Managing Information Sharing in Patient-Centered Healthcare

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***Abstract*-Patient-centric healthcare is an emerging healthcare model that optimizes the healthcare system to focus on patient experience and outcomes for better health and well-being. It requires that patients as well as physicians have the ability to obtain and understand health information, and make appropriate health decisions. A problem is how such information should be gathered from a variety of heterogeneous data sources, and how patient and physicians should access such information. Our argument is that the gathered information should not be presented as a collection of XML-documents but rather as an ontology. The main problem with XML-based solutions is that, depart from ontology-based data stores, they do not support queries that require extracting and integrating data from various documents. Further by storing the ontology in a cloud we can easily share patients' health information among patient's healthcare team. How this kind of solution can be implemented by exploiting healthcare standards, ontology languages and cloud technologies is the topic of this article.**

Keywords- Personal Health Records; Patient-centered healthcare; Information Based Medicine; Information Therapy; HL7 RIM; Interoperability; Ontologies

I. INTRODUCTION

The introduction of new emerging healthcare models, such as patient-centered care, is changing how people think about health and patients themselves. Patient-centered healthcare optimizes the healthcare system to focus on patient experience and outcomes for better health and well-being [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 requires that health information should be presented according to understanding and abilities of an individual.

Though patient-centered healthcare is widely studied (e.g., in [3, 4, 5, 6, 7, 8, 9]) its challenges of sharing relevant health information is not well addressed from technology point of view. We have recognized three interesting questions:

- What health information should be provided to patient-centered healthcare?
- How should relevant healthcare information be gathered from heterogeneous data sources?
- How the gathered information should be modelled and presented to patients?

It is obvious that the vast majority of the required health information can be gathered from other e-health tools such as from electronic health records, personal health records (PHRs), and from the tools supporting information therapy and information based medicine. In gathering information for patient-centered healthcare, we could follow at least the following three ways:

1. Accessing relevant information sources on demand,
2. Implementing a specific data store for patient-centered healthcare, or
3. Extending the content of PHRs by relevant health information, and using the extended PHR in patient-centered healthcare.

The drawback of the first approach is that it would require a huge amount of exchanged messages between heterogeneous data sources. The drawback of the second approach is that the maintenance of one more data store would not be cost effective, and the management of replicated data would cause consistency problems. In contrast, extending PHRs is not necessarily a big effort as they already include a wide variety of relevant health information. For example, they include information about medications, allergies, vaccinations, illnesses, laboratory test results, and surgeries and other procedures. Instead extending electronic health records would not be appropriate as they are designed for use only by healthcare providers.

The introduction of PHRs has drawbacks too. First, clinical documents have a number of properties, such as persistence, stewardship, authentication, wholeness, and human readability. The problem here is that these properties are not necessary shared with PHRs. For example, the data in PHRs is not always authenticated although only authenticated documents are likely to be of value in medico-legal disputes. As a result many physicians do not want patients to have greater access to their records.

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Another barrier in introducing PHRs is the digital divide, i.e., the population-level gap in internet and computer access may prevent certain groups from accessing the PHR.

On the other hand, PHRs have the potential to significantly change healthcare in the future as they enable patients to become more involved and engaged in their care. It is also turned out that patients who do not understand their treatment instructions, disease management, or prescription requirements are more likely to mishandle their health, be hospitalized more frequently, and have much higher medical costs than their more involved counterparts [8]. They also allow other authorized stakeholders to access information about patient that was previously not available.

In order to avoid the compatibility problems in importing data to PHRs, various standardization efforts on PHRs have been done. In particular, the used of the XML-based standards have been proposed. However, a problem with XML-based PHRs is that they do not support queries that require extracting and integrating data from various documents. In order to allow such queries we have developed a methodology for developing and maintaining ontology-based PHRs.

In this paper, we extend our earlier work on modelling clinical documentation. In particular, we report our work on developing an *extended PHR*, which extends the traditional PHRs by providing the features required in patient-centered healthcare. Our argument is that information in PHRs should not be presented as a collection of XML-documents, instead, the information should be stored in an ontology based data store (knowledge base), which provides sophisticated features for accessing health information. In addition, the ontology can be exploited in information therapy as well as in information based medicine. The key idea behind these e-health models is to provide the right information in the right format to the right individual at the right time. The former studies this principle from patients' point of view while the latter studies it from physicians' point of view.

Inspired by the semantic web technologies and the flexibility of cloud computing, we have also studied their suitability for supporting the emerging healthcare models. Our studies have indicated that PHR systems should also support the functionalities of many traditional e-health tools such as remote patient monitors, health-oriented blogs, and health-oriented information servers. It also turned out that by gathering these functionalities into one system we can achieve synergy, i.e., achieve functionalities that would not be obtainable by any of the e-health tools independently.

