ON THE USE OF openEHR IN A PORTABLE PHR

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Abstract: Quality medical acts rely on patient medical information. With paper records, the responsibility of gathering the disparate information and making it available to the caregivers, falls exclusively upon the patient. This still is, to great extent, the case with electronic health documents. The consensus is that the advantages of patient involvement in his own health are numerous. With the advent of recent technologies and their deployment in healthcare, new ways of involving the patient and making him an active part of his own health are possible. Electronic Health Records (EHR) and specially Personal Health Records (PHR) are important tools for patient empowerment but data population and management through non-intuitive structured forms is time consuming, takes a great amount of effort, and can be deterring specially for people that are not very computer-oriented. PHRs can be simple and scalable applications that the patient uses to get started and afterwards evolve towards complexity. In any case, compliance with standards must be accomplished. In this paper we present a PHR simple to use, implemented on a USB Flash pen for mobility, and compliant with the *open*EHR specification. Our model builds on *open*EHR and adds security and privacy features, allows patient data management and can work as an information repository.

1 INTRODUCTION

Healthcare is currently undergoing profound changes. New diagnose and treatment techniques make possible to address more conditions thus increasing personal life quality but also the number and severity of illnesses per patient. People pay an increasing attention to their own health, demanding for quality healthcare. Population ageing leads to an increase in the number and seriousness of medical conditions per patient, and to continuous and integrated healthcare.

All the aforementioned factors result in an increase in the number of medical acts, their improved quality, the rise in health costs, and the exponential escalation of the amount of existing information per patient. Of special interest to us is the latter.

Personal Health Information (PHI) is typically generated in many different places making its collection and management difficult for the patient.

With great amounts of PHI to process, existence doesn't necessarily mean availability and availability doesn't necessarily mean usability. Information can exist and not be available to the professional caregiver, or it can be available but take too much time to browse through.

It is common sense that involving patients in their own healthcare is positive. The more involved and informed a patient is, the more useful information he will supply and more informed medical decisions will be made by healthcare professionals.

Information technologies bring new possibilities to PHI management through the use of computerized medical records that can assume many forms. The deployment of Electronic Health Records (EHR) in general replaces with advantages the paper-based records. Personal Health Records (PHR) are an important factor contributing for patient empowerment.

Patient management of PHI through the use of a PHR can be daunting, specially for people not very familiar with computers. Meticulous, regular and timely data input by the patient is undoubtedly clinically relevant and helpful. But most implementations force the use of complex and user-unfriendly screen forms. Thus, instead of acting as

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positive factors in involving the patient in his own health, these implementations can easily deter an individual away from technology, accomplishing exactly the opposite objective they were designed for.

We share the vision that PHRs are an important factor in positive patient involvement in his own health, and ultimately in total patient empowerment. But we take a simplistic approach and propose that complicated computerized PHI management schemes can be more prejudicial than beneficial. Instead, a minimal PHR, conformant with current standards, and easy to use can serve as an entry point specially for users that are not too computer-skilled. If, later on, those users decide they want extra features in their PHR, more complex implementations are available.

In this paper we review the current situation concerning patient's medical records and advocate steps towards patient empowerment through PHRs.

Considering that a) A great percentage of data that is accessible to patients consists of Complementary Diagnose Tests (CDT), mostly in paper format; b) When converted into electronic format, this data will also be responsible for the greatest demands in terms of storage and management needs; c) The open source standard specification *open*EHR allows integration with legacy systems (assumed to be professionally managed); a simple system for the patient to perform that integration and PHI management at a personal level is worthy of attention.

Most PHR proposals state that it must be patient-centric, but that usually just means that the health information revolves around the patient. We propose a PHR that is patient-centric in information terms, and that is also user-centric in terms of easiness.

2 BACKGROUND

One way of making the patient a more active participant in the healthcare services he seeks throughout his lifetime is by allowing him to responsibly manage his own PHI. Population ageing is changing some paradigms in healthcare, making it more patient-centric and increasingly relying on the patients' responsible actions in the management of their own conditions like diabetes, for example.

With the objective of giving the patient some form of access to his health information, some PHI management schemes have been proposed, namely through the use of EHRs and PHRs operated on servers, personal computers and mass storage devices and accessed locally or remotely via smart cards, as proposed by Costa (2003) and Costa (2004) and other portable devices like USB pens.

2.1 Patient Empowerment

Anderson and Funnel (2009) argue that patient empowerment in healthcare can be conceived as the capacity of patients to think critically and make autonomous decisions. In order to achieve this, the patient must have access to a comprehensive set of his own PHI and be capable of managing that data in the way he sees fit. To achieve this goal, the control of the medical information has to fall under the full responsibility of the patient, i.e. the patient must have physical possession of all the data pertaining to his health.

