

Personal Health Records: Design considerations for the South African context

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Abstract:

A Personal Health Record (PHR) is a set of internet-based tools that allow individuals to create, store and coordinate their lifelong health information in one place making it available to relevant parties. It typically contains the individual's demographic information, medical care providers' details, health summary, family history, list of past and current illnesses, symptoms, allergies, medication and so forth. A PHR introduces many advantages as far as improving the health status of people. These include better doctor-patient relationships, improved health knowledge, better monitoring of chronic illnesses and many others. The South African health system is in need of a more preventative approach to healthcare as opposed to its current system that is considered as a highly curative. South Africa's planned National Health Insurance (NHI) aims at achieving this. The South African Department of Health also aims at improving access to quality health care, increasing patients' participation and the dignity afforded to them, reducing underlying causes of illnesses, injury, and disability, to mention a few. A PHR can prove useful to achieve these health goals and more in South Africa.

There is, however, no PHR that is specifically aimed at the South African population and thus adoption rates in South Africa are typically low. There is also a lack of design guidelines for PHRs that are suitable for the needs of South African consumers. This paper highlights

design guidelines and other factors that should be considered when developing a PHR for use in the South African context. Guidelines related to the interoperability, comprehensiveness, legal value, and availability of PHRs are discussed.

Keywords:

Personal Health Record, South Africa, Design guidelines

1. Introduction

South Africa as a developing country is faced with many challenges, quality healthcare provision being one of them. The country is faced with a burden of disease which deteriorates the quality of healthcare. A Lancet report terms this as the quadruple burden of disease which consists of (Department of Health 2011):

- HIV/AIDS and TB;
- Maternal, infant and child mortality;
- Non-communicable diseases; and
- Injury and violence.

These demand a preventative approach to healthcare provision rather than the current health system of South Africa which is considered highly curative (Department of Health 2011). According to the National Health Act (2004), the people of South Africa using health services have the right to participate in decisions that affect their personal health and treatment. It is recommended that the National Department of Health's e-Health infrastructure should focus on person-centric healthcare (Department of Health & CSIR 2014). There is a National e-Health strategy (2012) that, amongst other principles, focuses on patient-centeredness. This means providing care that focuses on respecting and being responsive to individual patient needs and values and also making sure that these guide all clinical decisions regarding the patient's health. This necessitates a solution that promotes the health goals of South Africa and a Personal Health Record (PHR) may be suitable for this.

A PHR gives individuals direct access to the health information as it allows them to create, manage and share their health information in one central place (The Markle Foundation 2003). They decide which parts to make available for other parties to see and this feature becomes useful when a doctor is involved in the monitoring of one's health status. Family

members can also participate in the health management of an individual that owns a PHR and this increases the involvement and promotes better care (Archer et al., 2011:515). PHRs introduce many benefits and these include but are not limited to the following (Kim & Johnson 2002; Tang et al. 2006; The Markle Foundation 2004):

- **Improved patient and doctor communication:** PHRs allow doctors and patients to communicate beyond the usual face-to-face encounters. This fosters a better relationship and better understanding between the two parties.
- **Better health information knowledge:** There are PHRs that provide individuals with health information to educate them about what is currently happening in the world of medicine.
- **Improved quality of care:** Individuals who use PHRs can take to their doctors a comprehensive health summary which contains past procedures that had already been conducted on the patient. This avoids duplication and speeds up the diagnosis process.
- **Increased patient safety:** Some PHRs provide individuals with information about possible drug interactions, side effects, allergic reactions and so forth.
- **Better family support:** There are PHRs that allow for family members to be involved in taking care of an individual's health granting them access to the PHR.

Despite these benefits of PHRs, adoption rates in South Africa are significantly low. A survey conducted in the Nelson Mandela Bay area of South Africa in 2012 indicated that 84% of participants were not aware of the existence of PHRs (Pottas & Mostert-Phipps 2012). It is vital to understand the types of individuals and consumers of PHRs and the functions they mostly use in order to create PHRs that will actually benefit them (Tang et al. 2006). There is no PHR system that has been developed specifically for the South African population.

This paper will highlight design considerations and other factors that should be considered when developing a PHR that will benefit South Africans. A literature review focusing on content relevant to the South African context was employed to gather data related to factors that should be considered when developing a PHR for the South African market.