In gathering the functionalities we have adapted the ideas of knowledge centric organizations to extended PHRs, i.e., we have revolved the e-health tools around a health oriented knowledge base. So, all the e-heath tools share patient's health data. Further by exploiting the characteristics provided by cloud computing, we can easily ensure the interoperation of patient's healthcare team: accessing the extended PHRs requires only internet connection. Instead the prevailing systems provided by healthcare organizations do not provide appropriate technology for co-operation as their use is devoted to organization's healthcare personnel only.

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 relating to health care and sets civil and criminal penalties for them. However, making sure that data security and compliance with key regulations are met then cloud computing will provide significant benefits to healthcare organizations and help them improve patient care. It also promotes the introduction of new healthcare delivery models that will make healthcare more efficient and effective [3].

The rest of the paper is organized as follows. First, in Section II, we give an overview of patient-centered healthcare. Then, in Section III, we consider information therapy and information based medicine from health information point of view. In Section IV, we present the standardization efforts of PHRs. In particular, we illustrate the problems that will arise in querying PHRs, which content are structured according to an XML schema. We also motivate the use of ontology languages in developing e-health tools. Then, in Section V, we present our chosen way of exploiting ontologies in PHRs. In particular, we first introduce our developed PHR-ontology. Then, we illustrate how we can integrate the PHR-ontology with other relevant ontologies, and thereby extend the functionalities of PHRs. In Section VI, we first present the architecture of the extended PHR system, and describe its document exchange with other health information sources. In Section VII, we analyze the suitability of cloud computing for implementing extended PHRs. Finally, Section VIII concludes the paper.

II. PATIENT-CENTERED HEALTHCARE

"Patient-centered healthcare" is the term that is used to describe healthcare that is designed and practiced with the patient at the center [6]. The terms "patient-centered care" and "patient orientation" are also used in the same meaning. There are also many proposed definitions, which encompass many of the same core principles. However, there is no globally accepted definition for it [8]. Instead it is often stated that what it is not, e.g., it is not technology centered, doctor centered, hospital centered or disease centered.

In [2] patient-centered healthcare is defined to be health care that is closely congruent with and responsive to patients' wants, needs, and preferences, and in [7] is characterized by placing patients at the center of the system of care and developing good services that revolve around them. The National Health Council (NHC) defines patient-centered care to be quality health care achieved through a partnership between informed and respected patients and their families, and a coordinated healthcare

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team [8].

Patient-centered healthcare subscribes to the belief that the patient has strengths, values and experiences that are important in the healthcare experience and relationship between those providing care and the patient.

The NHC has defined the following three principles of patient-centered care [10]:

- Patients and their families manage their health care in partnership with a coordinated health care team that recognizes, respects and acts upon their goals, needs, values, preferences, cultural wishes, and/or other factors identified by patients and their families.
- Patients and their families receive evidence-based, cost-effective quality care that maximizes health, alleviates discomfort and is safe and free from avoidable problems.
- Patients and their families have the ability to obtain and understand health information and services, and make appropriate health decisions.

Our research is focused on the last principle. We argue that health information should be accurate, relevant and comprehensive to enable patients and carers to make informed decisions about healthcare treatment. In particular, health information should be presented in appropriate format according to individuals understanding and abilities. How extended PHRs can be exploited in achieving this goal is the topic of our research.

III. INFORMATION THERAPY AND INFORMATION BASED MEDICINE

Information therapy (Ix) [11] and information-based medicine represent [12] e-health models that encompass many of the same principles as patient-centered healthcare, and thereby they can be exploited in developing e-health tools for patient-centered healthcare.

A. Information Therapy

A widely used definition of information therapy is that it is the therapeutic provision of information to people for the amelioration of physical and mental health and well-being [13, 14]. Information therapy is also described as "the prescription of specific evidence based medical information to specific patients at just the right time to help them make specific health decisions or behavior changes" [11].

Information therapy is a type of healthcare information service that has emerged in the past decade. It applies to a wide range of situations and context. For example, information therapy may be a physician-written prescription telling a patient what to read, or it may use to help a patient to make treatment decision such as whether to continue medication.

Information therapy can be compared to similar concepts in medicine such as drug therapy, physiotherapy, helping with books or bibliotherapy. (The term "biblio" refers to book, and therapy is derived from "therapeia", which means to serve and to help medically.) However, information therapy differs from these in the sense that by exploiting information technology information therapy aims at providing personalization, targeting and documentation. Personalization means that the content of the delivered information depends on the familiarity of the user. Targeting means that the information prescriptions are targeted according to patient's moment in care, i.e., information is delivered at right time. Documentation means that information prescriptions are documented as part of the provided treatment.

Many studies have demonstrated that the provision of information therapy can increase compliance with treatment regimens, satisfaction with the health care provider and medical facility, and improve the ultimate health outcome for the individual [9, 12, 13]. It is also turned out that patients who do not understand their treatment instructions, disease management, or prescription requirements are more likely to mishandle their health, be hospitalized more frequently, and have much higher medical costs than their more involved counterparts [14].

