Towards Patient-Centered Telemedicine

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Abstract— **Patient-centered care is an emerging healthcare model that is changing how people think about health and about the patients themselves. It emphasizes the coordination and integration of care, and the use of appropriate information, communication, and education technologies in connecting patients, caregivers, physicians, nurses, and others into a healthcare team where the health system supports and encourages cooperation among team members. However, in spite of the widespread adoption of telemedicine, existing telemedicine applications do not support patient centered-care. In this paper, we present our designed cloud based telemedicine system that supports patient-centered care. It exploits Personal Health Records (PHRs) in sharing patient's clinical documents, and it manages medical consultation requests by exploiting a Consultation ontology. The system and the PHRs may be located anywhere in the Internet, and its consulting organizations may include any healthcare provider having the ability for consultation.**

Keywords - telemedicine; patient-centered care; personal health records; CCD standard, cloud computing; ontologies; eHealth ecosystem

I. INTRODUCTION

Telemedicine is the use of telecommunication and information technologies in order to provide clinical health care at a distance [1]. It aims to eliminate distance barriers and can improve access to medical services that would often not be consistently available in distant rural communities [2]. In particular, telemedicine is viewed as a cost-effective alternative to the more traditional face-to-face way of providing medical care [3].

At the same time, the introduction of new emerging healthcare trends, such as patient-centered care [4], pharmaceutical care [5], and personal health records (PHRs) [6], are changing how people think about health and about the patients themselves. In addition, many studies have demonstrated that the provision of these healthcare models can increase compliance with treatment regimens, satisfaction with the health care provider and medical facility, and improve the ultimate health outcome for the individual [7].

It is also true 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].

Unfortunately, none of the categories of telemedicine support these emerging healthcare trends: *Store-and-forward telemedicine* involves acquiring medical data and then transmitting this data to the system that is accessible to patient's physician. *Interactive services* provide real-time interactions between patient and physician. It includes phone conversations, online communication and home visits. *Remote monitoring* enables medical professionals to monitor a patient remotely using various technological devices.

Patient-centered care emphasizes the coordination and integration of care, and the use of appropriate information, communication, and education technologies in connecting patients, caregivers, physicians, nurses, and other into a healthcare team where health the system supports and encourages cooperation among team members [9]. 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.

Pharmaceutical care emphasizes the movement of pharmacy practice away from its original role on drug supply towards a more inclusive focus on patient care [10]. It emphasizes the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve patient's quality of life [11].

A PHR is a record of a consumer that includes data gathered from different sources such as from health care providers, pharmacies, insures and the consumer [12]. It includes information about medications, allergies, vaccinations, illnesses, laboratory and other test results, and surgeries and other procedures [13]. PHRs are owned by the patients and they can only be accessed by the patient and those that are authorized by the patient.

In our vision PHRs can significantly contribute to the introduction of patient-centered care. Further in telemedicine they do not only improve the quality of care but also significantly increase the efficiency of consulting physicians. PHRs also 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 [14].

Further, cloud computing [15] provides an ideal technical infrastructure for a variety of e-health services including PHRs. As anyone with a suitable Internet connection and a standard browser can access an application in a cloud, sharing patient's clinical documentation among the healthcare team is straightforward to those that are authorized by the patient.

In this paper, we describe our work on designing a cloud-based telemedicine system that captures PHRs and manages consultation requests by a software module called *Consultation server*. It changes the traditional telemedicine paradigm: its main goal is not only to provide a cost-effective alternative to the more traditional face-to-face way of providing medical care but rather to provide a data infrastructure for information sharing among patient's healthcare team.

Further, our designed telemedicine infrastructure allows location independence in the sense that the consultation manager, called *Consultation Server*, and the PHRs may be located anywhere in the Internet, and its stakeholders may include any healthcare provider having the ability for consultation. Further, a patient can be cared in any place having an Internet connection. Thus, such a global architecture also changes the traditional telemedicine ecosystems which only aim to provide clinical health care at a distance.

In the design of the Consultation Server we have followed the idea of knowledge oriented organizations [16]. Its key idea is to revolve all applications around a shared ontology. The main gain of such architecture is that the applications that manage the consultation related data can interoperate by accessing the shared ontology, which in our architecture is called *Consultation ontology*. It is specified in OWL (Web Ontology Language) [17], and so the applications can query the ontology by SPARQL [18]. As OWL ontologies and its instances are presented in RDF (Resource Description Framework) [19], the ontology is updated by inserting RDF-statements in the ontology.