2. Design considerations for a South African PHR

This section will highlight some design considerations that should be considered when developing a PHR for the South African market. A PHR is a lifelong health record that has been gathered from different sources at different time intervals. It is crucial that the information contained in such a record has some qualities that will ensure its usefulness in decision-making for a patient's health. There are four core characteristics of lifelong health records as identified by Van der Westhuizen and Pottas (2010) that should be considered when designing a PHR. These are interoperability, comprehensiveness, legal value and availability. The subsections below elaborate on these characteristics and design associations related to them.

2.1 Interoperability

Interoperability refers to the ability of information and communication technology (ICT) systems as well as the business processes they support, to communicate through the sharing and exchange of information and knowledge (IDABC 2004). This allows for a greater two-way communication of the patient's health data. PHRs are managed and owned by the patient. He can decide if he wants to share the content of his PHR with his healthcare provider or not and that also depends if that particular PHR has that feature. This, however, limits the chances of better coordination and continuity of care as the data stored in the PHR may only be recorded by the patient. There are other health systems in place that contain patient health information but are not owned by the patient.

An Electronic Medical Record (EMR) contains medical information and treatment history of a patient gathered in one practice while an Electronic Health Record (EHR) contains data collected from more than one practice (Garrett & Seidman 2011). An EHR is a patient's medical record collected from various health organizations. It may include data such as patient demographics, test results, images, symptoms and so forth. This data may be gathered from various stakeholders such as the patient's primary healthcare provider, specialist, pharmacists, nurses etc. (Ludwick & Doucette 2009). Everyone involved in the patient care can have access to the EHR, including the patient (Caligtan & Dykes 2011). A patient can upload information from their PHR to the EHR and vice versa (Mostert-Phipps 2012). This improves the quality of data in that the patient's health record is more

comprehensive, containing all relevant information from the various sources which aids in better decision-making (Caligtan & Dykes 2011; Hargreaves 2010).

Interoperability between health systems such as EMRs, EHRs and PHRs is critical in a national healthcare system (Department of Health & CSIR 2014). South Africa, according to the eHealth Strategy South Africa (2012), is planning on implementing a National Health Insurance (NHI) and this is dependent on an effective national electronic, patient-based information system. South African health information systems have, however, been faced with some challenges namely: fragmentation and lack of coordination, too many manual systems and where automation existed, a lack of interoperability was a problem (NDoH 2012).

The question always rises with regards to how PHR applications can interact with EHRs (Kharrazi et al. 2012). The lack of interoperability between various systems is a major obstacle to realizing the potential benefits of eHealth (Department of Health & CSIR 2014). Amongst others, the eHealth strategy of South Africa (2012) has principles that address this problem.

One of the principles is to enable integration between systems wherever appropriate. One of the ways they aim to achieve this is through the establishment of common data standards and terminology across information systems. The document has objectives for the e-Health interventions that are required and these include eHealth standards. Establishing a national standards authority, facilitating training in eHealth standards and finally localizing eHealth interoperability standards and mandating their use all form part of the objectives. The eHealth strategy has priorities and strategic priority three is standards and interoperability, this highlights the importance of interoperability between the country's health systems.

This need for interoperability has led to the development of a National Health Normative Standards Framework for eHealth in South Africa (HNSF). Its primary objective is to set the foundational basis for interoperability (Department of Health & CSIR 2014)

Using standards to govern the development of IT systems yields great advantages such as alignment, integration, flexibility, reusability, portability and reduced time to market (Department of Health & CSIR 2014). The implementation of proper standards is critical to the

successful integration of PHRs with systems such as EHRs and EMRs. This can be achieved through the use of standardized messaging structures, medical vocabularies, comparable information, comparable terminology and agreed-upon means of communication, amongst others (Kharrazi et al. 2012; van Heerden, Tomlinson & Swartz 2012).

2.2 Comprehensiveness

For a health record to be useful, it should be comprehensive. This means the data entered in it must come from trusted parties, it must be up-to-date, correspond to real world objects, and it must be complete i.e. contain the entire health history (van der Westhuizen & Pottas 2010). There are standards that should be followed in order to ensure that the information contained in a PHR is comprehensive. The ISO multi-part standard on health informatics for the patient healthcard data includes the following standards that can be used to ensure comprehensiveness of a PHR (Department of Health & CSIR 2014; International Organization for Standardization 2004):