B. Information Based Medicine

Healthcare is a field where the fast development of drug treatment and technologies requires specialized skills and knowledge that need to be renewed frequently. Furthermore, the number of new medications increases every year. As each drug has its unique indications, cross-reactivity, complications and costs also the prescribing medication as well as the distribution of medicinal products becomes still more complex. As a result also the amount of new instructions concerning new medication increases rapidly. An interesting question arising from this reality is how medicinal instructions should be organized and retrieved to ensure that the employees are aware of the relevant medicinal instructions.

It is estimated that over 100.000 patients die annually from medical errors and adverse drug reactions [15]. The need to minimize adverse drug reactions and medical errors is contributing to the drive towards information based medicine. It addresses the challenge of finding a way to ensure that clinicians base their day-to-day decision-making on current best evidence.

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Information based medicine is an enabling paradigm that creates more efficient, and thus more effective practices in healthcare. It can also be seen as a paradigm of healthcare that complements traditional, opinion based diagnoses with functional information gleaned from computerized data acquisition, management, and analysis. Fundamentally, it is about providing the right information in the right format to the right individual at the right time. Its primary goal is that the physician has access to clinical information, not only about the patient laboratory and radiological tests, but to give him context he needs to have the most up-to-date information about the condition and the guidelines for treatment. This context may include familial, historical, and environmental information about the patient. Further, all required information should be available at easily accessible format.

Appropriate healthcare information systems are crucial to enabling information based medicine. They will increasingly enable physicians to access patient data stored in a variety of data stores across enterprises as well as between enterprises.

IV. PERSONAL HEALTH RECORDS

A. Classifying Personal Health Records

A PHR is a confidential and easy-to-use tool for managing information about patient's health [16, 17]. It can include a variety of information depending on where that information comes from, e.g., from patient himself, health care providers, pharmacies, insures, and the consumer [18]. It includes information about medications, prescriptions, allergies, vaccinations, illnesses, laboratory and other test results, and surgeries and other procedures [19].

In principle, a PHR should provide a complete and accurate summary of the health and medical history of a consumer [18]. It is accessible to the consumer and to those authorized by the consumer [19]. It is not the same as electronic health record (EHR) [16], which is designed for use by health care providers.

There are a variety of business models in the PHR-market. The three common used models are the following:

- the consumers pay for the PHR,
- the PHR service is free for the consumer as the service is supported by advertising, and
- the PHR service is supported by the employer with the hope of savings on healthcare costs.

We can also classify PHRs according to the platform by which they are delivered. In internet-based PHRs health information is stored at a remote server, and so the information can be shared with health care providers. They also have the capacity to import data from other information sources such as a hospital laboratory and physician office. However, importing data to PHRs from other sources requires the standardization of PHR-formats.

B. Using XML for Formatting Personal Health Records

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 [21] Continuity of Care Document (CCD standard) has been proposed. From technology point of view CCR- [22] and CCD-standards [23] represent two different XML schemas designed to store patient clinical summaries. However, both schemas are identical in their scope in the sense that they contain the same data elements.

A simplified example of a CCR file is presented in Fig.1. It 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.

A problem with XML-based PHRs is that their data is document-centric-data, i.e., they are collections of documents such as documents including lab tests, prescribed medications and illnesses. By contrast, PHR usage is often data centric, meaning that data should be extracted from various documents and then integrated according to certain criteria. For example, a consumer may be interested to know the average blood pressure or blood sugar concentration during the time periods he or she was using a drug for blood pressure, or the consumer may be interested to know the cholesterol values when he or she was on a diet. Unfortunately the computation required by such queries is not provided by the query languages such as XPath [20] and XQuery [25] that are designed to address XML documents.

Note that XML [26] is just a metalanguage for defining mark-up languages. By a metalanguage we refer to a language used to make statements about statements in another language, which is called the object language. For example, RDF (Resource Description Framework) [27] and OWL (Web Ontology Language) [28] are object languages.

As a matter of fact, the name "extensible mark-up language" is misleading in the sense that XML is not a single mark-up language that can be extended but rather it is a common notation that mark-up languages can build on. XML is merely a standard notation for mark-up languages. It serves as an interchange format for exchanging data between communicating applications.

