The design and implementation of a ubiquitous personal health record system for South Africa

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Abstract. Doctors can experience difficulty in accessing medical information of new patients. One reason for this is that, the management of medical records is mostly institution-centred. The lack of access to medical information may affect patients in several ways, such as: new medical tests may be carried out at a cost to the patient, and doctors may prescribe drugs to which the patient is allergic. This paper presents the design and implementation of a ubiquitous Personal Health Record system for South Africa. The design was informed by a literature review of existing personal health record standards, applications and the need to ensure patient privacy. Three medical practices in Port Elizabeth were interviewed with the aim of contextualizing the personal health record standards from the literature study. The findings of this research provide an insight as to how patients can bridge the gap created by institution-centred management of medical records.

Keywords. Personal health records, ubiquitous access, design, cloud storage

Introduction

Electronic Health Information is categorized as follows:

1. Electronic Medical Records (EMRs): Issued by each medical practice for their record keeping purposes;
2. Electronic Health Records (EHRs): A legal collection of various electronic medical records by a government body; and
3. Personal Health Records (PHRs): Collection of various medical records that is initiated and maintained by an individual for purposes of continuity of care [1, 2, 3].

Medical records in South Africa are mostly institution-centred [2, 4], which causes fragmenting of medical history. The lack of a complete medical history for patients in South Africa may require patients to take an active role in managing their medical information. Patients can do this by requesting their doctor’s notes when travelling.

Current measures that aim to provide complete medical records for patients in South Africa include setting up a nationally accessible Electronic Health Record (EHR) system [5]. Currently, patient management systems do exist at provincial level in public sector hospitals. The South African National Department of Health has recognized the need for eHealth research that aims to improve the effectiveness of the National Health System [6].

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This paper proposes a practical design of how PHRs can be utilized by both patients and medical practices, which require medical histories of their new patients. The pervasive nature of mobile devices makes them an ideal tool for capturing, measuring and monitoring an individual’s health and well-being. This has given rise to mHealth, which is defined as the provision of health-related services via mobile communications [7]. Mobile phones are a versatile tool, which can facilitate ubiquitous access to PHRs. However, little research has been done in South Africa and little attention has been given to the design and implementation of PHR systems to determine their effectiveness and potential usefulness in South Africa [8].

The aim of this paper is to present the design and implementation of a PHR system in South Africa and results from an interview study carried out with three medical practices in Port Elizabeth, South Africa regarding the management of PHRs.

The remainder of this paper is organized as follows. Section 1 discusses PHRs in detail and existing international PHR standards. Sections 2 and 3 discuss related work and the results of an interview study carried out with three medical practices in Port Elizabeth. Section 4 discusses the design and implementation of a PHR system. In Section 5, we suggest opportunities for future research and also conclude the paper.

1. Personal health records

Szolovits, Doyle, Long, & Kohane [9] highlighted the shortcomings of centralised patient management systems that directly exclude patients from the management of their health records. They proposed a personal health system referred to as “Guardian angel” that collects medical data, checks and interprets it and explains medically relevant facts and plans. This was envisioned to improve the quality of medical decision making and minimize medical errors.

The following benefits can be realised with PHRs [10, 11]:
1. They provide a unified summary of an individual’s health history;
2. They encourage family health management, that is having a system for tracking and updating healthcare information can help care givers such as those caring for young children and elderly patients to manage their care;
3. They are easy to understand and use;
4. They provide access to healthcare data from anywhere in the world; and
5. They facilitate continuous communication between patients and physicians.

The benefits of PHRs have been well documented. It is also important to review existing PHR standards before actual design and implementation is carried out. Standards exist to ensure that a given product or service meets acceptable criteria of a given community. Standards are usually documents that provide requirements, specifications, guidelines or characteristics that can be used consistently to ensure quality [12]. Below is a discussion of data encoding standards for PHRs.

1.1. Data Encoding Standards

Health records should be encoded using best practices and globally accepted standards in order to ensure interoperability of the data. Two of the prominent standards are the Clinical Document Architecture (CDA) by Health Level Seven (HL7) and the Continuity of Care Record (CCR) by the American Society for Testing and Material International [13].
1.1.1. Continuity of Care Record (CCR)

The Continuity of Care Record (CCR) standard was created by the American Society for Testing and Materials to enable physicians to collect patient care information in a structured, human-readable and transferable format [13]. This standard was incorporated by Health Level Seven (HL7) into their Clinical Document Architecture (CDA).