In our introduced terminology the participants of the Consultation Server that agree to work together for practicing telemedicine is called as a *telemedicine affinity domain*. Examples of possible telemedicine affinity domains include nationwide and regional affinity domains, regional federations made up of several local hospitals, healthcare providers, and insurance provider supported communities.

A useful feature of a telemedicine affinity domain is that it is global: its components can locate anywhere in the Internet, and it can be exploited by patients and consulting physicians as far as they have an Internet connection.

The notion of telemedicine affinity domain has similarities with the *clinical affinity domain* of the IHE XDS [20], which studies the problem of patient's scattered clinical documentation. Its key idea is that patient's clinical documents are dynamically retrieved from a clinical affinity domain by exploiting relevant registries. This model assumes that patients' clinical documentation follow them as they move from one clinical affinity domain to another. Another difference between IHE XDS and PHRs is that in the former patient's clinical documentation is managed by healthcare authorities while in the latter they are managed by a patient.

The rest of the paper is organized as follows. First, in Section 2, we give a motivating scenario of our ideas in practice. Then, in Section 3, we consider the structure of CCD documents and show how they can be used for exchanging clinical information as well as structuring PHRs. In Section 4, we present the architecture of the Consultation Server and the Consultation Ontology in a graphical way. We also give a variety of useful queries that the ontology enables. In Section 5, we do not consider the Consultation Server from technology point but rather as ecosystems having many interconnected parts. Finally, Section 6 concludes the paper by analyzing potential risks that may jeopardize the deployment of our designed telemedicine system. We also shortly consider our future work on integrating the Consultation Server with other e-health tools used by the physicians.

II. MOTIVATING SCENARIO

Assume that a patient, named Nancy Taylor, has an online Web-based free personal PHR, where her health data and information related to the care given to her is stored. She can access her PHR from any place having an Internet connection.

One day Nancy discovered a rash on her waist, and so she decided to visit the nearest general practitioner having a contract with a telemedicine affinity domain. The practitioner examines Nancy's rush but the practitioner does not know what kind of treatment or medication should be prescribed for Nancy, and so the practitioner decides to request medical consultation by his Web browser.

To carry out the consultation the practitioner first takes a photo from Nancy's waist. Then the practitioner fills the request document by describing the symptoms of the rash and attaches the photo to the document. The document also provides a hierarchical classification (i.e., a taxonomy) of diseases. The practitioner marks the node "skin disease". In addition, authorized by Nancy the practitioner adds a link to Nancy's PHR and authorization for its use (including required access rights). Finally, the practitioner clicks the submit button, and so the document is delivered to the Consultation Server, which maintains a queue of the pending requests.

Each request includes a set of metadata items such as disease(s), source of request, language and possible priority of the request. The function of the metadata items is to enable automatic matching of the requests and the consulting physicians. So the Consultation Server shows for a consulting physician only the requests that match with his or her profile. Therefore, each consulting physician of the affinity domain also has a profile, which has values for the metadata items and is stored in the Consultation Server.

Assume that a physician, named John Smith, is a specialist in a hospital of a telemedicine affinity domain. In addition his profile matches with the request concerning Nancy, and so the request is in the consultation request queue shown for him.

After a few minutes John Smith picks up the consultation request document and examines the symptoms described in the document as well as the attached photo. Immediately he recognizes Nancy's rash as shingles (herpes zoster), which can be treated by a medicinal product named Aciclovir. Then he checks from Nancy's PHR whether Nancy has some allergies that would prevent the use of the drug or whether she has some ongoing medical treatment that could cause mutual negative effects. As there are no such findings the

physician updates Nancy's PHR by the prescribed medication and by the diagnosis he made. Finally John constructs and signs the prescription electronically, which is then electronically delivered to the general practitioner visited by Nancy.

III. USING CCD STANDARD IN PHRS

A. PHRs vs. EHRs

In medical consultation, as well as in any medical treatment, a complete and accurate summary of the health and medical history of the patient is of prime importance. A problem here is that as a patient may have lived in various places and a patient may have many healthcare providers, including primary care physician, specialist, therapists and other medical practitioners, patient's health documentation may be distributed over several healthcare providers.

