals to access and coordinate their lifelong health information and make appropriate parts of it available to those who are authorized by the individual [14]. The commonly accepted goal of a PHR is to provide a complete and accurate summary of the health and medical history of a consumer [15]. A PHR typically includes information about medications, allergies, vaccinations, illnesses, laboratory and other test results, and surgeries and other procedures.

PHRs can be classified according to the platform by which they are delivered, and so the distinction between paper-based, portable-storage based, PC-based and Internet-based PHRs can be made. In this paper, we refer only to Internet-based PHRs.

PHRs have the potential to dramatically change healthcare in the near future as they enable patients to become more involved and engaged in their care and allow other authorized stakeholders to access information that was previously not available [16]. The changes effected by PHR systems could have a significant, positive impact on the efficiency of healthcare sector and thus resulting in considerable cost savings to the healthcare systems [17]. However, many barriers exist in widespread PHR installation, adoption, and use, and the foremost among them is the lack of the compatibility of the systems within healthcare sector [18].

In order to avoid the compatibility problems in importing data to PHRs various standardization efforts for PHRs have been done. In particular, the use of ASTM’s Continuity of Care Record (CCR standard) [19] and HL7’s Continuity of Care Document (CCD standard) [20] have been proposed for standardizing the structure of PHRs. CCR and CCD standards represent two different XML schemas designed to store patient clinical summaries meaning that they structure the content of the documents in different ways. However, both schemas are identical in their scope in that they contain the same data elements.

The sections of the CCR or CCD compliant XML document include patient insurance information, immunizations, allergies, diagnoses, procedures and medication list. Each section contains elements that can represent free text or structured XML-coded text. The content of each CCR file is captured from various sources such as hospital information systems, clinical laboratories, pharmacies or from the patient. In order to know who or what organization is the source of each element in a CCR or CCD file each data element is time and source stamped.

In order to illustrate CCR compliant documents let us consider the XML-document of Fig. 1.

```
<ContinityOfCareRecord>
  <Patient>
    <ActorID>AB-12345</ActorID>
    <Patient>
      <Medications>
        <Medication>
          <Source>
            <ActorID>Pharmacy of Kaivopuisto</ActorID>
          </Source>
          <Description>
            <Text>One tablet ones a day</Text>
          </Description>
        </Medication>
      </Medications>
    </Patient>
  </Patient>
</ContinityOfCareRecord>
```
Fig. 1 represents a CCR file that has a medication list (element Medications), which is comprised of one medication (element Medication) that is source stamped by the Pharmacy of Kaivopuisto.

The use of XML assures that the data contained in CCR or CCD documents can be expressed in multiple media formats (e.g., in HTML that can be accessed by a browser) that are friendly to both consumers and providers. However, the problem lies in that the data included in CCR or CCD file are not relevant for patient’s abilities or understanding. To see this let us next consider the imaginary scenario behind the CCR file of Fig. 1.

B. Motivating Scenario

Assume that patient, named Susan Taylor, having ID AB-12345, visits a physician for a diagnosis. After the diagnosis the physician sends (through the electronic prescription writer) the prescription to an electronic prescription holding store and gives the prescription in a paper form to Susan. It includes two barcodes: the first identifies the address of the prescription in the holding store, and the second is the encryption key which allows the pharmacist to decrypt the prescription.

At the pharmacy Susan gives the prescription to a pharmacist. The pharmacist scans both barcodes by the dispensing application, which then loads the electronic prescription from the prescription holding store. Then the pharmacist delivers the prescription into pricing system, which checks whether some of the drugs could be changed to a cheaper one. The pricing system notifies that Diovan should be changed to Valsartan as it is substitutable and cheaper, and so only Valsartan is repayable. Then by the permission of Susan the pharmacist replaces Diovan by Valsartan in Susan’s prescription. Finally the pharmacist dispenses the drug to Susan and generates the CCR-file of Fig. 1 and sends it into Susan’s PHR.

Later on at home Susan opens her PHR and looks at the prescription received from the physician. She worried about the change in the prescription as she does not have Diovan though her trusted physician prescribed it for her. She hesitates whether she should contact her physician before taking her new medicine.

This kind of scenario where a patient is unaware about the principles of her medication should not happen. Instead, according to the goals of patient-centered healthcare all relevant health information should be delivered to patient and presented according to patient’s understanding and abilities.

