A Personal Health Ecosystem: SharingCare

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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.**

Overview

Although Personal Record Systems are becoming popular in some countries such as the US [1], many governmental and private PHR activities are being suspended [2] 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:

- 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 [3]. On the other hand, physicians are less likely than patients to anticipate the benefits of PHRs [4], and more likely to anticipate problems from patient PHR use [5]. The main objection is that PHR adoption will create unreimbursed work [6], although some providers seemed to view PHRs very useful as a source of medical information when the patient's record is unavailable [7]. 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", must 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 [8]. 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.

Methods

A comprehensive literature survey and a requirements analysis have been carried out. Usability issues both for patients, physicians as well as 3rd party developers have been clarified through workshops and discussions.

Results

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 3rd 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;
- 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.

To address the adoptability challenges of the personal health record systems, SharingCare:

- Enables physicians or healthcare organizations to register to the ecosystem and publish their care service offers. 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.
- 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 and this approach is taken 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.
- 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.

Discussion

Current barriers to PHR adoption among patients include cost, concerns that information is not protected or private, inconvenience, design shortcomings, and the inability to share information across organizations. SharingCare is designed and implemented to address these issues.

References

[1] MyPHR, http://www.myphr.com/.
[2] Caumanns, Jörg. Health Record Architecture(s) in Germany: Motivation and Architecture, congres 'Architectuur in de zorg', Utrecht, June 2012.
[3] 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.
[4] 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.
[5] 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.
[6] 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.
[7] Witry MJ, Doucette WR, Daly JM, et al. Family physician perceptions of personal health records. Perspect Health Info Managmnt, 2010:1–13.
[8] 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/