PERSONAL HEALTH BOOK
A Novel Tool for Patient Centered Healthcare

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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, who are involved in patient's healthcare, augment the PHB by links to relevant information entities. 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 semantic web technologies such as RDF and OWL.

1 INTRODUCTION

"Patient centered healthcare" is the term that is used to describe healthcare that is designed and practiced with the patient at the centre (Bauman et al., 2003). 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 (Gillespie et al., 2004). 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) (Agarwal et al., 2006; Kaelber et al, 2008; Lewis et al., 2005; Tuil et al, 2006) support patient centered healthcare in an appropriate way. 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 (Little et al., 2001; Michie et al., 2003; Stewart, 2004; Thompson, 2004; Puustjärvi and Puustjärvi, 2010).

In particular, we have analyzed the following questions:

- What are the shortcomings of XML-based PHRs in supporting individuals 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 blood pressure. Correspondingly, in dispensing a drug a pharmacist

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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 of patient's information therapy and pharmacists who dispense drugs for patient are responsible of patient's drug therapy. Correspondingly all sources, such as a trainer in patient's gym, that are involved in 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 already exist in digital form, and 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.

From technology point of view the PHB-based healthcare model presumes that PHBs are internet based meaning that the PHBs are stored at a remote server. So PHBs can be shared with healthcare providers that 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 this paper, we restrict ourselves on analyzing how modern ICT-technology can be exploited in implementing PHBs. First, in section 2, we motivate the introduction of PHBs by considering the problems encountered in using standard PHRs in patient centered healthcare. By the term "standard PHR" we refer to PHRs, which are based on a standardized XML schema such as the schemas presented in CCR- (CCR, 2009) and CCD-standards (CCD, 2009). As we will illustrate, the drawback of these standard PHRs is that they are focused on storing health oriented data instead of supporting health oriented information that is required in patient centered healthcare.

In Section 3, we consider the development of PHBs by extending standard PHR by information therapy (Ix) (Trevena et al., 2006) and drug therapy (Metler and Kempler, 2004). Then, in Section 4, we consider the advantages that can be achieved in implementing the PHB by exploiting semantic web technologies. In particular, we present the advantages that can be achieved in using RDF (RDF, 2004) and OWL (OWL, 2006) in developing an ontology (Davies et al., 2007) for the PHB. Finally, Section 5 concludes the paper by considering the drawbacks and advantages of PHBs as well as our future research.

2 STANDARD PHR AND PATIENT CENTERED HEALTHCARE

2.1 Standard PHRs

PHRs allow individuals to access and coordinate their lifelong health information and make appropriate parts of it available to those that are authorized by the individual (Puustjärvi and Puustjärvi, 2009). The commonly accepted goal of a PHR is to provide a complete and accurate summary of the health and medical history of a consumer (Angst et al., 2008). 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. However, in this paper by the acronym PHR 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 about patients that was previously not available. The changes effected by PHR systems could have a significant, positive impact on the efficiency of healthcare sector and thus resulting considerable cost savings to the healthcare systems. However, many barriers exist to widespread PHR installation, adoption, and use, foremost among them the lack of the compatibility of the systems within healthcare sector (Puustjärvi and Puustjärvi, 2008).

In order to avoid the compatibility problems in importing data to PHRs various standardization efforts on PHRs have been done. In particular, the use of the Continuity of Care Record (CCR standard) of ASTM and HL7's Continuity of Care Document (CCD standard) has been proposed for using in standardizing the structure PHRs. From technology's point of view CCR and CCD-standards represent two different XML schemas designed to store patient clinical summaries. On the other hand, both schemas are identical in their scope in the sense that they contain the same data elements.

The sections of the CCR compliant XML-document include for example 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 from hospital information system, a clinical laboratory, from a pharmacy or from the patient him or herself. In order to know who or what organization is the source of each element in a CCR file each data element is time and source stamped.

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

```xml
<ContinityOfCareRecord>
   <Patient> <ActorID>AB-12345></ActorID></Patient>
   <Medications>
   <Medication>
      <Source>
         <ActorID>Pharmacy of Kaivopuisto</ActorID>
         <ActorRole>Pharmacy</ActorRole>
      </Source>
      <Description>
        <Text>One tablet ones a day</Text>
      </Description>
      <Product>
        <ProductName>Valsartan</ProductName>
      </Product>
      <Strenght>
        <Value>50</Value>
           <Unit>milligram</Unit>
      </Strenght>
      <Quantity>
         <Value>30</Value>
           <Unit>Tabs</Unit>
      </Quantity>
   </Medication>
  </Medications>
</ContinityOfCareRecord>
```

Figure 1: A CCR compliant XML-document.