PHRs provide a simple way for solving the problem of patients' scattered clinical documentation [21]. They differ from EHRs (Electronic Health Record) [22] in that they are owned by the patients and they can only be accessed by the patient and those that are authorized by the patient while EHRs assume that the health records are designed only for use by health care providers and are owned by medical authorities.

Managing fragmented healthcare documentation by EHRs has been successful only in a very few industrialized countries, such as in Singapore and Denmark [23]. Instead successful results from the use of PHRs are reported from many countries and communities. Therefore we have also concluded that the use of PHRs instead of national EHR's in managing patients' health documentation is a more appropriate solution in the context of telemedicine.

B. Web-Based PHRs

PHRs can be classified according to the platform by which they are delivered. In web-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.

Various standardization efforts on PHRs have been done. In particular, the use of the Continuity of Care Record (CCR standard) of ASTM [24] and HL7's [24] Continuity of Care Document (CCD standard) [25] has been proposed. From technology point of view CCR and CCD-standards represent two different XML schemas designed to store patient clinical summaries [23]. However, both schemas are identical in their scope in the sense that they contain the same data elements.

Web-based PHRs are core components in our proposed ecosystem. However, it does not assume that all patients have a PHR, but it encourages patient to acquire a PHR. Using a PHR does not require patients to own any personal devices for internet connection nor any efforts for managing it. Rather it requires patient to authorize healthcare personnel to maintain and access their PHR.

Acquiring a PHR is a tempting opportunity as there are many freely available web-based PHRs available, and moving personal data between standard-based PHR is supported by the vendors. For example, as the support of the Google Health was retired on January 2012 Microsoft has developed a transfer process for the user of the Google Health for moving their health records into Health Vault. Similar to Dossia and World Medical Card, it is a web-based system to store, maintain and share health and fitness information. They support a number of exchange formats including industry standards such as the CCR and CCD standards.

C. CCD Standard

We have given preference to CCD standard (an XML schema) as it is nowadays increasingly used for specifying the structure of exchanged clinical documents as well as specifying the structure of the PHR. This feature simplifies the update of the PHR as well as the generation of the clinical documents that will be stored in the PHR.

Further, we have assumed that XML based CCD and CCR standards are the most appropriate standards as they are commonly used within PHRs. Their schemas contain the same data elements, and thereby transformation between these formats can be easily done.

The CCD standard is a constraint on the HL7 CDA standard. The CCD standard has been endorsed by HIMMS (Healthcare Information and Management Systems Society Though) [26] and HITSP (Healthcare Information Technology Standards Panel) [27] as the recommend standard for exchange of electronic exchange of components of health information.

Although the original purpose of the CCD documents was to deliver clinical summaries between healthcare organizations, nowadays the XML schema of the CDD documents is increasingly used for specifying the structure of the PHRs. The same schema can be used in message as all its parts are optional, and it is practical to mix and match the sections that are needed.

D. The Structure of a CCD document

Each CCD document have one primary purpose (which is the reason for the generation of the document), such as patient admission, transfer, or inpatient discharge. Further, each CCD document, as well all HL7 CDA documents, is comprised of the Header and the Body.

A CCD document that includes a header and the Medications section from the Body is presented in Fig. 1. The content of the document is derived from the scenario presented in Section 2, i.e., the document would be inserted in Nancy Taylor's PHR, which is based on the CCD-standard.

In a PHR the CCD documents are usually organized into hierarchical structures that simplify the search of documents, e.g., grouping together the documents by episode, clinical specialty or time period. Yet each clinical document is stored as a stand-alone artifact, meaning that each document is complete and whole in itself.

```
<CCDfile>
  <DocumentID>DOC_123</DocumentID>
  <Patient>
    <PatientID>AB-12345></PatientID>
    <PatientName>Nancy Taylor></PatientName>
  </Patient>
  <Medications>
    <Medication>
      <MedicationID>Medication.567</MedicationID>
      <DateTime>
        <ExactDateTime>2012-03-01TO12:00</ExactDateTime>
      </DateTime>
      <Source>
        <Actor>
          <ActorID>Pharmacy of Health</ActorID>
          <ActorRole>Pharmacy</ActorRole>
        </Actor>
      </Source>
      <Description>
        <Text>Two tablets twice a day</Text>
      </Description>
      <Product>
        <ProductName>Aciclovir </ProductName>
        <BrandName>Zovirax</BrandName>
      </Product>
      <Strenght>
        <Value>400</Value>
        <Unit>milligram</Unit>
      </Strenght>
      <Quantity>
        <Value>40</Value>
        <Unit>Tabs</Unit>
      </Quantity>
    </Medication>
  </Medications>
</CCDfile>
```

Figure 1. A simplified example of a CCD document.

