An overview of electronic personal health records

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Abstract

Electronic Personal Health Record systems are providing health consumers with greater access and control to their health records by shifting these records from being a health provider-centred Electronic Health Record, to a patient-centred, Electronic Personal Health Record (ePHR). Based on the delivery system, ePHR systems are classified into standalone, tethered, and integrated or unified ePHRs. While national approaches of implementing integrated ePHR vary, the middle out method has been recognised as the ideal approach. It is worth considering the adoption of ePHRs has been slow due to several factors, including technical, individual, environmental, social, and legal factors. This paper provides a representative overview of an ePHR system, outlining its definition, types, architectures, and nationwide approaches of its implementation. Additionally, the drivers and hindrances to health consumer adoption are discussed.

Introduction

Nowadays, a patient's healthcare record is usually kept in an Electronic Health Record (EHR) system. As explained by Khangura et al. [1], EHR systems are usually administered by healthcare organisations and have played a major role in enhancing the quality, as well as the safety, of healthcare. In addition, an EHR system represents a key element of a healthcare organisation's application of information technology innovations. Health records are normally kept by the healthcare organisation attending to the patient, however individuals often find it very challenging to access their own health records. In order to address this challenge and ensure patients have access to this information, some healthcare organisations now provide their patients with either paper or electronic versions of their records, while other organisations with more advanced systems go to the extent of offering their patients secured access to their health records [2].

A key challenge is having a central source of information for medical records, as an individual will often seek the services of different healthcare providers during his lifetime [3]. With no ideal mechanism to provide the interaction and sharing of data among various EHR systems, it can be very difficult to access in-depth information covering an individual's entire medical history. This can also make it challenging for patients who want access to their personal health information, either urgently, or simply when they want to be proactively involved in the management of their health.

The difficulties patients experience in trying to access their health records indicates that existing healthcare systems are not well integrated and only function on a healthcare provider's level. This may hinder healthcare providers from successfully taking care of a patient's specific needs, even though efforts have been made to ensure health organisations move towards a patient-centred model [4]. The trend towards a patient-centred approach has resulted in a change from the present health provider-centred capture and storage of information to a more patient-controlled information management system. Such an approach makes it possible for patients to keep and easily access their health records by making use of different technologies and devices [5]. Nevertheless, challenges, such as achieving interoperability between various EHR systems via nationally agreed upon standards, costs, privacy, security, and healthcare consumers' acceptance of Electronic Personal Health Records (ePHRs), need to be addressed [6]. In this work, we provide a representative overview of an ePHR system, outlining its definition,

types, architectures, and nationwide approaches to its implementation. Finally, we close by discussing the drivers and hindrances to adoption of the system by health consumers.

Electronic Personal Health Records

The notion of a Personal Health Record is not new since, for many years, patients' personal health information has been stored and kept in paper-based records [7]. Nevertheless, nowadays, health information technology has made it possible for individuals to store and maintain their own health information electronically, making it possible for them to access it anytime the need arises [6].

Definition of Electronic Personal Health Records

Electronic Personal Health Records (ePHRs) are a representation of health records connected to the care of a patient and are managed by the patient [6], unlike EHRs, which are managed by health care providers. ePHRs allow healthcare consumers the luxury of deciding which health information to share with healthcare providers [4]. Ozok et al. [8] defined ePHR systems as patient-centric, multi-functional, health management systems developed for managing and storing lifelong personal health information for various purposes from chronic to critical, medical and preventive care.

Variations between EHRs and ePHRs

The information in an EHR is keyed in by healthcare providers and is only accessible to healthcare providers. In addition, an EHR might only contain information from a single healthcare provider. On the other hand, an individual will retain control of their own ePHR, which might encompass health information from different sources, such as various healthcare providers, as well as from the patient, as integrated ePHRs have the capability to incorporate data from different sources [2]. Thus, at any one time, there may be various EHRs for one person but only one ePHR.