Figure 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 file is not relevant for patient's abilities or understanding. To see this let us next consider the imaginary scenario behind the CCR file of Figure 1.

2.2 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 Figure 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 is 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 presssure?
- 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 also 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.

3 TECHNICAL ASPECTS OF THE PHB

We use the term PHB system of the software application that manages PHBs. The connections of PHB system to other components are illustrated in Figure 2. In the figure, 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.

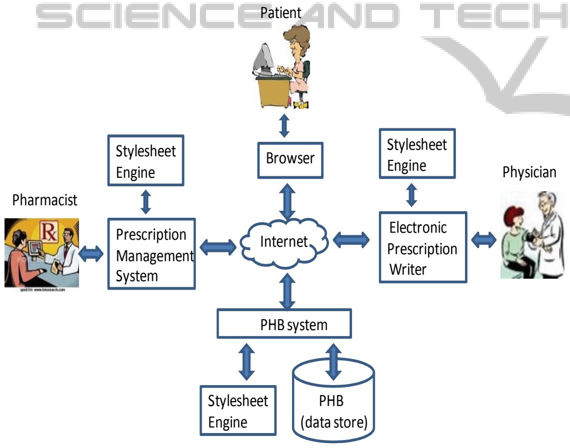

Figure 2: The components of the PHB-based healthcare model.

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 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* (Daconta et al., 2003) (also called XSLT engine). It takes an original XML document, loads into a DOM source tree (Daconta et al., 2008) and transforms that document with the instructions given in the style sheet. The instructions use XPath (XPath, 2008) 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.

Our used two alternatives are different with respect to the used stylesheets: one transforms the document into an XML document and the other into RDF/XML document. These two alternatives and the transformation process are illustrated in Figure 3.

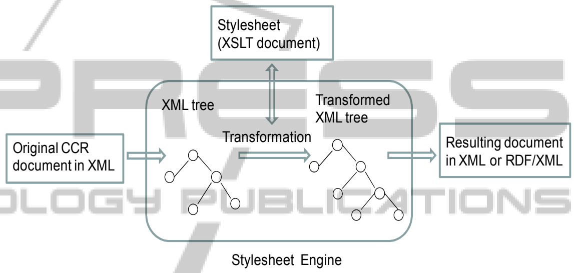

Figure 3: Augmenting a document by relevant links by using a stylesheet engine.

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

3.1 XML-based PHB

In order to illustrate the transformation into an XML document let us consider the CCR-file presented in Figure 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 replace 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 stylesheet engine that returns the XML document presented in Figure 4. Note that in this resulted XML-document the link to *Valsartan* is included in the element ProductInfo, and the link to generic substitution is included in the element GenericSubstitutionInfo.

```
<ContinityOfCareRecord>
   <Patient> <ActorID>AB-12345></ActorID></Patient>
   <Medications>
  <Medication>
      <Source>
          <ActorID>Pharmacy of Kaivopuisto</ActorID>
          <ActorRole>Pharmacy</ActorRole>
      </Source>
      <Description>
        <Text>One tablet ones a day</Text>
        <GenericSubstitutionInfo>
            http://www.../medicalinfo/SubstitutionInfo
         </GenericSubstitutionInfo>
       </Description>
       <Product>
     <ProductName>Valsartan</ProductName>
     <ProductInfo>
            http://www.../medicalinfo/ValsartanInfo
        </ProductInfo>
       </Product>
       <Strenght>
        <Value>50</Value>
           <Unit>milligram</Unit>
      </Strenght>
       <Quantity>
          <Value>30</Value><Unit>Tabs</Unit>
     </Quantity>
   </Medication>
  </Medications>
</ContinityOfCareRecord>
```

Figure 4: An XML-coded prescription including links to relevant information entities.

3.2 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 an ontology. Instead we have to use query languages that access tree-structured data such as XPath and XQuery, which expression power 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 been using *Diovan* ?" and

"What is my average blood pressure during the time when I have been using *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 an ontology, called *PHB-ontology*.