When considering PHI management through the use of information technologies, different levels of computer knowledge have to be considered since some people are not technology-oriented. A scalable solution adaptable to different user technology awareness is a major advantage.

2.2 EHRs and PHRs

PHI management is achieved through EHRs and PHRs but various problems presently afflict this technological field, in particular the lack of data representation and data transfer standards widely accepted, the non-agreement on the basic data fields that make up an EHR/PHR, the varying definitions of EHRs and PHRs, and legal issues concerning data ownership.

There are no generally accepted definitions for EHRs and PHRs but most of the literature seems to agree at least on one basic difference between them: an EHR contains PHI and is usually stored and managed by a healthcare institution for the use of healthcare professionals, while a PHR consists of a set of PHI (that might be the same or different from the data set contained in the EHR) that is usually stored under the patient's ownership and management, and for his own use.

Of special concern to us is the concept of PHR. According to Tang et al (2006) a PHR is more than a simple means to gather all the scattered information, it encompasses a set of data, knowledge and applications that allow the patient to become actively involved in his health by providing a set of functionalities. Kaelber et al (2008) have presented a general description of most of the work that remains to be done in the field of PHRs.

One of the problems that face developers is the right choice of model to work with. Given the present interest surrounding this theme, it's only natural that various classifications arise. For example, Kaelber and Pan (2008) classified PHRs according to their degree of interconnectivity as a) Stand-alone; b) Tethered. The later being subdivided in provider-tethered, payer-tethered, third-party-tethered and interoperable.

The stand-alone model has the advantage of being non-biased in terms of the focus it presents towards parts of the data contained in the PHR but the disadvantage of having to be bought, while the tethered models tend to be offered as fidelity factor or, at least, to be less expensive. Another important factor to have in mind is the record data population method.

The tethered models present the advantage of being frequently given by institutions free of charge and being already populated with some information. But also have the disadvantage of each particular type of PHR being too focused on the type of information more relevant to that institution.

Tang et al (2006) consider that the most promising architecture for a PHR is the one that integrates with an existing EHR. According to the classification presented this corresponds to the tethered-interoperable model.

From the perspective of patient empowerment data ownership and management assume a crucial importance. Maloney and Wright (2010) classify PHRs in four categories: a) self-contained EHR, maintained and controlled by the patient; b) self-contained EHR, maintained by a third-party such as a web service provider; c) component of an integrated care EHR maintained by a health provider (e.g. a general practitioner) and controlled at least partially by the patient; d) component of an integrated care EHR but maintained and controlled by the patient.

2.3 PHRs in Portable Devices

Smart Cards (SC) are very secure authentication tokens and some of them have very useful cryptographic capabilities, thus providing very interesting characteristics when deployed in healthcare in general namely as remote PHI access tokens. Some of the proposed models of PHR in smart cards are remote information aggregation tokens that allow the patient to visualize some of his PHI contained elsewhere and to manage some of that information in a necessarily limited manner.

Some countries are shifting from traditional paper-based national identification cards and passports towards smart cards. This evolution towards a technological overlap between identification, health information access, and management makes possible to envision many forms of integration.

The storage capacity of smart cards is on the constant rise but more so is the amount of medical information generated per patient that can nowadays take some gigabytes of storage space, and this is an important limitation at the moment. For all their security features, SC's are undoubtedly a type of device to keep under close observation in search of future developments.

Among the logical candidates for storage devices capable of holding a PHR under the patient's responsibility are external hard drives, CDs, DVDs, and USB flash pens. According to Srinivasan and Datta (2007), because of issues like physical resistance to damage, better performance under electromagnetic fields, the fact that they have no moving parts, don't need any additional hardware, are not susceptible to dust, and that can come in a variety of shapes and forms, the USB pens are the most advantageous of them.

On top of all those advantages, there are now a number of portable applications described by PortableApps (2010) and Pendriveapps (2010) that don't need installation and can be executed from the pen, an additional security factor.

2.4 Standards

In this field of work the lack of widely accepted standards is a reality, there is no shortage of proposed standards, the shortage is at the acceptance level. At the core of data representation, structure and storage there are three well positioned candidates: *open*EHR as described by openEHR (2007); HL7-CDA (Health Level 7 – Clinical Document Architecture), described by Dolin et al (2006); and CCR (Continuity of Care Record) described by Ferranti et al (2006). At the communication level, HL7 seems to hold the advantage at the moment. We will not get into an in-depth analysis of these standards and will focus our attention on the *open*EHR specification mainly because it is open source and attempts to comply both with HL7 and HL7-CDA.