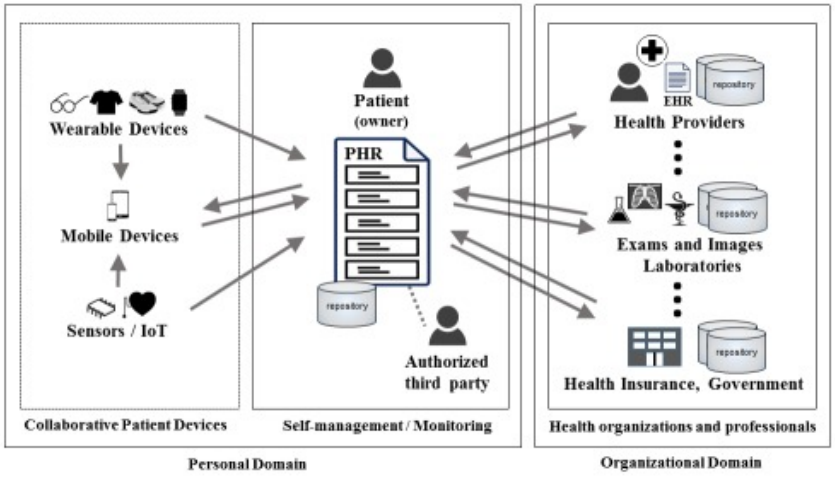

Figure 1: Difference between an EHR and ePHR (adapted from [2])

ePHRs goals, types, and architectures

- **ePHRs goals**

The main goals of ePHR systems, as discussed by Archer et al. [6], are integration, enhancing portability, and preventing the replication of healthcare information. Oftedahl et al. [9] also added that the goal of an ePHR is to enhance the patient's access to, as well as ownership of, his/her health information. Additionally, ePHR systems seek to standardise and formalise the interchange of an individual's health record with different healthcare providers [10].

- **ePHRs types**

A review of the classification of ePHRs shows that the existing classifications have been differentiated based on service providers, type of user, and system channels. For example, the Committee on The Future of Rural Health Care [11] classified ePHRs as either off-line, web-based, purpose based, provider based, or partial. On the other hand, Maloney et al. [12] classified ePHRs as either offline ePHRs, smart cards, ePHR kiosk, web-based, or USB-based PHRs.

- **ePHRs architectures**

As expounded by Tang et al. [3], health data repository, administration, and disposal of health records are greatly influenced by the architecture in place. Based on a review of the literature, the architecture of ePHR systems can be grouped into three various models, mainly founded on the delivery system by which consumers and healthcare providers communicate [13, 14]. These three models are:

a) Standalone ePHRs: users are responsible for creating and maintaining their own health information. In a standalone or web-based PHR, the user is responsible for keying in all medical information retrieved

from EHRs, which can be time consuming. This type of ePHR is kept on a personal computer or on the Internet and is used to monitor and track different health-related aspects, for instance physical exercise and food consumed.

b) Tethered ePHRs: consumers are allowed to access the information stored by a healthcare provider. According to Nazi et al. [14], tethered ePHRs can be linked to a provider's EHR, which provides a subset of the data stored.

c) Integrated or unified ePHRs: enable the gathering and viewing of health information from multiple sources, i.e. from several healthcare providers, and could be used regionally as well as at the national level. Some of these systems allow healthcare consumers to maintain some control over the information; they can add or amend some information or even set limitations as to who can access certain information in their ePHRs.

Key capabilities of integrated ePHRs as a transformative health technology

The implementation of an integrated ePHR system has gained significant attention by governments and policy makers. Application of health technologies in this way has the potential to transform and enhance the quality, accessibility, and delivery of healthcare. Integrated ePHR systems has been a goal for governments worldwide due to the capabilities of this technology in transforming healthcare delivery [15]. The capabilities of integrated ePHR systems include:

- **Accuracy, Depth, and Availability of Health Information**

Integrated ePHR systems represent a promising technology capable of enhancing the accuracy and extensiveness of health information by aggregating health data from various health systems as consumers receive medical services or use at-home monitoring systems [6]. For example, wearable sensor systems could be used to constantly upload real-time health data to an integrated ePHR database. The health data acquired by wearable sensors would be transmitted via Bluetooth or Wireless technology to a gateway to be transmitted to integrated an ePHR database server in real-time [16]. This captured data can be relayed directly to various healthcare providers as required. It is worth noting that such a system requires high security, given the presence of multiple users necessitating different access policies to protect the privacy of healthcare consumers' data [17]. Based on the permission of healthcare consumers, this generated data can be further

utilised in studies focusing on various aspects of public health and can also be used for the purpose of performance measurements [18].

- **Prompt Communication**

Integrated ePHRs enable both synchronous, as well as asynchronous, interaction between healthcare consumers, healthcare givers, and casual care providers, offering a mechanism for collaborative decision making [15].

- **Accessibility to Health Knowledge**

Through utilising the Internet, integrated ePHRs enable ease of access to health knowledge, thus enhancing healthcare consumers' awareness and wellbeing by providing general health information bases, guidelines for preventive health activities, and ideal approaches for medical and self-care [5].