IV. CONSULTATION SERVER

A. The Architecture of the Comsultation Server

In designing the internal architecture of the Consultation Server we have followed the idea of knowledge oriented organizations [16, 28], where the key idea is to revolve all applications around a shared ontology. As illustrated in Fig. 2, in our solution all the applications of the Consultation Server are revolved around the Consultation Ontology.

The users access the Consultation Ontology through the Consultation Portal, which provides connections to the relevant cloud applications. The applications are based on the use cases of the various user groups. For example, Submit Consultation Request and Pick-up a Consultation Request are two typical applications developed for physicians. These applications interoperate through accessing the same data items included in the Consultation Ontology.

Note that although the Consultation ontology is specified in QWL and queried by SPARQL (i.e., by a RDF-based query language), it is stored for the efficiency reasons in a relational database [29].
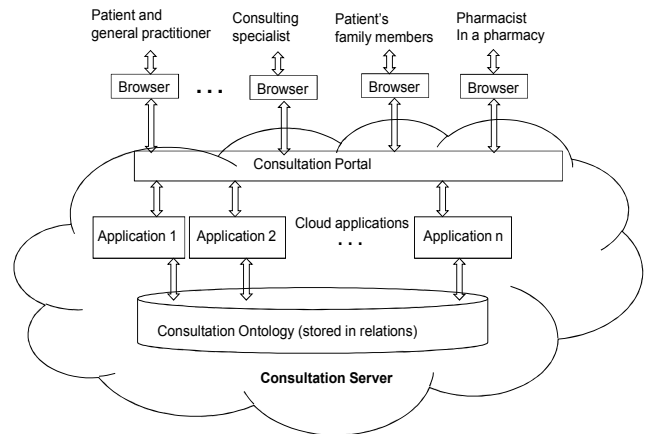
Figure 2. The components of the cloud-based Consultation Server.

B. The Structure of the Consultation Ontology

A portion of the Consultation ontology is graphically presented in Fig. 3. In this graphical representation ellipses represent classes and rectangles represent data type and object properties. *Object properties* relate objects to other objects while *data type properties* relate objects to datatype values. Classes, data type properties and object properties are modelling primitives in OWL [17].

Note that in Fig. 3 we have presented only a few of objects' datatype properties. For example, in the figure we have omitted most of the datatype properties from the classes Physician and Organization. Instead all the datatype properties of the class Consultation request are presented in the figure. The class Speciality and its datatype property Class represent a taxonomy. That is, except for the root node there is a link from each class instance to its parent.

The idea behind this taxonomy is that the symptoms and the specialities of the physicians are specified by the same vocabulary. This feature simplifies the matching of consultation requests and physicians' specialities.
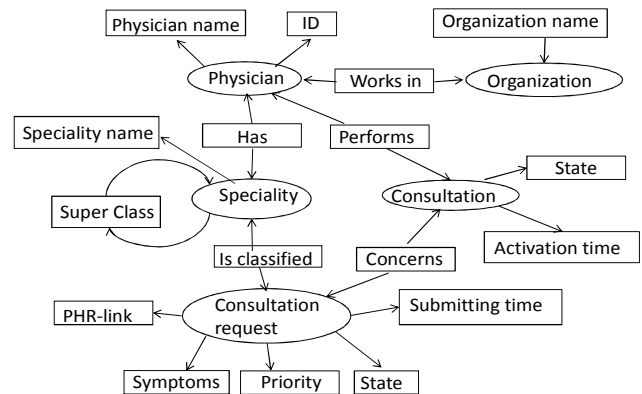
Figure 3. Graphical presentation of a portion of the Consultation Ontology.

The Consultation Ontology enables a variety of useful queries for physicians such as the followings:

- Is there any pending consultation request having classification "Skin diseases".
- Is there (in the affinity domain) any physicians having speciality in diabetes.
- Is there any consultation request matching with my speciality.
- Is there any pending consultation request that is submitted by a physician of the University Hospital.
- Is there any consultation request that has been pending over ten minutes.
- Give me the names and specialties of the consulting physicians that work in a specific affinity domain.