1.1.2. Clinical Document Architecture (CDA)

HL7 is an international organization focused on developing standards to enable the interoperability of different medical information systems [14, 15]. HL7 created the CDA as the standard format for exchanging clinical documents [16].

The HL7 has several working groups each concerned with an aspect of eHealth. One of such groups is the Mobile Health Work Group which is tasked with the creation, promotion and the maintenance of Mobile Health (mHealth) related standards and frameworks [17]. Figure 1 highlights the functions in the PHR standard.

![Figure 1. PHR System functions [15].](image)

The functions (PH.1, PH.2, PH.6, S1, IN.1, IN.2 and IN.3) were selected for the proposed system because they are closely related to the main objective of this research, that is, to facilitate the management of PHRs.

Kharrazi, Chisholm, VanNasdale, & Thompson [18] motivate the following data elements as essential for a complete PHR: allergies, immunizations, surgeries, chronic conditions, medications, family history, contact information and imaging data.
1.2. PHR Architectures

Fong & Goldfine [19] argued that there is no single correct way to develop architectures for every enterprise. They concluded by stating that an architecture must be customized to a given environment. They identified five components of any given architecture as: business unit, information, information system, data, and delivery system. A detailed explanation of the five components was not presented by Fong & Goldfine. However, Steele & Lo [20] extend the argument by Fong & Goldfine [19] and define a PHR architecture as one that provides a description of how it addresses the storage, management and access of its health data. It also provides descriptions of the hardware, software and networking components required for the delivery of data to allow for goals such as the enablement of on-demand access to data. Steele and Lo present three PHR architectures namely: Local (no internet connectivity is required), Remote (continuous internet connectivity) and Hybrid (intermittent internet connectivity). The design presented in Section 4 makes use of the Hybrid PHR architecture.

2. Related work

Several issues should be considered when innovating health information technologies. These include:

1. Addressing the privacy concerns of system stakeholders (patients and medical practices);
2. Ensuring that the developed artefacts comply with the legislation governing a given geographical area; and
3. Ensuring that system use cases are acceptable to the stakeholders, especially the medical practices.

This related work section takes a high level view of PHR use case scenarios. For the purpose of focusing the discussion, literature on the privacy mechanisms used to secure PHRs is not described here.

Avancha et al. [21] refer to Microsoft Health vault (MHV) and Google health (GH) as two well-known PHR services, however Google health was permanently discontinued because of the lack of widespread adoption [22]. MHV is a cloud-based platform that offers a privacy and security-enhanced foundation on which a broad ecosystem of solution providers, device manufacturers, and developers can build innovative new health and wellness management solutions [23].
Microsoft Health Vault is positioned as a one-size-fits-all platform that facilitates ubiquitous management of health related data. The data elements highlighted in Section 1.1.2 are captured in MHV. The MHV’s one size fits all approach does not cater for the various contexts of use. For example employers and medical providers have different interests in health data. The interview study in Section 3 highlights this limitation.

There are a number of PHR applications, including HealthSpek. HealthSpek was chosen as the winner of the AppyAwards 2013 under the medical category. These awards are dedicated to acknowledging creativity and excellence in application design [24]. Healthspek enables individuals to keep track of their medical history and allows continuous updates with health providers [25]. The data elements specified in Section 1.1.2 are captured by HealthSpek. The American Health Information Management Association maintains a listing of existing PHR applications categorized as either web based, software based or paper based, a total of over 20 applications are listed in their directory [26].

The goal is not to develop yet another PHR application; rather it is to increase the chances of designing and implementing a successful PHR system. Three medical practices were interviewed in order to understand their views on PHRs and how they can make use of them.

3. Interview Study

The aim of the interview study was to understand how medical records are currently managed in South Africa and how medical practices can make use of PHRs. Emphasis was put on small practices. The functional and privacy requirements of PHRs that were considered during the interview study were taken from the international PHR System standard by HL7 discussed in Section 1.1.2. The aim was to contextualize the PHR data elements (Section 1.1.2) for use in South Africa.