The problem here is that by just storing the prescription in PHR is not the key point but rather Susan should be informed about:

- What is the relationship between Diovan and blood pressure?
- What is the relationship between Diovan and Valsartan?
- What does generic substitution mean?

In our PHB the key idea is that within each action that generates an input to a PHB, an appropriate information entity or entities (or their links) are also stored in the PHB. With respect to the previous scenario it means that the physician should have stored two information entities: one focusing on blood pressure and the other focusing on Diovan. Further the pharmacist should have stored two information entities: one focusing on general substitution and one focusing on Valsartan. We next present how such additional functions can be technically performed.
III. TECHNICAL ASPECTS OF THE PHB

We use the term PHB system of the software application that manages PHBs. Its connections to other components are illustrated in Fig. 2.

![Fig. 2 The components of the PHB-based healthcare model](image)

In Fig. 2 there are only three parties (patient, pharmacist and physician) that communicate with the PHB system, but in reality, similar to PHR systems there may be many more parties that are authorized by the patient.

In the emergence of many new technologies based on Web services and Semantic Web, there are many chances for modelling PHB’s content as well as implementing PHBs and the message exchange between the communicating parties. Each chance has its limitations and opportunities.

We have developed two alternative ways for importing data into PHBs and modelling the content of the PHBs. However, both alternatives are similar in that they are able to receive CCR (or CCD) files (XML-documents), which are then transformed in the format that contains links into relevant information entities. After the transformations the documents are then inserted in the PHB.

The transformations are carried out through a stylesheet engine [21] (also called XSLT engine). It takes an original XML document, loads into a DOM source tree [21] and transforms that document with the instructions given in the style sheet. The instructions use XPath [22] expressions in referencing to the source tree and in placing it into the result tree. The result tree is then formatted, and the resulting element is returned.

We can use two alternatives with respect to the used style sheets: one transforms the document into an XML document and the other into RDF/XML document [23]. These two alternatives and the transformation process are illustrated in Fig. 3.

![Fig. 3 Augmenting a document by relevant links by using a stylesheet engine](image)

We next consider the limitations and opportunities of these two alternatives.

A. XML-Based PHB

In order to illustrate the transformation into an XML document let us consider the CCR-file presented in Fig. 1. The figure includes Susan Taylor’s prescription in XML format. As we presented in the imaginary scenario the final prescription was
developed as a result of generic substitution, i.e., Diovan was replaced by Valsartan. So, according to the PHB-based healthcare model the prescription should be augmented by two links: one link to the information entity that deals generic substitution, and the other link to information entity that deals Valsartan.

In order to produce such an augmentation the pharmacist activates (through the prescription management system) the style sheet engine that returns the XML document presented in Fig. 4. Note that in this resulted XML document the link to Valsartan is included in the element Product Info, and the link to generic substitution is included in the element Generic Substitution Info.

![XML-coded prescription including links to relevant information entities](image)

**Fig. 4** An XML-coded prescription including links to relevant information entities

### B. Ontology-Based PHB

Using the XML-based PHB we can solve the problems that Susan Taylor encountered in the scenario presented in Section 2. However, we still have a problem; namely in retrieving XML data we cannot use the expression power of the query languages developed for retrieving data that are organized according to ontology. Instead, we have to use query languages that access tree-structured data such as XPath and XQuery, expression power of which is too limited for our purposes.

In order to illustrate this we will continue our scenario. Let us assume that Susan Taylor has stored daily her blood pressure in her PHB as her medication (Diovan and Valsartan) should decrease her blood pressure. After using Valsartan a couple of weeks Susan still suspects whether Valsartan is equally effective as Diovan. So she would like to make the following queries:

- **“What is my average blood pressure during the time when I have used Diovan?”**

- **“What is my average blood pressure during the time when I have used Valsartan?”**
Unfortunately these queries are outside of the expression power of XPath and XQuery that can be processed on XML-documents, and so Susan’s XML-based PHB fails in retrieving this important information.

In order to allow this kind of data-centric queries (i.e., queries where data is extracted from various documents and then integrated according to certain criteria) on PHBs, we have also developed an ontology based PHB. Its content is structured according to ontology, called PHB-ontology.

