Addressing the Adoptability Challenges of the PHR Systems: SharingCare

Tuncay NAMLI[1], Senan POSTACI[1], Mert GENÇTÜRK[1], Asuman DOĞAÇ[1], Anıl YALÇINKAYA[2] and Cebrail TAŞKIN[2]
[1]*Software Research, Development and Consultancy Ltd., METU Technopolis, METU, Ankara, 06531, Turkey*
Tel: +90 312 2101763, Fax: + 90 312 2101837, tuncay@srdc.com.tr
[2] *Argela Software and Informatics Technologies,* METU Technopolis, METU, Ankara, 06531, Turkey
Tel: +90 312 5556710, Fax: + 90 312 2101290, cebrail.taskın@argela.com.tr

Abstract: This article describes a Personal Health Ecosystem, namely SharingCare, designed to address the adoption challenges of the Personal Health Record Systems which can be categorized as lack of effective computer mediated doctor-patient relationship; the increasing cost of integrating PHR systems with the existing healthcare systems, and the security and privacy concerns of the patients. To address these challenges SharingCare is designed as a Personal Health Ecosystem by providing a common personal health data model, a secure PHR storage account, and a central repository to be operated by Turkish Telekom. However, in SharingCare, the personal health ecosystem concept is extended with functionalities such as maintaining terminologies and value sets, integrating with medical knowledge and resources; utilization of social networks; and implementing a publish/subscribe mechanism as well as a marketplace for discreet bundles of care services that physicians or healthcare organizations provide for patients. Additionally, SharingCare acts as a utility or assistant and give the physicians the choice to access the PHR of the patient only during face-to-face encounters; utilizes a granular approach to interoperability rather than using the existing "Message" or "Document" standards and provides patient controlled privacy measures.

1. Introduction

Although Personal Record Systems are becoming popular in some countries such as the US [1] and France [2], many governmental and private PHR activities are being suspended [3] due to low acceptance, increasing costs and the privacy/security concerns of the patients. In this article, we describe a PHR system, namely, SharingCare implemented to address these challenges:

- Many PHR systems struggle with the adoption problem because they cannot establish an effective computer mediated doctor-patient relationship. The studies show that patients not only want free access to their health records, but also expect to use technologies to communicate with the clinicians [4]. Furthermore, most of the personal health applications enable patients to continuously note health events or measurements either manually or by personal medical devices and provide some level of decision support but all this data would be more meaningful when a physician reviews them stating his comments. On the other hand, physicians are less likely than patients to anticipate the benefits of PHRs [5], and more likely to anticipate problems from patient PHR use [6]. The main objection is that PHR adoption will create unreimbursed work [7], although some providers seemed to view PHRs very useful as a source of medical information when the patient's record

is unavailable [8]. SharingCare solution to this problem is to act as a utility or assistant and give the physicians the choice to access the PHR of the patient only during face-to-face encounters.

- The second challenge, the cost of PHR systems lies in the difficulty in integrating them with the existing healthcare systems. Given that the new generation personal health applications are provided as Web or mobile applications; they need to operate on patient data in a more granular way on remote servers. For example, in a HL7 CDA based environment, a diabetes management application trying to render latest diagnoses of a patient has to retrieve all "Discharge Summary Documents", process the related sections, and collect the diagnosis entries from each document. For a Web based or a mobile application that has limited resources this is inefficient and very hard to implement. SharingCare addresses this challenge by using a granular approach to interoperability rather than using the existing "Message" or "Document" standards.
- As for the security/privacy issues which are already a concern in any web-based application, it is more profound for PHR systems where patients are uploading private health information to a server [9]. On the other hand, evaluations show that most of the users welcomed the idea of sharing data with clinicians and many with other individuals as well. Clinicians also believe that data sharing and collaboration as one of the key component that would be helpful in care process. The patient controlled privacy would seem the basic solution that effectively addresses privacy concerns and this approach is chosen in the SharingCare.