*Open*EHR is a set of specifications for an EHR focusing mainly on structure and content. An EHR compliant with *open*EHR consists of a logically organized structure of folders, each containing versioned healthcare events. Versioning is accomplished through recording every data change in special data structures (Contributions).

All the interaction with data is achieved through the use of Archetypes and Templates. An archetype is a component that allows standardization by mapping each medical event into pre-agreed individual fields of information (Entries) forming a Composition. A Template serves both as a messaging standardization structure and is closely related to screen forms. It aggregates one or usually more archetypes.

An archetype can be used to manage data referring, for example, to a blood pressure monitoring event, that are mapped into various information fields (date, systolic, diastolic, respective values, etc), forming a Composition, e.g. "blood pressure measurement". A Template can be an aggregate of information, e.g. "discharge summary" that manages the information relative to various healthcare events, each one of them created through a particular archetype.

Archetypes are meant to be created by other parties, namely in close collaboration with medical experts, and Templates are mostly to be developed by local implementations. Archetypes are also the structures that allow the use of terminologies.

*Open*EHR's main focus is on components instead of documents and its main specification is the openEHR EHR Reference Model, namely its EHR Information Model described by Beale et al (2008). An *open*EHR system is composed of an EHR Repository, an Archetype Repository, Terminology, and Demographic or identity information. A high-level *open*EHR EHR structure consists of Contributions, EHR_id, EHR_Access, EHR_Status, Directory, and Compositions.

3 A PORTABLE PHR *open*EHR-Compliant

The basic paradigm of the Portable PHR (p.PHR) is simplicity in order to attract users to the world of PHRs. The best way to start is by allowing individuals to scan their current paper records, mostly CDTs and to provide a simple means to store, organize and manage that information that will be kept in a USB flash pen for total portability. The proposed model also accommodates a workflow similar to the paper-based but in which CDTs are handed to the patient in electronic format both by e-mail and in physical presence.

In another work (Santos et al, 2010), we proposed a p.PHR, implemented on a USB flash pen, based on secure virtual containers with characteristics briefly summarized below. In this paper we present the necessary steps to make it compatible with the *openEHR* specifications.

One of the key concepts of the previously proposed PHR model is the existence of five different conceptual data types implemented through individual document classification or by placing the documents in different data storage areas or virtual containers: a) Confidential Data (extremely sensitive); b) Normal Data (disclosed to health professionals); c)Transfer Data (recently entered the PHR); d) Prescription Data; e) Emergency Data.

This model allows patient mobility, provides an emergency data repository, and can be used, by a patient with just basic computer skills, as a passive information repository to be carried between healthcare facilities, thus mimicking the existing social habit with paper-based records.

In order to achieve this, the p.PHR's structure needs to be secure and to allow for different data storage areas depending on the degree of confidentiality the patient deems the particular data items that make up his PHR. The information contained in the p.PHR is controlled, managed, and made available to third parties by the patient and only under his explicit consent.

In order to allow the patient to both manage the PHI contained in the p.PHR and to make it available to other actors in a scalable manner, various operating modes are available upon patient's option. These operating modes are shown in figure 1.

Upon receiving the p.PHR in the respective device, the patient authenticates himself for account provisioning. The device is supplied with a master-password that will be used for the initial setup of p.PHR native applications and for the creation of a working-password (*password*). When the patient accesses the p.PHR an operating mode is selected.

Each actor in healthcare delivery has different information access needs, therefore with different access privileges to each data type. Figure 1 shows these data types in usage context.

Although an EHR is conceptually different from a PHR, the *open*EHR specification can be deployed for data structure. In terms of data, the EHR *open*EHR-compliant's structure can be deployed with the added feature of the secure virtual containers (containing the classified compositions) reflected at the *open*EHR directory level.

In terms of the overall system the EHR repository will be reduced to just one PHR and the

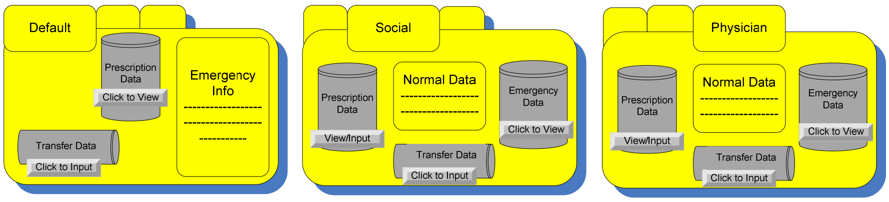

Figure 1. p.PHR data and user-access.