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```
<ContinityOfCareRecord>
  <Patient>
    <ActorID>Person.12345></ActorID>
  </Patient>
  <Medications>
    <Medication>
      <CCRDataObjectID>Medication.567</CCRDataObjectID>
      <DateTime>
        <ExactDateTine>2009-03-01TO12:00</ExactDateTime>
      </DateTime>
       <Source>
        <Actor>
          <ActorID>Pharmacy of Kaivopuisto</ActorID>
          <ActorRole>Pharmacy</ActorRole>
        </Actor>
      </Source>
      <Description>
        <Text>One tablet three times a day</Text>
      </Description>
      <Product>
        <ProductName>Voltaren</ProductName>
        <BrandName>Diclofenac</BrandName>
      </Product>
      <Strenght>
        <Value>50</Value>
        <Unit>milligram</Unit>
      </Strenght>
      <Quantity>
        <Value>30</Value>
        <Unit>Tabs</Unit>
      </Quantity>
    </Medication>
  </Medications>
</ContinityOfCareRecord>
```

Fig. 1 A simplified example of a CCR file

V. EXPLOITING ONTOLOGIES IN PERSONAL HEALTH RECORDS

A. Ontology Languages

XML is a mark-up language that defines a set of rules for encoding documents in a format that is both human-readable and machine-readable [26]. However, XML says nothing about the semantics of the used tags. Hence, by just presenting exchanged documents in XML does not mean that the applications understand each other. It just provides a means for structuring documents. Due to the lack of semantics we do not use XML for representing PHRs but rather we use ontology languages.

Originally ontology is the philosophical study of the nature of being, existence or reality in general, as well as of the basic categories of being and their relations [29]. In computer science, an ontology is a general vocabulary of a certain domain, and it can be defined as “an explicit specification of a conceptualization” [30]. Essentially the used ontology must be shared and consensual terminology as it is used for information sharing and exchange.

Fundamentally an ontology tries to capture the meaning of a particular subject domain that corresponds to what a human being knows about that domain. It tries to characterize that meaning in terms of concepts and their relationships. It is typically represented as classes, properties, attributes and values.

An ontology language is a formal language used to encode the ontology. There are a number of such languages including OWL as well as earlier developed ontology languages such as OIL, DAML and DAML+OIL [31]. OWL is intended to be used when the information contained in documents needs to be processed by applications, as opposed to situations where the content only needs to be presented to humans. In particular, OWL is a language for making ontological statements, developed as a follow-on from RDF. OWL is intended to be used over the World Wide Web, and all its elements (classes, properties and individuals) are defined as RDF resources, and identified by URIs. However, by generalizing the concept of a Web resource, it

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can also be used to represent information about things that can be identified on the Web, even when they cannot be directly retrieved on the Web, e.g., items and their prices that are available from on-line shops.

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. In particular, RDF defines a language for describing relationships among resources in terms of named properties and values. The relationship of XML and RDF is that XML provides a way to express RDF-statements. In other words, RDF is an application of XML.

OWL has more facilities for expressing meaning and semantics than XML and RDF, and thus OWL goes beyond these languages in its ability to represent machine interpretable content of the ontology. In particular, it adds more semantics for describing properties and classes, for example relations between classes, cardinality of relationships, and equality of classes and instances of the ontology.

B. Developing the PHR-Ontology

Ontology development process is comprised of many stages. First the scope of the ontology should be specified. What is included in the ontology should be determined by the use to which the ontology will be put, and possible anticipated extensions [31].

The purpose of our introduced PHR-ontology is to describe the concepts of the domain in which PHRs take place. Hence, the PHR-ontology describes the concepts (as well as their relationships) such as demographics, insurance information, immunizations, allergies, diagnoses, procedures and medication.

In developing ontologies we rarely have to start from scratch. For example, the first step in ontology development process is to write down the relevant terms that should appear in the ontology. In this stage we have exploited the XML-schema of the CCR file, which is developed for personal health records. In transforming the XML schema to OWL-ontology we have used on the following rules:

- The complex elements of the XML-schema are transformed to OWL classes.
- Simple elements are transformed to OWL data properties.
- Element-attribute relationships are transformed to OWL data properties.
- The relationships between the 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 complex element Strenght of the CCR file of Fig. 1

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

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 the PHR-ontology is presented in Fig. 2. In this graphical representation ellipses represent OWL classes and subclasses, and rectangles represent OWL data and object properties. Note that based on this ontology one can query the average blood pressure or blood sugar concentration during the time periods the patient was using a drug for blood pressure. However, as we already stated (in the context of Fig. 1) the computation required by such queries is not provided by the query languages that are designed to address XML documents.

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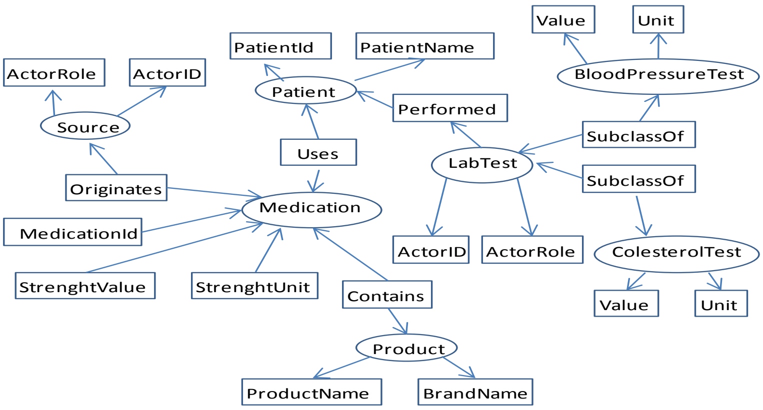

Fig. 2 A subset of the PHR-ontology

The graphical ontology of Fig. 2 is presented in OWL in Fig. 3. Due to the space limits, we have omitted the specifications of the data properties such as PatientName, ProductName 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="Sourcet/">
        <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="#aMedication"/>
        </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>
```

Fig. 3 A subset of the PHR-ontology in OWL

Note that OWL ontologies are represented by RDF (i.e., they are RDF-elements such as the OWL ontology of Fig. 3), and thus we can query PHRs by query languages developed for RDF, e.g., by SPARQL [31]. It is standardized by the RDF Data Access Working Group (DAWG) of the World Wide Web Consortium.