Finally, SharingCare is implemented as a personal health eco system by providing a common personal health data model, a secure PHR storage account, and a central repository to be operated by Turkish Telekom. However, in SharingCare, the personal health ecosystem concept is extended with functionalities such as maintaining terminologies and value sets, integrating with medical knowledge (e.g. description of medical concepts for patients) and resources (e.g. a database of nutritional values of foods); utilization of social networks; and implementing a publish/subscribe mechanism as well as a marketplace for discreet bundles of care services (e.g. periodic diabetes monitoring, dietetic service, exercise coaching, etc) that physicians or healthcare organizations provide for patients.

2. SharingCare "Personal Health Ecosystem"

The first generation of PHRs and personal health applications, that is untethered PHRs, lacked this functionality because only the patient himself entered and maintained personal health data. However, it quickly became clear that these types of PHRs have very little clinical and economical value and the ideal PHR appears to be one that provides access to all or most of the patient's clinical information [10,11]. The second generation is the tethered PHRs where data from a medical provider's healthcare information system such as an EHR or a laboratory system is stored into the PHRs automatically via the data exchange interfaces established among these systems. However, although several standards addressing PHR-to-EHR and PHR-to-PHR interoperability exist; achieving interoperability platforms is still an expensive process given the semantic and technical diversity of eHealth systems. As a result, many sophisticated, but partially isolated (specific to an EHR system, bound to a healthcare organization) proprietary solutions turned up in the PHR market today.

Another type of PHR solution as provided by systems like HealthVault [12], and Dossia [13] offer a common personal health data model and a secure PHR storage account, a central repository, for patients and provide the mechanisms for small vendors to utilize the repository as central PHR while providing meaningful personal health applications to

patients. Such an architecture is called a personal health eco system. This eliminates the burden of developing secure storage for PHR developers while they still can serve their applications over Web. Furthermore, since different personal health applications operate on the same repository with the same data model, interoperability is achieved among these applications.

However, persistency and data integration are not the only implementation burdens that a personal health application vendor has to deal with. The development process is difficult and costly because it involves further tasks including maintaining terminologies and value sets, integrating with medical knowledge (e.g. description of medical concepts for patients) and resources (e.g. a database of nutritional values of foods); utilization of social networks; and implementing a publish/subscribe mechanism. Realizing these functionalities requires not only specialized knowledge in technology and medicine but also tedious and costly integration tasks. This is another reason why personal health applications are currently provided only in a fragmented fashion, as standalone applications or services.

SharingCare provides the same functionalities as the other personal health eco systems, including a single data model for PHR; a secure storage and easy to use REST services for securely access to the PHR and administrative records of patients and perform CRUD (Create, Read, Update, Delete) operations on them. However, to facilitate its use by third party developers, SharingCare also:

- Handles terminology maintenance and provides services for personal health applications to retrieve and query these terminologies;
- Provides REST services for personal health applications to access to certain medical or scientific knowledge such as nutritional facts on foods, information for certain exercises like calories burned, or performance guidelines, all in the form of structured resources;
- Enables physicians or healthcare organizations to register to the ecosystem and publish their care service offers.
- Another utility service that SharingCare Mobile platform provides is the medical device integration. A device connector component enables the user to connect to Continua Health Alliance compliant medical devices and retrieve the measurements from them. The measurements are integrated into the PHR of the patient and sent to SharingCare repository like other PHR records. Furthermore, several adapters are integrated with the device connector to support some specific medical devices that are popular in Turkey.
- By considering the shift towards smart mobile devices, the SharingCare extends the idea of personal health ecosystem into IOS and Android mobile environments by providing native libraries for these environments that facilitate the communication with the SharingCare repository and offline caching of records. In this way, the application developers can only concentrate on the functionalities of their applications and their visualization.

The SharingCare has two different account types; one for patients and one for physicians. By having an account, patients own an online PHR storage which they can access by the help of applications provided in the ecosystem. On the other hand, the physicians basically get a chance to utilize the applications in the ecosystem to access the patients that they provide care. Other than the personal health records, there are administrative records maintained by the system for patients and physicians.