- **ISO 21549-1:2004(General Structure):** This standard defines the general structure of data that is contained in a PHR.
- **ISO 21549-2:2004(Common Objects):** It specifies a common framework for the content and basic structure of common objects used to construct PHR data. It does not define the specific data-sets for storage on devices.
- **ISO 21549-3:2004(Limited Clinical Data):** This provides the basic structure of data contained within the limited clinical data object. It does not specify the particular data sets for storage on devices.
- **ISO 21549-4:2004(Extended Clinical Data):** Specifies the basic structure of the data contained in the extended clinical data object. It is only applicable to situations where such data are recorded on, or transported by patient healthcare data cards
- **ISO 21549-5:2004(Identification Data):** Provides a common framework for the content and the structure of identification data held on healthcare data cards. It gives the specification for the basic structure of the data, without specifying the particular data-sets for storage on devices.
- **ISO 21549-6:2004(Administrative Data):** Specification of the basic structure of the data held within the administrative data object, without specifying the particular data-sets for storage on devices.

- **ISO 21549-7:2004(Medication Data):** Specification of the basic structure of the data held within the medication data object, without specifying the particular data-sets for storage on devices.
- **ISO 21549-8:2004(Links):** It defines a way to facilitate access to distributed patient records and/or administrative information using the PHR through references to individual patients' records and their subcomponents. The standard does not cover services relating to access control mechanisms, data protection mechanisms, access methods and other security services.

2.3 Legal Value

This characteristic speaks to the fact that the patient should have a way to grant/revoke access to his PHR. Only authorized parties should have access and be able to make changes to the PHR and there should be audit logs to monitor who had access to the PHR (van der Westhuizen & Pottas 2010). The most commonly recognized PHR adoption barriers are privacy and confidentiality concerns (Wynia & Dunn 2010). A study conducted in the Nelson Mandela Bay in South Africa by Jojo and Mostert-Phipps (2013) however, reveals that 70% of the participants are willing to share their PHR information with their primary care doctors, 52% with family members or friends and 48% with other healthcare providers. Participants were less inclined to share their health data with their employer (3%) and government officials (2%). This suggests that they are willing to have some parties access their PHRs but there is the concern of unauthorized parties gaining access too. A similar study was conducted in the Nelson Mandela Bay municipal area to gain insight on the attitudes of the citizens towards PHRs (Pottas & Mostert-Phipps 2012). It was found that 58% of the participants were concerned about their privacy when using a PHR.

In order to protect the PHR, some safeguards need to be implemented and these can be categorized as administrative, technical and physical safeguards (Maglogiannis 2011).

- **Administrative safeguards:** These address the security management process, assigned security responsibility, security aware and training and contingency planning.
- **Technical safeguards:** Access controls, audit controls, integrity and person or entity authentication and transmission security.

- **Physical safeguards:** These include facility access control, secure installation environment protection of devices and media controls.

Since the PHR is in full control of the individual, they play a huge role in ensuring their privacy. PHR users should therefore choose wisely when deciding on a PHR provider. They can also apply encryption methods to protect their data before handing it over to the provider which will be responsible for storing it (Li et al. 2013). According to Tang and Lansky (2005), a strong national leadership also plays a huge role in ensuring that the legislative and regulatory policies to protect the PHRs privacy and confidentiality are in place.

2.4 Availability

It is important that a PHR is available when a healthcare provider needs it. Failure of the PHR is not acceptable because once that happens, lives are put at risk. A health record should be continuously available for it to be deemed lifelong (van der Westhuizen & Pottas 2010). A PHR, therefore, should be made available at all times and should be easily accessible. This subsection will introduce some options that can make this possible.

South Africans that have access to the Internet at home are only 10% according to Statistics South Africa's General Household Survey (2013). 9.6 % of the population accesses the Internet at Internet cafes or at educational facilities while 16.1 % access the Internet at work (Statistics South Africa 2013). This shows that South Africans have little access to the Internet. Looking at households that only use cellphones for their telecommunications, Statistics South Africa's General Household Survey (2013), shows that they cover 81.9 %. This accounts for the high Internet access via mobile phones which is 30.8% (Statistics South Africa 2013).

Patients are increasingly searching for means to access their health records that are more accessible and portable (Archer et al. 2011; Maloney & Wright 2010). This creates the opportunity to utilize mobile PHRs (mPHRs) in order to better manage the health of the South African population. MPHRs are mobile applications that enable an individual to record, manage and store their health data (Dohan & Tan 2014). One can record symptoms, allergies, medications, access emergency information and so forth depending on the features offered by the mPHR they are using (Dohan & Tan 2014). They can also decide if they want

to share this with others e.g. doctors or family members. The use of mPHRs in a diabetes case study has proven them to be successful as the participants could better manage their health (Preuveneers & Berbers 2008). People already access sensitive information via their cellphones such as cellphone banking, shopping, and maintaining their financial data. It is therefore highly likely that they will be comfortable with using mPHRs (Kharrazi et al. 2012).