We have specified the PHB-ontology by Web Ontology Language (OWL) [24], and Resource Description Language (RDF) is used for representing the actual PHBs, i.e., the instances of the PHB-ontology.

In developing the PHB-ontology we have exploited the XML-schema of the CCR-standard. In transforming its XML-schema to OWL-ontology we have used on the whole the following rules:

1. The complex elements are transformed to OWL classes.
2. Simple elements are transformed to OWL data properties.
3. Element-attribute relationships are transformed to OWL data properties.
4. The relationships between complex elements are transformed to class-to-class relationships (object properties).

However, as the OWL does not support structured attributes we have not transformed all complex elements to classes, but rather the complex elements that do not have identification have been transformed to a set of properties. For example, the following complex element:

```xml
<Strenght>
  <Value>50</Value>
  <Unit>milligram</Unit>
</Strenght>
```

In the CCR-file of Fig. 1 is first transformed into data properties Strenght Value and Strenght Unit, and then connected to the OWL class Medication. To illustrate this kind of transformation, a subset of PHB-ontology is presented in Fig. 5. In this graphical representation ellipses represent classes and subclasses, and rectangles represent data properties and object properties.

![Graphical representation of PHB-ontology](image)

Fig. 5 A subset of the PHB-ontology in a graphical form

The graphical ontology of Fig. 5 is presented in OWL in Fig. 6. Due to the space limits, we have omitted the specifications of the data properties such as Patient Name and Brand Name.

```OWL
<owl:Ontology rdf:about="PHR"/>
<owl:Class rdf:ID="Patient"/>
<owl:Class rdf:ID="Medication"/>
```

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In data storage (knowledge base) the instances of the PHB-ontology are presented by RDF-elements. To illustrate this, Susan’s augmented prescription in RDF/XML format is presented in Fig. 7.

RDF is a language for representing information about resources in the World Wide Web. It is intended for situations in which this information needs to be processed by applications, rather than being only displayed to people. RDF provides a common framework for expressing this information, and so it can be exchanged between applications without loss of meaning. The ability to exchange information between different applications means that the information represented in RDF may be made available to applications other than those for which it was originally created.

RDF itself is a data model. Its modelling primitive is an object-attribute-value triple, which is called a statement. A description may contain one or more statements about an object. For example, in Fig. 7, the description concerning “Valsartan” contains two statements: the first states that its type is Product in the PHB-ontology, and the second states that Valsartan is dealt in Valsartan Info.

```
<rdf:RDF
   xmlns: rdf=http://www.w3.org/1999/02/22-rdf-syntax-ns#
   xmlns: info=http://www.lut.fi/ontologies/PHB-infoentities#
   xmlns: po=http://www.lut.fi/ontologies/PHB-ontology#>
   <rdf:Description rdf:about="AB-12345">
     <rdf:type rdf:resource="&po;Patient"/>
     <po: PatientName>Susan Taylor</po:PatientName>
     <po: Uses rdf:resource="&po;Med-07092010"/>
   </rdf : Description>
   <rdf:Description rdf:about=" Med-07092010">
     <rdf:type rdf:resource="&po;Medication"/>
     <po: Contains rdf:resource="&po;Valsartan"/>
     <po : StrenghValue rdf:datatype="&xsd;integer">30</po : StrenghValue>
     <po : StrenghUnit>Tabs</po : StrenghUnit>
</rdf: RDF>
```

Fig. 6 A subset of the PHB-ontology in OWL
Note that OWL ontologies are also represented by RDF (i.e., they are RDF-elements such as the OWL ontology of Fig. 6), and thus we can query PHBs by querying languages developed for RDF, e.g., by SPARQL [25], which is standardized by the RDF Data Access Working Group (DAWG) of the World Wide Web Consortium, and is considered a component of the semantic web. On January 2008, SPARQL became an official W3C Recommendation.

IV. CLOUD-BASED PHB

Cloud computing is a technology that uses the Internet and central remote servers to maintain data and applications [26]. It is an evaluation of the widespread adoption of virtualization, service oriented architecture and utility computing. The name cloud computing was originally inspired by the cloud symbol which was often used to represent the Internet in diagrams.