3. Addressing the PHR Adoption Challenge: Improved Patient-Physician Relationship and Social Networks

In order to improve the communication between the patients and physicians while realizing the actual care services, the personal health applications served over SharingCare are designed to be a utility or assistant. Hence, based on the care service that they want to provide, the physicians have the flexibility to decide on the extent to use the personal health applications in the care processes. The physicians who prefer routine interactions can use the personal health ecosystem to advertise their care services and use the personal health applications to view and analyze the patient records only during face-to-face encounters or consultations together with the patient. This will be beneficial for physicians as they can easily access the whole patient summary and the patient recorded events and measurements such as symptoms, dietary intakes, or blood pressure measurement. It will also be beneficial for patient as he will be more prepared for the consultation. Yet for the physicians who are open to the idea of remote consultations or providing care services remotely, they will have a chance to realize this by using the personal health ecosystem and provided applications. In both ways, it will improve the PHR adoption as patient will have a chance to utilize the PHRs in a meaningful way.

Another factor that can help PHR adoption is utilizing social network paradigm in personal health applications. According to "Social Networks in Health Care: Communication, collaboration and insights," [14] a new Issue Brief by the Deloitte Center for Health Solutions, public, internet-based social networks can enable communication, collaboration and information collection and sharing in the health care space. The study shows that about one-third of Americans who go online to research their health currently use social networks to find fellow patients and discuss their conditions. Although, there is no such detailed study in Turkey, it is a cultural fact that people freely discuss their medical problems with others who had similar problems to get their advice on treatment, symptoms or the names of physicians. Therefore, we can expect that integrating social network paradigm to personal health applications will have a similar effect in Turkey.

In order to support personal health applications that have social networking functionalities, a strong consent mechanism is designed in SharingCare. The mechanism enables patients to share their specific set of records with others (e.g. a side effect incident for a medication use, personal dietary program, etc).

4. Addressing the Interoperability Challenge in SharingCare

Existing healthcare standards like HL7 v2, HL7 v3 and ISO/EN 13606 have originated from the requirements of traditional healthcare and provide interoperability based on the concepts of "Message" and "Clinical Document". On the other hand, new generation personal health applications are provided as Web or mobile applications. Therefore they need to operate on patient data in a more granular way on remote servers. For example, in a HL7 CDA based environment, a diabetes management application trying to render latest diagnoses of a patient has to retrieve all "Discharge Summary Documents", process the related sections, and collect the diagnosis entries from each document. For a Web based or a mobile application that has limited resources this is inefficient and very hard to implement. Therefore, the PHR systems need different set of standards that define the electronic exchange of granular medical or administrative data like the personal health ecosystem solutions such as HealthVault [12] and Dossia [13] propose. When this approach is taken then the PHR systems must have the ability to extract the information from messages or clinical documents and convert them to the new format while integrating with existing external EHR systems.

In the SharingCare, we have chosen a newly emerging standard, namely, HL7 “Fast Healthcare Interoperability Resources (FHIR)” [15] rather than developing our own clinical and administrative concepts which would be proprietary as in the case of HealthVault. HL7 FHIR defines a set of 'Resources' to represent health and healthcare administration related information. These resources express granular clinical and administrative concepts that can be electronically exchanged in order to quickly and effectively solve system interoperability problems in healthcare and related processes. The draft standard also provides informative specifications about the RESTFUL implementation of the architecture, the JSON serialization of resources and possible security mechanisms.

In the SharingCare, for the PHR content, the Continuity of Care Record (CCR) [16] is taken as the base reference, and 38 records (e.g. Allergy, Problem, Symptom, Medication, Prescription, Encounter, Dietary Intake, Care Plan, etc) are defined as granular resources.

5. Addressing the Security/Privacy Challenges in SharingCare

The personal health ecosystems provide a good opportunity for healthcare systems to implement efficient patient controlled privacy mechanisms. They can act as an Identity, Assertion and Consent (Privacy Policies) Provider on behalf of patients not only for the privacy of PHRs but also for all medical information of patients scattered among different healthcare systems. In SharingCare, we extend the general personal health ecosystem idea with these mechanisms.

A two layered patient controlled privacy mechanism is implemented within SharingCare. The base layer enables the access control with the granularity of ‘Resource’ (PHR Record) types defined in the ecosystem and instances of those resources. A Hierarchical Role Based Access Control (RBAC) mechanism is implemented for this layer. The role hierarchy is extendible and define the functional roles representing the relation (e.g. a care relation or social relation i.e. follower, care supporter, etc for social networking) of a person (a physician or another patient) with a patient within the ecosystem. In this way, patients has the ability to define consent rules allowing or denying access to specific type or instances of PHR records for a specific role.