C. Representing Ontology Instances

The purpose of the PHR-ontology is to describe the concepts of the domain in which PHRs take place. Its instances are

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presented by RDF-elements. To illustrate this, in Fig. 4 an instance of the PHR ontology is presented.

```
<rdf:RDF
        xmlns : rdf=”http://www.w3.org/1999/02/22-rdf-syntax-ns#”
        xmlns : xsd=”http://www.w3.org/2001/XMLSchema#”
        xmlns : po=http://www.lut.fi/ontologies/p-ontology#>
        <rdf:Description rdf:about=”120962-K3”>
          <rdf:type rdf:resource=“&po;Patient”/>
           <po : PatientName>Lisa Smith</po : PatientName>
            <po : Uses>MO-5481</po:Uses>
           <po : Performed>H-257L</po : Performed>
        </rdf : Description>
        <rdf:Description rdf:about=” MO-5481”>
            <rdf:type rdf:resource=“&po;Medication”/>
            <po : Contains>Voltaren</po : Contains>
            <po : StrenghtValue rdf:datatype=
                  ”&xsd;integer”>30</po : StrenghtValue>
            <po : StrenghtUnit>Tabs</po : StrenghtUnit>
        </rdf : Description>
        <rdf:Description rdf:about=” 211708-8”>
            <rdf:type rdf:resource=“&po;Source/>
            <po : ActorRole>Pharmacy</po : ActorRole>
        </rdf : Description>
        <rdf:Description rdf:about=” Voltaren”>
            <rdf:type rdf:resource=“&po;ProductName”/>
            <po : BrandName>Diclofenac</po : Contains>
        </rdf : Description>
 </rdf:RDF>
```

Fig. 4 A PHR in RDF/XML serialization format

RDF’s modeling primitive is an object-attribute-value triple, which is called a statement [27]. A description may contain one or more statements about an object. For example, in Fig. 4, the description concerning “Voltaren” contains two statements: the first states that its type is ProductName in the used ontology, and the second states that its BrandName in the used ontology is Diclofenac.

D. Transforming XML Documents into RDF/XML Format

Gathering XML coded data in to the PHRs can be done automatically by transforming the XML-documents into RDF/XML serialization format before their insertions into the PHRs. This however requires that a specific style sheet is specified for the translation for each document type (i.e., used XML schema). A language associated with style sheets is XSLT (Extensible Stylesheet Language) [30]. It is a mark-up language that uses template rules to specify how a style sheet processor transforms an XML document.

Fig. 5 illustrates this transformation and formatting process. The Stylesheet Engine takes an XML document, loads it into a DOM (Document Object Model) [30] source tree, and transforms that document with the instructions given in the stylesheet into RDF/XML format. The instructions use XPath [24] expressions in referencing to the source tree and in placing it into the result tree. As illustrated in Fig.5, the result tree is then formatted, and the resulting element in RDF/XML format is returned. After this the element is inserted into a PHR.

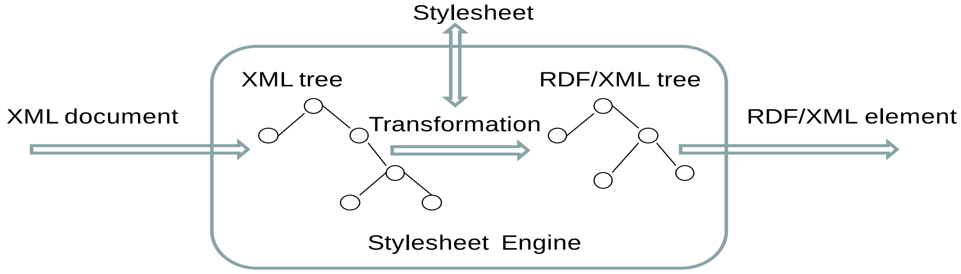

Fig. 5 Transforming an XML document into RDF/XML element

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E. Integrating Ontologies

After the schema of the CCR file is transformed, then the PHR-ontology is extended by information entity ontology (Ix-ontology). It extends the PHR-ontology by the class Information Entity. Further it has subclasses that are specified according to the concept they deal with. For example, subclass Disease IE is comprised of information entities that deal with diseases.

A subset of the extended PHR-ontology is presented in Fig. 6. In this graphical representation ellipses represent classes and subclasses, and rectangles represent data properties and object properties.