Cellphones offer a sense of mobility as well as instant accessibility. This means a person will have access to his medical data anywhere and anytime he needs it. According to Kharrazi et al (2012), having instant access to one's PHR can significantly decrease errors and time needed to repeat health history, the need to recall past immunizations and medication history. Cellphones also come with features such as a camera, Global Positioning Systems (GPS), and touch-screen. These can prove to be useful to an mPHR because the camera can be used to scan and import documents, take pictures to describe symptoms, take video notes, or scan medication barcodes. The GPS may be used to locate healthcare providers nearby. Touch-screen interfaces can provide better data entry and navigation mechanisms hence improving usability (Kharrazi et al. 2012). The advancement in technology allows for the creation of new applications that can be applied to healthcare. South Africa is said to have the most advanced mobile phone and Internet industries in Africa therefore, mPHRs can prove useful in the eradication of poor health management in the country.

Using the mobile phone to access health applications demands infrastructure such as storage, processing power and bandwidth and this creates the need to make use of Cloud Computing (CC) capabilities (Dinh et al. 2013; Dohan & Tan 2014). CC can be defined as "a model for enabling ubiquitous, convenient, on-demand network access to a shared pool of configurable computing resources (e.g. networks, servers, storage, applications, and services) that can be rapidly provisioned and released with minimal management effort or service provider interaction" (Mell & Grance 2011). NIST describes the following major characteristics of CC (Mell & Grance 2011):

- **Ubiquitous network access:** resources are made available over the network through standard mechanisms that can be accessed over different platforms (e.g. smartphones).
- **On-demand self-service:** a user can have access to computing capabilities as needed without interacting with the service provider.

- **Resource pooling:** computing resources are pooled to help multiple users through a multi-tenant environment. The users share physical and virtual resources dynamically and these are assigned and reassigned as the users demand them.
- **Rapid elasticity:** this is the ability to dynamically scale the resources according to the user' demand.
- **Measured service:** a pay-per-use method is used to automatically control and optimize resource usage. This allows for resource usage to be monitored, controlled and reported, which promotes transparency between the service provider and user.

Using CC to access mPHRs means mobile devices will not require a powerful configuration such as CPU speed and memory because all the computing modules have been transferred to the Cloud (Dinh et al. 2013). Some of the advantages of using CC with the mobile phone also include extended battery life, and improved reliability. MPHRs used in conjunction with CC will provide pervasive access to Cloud-based health services thus promoting self and domestic care. This in turn will blur the boundaries that currently exist between the physical and digital worlds, allowing personalized and universal healthcare services (Sultan 2014).

Apart from interoperability standards, CC is another important cornerstone needed to streamline healthcare for maintaining health records, monitoring patients, managing diseases and care more efficiently and effectively (Zhang & Liu 2010). Healthcare providers are looking for more innovative and cost-effective means to address many of the problems facing healthcare (Sultan 2014). Cloud Computing has the potential to address some of these problems.

It can reduce healthcare integration costs, optimize resources and introduce a new era of innovations (Ahuja, Mani & Zambrano 2012). There is a great potential in CC for managing EHR/PHR systems in the US (Alagoz et al., 2010). CC can play a vital role in ensuring interoperability between disparate systems such as EMRs, EHRs and mPHRs. The fact that CC services can be accessed on any device ensures that these systems can communicate together. This feature is something healthcare IT is desperately in need of (Ahuja, Mani & Zambrano 2012). Data stored on a Cloud-based system would eliminate the need for an EHR to communicate with a PHR if a Cloud service can act as a storage mechanism and intermediary for data transfer between these health systems. This may also eliminate the problem with platform-specific software as well as incompatibilities between different

operating systems used by different manufacturers (Kharrazi et al. 2012). CC is offered in three service models (Mell & Grance 2011; Gong et al. 2010):

- **Software as a Service (SaaS):** The software or applications that users use are provided to them via the Internet on a pay-per-use basis instead of them incurring costs of downloading and maintaining software on the computers.
- **Platform as a Service:** The user has the ability to deploy applications they have acquired or created using a programming language that is supported by their vendor.
- **Infrastructure as a Service:** Infrastructure providers are able to deliver huge computing resources such as storage, network and processing power.