The second layer is the abstraction layer to hide the details and eliminate the burden of defining rules for different roles. Each personal health application within the SharingCare ecosystem should define a privacy profile that describes the roles that can use the applications and the PHR record types that these roles need to access to perform the intended care process accurately and completely. Therefore, when the patient decides to receive a care service from a care provider using a SharingCare application, he is asked if he is accepting to assign the role to the care provider as well as the resulting access rights that will be given to the user by assigning the role. In this way, with a simple operation, all detailed consent rules will be ready for the access control decisions. The SharingCare also provides the interfaces to manage the rules and role assertions in detail. Users can visualize the individuals assigned to roles and which individuals or roles have rights to access which PHR records.

In addition to other common security mechanisms, the SharingCare provides two further functionalities to overcome the privacy concerns. One of them is the auditing mechanism that logs any access to the PHRs and generates notifications for patients to notify them about who are accessing their records. The other functionality is to store provenance of the information within the record itself. In this way, users can view the source of the information and can evaluate its context and accuracy.

6. Conclusions

PHRs are generating interest because they offer tremendous new opportunities to influence health and provide tools to assist consumers as they make treatment choices. However, current barriers, which include cost, concerns that information is not protected or private, inconvenience, design shortcomings, and the inability to share information across organizations, limit their adoption [17]. In this article, we describe a personal health eco system specifically designed to address these challenges.

Acknowledgements

The work done for the SharingCare was supported by Turk Telekom.

References

[1] MyPHR, http://www.myphr.com/.
[2] Dossier Médical Personnel, DMP, http://www.dmp.gouv.fr/
[3] Caumanns, Jörg. Health Record Architecture(s) in Germany: Motivation and Architecture, congres 'Architectuur in de zorg', Utrecht, June 2012.
[4] Walker J, Ahern DK, Le LX, et al. Insights for internists: "I want the computer to know who I am". J Gen Intern Med 2009;24:727–32.
[5] Division HCM Archer N, Fevrier-Thomas U. An empirical study of Canadian consumer and physician perceptions of electronic personal health records. In: Division HCM, ed. Annual Conference, Administrative Sciences Association of Canada. Regina, Saskatchewan: ASAC, 2010.
[6] Ross SE, Todd J, Moore LA, et al. Expectations of patients and physicians regarding patient-accessible medical records. J Med Internet Res 2005;7:e13.
[7] Kittler AF, Carlson GL, Harris C, et al. Primary care physician attitudes towards using a secure web-based portal designed to facilitate electronic communication with patients. Inform Prim Care 2004;12:1, 29–38.
[8] Witry MJ, Doucette WR, Daly JM, et al. Family physician perceptions of personal health records. Perspect Health Info Managment, 2010:1–13.
[9] L.S. Liu, P.C. Shih, G.R. Hayes. Barriers to the adoption and use of personal health record systems, iConference '11 Proceedings of the 2011 iConference Pages 363-370Open Handset Alliance http://www.openhandsetalliance.com/
[10] Tang PC, Ash JS, Bates DW, et al. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. J Am Med Inform Assoc 2006;13:121–5.
[11] Detmer D, Bloomrosen M, Raymond B, et al. Integrated personal health records: transformative tools for consumer-centric care. BMC Med Inform Decis Mak 2008;8:45.
[12] http://www.microsoft.com/en-us/healthvault/
[13] http://www.dossia.org
[14] http://www.deloitte.com/assets/Dcom-UnitedStates/Local%20Assets/Documents/US_CHS_2010SocialNetworks_070710.pdf
[15] http://hl7.org/implement/standards/fhir/
[16] ASTM E2369 - 05e1 Standard Specification for Continuity of Care Record (CCR). 2005. http://www.astm.org/Standards/E2369.htm.
[17] James S. Kahn, Veenu Aulakh and Adam Bosworth, "What It Takes: Characteristics Of The Ideal Personal Health Record", Health Affairs, Vol. 32, No. 1, January 2013.