- **Portability**

The capacity for healthcare consumers to access their health information via a single interface regardless of location and time represents the real value of any portable health record systems. Integrated ePHRs assure this potential [10].

- **Auto-aggregation**

For healthcare consumers, manually assembling and incorporating health records from various healthcare providers is difficult, particularly for those who lack the necessary skills and recourses [5]. Therefore, the automatic collection and insertion of health information from several EHR systems is a crucial element in the feasibility of ePHRs. Integration between various EHR systems operating within local healthcare providers, through national interoperability standards, is the only way to facilitate the sharing of health information [2]. As the alternative approach, which involves manually entering and transferring data, is not only strenuous but also prone to errors, auto-aggregation of reusable content is a fundamental factor in the implementation of integrated ePHRs. Integrated ePHRs will further increase the value of ePHRs for healthcare consumers, as well as healthcare providers, because unnecessary data will be eliminated while accuracy, thoroughness, and up-to-date content will be ensured.

Nationwide approaches of implementing integrated ePHRs

The development of nationwide infrastructure to enhance the safety, quality, and delivery of healthcare has been a goal for several countries. Such infrastructure is essential for facilitating and supporting secure accessibility to health-related information from various EHR systems across several regions of a country. This integration between numerous EHR systems is a key element in implementing national integrated ePHRs, promising numerous benefits to all healthcare stakeholders, including healthcare consumers, healthcare providers, health professionals, and the healthcare system as a whole. Enhancing the effectiveness of healthcare services is one of the natural advantages of executing national integrated ePHRs through an increase in information sharing, accessibility, security, and quality. Likewise, it can expand healthcare consumers' involvement in managing their health and thereby spare specialists' time. National implementation of integrated ePHRs has taken the form of different approaches, including top-down, bottom-up, and middle-out [19].

In the top-down approach, implementation is directed by centralised management. Such an approach has been used in England, where the government has directed the implementation of nationwide integrated ePHRs [20] by establishing a centralised-shared ePHR system. In so doing, healthcare providers will be able to access, add, and exchange health information. This approach entails the essential step of replacing the existing, local non-compliant EHR systems with alternative software that meets the correct criteria in order to attain a national integrated ePHR system that is accessible throughout the country [19]. However, the new system, which will replace the locally installed system in a healthcare setting, raises some issues, including whether the new system meets the needs of a local healthcare setting, the required cost for employees' training, and the effort necessary to alter work processes [19]. Such issues, among others, have proved to be obstacles in the national implementation of an integrated ePHR in England and have contributed to slowing down its rollout [21].

In the bottom-up approach, it is the local healthcare providers' responsibility to ensure their existing EHR system, or newly obtained software, complies with interoperability standards. The idea of this model is to have various EHR systems running locally, with the aim of data sharing through integration over time. The benefit of this model is that it fulfils the requirements of local healthcare providers and eliminates the need to acquire a new system and accompanying need for staff training. However, one of the hindrances to this model is the possibility of local healthcare providers using EHR software that does not conform to the interoperability measures necessary to help the trading of personal health information between various locally used EHR systems [20]. Within the United States, this issue has been handled by the Certification Commission for Health Information Technology (CCHIT),

which is a free, non-revenue-driven association. The principal obligation of CCHIT is to create acceptable, efficient, and sustainable affirmation programs for EHRs [22].

Finally, the middle-out approach utilises elements of both the top-down and bottom-up approaches; this approach has been embraced in Australia [19]. In this approach, the government concentrates on nationally accepted interoperability standards, with goals implemented by local health agencies. Thus, it focuses on developing standards, rather than government directed implementation. In addition, the government encourages local healthcare providers to ensure their local software is compliant with national standards of interoperability by offering incentives and support [20]. The expense for actualising this model is approximately equivalent to the value of the bottom-up approach of implementing nationally integrated ePHRs; notwithstanding, the final outcome empowers more data sharing. According to Coiera [19], the middle-out approach seems the right approach to follow when setting up national integrated ePHRs. It has been indicated that countries that implemented top-down or bottom-up models could switch to the middle-out approach at their own convenience, with a specific end goal to achieve nationally integrated ePHRs. For instance, the Health Information Technology for Economic and Clinical Health (HITECH) Act has been presented in the United States, keeping in mind the end goal, to offer financial incentives under Medicare and Medicaid for qualified healthcare providers when they introduce, upgrade, or demonstrate significant utilisation of confirmed standards in their locally used EHR system.