The interview questions were:
1. Explain how you currently manage your patient medical records.
2. What challenges are you facing in relation to managing patient medical records?
3. What is the process that you use when you get a new patient?
4. Do you think this process could be improved?
5. What is your opinion on patients having an electronic copy of their medical records?
6. Which of the PHR data elements do you currently capture and why?

Participants from two medical practices and a student medical centre at a local university were interviewed. For confidentiality purposes, the medical practices are referred to as Medical Practice A and Medical Practice B.

3.1. Medical Practice A

A medical doctor at Medical Practice A was interviewed. The practice stores patient data in paper files and a spreadsheet is used to cross-reference files. The administrative users find the filing system easy and manageable. The spreadsheet contains patient contact data, insurance data and file look up information, while the paper file contains the actual medical records.

The data is entirely managed by the administrative assistant who is tasked with capturing details and filing. The doctor is not involved with filing patient medical records. The doctor records medical details of the patient onto sheets of paper, which are then passed onto the administrative assistant for filing. The doctor was open to the idea of having a copy of a patient’s medical history presented to him by the patient either in paper or digital format. However, the doctor wasn’t open to the idea of having to enter the patient’s medical details into a computer or mobile device as this would take up his time.

The doctor motivated the need for the following PHR data elements:
1. Allergy Data: If a doctor prescribes a drug and the patient develops an allergic reaction to it, a subsequent doctor may not know about the allergy. In order to prevent more harm to the patient, such data should be made available.
2. Immunization Data: Repeating vaccines makes them ineffective and expensive.
3. Operational Surgery Data: For example, if a patient has had gall stones removed in the Eastern Cape and she shows up elsewhere with the same symptoms, the doctor shouldn’t consider gall stones as the possible diagnosis.
4. Chronic Condition Data: Patients may have chronic prescription scripts, such as for diabetes or hypertension. A need exists to keep that information to ensure continuity of care.
5. Medication Data: Doctors need to know what kind of medication a patient has been taking.
6. Family History: A patient’s family history can help a doctor in diagnosing an ailment.
7. Imaging Data: The X-ray department sends the doctor medical images, which is considered to be convenient.

The doctor also highlighted the importance of the privacy of medical records. Their medical data is stored in a locked wall filing cabinet.
3.2. Medical Practice B

An administrative clerk at Medical Practice B was interviewed. Practice B is a small sized medical practice with one general practitioner and a dentist. The practice stores its patient data in paper files. A file is opened for each new patient. The files are managed by an office assistant. The practice currently captures the following data: immunization, surgeries, chronic conditions, medications, family history and imaging data. They said that doctors need this information when examining patients.

The practice is open to the idea of patients having an electronic copy of their medical records. However, they are concerned about safeguarding the privacy of the patient data. They currently capture all the PHR data elements in physical files and use a computer for file referencing.

3.3. Student Medical Centre

A medical administrative clerk at the student medical centre was interviewed. The centre provides the following services to their students: primary health care, occupational health services and HIV and Aids services. The medical centre stores student medical data in paper files. The centre currently captures the following data: immunization, surgeries, chronic conditions, medications, family history and imaging data. The centre currently faces the problem of not having access to student medical histories. Few students are able to provide this information, which the centre deems essential for continuity of care.

The medical centre welcomed the idea of students having partial access to electronic copies of their medical records. However, they argued that information such as doctors’ notes should only be shared amongst medical practices. They highlighted the need to have access to medical records from desktop computers rather than mobile devices. The medical centre is concerned about electronic medical records being accessed by unauthorized persons because this violates the privacy of their patients.

3.4. Summary of findings from the interview study

The three practices have processes in place that enable them to adequately manage their patient medical records. However, it was observed that none of the three practices could share medical records amongst themselves. The patient would have to physically request a copy of his/her medical records and take the copy to a different medical practice. One way of addressing this is by empowering patients to be actively involved in the management of their medical records.

Medical practices would like to access complete medical histories of their patients. However, the patient should have little or nothing to do with the actual management of their records. It was also noted that medical doctors should not be tasked with entering medical data for patients as this can waste their valuable time. However, they can be presented with a digital copy of medical data. This information should be presented using desktop computers as this caters for the doctors’ context of use. Section 4 presents a ubiquitous PHR design and implementation that limits patient involvement in the management of their records whilst ensuring that medical practices that are geographically separated can easily access this information as needed.
4. Design and Implementation

The design caters for both Patients and Medical Practices. Patients will make use of their mobile devices to search and connect with registered medical practices. The medical practices will use their desktop computers to manage medical information of their connected patients.