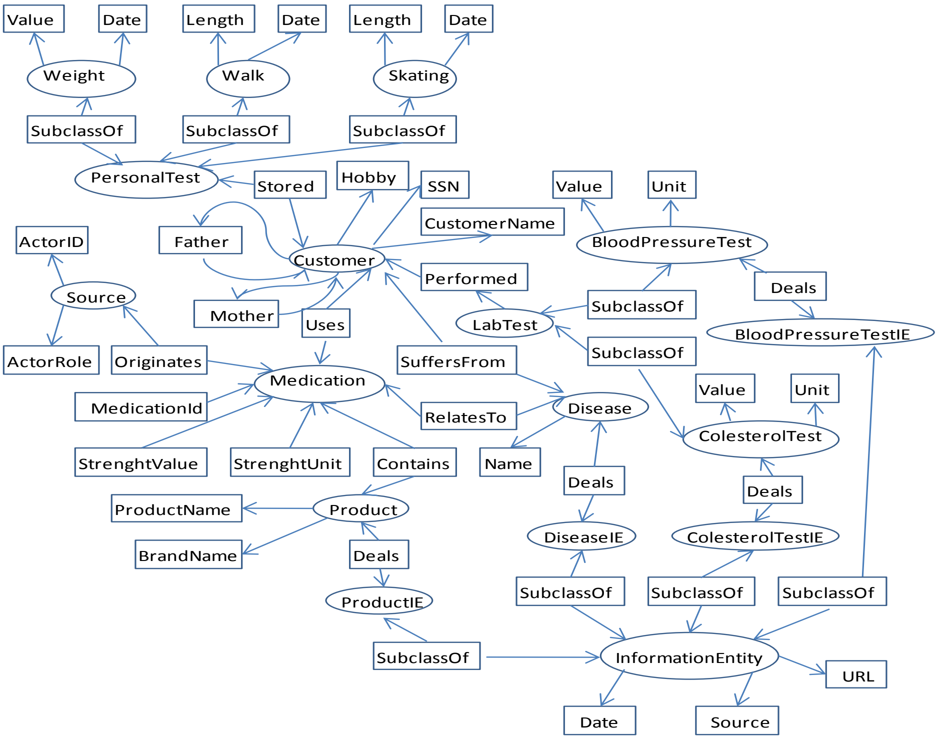

Fig. 6 A subset of extended PHR-ontology

Finally, the concepts related to information based medicine are captured to the ontology. Note that integrating ontologies, i.e., extending an ontology by other ontology, does not require the insertion of the elements of the ontology as OWL support specific operation for including ontologies. Fig. 7 illustrates the idea of ontology integration: integrated ontology is developed by integrating the Blog-ontology, the Ix-ontology, the PHR-ontology and RM-ontology (Remote Monitoring ontology). In the figure ellipses represent OWL´s classes, rectangles represent OWL's data properties and the lines between ellipses represent OWL's object properties. Accordingly, class A is shared by all the four ontologies.

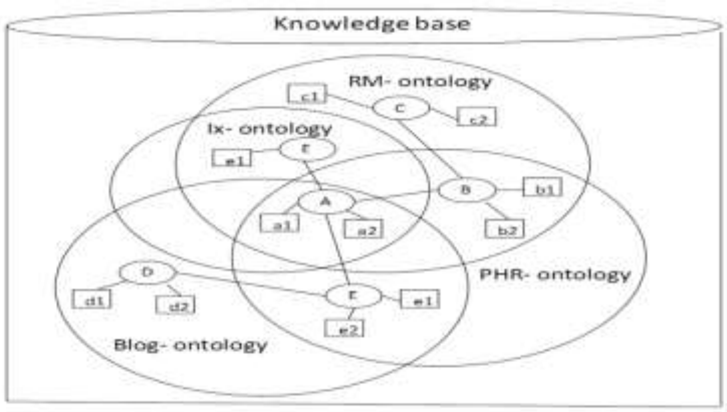

Fig. 7 An integrated ontology (the extended PHR-ontoloy) stored in a knowledge base

In order to illustrate shared classes of the figure, *A* could represent class *Disease*, *B* class *Patien*t, and *C* class *Informal entity*. Further assume that object property *A-B* is *suffer_from*, object property *A-E* is *deals*, data property b1 is patient name, and data property e1 is a url. In such setting we could specify by RDF that John Smith suffers from diabetes and the educational material dealing with diabetes is stored in a specific *url*.

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VI. MESSAGE EXCHANGE

A. Communication Architecture

In this section we present the environment where the extended PHRs take place. In particular, we make the difference between PHR's message exchange between medical organizations, and message exchange between non-medical organizations (Fig. 8). In the former, the message exchange is carried out by CDA-documents while in the latter it is carried out by Semantic documents.