Note that the Consultation Server can support more than one telemedicine affinity domain. Further, as most OWL ontologies, such as the Consultation Ontology, are usually stored in relational database systems, it is also possible to use the triggering mechanism of the SQL [30] in automating the management of the consultation requests. For example, a request can be automatically allocated to a physician having required speciality and having no ongoing consultation.

C. Cloud Computing and SaaS

Cloud computing is an appropriate choice for telemedicine consultation management as it allows organizations to use applications without installation. Moreover, in most cases cloud-based solutions reduces the cost of acquiring, delivering, and maintaining computing power [15]. However, in our vision the main goal behind cloud computing is to achieve synergy through controlled sharing of data.

In particular the Saas (Software as a Service) model of cloud computing is appropriate for the Consultation Server. It is a software delivery model in which applications are hosted by service provider and made available to customers over the Internet. It provides access to software and its functions remotely as a Web-based service.

Further, there are various architectural ways for implementing the SaaS model. For example, in the case where the Consultation Server serves more than one telemedicine affinity domain we could use the following software architectures:

1. Each telemedicine affinity domain has a customized version of the Competence Server that runs as its own instance.
2. Many telemedicine affinity domains use separate instances of the same application code.
3. A single program instance serves all telemedicine affinity domains.

In our designed version the Consultation Server supports only one clinical affinity domain as so only one version and one instance is required.

V. TELEMEDICINE ECOSYSTEM

To succeed e-health systems should not be considered just as a technical infrastructure but rather as ecosystems having many interconnected parts [31].

So far we have considered the technical infrastructure and the services of our designed telemedicine oriented cloud-based ecosystem. The other key parts of the ecosystem are governance regulations, financing and stakeholders. For now, we shortly consider what kind of new alternatives the introduction of cloud-based solutions gives for these parts of the ecosystem.

A. Governance Regulations

E-health application that maintains patients' health documentation must adhere to national legislated policies and regulations, which concerns privacy and security issues. One problem is that in many countries that are just beginning to investigate on e-health application do not yet have enough mature legislation with respect to e-health. Thereby national governments have an important role in promoting the development of appropriate legislation concerning e-health.

In our developed telemedicine ecosystem patient's health documentation is not stored in the national archives but rather on PHR system, where the patient's health documentation is owned by the patient and only used by the physicians, patient's family members and healthcare personnel authored by the patient. As a result, patients' health documentation is not under the control of national healthcare authorities, and thus is not so tightly dependent on whether there is advanced legislation for e-health.

B. Financing Cloud-Based E-Health Ecosystems

In designing an e-health ecosystem it is important to ensure that appropriate funding is in place for its implementation and operation. Financing can come from a variety of sources, such as government or public-private partnerships.

Financing PHRs is not an actual problem as there are many freely available web-based PHRs available. Further there are many freely available PHRs for specific communities, e.g., for employees of specific organization, customers of a specific insurance company or for the customers of a specific healthcare provider.

C. Stakeholders of Global Ecosystem

In designing the implementation of an e-health ecosystem, it is of prime importance to involve in preparation all the key stakeholders, such as governments, public and private healthcare providers, patients, as well as patient advocacy groups [31].

As our proposed ecosystem is not nationwide but rather "internet-wide", the system itself as well as its stakeholders may span over many countries. For example, governments and healthcare providers from a variety of countries may be involved in the ecosystem, and each stakeholder has different objectives and motivations for participating in the ecosystem.

VI. CONCLUSION AND FUTURE WORK

The goal of our work has been to show that cloud-based global telemedicine ecosystems that support patient centered care can be implemented from technology point of view. Yet there are many problems that may jeopardize the success of such ecosystems. In particular, the introduction of new technology requires training: the incorrect usage of a new telemedicine technology, due to lack of proper training, may ruin the whole ecosystem. In addition, a consequence of introducing a new telemedicine practice is that it significantly changes the daily duties of the healthcare personnel, and the role of patient and patient's family members. Therefore one challenging aspect is also the changing the mind-set of the involved healthcare personnel.

The introduction of a new technology in telemedicine is also an investment. It includes a variety of costs including software, hardware and training costs. Introducing and training the staff on new technology is a notable investment, and hence many organizations like to cut on this cost as much as possible.

In order to minimize the changes that the introduction of the system will cause on healthcare personnel, in our future work we will investigate how telemedicine consultation can be linked into physicians' day-to-day work patterns. In particular, we will consider how the functionalities of the Consultation Portal can be integrated with other e-health tools used by the physicians.

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