The Hybrid storage architecture [20], which allows data to be stored both on the mobile device and cloud servers for everywhere access will be used. The design supports the two different contexts of use; that is mobile devices for patients and a web application for medical personnel as illustrated in Figure 3.

Figure 3. Simplified PHR system architecture showing the different contexts of use.

4.1. Data Requirements

Other than the PHR data elements described in Section 1.1.2, the following elements are also required:
1. Personal data about patients;
2. Data about medical providers; and
3. Data about the medical doctors consulted.

The medical provider and doctor data is important in order to link prescriptions and diagnoses to specific doctors. The medical practices have to be granted explicit permission by a patient in order for them to manage a given patient’s PHR data.
4.2. Implementation

This section presents the implementation of the ubiquitous PHR system as illustrated in Figure 3.

4.2.1. Mobile Application

The mobile user interface as depicted in Figures 4 and 5 presents the data in a format that is easy to use and navigate for the patient. An Android mobile application was developed. The application uses SQLite for local phone storage[27]. MongoDB, which is a JSON document store is used as the cloud database [28].

A login screen ensures that only the data owner can access their records. The home screen lists the various functionalities which are:

1. Health data: Individuals can contribute to their health record by self-reporting medical conditions;
2. Consultation Data: Individuals can access a view only version of their medical record or their dependents’ medical records;
3. Medication Data: Individuals can access a view only version of their medication record or their dependents’ medical records; and
4. Dependents Data: Individuals can contribute to the medical records of their dependents.

The mobile and web applications use the cipher-text policy attribute encryption scheme (CP-ABE) [29] and depersonalization of medical information as mechanisms to ensure that the privacy of individuals is guaranteed. The CP-ABE scheme was chosen because an individual can use their public and master private keys to generate...
more restricted private keys for medical practices. The private keys have attributes. The individual can revoke a medical practice’s access by removing the practice’s attribute from a predefined access policy and re-encrypting the given object.

The CP-ABE’s Setup algorithm is run on mobile devices of patients. The algorithm generates a public key (PK) and master key (MK) for the patient. When a patient links their account to a medical practice, the CP-ABE’S key generation algorithm is used to generate a private key (SK) for the given medical practice. The select practice’s email address and the MK are passed as the arguments to the key generation algorithm. The practice’s email address is also added to the access policy (A). Encryption of medical record identifiers is done on the phone and the resultant ciphertext is uploaded to the cloud. The encryption algorithm takes the following arguments: patient public key, message to encrypt and the access policy (A). The CP-ABE decryption algorithm is run on a server. The medical practices are able to decrypt the medical record identifiers using their patient generated private keys.

![Figure 5. Search results and permissions screen](image)

An individual is able to search for a given medical practice and selectively grant and revoke access to their medical data with ease.

4.2.2. Web Application

A java web application was developed. The web application connects to the same MongoDB server as the mobile application. The web application provides medical practices access to the medical records of all the patients that have explicitly connected with them. Figure 6 illustrates the home screen of a medical practice with four patients.
A hospital can register the medical doctors associated with them. This allows medical notes to be associated with medical doctors.

Figure 7 illustrates the detailed view of a patient’s medical information. The doctor’s notes tab enables medical practices to upload scanned medical records for storage. The practice can also view doctors’ notes from other practices. The medical notes tab enables medical practices to upload and view medication related information. The health summary tab enables practices to view self-reported medical information by individuals.
5. Conclusions and Future work

The paper has discussed the need for a ubiquitous PHR system in South Africa. The requirements for this system were obtained from a literature review of existing health standards and contextualized by an interview study of three local medical practices. The PHR system design was presented and motivated. An implementation of the design was also presented.

Privacy of health records is critical and failure to address this issue can affect the success of a PHR system. The proposed system uses the CP-ABE scheme to ensure privacy of medical information in a cloud storage environment. Mechanisms such as the separation of medical information from personal information and user login are employed to ensure the privacy of patients.

Preparations are underway for a field study with the student medical centre and their patients. The study will enable us report on the real world impact of PHR systems in a South African medical practice context.

Future work can extend this design to a distributed environment. This is important because, some medical providers may not want to use centralized cloud storage.

References