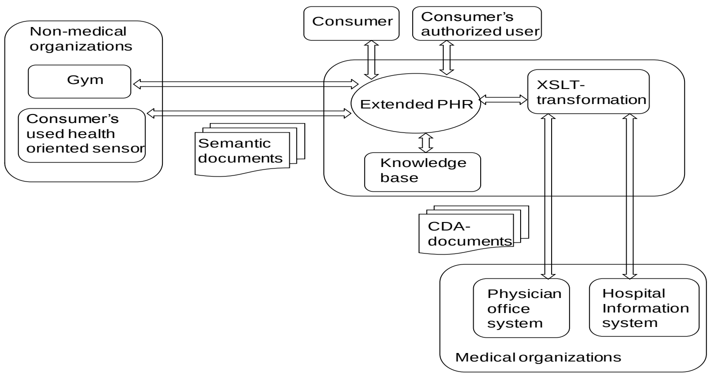

Fig. 8 Message exchange between extended PHR and its information sources

B. CDA-Documents

The content of the PHRs is stored in a knowledge base. The format of the stored data is based on RDF. Therefore in importing data from XML-based data sources (e.g., from HL7 CDA [21] compliant systems) requires that the XML-formatted data is first translated (by an XSLT-based style sheet engine [26]) into RDF and then inserted into the knowledge base.

The Clinical Document Architecture (CDA) is an ANSI approved HL 7 standard [21]. It is proven to be a valuable and powerful standard for a structured exchange of persistent clinical documents between different software systems. However, in the case of non persistent documents with CDA we encounter many problems. The main reason for this is that the semantics of the CDA documents is bound to the shared HL7 Reference Information Model (RIM) [21]. Thereby introducing new document types would require to extending the RIM, which is a long lasting standardization process. So this approach contradicts with our requirement of flexibility in introducing new document types in importing health information into the knowledge base.

C. Semantic Documents

By semantic documents we refer to the practice where the documents are coded by RDF using an OWL-ontology as a vocabulary. In message exchange semantic documents are carried in the body-part of the SOAP messages. SOAP, originally defined as Simple Object Access Protocol, is a protocol specification for exchanging structured information in the implementation of Web Services in computer networks.

The extended PHR ontology specifies the vocabulary for the semantic documents. Hence, for example, as the ontology includes class Weight having attributes Value and Date, a patient can daily store his weight to his PHR. On the other hand, if the vocabulary does not include, say Length, a patient is allowed to first extend the ontology by class Length (or by data property Length), and then insert the measured values for length. Further, the extended PHR-ontology includes object property Father, meaning that a patient may store in his PHR the SSN (a key of the class Patient) of his father. Then assuming that patient's father has authorized his child to use his PHR, a patient (or a user authorized by the patient) may for example make a query “give me all the diseases that I as well my father suffer from”. In principle, the more information a PHR includes the more expressive queries on it can be made.

As an example of a semantic document consider Fig. 9, where a semantic document is presented by an RDF-description.

```
<rdf:RDF
    xmlns : rdf=”http://www.w3.org/1999/02/22-rdf-syntax-ns#”
    xmlns : po=http://www.lut.fi/ontologies/p-ontology#>
    <rdf:Description rdf:about=”1101272-F349”>
     <rdf:type rdf:resource=“&po;Patient”/>
          <po : PatientName>John Ford</po : PatientName>
          <po : Hobby>Sailing</po:Hobby>
          <po:PatientDisease rdf:resource=“&po;Diabetes”/>
          <po:Uses rdf:resource=“&po;Metformin”/>
          <po:Father rdf:resource=“&po;121141-K45”/>
    </rdf : Description>
</rdf:RDF>
```

Fig. 9 An example of a semantic document

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In this semantic document, the RDF-description concerning patient having Social Security Number (SSN) 1101272-F349 states that

- his name is John Ford,
- his hobby is sailing,
- he suffers from diabetes,
- he uses Metformin, and
- the SSN of his father is 121141-K45.

VII. EXPLOITING CLOUD COMPUTING IN PERSONAL HEALTH RECORDS

Cloud computing is a technology that uses the internet and central remote servers to maintain data and applications [32]. 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 that's 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 but a personal computer with internet access.

The terms cloud applications and web applications are very similar, and they are also used interchangeable. This similarity stems from the natural similarities that exist between these terms. However, a difference is that web applications do not offer the same richness in functionality and customization as cloud applications. That is, cloud applications are web applications in that they can be used through web browsers, but not all web applications are cloud applications. Thus, web applications comprise a subset of cloud applications.

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 [33]. 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 [32]:

- 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 Personal Health Information Systems (PHISs), such as the extended PHR, the required computation is rather small compared to traditional business applications and thus the last mentioned architecture is appropriate for the implementation of the extended PHR, i.e., a single extended PHR 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 extended PHR and its users are presented in Fig. 10.We next itemize some clarifying aspects of the figure:

- 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 PHIS-server interoperates with the servers of other healthcare organizations including hospitals and physicians’ offices.
- As the figure 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 PHIS.
- The patient accesses his or her health data stored in PHIS through the browser. As the patient needs nothing but an internet access, the patient can easily connect to the PHIS 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.