Cloud computing allows consumers and businesses to use applications without installation, and they can access their personal files at any computer with Internet access. This technology allows for more efficient computing by centralizing storage, memory, processing and bandwidth. Further, unlike traditional hosting it provides the following useful characteristics:

- The resources of the cloud can be used on demand, typically by the minutes.
- The used resources are easily scalable in the sense that users can have as much or as little of a service as they want at any given time.
- The resources are fully managed by the provider. The consumer does not need any complex resource, only a personal computer with Internet access.

Software as a service (SaaS), is a type of cloud computing. In this service model, a service provider licenses an application to customers either as a service on demand, through a subscription, in a "pay-as-you-go" model, or at no charge [26]. The SaaS model to application delivery is part of the utility computing model where all of the technology is in the "cloud" accessed over the Internet as a service.

There are various architectural ways for implementing the SaaS model including the followings [12]:

- Each customer has a customized version of the hosted application that runs as its own instance on the host’s servers.
- Many customers use separate instances of the same application code.
- A single program instance serves all customers.

In the case of PHBs the required computation is rather small compared to traditional business applications and thus the last mentioned architecture is appropriate for the implementation of the PHB, i.e., a single PHB serves all patients. However, patient specific data can only be accessed by the patient and those that are authorized by the patient.

The SaaS-based PHB and its users are presented in Fig. 8.

We next itemize some clarifying aspects of Fig. 8:

- The cloud takes the advantages of SOA (Service Oriented Architecture) in the interoperation of the services, e.g., in importing patient’s health data the PHB-server interoperates with the servers of other healthcare organizations including hospitals, physicians’ offices and health centers.
- As Fig. 8 illustrates the peripheral devices that the patient has at home are connected to patient’s PC, and so the vital signs collected by the devices are transmitted via the PC to the cloud, i.e., to the PHB.
- The patient accesses his or her health data stored in PHB through the browser. As the patient needs nothing but an Internet access, the patient can easily connect to the PHB at home, as well as being away from home.
- Healthcare providers and patient’s family members that are authorized by the patient can access patient’s health data as well as communicate through their browsers.
V. CONCLUSIONS

The sophistication of information technology and communications is changing our society. In the ongoing healthcare reform, there is an increasing need to control the cost of medical care. In this context the significance of patient centered healthcare is extensively recognized as it can help by providing information to the patients, their families and physicians, not only for illnesses, but also for prevention and wellness. This, however, requires that patient’s health information as well as other relevant medical information is presented in appropriate format according to individuals understanding and abilities.

PHRs have the potential to dramatically contribute to patient centered healthcare as they enable patient to become more involved and engaged in their care, and allow other authorized stakeholders to access information about patient that previously has not been available or is difficult to access electronically. Hence, the change that can be caused by the deployment of PHR systems could also have a significant impact on the efficiency of administrative and clinical process in healthcare sector, and thus will give rise to considerable cost savings.

However, there are many obstacles to the widespread use of patient centered healthcare. For example, it is turned out that most patients are not satisfied with the medical treatment information on the Web. Instead, they trust on the medical information that is managed by medical authorities. A problem however, is that how this information can be targeted for patients.

The analysis of this problem led to the introduction of the notion of the PHB, which is an extension of PHR in that all healthcare providers, who are involved in patient’s healthcare, augment the PHB by links to relevant information entities.

This PHB-based healthcare model presumes that the information entities used in a therapy are accessible from the web, i.e., each entity should have a url (uniform resource locator). This, however, does not require the creation of new content as relevant information entities have already existed in digital form, which can be accessed by the systems used by the healthcare providers.

An interesting arising question is also that how we can get patients involved in maintaining and using a PHB (or PHR in general). Obviously, at least by providing them with incentives we can increase the amount of patients that keep PHBs, e.g., by providing a discount for the patients who keep a PHB faithully. Also by showing that using a PHB will help them to get better medical care would increase their use.

In our future work we will extend the PHB system by active elements. By an active element we refer to an expression or statement that is stored in PHB, and expect the element to execute at appropriate time. The time of action might be when a certain event occurs such as an insertion of a blood test result. Then depending on the inserted values an appropriate action can be taken, e.g., generating an email to patient’s personal physician.

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In addition, we will study the effects of introducing cloud-based health information systems on the mind-set of patient and healthcare personnel as the introduction of these technologies also changes the daily duties of the patient and many healthcare employees. Therefore we assume the most challenging aspect will not be the technology but rather the changing of the mind-set of patient’s healthcare team.

REFERENCES