The ability for accessing a PHR on different platforms such as a mobile phone is supported by the SaaS model. This type of service would also be marketed to small practices that are looking to adopt EMR usage (Schweitzer 2014). The ability for patients to provide access to their health history and other information from their PHR stored in the cloud to hospitals is also made possible through the use of SaaS (Bahga & Madiseti 2013). EMRs built with the PaaS model could be offered to practices large enough to have their own IT support and are interested in rapidly customizing their EMR (Moore 2009). PaaS systems could also supply the software developers with the tools needed to add on the basic functionality that comes with an EMR. This would address the clinicians' concerns about EMR applications' agility and adaptability to local business workflow (Schweitzer 2014)

In terms of mPHR integration with EMRs, IaaS can be used in order to transfer the resources needed to support these healthcare systems. The costs of building and maintaining infrastructure will decrease while allowing better access to health information (Dohan & Tan 2014).

Cloud services are deployed according to different deployment models (Kuo 2011; Mell & Grance 2011; Zhang & Liu 2010):

- **Public cloud:** Cloud Computing resources are made available to the general public on a pay-per-use basis via the Internet. This Cloud is owned by the Cloud provider.
- **Private cloud:** This is operated exclusively for a particular organization e.g. healthcare facility. It is managed by that organization or by a third party.

- **Community cloud:** Cloud services are shared by a community of organizations that share a common goal e.g. healthcare facilities that want to share their EMRs. This is managed by the organizations or outsourced.
- **Hybrid cloud:** This is a combination of two or more cloud models (public, private or community). An organization may decide to manage some resources internally while outsourcing others.

Depending on the deployment model that an organization chooses, there are security issues that they should consider. Healthcare facilities, for instance, should decide whether they want to use private or public clouds. They should look at regulations that govern access to healthcare systems and how they can ensure the privacy and security of patient data (Dohan & Tan 2014). An in-depth understanding of the healthcare security and privacy concerns could be the first step towards the adoption of CC for healthcare systems (Zhang & Liu 2010). Once the challenges of CC have all been addressed, it seems that Cloud-based systems will likely become the norm in healthcare (Ahuja, Mani & Zambrano 2012).

3. Discussion

Health plays an important role in a country's well-being and should be treated as such. There are Health Information Technologies available that can play a supporting role in improving healthcare services such as EMRs, EHRs and PHRs. The challenge with these systems is that they operate in isolation and so do not fully benefit a country's health status. This paper highlighted that South Africa is currently in need of a patient-centric health system that will promote preventative care and aid in improving the quality of care. The use of a mobile PHR was suggested because of the fact that South Africans have high access to the Internet via their mobile phones. Achieving this, however, will require a lot of collaboration from all parties involved in the care of an individual.

Healthcare systems exist but for as long as they work in isolation they will not yield the results that the South African health system is currently in need of. Interoperability between these systems would play an important role in ensuring that they communicate together in order to provide a better health system. Universal standards need to be adopted by the different organizations that participate in providing healthcare systems so as to reach the goal of integration and interoperability. This in turn will offer a faster and more efficient method of

improving the patient care process. CC has proven to be another vehicle that can drive better collaboration between systems. Healthcare stands to benefit from this technology not only through better communication between health systems but it can also cut operational costs.

4. Conclusion

The lack of design guidelines for a PHR system aimed at the South African context has led to the problem of not having a PHR specifically designed for the country. This plays a role in the poor adoption rates of PHRs in South Africa. The suggested design considerations in this paper may guide PHR developers and relevant stakeholder when designing a PHR for the South African market. Such a PHR has the potential of improving the current state of health for South Africa through better decision-making, diagnosis and treatment, which will yield better health outcomes.

The high usage of mobile phones by South Africans to access the Internet and the great need for a highly curative approach expressed by the National Department of South Africa advocates for the need of a mobile PHR in South Africa. The use of CC and the implementation of eHealth standards provide means to make this system both interoperable and affordable.

This explorative study highlights design considerations for PHRs based on a thorough literature review. Future research will focus on gathering primary data to further develop these design guidelines. There will also be a focus on establishing the functional requirements of a PHR that will better serve the needs of the South African market. Usability aspects related to the use of mPHRs on mobile devices will also be investigated.

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