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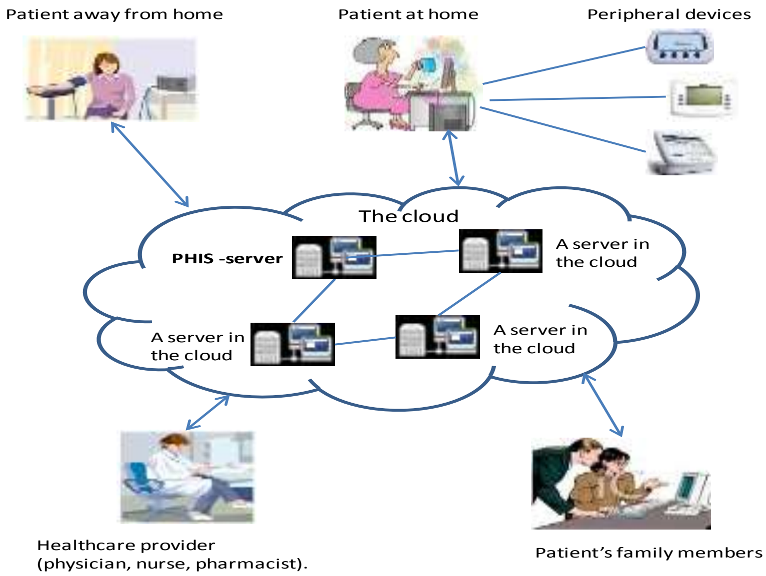

Fig. 10 The users of the cloud-based PHRs

VIII. CONCLUSIONS

The sophistication of information technology and communications is changing our society. Especially during the last decade, Internet has changed the way people work, bank and shop, but a similar change in health care has been small-scale. However, recent interest in e-health will speed this change: in the ongoing healthcare reform, there is an increasing need to control the cost of medical care. In particular, preventive medical care can help by providing information to the patients, their families and physicians, not only for illnesses, but also for prevention and wellness. On the other hand, many studies have indicated that most patients are not satisfied with the medical treatment information on the Web though many e-health tools provide links to materials or other websites that have information about patient's health conditions or medications. In particular, they have regarded many sites to be overly commercial, or they could not determine the source of the information.

Patient-centered healthcare is an emerging e-health model that contributes to preventive medical care. It optimizes the healthcare system to focus on patient experience and outcomes for better health and well-being. A key point in patient-centered healthcare is that patients and their families have the ability to obtain and understand health information and services, and make appropriate health decisions. This requires that patient's health information as well as other relevant medical information is presented in appropriate format according to individuals' understanding and abilities.

From technology point of view integrating information in an ever growing internetworking world is likely to be the most urgent need for any kind of business, trade or science. Daily work in e-health is not an exception: a huge and increasing amount of heterogeneous data is distributed over network of computing system, and the efficient usage of this heterogeneous data requires the introduction of interoperability and integration technologies. An example of the necessity of integration and interoperability in e-health sector is a PHR.

The corner stone of our approach is our developed PHR-ontology on which the communicating information systems have to commit in their mutual communication. It, however, does not suppose the introduction of a universal ontology for the healthcare sector. This situation is analogous with natural languages: a gym, or any medicinal organization, may communicate in Finnish with medicinal authorities and in English with gyms. Just as there is no universal natural language, so there is no universal ontology.

Our argument is that traditional XML-based approaches for presenting health information do not satisfy the requirements of patient-centered healthcare but rather ontology languages are required for representing health information as well as health ontologies. The problem here is that the efficient usage of patients' health documentation often is data centric, meaning that data should be extracted from various documents and then integrated according to specific criteria. However, the computation required by such queries is not provided by the query languages that are designed to address hierarchical structures such as XML documents. As a result, to find out such dependencies, the physician first has to retrieve the relevant documents, and then search for the required data from the documents. Such a navigation and searching is frustrating and time consuming.

Moving from XML-archives to ontology based e-health tools requires transforming the XML-based medical and health information into the format that is compliant with the ontology. This is the extra work required from the health care organizations.

Regardless of the recent progress in patient-centered healthcare, there are still many obstacles to the widespread use of patient-centered healthcare that must be addressed. For example, the quality of the content of the health information should be

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ensured. Also the liability and confidentiality issues of sharing patient's health information must be addressed. In addition, as the patient-centered healthcare requires third-parties in managing information systems, also their reimbursements have to be considered.

An interesting arising question is also that how we can get patients involved in patient-centered healthcare, e.g., to keep a PHR. Obviously, at least by providing them by incentives we can increase the amount of patients that keep PHRs, e.g., by providing a discount for the patients who keep a PHR faithfully. Also by showing that keeping a PHR will help them to get better medical care would increase their use. In our future work, 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 the mind-set of patient's healthcare team.

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