We have specified the PHB-ontology by Web Ontology Language (OWL), 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:

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

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

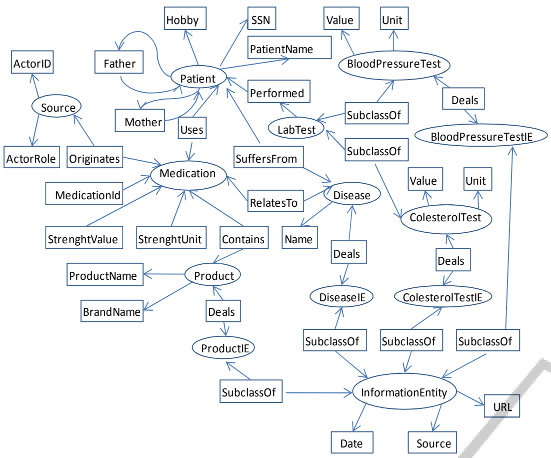

Figure 5: A subset of the PHB-ontology in a graphical form.

The graphical ontology of Figure 5 is presented in OWL in Figure 6. Due to the space limits, we have omitted the specifications of the data properties such as PatientName and BrandName.

```
<rdf:RDF
    xmlns:rdf=http://www.w3.org/1999/02/22-rdf-syntax-nsl#
    xmlns:rdfs=http://www.w3.org/2000/01/rdf-schema#
    xmlns:owl=http://www.w3.org/2002/07/owl#>
    <owl:Ontology rdf:about="PHR"/>
    <owl:Class rdf:ID="Patient/">
    <owl:Class rdf:ID="Medication/">
    <owl:Class rdf:ID="Source/">
    <owl:Class rdf:ID="Product/">
    <owl:Class rdf:ID="LabTest/">
    <owl:Class rdf:ID="BloodPressureTest">
      <rdfs:subClassOf rdf:resource="#LabTest"/>
    </owl:Class>
    <owl:Class rdf:ID="ColesterolTest">
      <rdfs:subClassOf rdf:resource="#LabTest"/>
    </owl:Class>
    <owl:ObjectProperty rdf:ID="Uses">
      <rdfs:domain rdf:resource="#Patient"/>
      <rdfs:range rdf:resource="#Medication"/>
    </owl:ObjectProperty>
    <owl:ObjectProperty rdf:ID="Contains">
      <rdfs:domain rdf:resource="#Medication"/>
      <rdfs:range rdf:resource="#Product"/>
    </owl:ObjectProperty>
    <owl:ObjectProperty rdf:ID="Originates">
      <rdfs:domain rdf:resource="#Medication"/>
      <rdfs:range rdf:resource="#Source"/>
    </owl:ObjectProperty>
    <owl:ObjectProperty rdf:ID="Performed">
      <rdfs:domain rdf:resource="#Patient"/>
      <rdfs:range rdf:resource="#LabTest"/>
    </owl:ObjectProperty>
              .
              .
              .
</rdf:RDF>
```

Figure 6: A subset of the PHB-ontology in OWL.

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 Figure. 7.

```
<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 : StrenghtValue rdf:datatype=
               "&xsd;integer">30</po : StrenghtValue>
         <po : StrenghtUnit>Tabs</po : StrenghtUnit>
   </rdf : Description>
   <rdf:Description rdf:about="Valsartan">
        <rdf:type rdf:resource="&po;Product"/>
          <po:Deals rdf:resource="&info;ValsartanInfo"/>
    </rdf : Description>
    < rdf:Description rdf:about=" Pharmacy of Kaivopuisto">
        <rdf:type rdf:resource="&po;Source/>
        <po : ActorRole>Pharmacy</po : ActorRole>
    </rdf : Description>
</rdf:RDF>
```

Figure 7: Augmented prescription in RDF/XML format.

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 modeling 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 Figure 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 dealed in *ValsartanInfo*.

Note that OWL ontologies are also represented by RDF (i.e., they are RDF-elements such as the OWL ontology of Figure 6), and thus we can query PHBs by query languages developed for RDF, e.g., by SPARQL (SPARQL, 2008), 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.

4 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 care 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 has not been previously been available or 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 for 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 are 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 models 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 already exist in digital form, and 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 by incentives we can increase the amount of patients that keep PHBs, e.g., by providing a discount for the patients who keep a PHB faithfully. 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 times. The times 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 action can be taken such as generating an email to patient's personal physician.

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