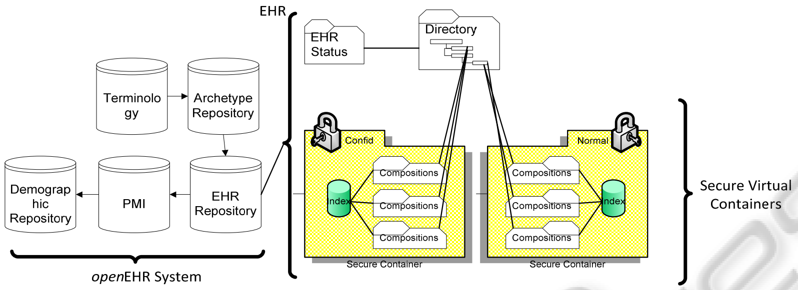

Figure 2. Containers, EHR, and HER system.

demographic repository will also be reduced to just the individual's information. There is no need for a Patient Master Index (PMI) since there is only one patient in the PHR system. The same applies to the EHR_id data structure since there is no need to make the p.PHR a part of any uniquely identifiable scheme. The Archetype Repository, residing outside any secure virtual container, is populated with the necessary Archetypes on a needed basis. Outside any container is also the EHR_Status data structure. This Architecture is depicted in figure 2.

Inside each secure container there are *open*EHR compositions, that are data previously instantiated by the Archetypes, optionally including, or referencing, CDT multimedia files, and the virtual container File Indexing Database that references all documents in the container.

The *open*EHR specification is directed towards various users creating data and populating the record. In our p.PHR implementation, the patient is the only data creator who shows different views of his PHI to various users, this fact carries some implications. There is no need to implement a heavy access control strategy and we can rely on the password-protected secure virtual containers for different user-access. The data structure EHR_ACCESS provided by *open*EHR is not used in our implementation. The versioning supported by *open*EHR can be discarded in favor of simplicity since there aren't many data alterations that can be foreseen. There is no internal electronic signature scheme for information integrity although, in the case of externally generated electronic data items should be signed by the respective institutions that generated them by their own software.

The data management functionality is implemented as document classification through the use of Archetypes, e.g the openEHR-EHR-CLUSTER.exam-generic.v1 that is simultaneously generic and allows for the storage of a multimedia file, which is very useful for CDT management.

Medication and allergies lists are entered through openEHR-EHR-COMPOSITION.medication-list.v1 and openEHR-EHR-EVALUATION.adverse.v1 Archetypes.

The pPHR is completely pen-resident and consists of a stand-alone application with various management functionalities allowing access to a virtual container where the various data items are stored. The virtual container is implemented in a zip-like manner (ZipArchive) with compression and file encryption via a soft-coded encryption key. AES encryption algorithm and the fact that, upon access by the application, the files are decompressed to computer RAM memory only, are important features contributing for enhanced security. Encryption capabilities are allowed by openEHR.

The access to any individual file stored inside a virtual container is subject to authentication and the decompression of the files is made to computer's memory. The fact that decompressed data is not written to hard disk or even to the USB pen is an increased security feature.

4 CONCLUSIONS

PHRs are a way of involving patients in their own healthcare but complex implementations can turn those users with just the basic computer knowledge away from technology.

An individual's PHI is at present generated dispersedly and is stored in many different locations under many physical formats. The responsibility of collecting it and making it available to the healthcare professionals falls upon the patient.

Our approach to PHRs is a simplistic one providing an implementation that can be a point of entry for the patient. Later he will be given the chance of more functional implementations and consequently more complex to use.

A portable PHR in a USB pen device can be envisioned as a complement, rather than a replacement for existing PHI management systems, such as EHRs. The p.PHR intends to be the initial step in letting the patient assume the responsibility of managing his own PHI, thus contributing for patient empowerment. The medical data pertaining to a patient and maintained in the p.PHR is kept under his direct control, allows patient mobility, and provides an emergency data repository. The patient decides which data becomes part of the record and who, and under what circumstances, has access to it.

Data is kept in conceptually different data containers and is controlled, managed, and made available to third parties by the patient and only under his explicit consent. Any access to the p.PHR and the data within depends exclusively on patient's authorization.

Standard conformity is achieved through the deployment of the *open*EHR specifications and their generic, multi-user, and EHR-oriented, adaptation to our specific, single-user, PHR needs.

Security features are added through the use of password-protected virtual containers.

Privacy concerns are addresses by different data containers and data-classification.

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