Hindrances and drivers of ePHR adoption

In spite of the widespread agreement on the advantages of ePHRs, there has been a slow uptake and adoption of such systems by health consumers. For example, Gaylin et al. [23] conducted a study in the United States to explore attitudes towards the adoption and use of health information technologies such as ePHRs. They found that 75% of the participants were aware of ePHRs before the interview, however, only 20% of them were using them. In Australia, the personally controlled electronic health record 'My Health Record' (MyHR), a secure electronic record of an individual's medical history, was rolled out in 2012 in order to improve the delivery of healthcare by making clinical information available for patients and health providers. However, a study conducted by Newton [24] indicated that some Australians did not understand the need to have a MyHR. The author concluded that such attitudes may limit the adoption for national implementation, and thus impact the utilisation of MyHR in Australia. A review of the literature on factors affecting the acceptance and adoption of ePHRs by consumers in developed and developing countries indicated that some factors are relevant to both developed and developing countries [25-27]; these include technical, individual, environmental, and social factors [27]. Technical factors relate to the

usability of the system or features that contribute to the feasibility of technology use, such as effort and performance expectancy of the offered technology. Individual factors include personal characteristics relating to demographics, and cognitive and biological aspects that affect an individual's intention to adopt such technology. Environmental factors are defined as physical and psychological contexts that may influence healthcare consumers' behaviour. Finally, social factors can be attributed to the influence of community, neighbours, friends, and family on a person's decision relating to the adoption of a novel technology.

However, some of these obstacles are found to be more noticeable in developing countries, which are often underprivileged in terms of resources, essential infrastructure, and literacy level [28-30]. Relevant research findings revealed some of the factors that determine whether ePHRs will be adopted or not. For instance, Nokes et al. [31] found computer skills healthcare consumers to be a key factor, while Najaftorkaman et al. [32] found self-efficacy was a determining factor. Perceived self-efficacy, as defined by Bandura [33], is "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives". So, it can be related to the belief that a person has, within his or her capacity, to carry out a certain behaviour. To enhance the confidence of healthcare consumers in using ePHRs, such factors need to clearly identified and addressed. Logue et al. [34], suggested offering ePHR system trialability to healthcare consumers, however it requires both facilitating conditions as well as the availability of the system.

Privacy and security of healthcare consumers

As is the case with any technological innovation, when it comes to the adoption of ePHRs, privacy and security have been a key concern for healthcare consumers. For example, Gaylin et al. [23] conducted telephone interviews in the United State to explore attitudes to the adoption and use of ePHRs. They found privacy and security of ePHRs were of concern to 49% of respondents. Specifically, users were hesitant to embrace the system because it contains sensitive personal information that could be hacked [26, 35, 36]. Therefore, information security is of significant importance when adopting ePHRs, due to external threats of unauthorised access to private sensitive information. Security threats may include various types of attacks, such as the disclosure of information, unauthorised use of resources, amendment of information, and a denial-of- service attack [13]. These issues have been extensively noted as one of the most significant hindrances for adoption of the system and need to be effectively addressed if ePHRs are to be widely implemented [6, 13, 23, 35].

Identification and security issues

Safeguarding the confidentiality and security of ePHRs, while also ensuring the simple, continuing exchange of information, is a major issue for healthcare consumers as well as healthcare providers [32]. Security failures, system intrusion, collapses in data security, and other abuses of data and trust are some of the potential risks. Consequently, it is a major concern how personal records are treated when it comes to sharing of information between healthcare providers and other parties. Open wireless Internet connections imply that many consumers' records become subject to others' eyes. Another key security area involves electronic prescriptions, which need procedures, such as electronic signatures, to make them valid. Consistently matching consumers' records demands inimitable identifier[37]. The present lack of a unique identifying number for each healthcare consumer implies that their health records are linked to their names or date of birth. Such information is often not distinctive to one individual, which makes it difficult to accurately identify healthcare consumers.

ePHR systems have to allocate special security to the ePHRs of public figures or prominent people due to the high risk of hacking involved. Safety assurances, seals of endorsement, reliable vendor authorisations, and other different security measures need to be put in place in order to enhance the security of ePHR systems. One of the measures adopted to enhance health security is The Health Privacy Project, which is implemented in the United States at the Centre for Democracy and Technology and is solely dedicated to addressing issues of personal privacy [38]. Since the way data is accessed is important, organisations have to develop protocols that facilitate requests for medical records to be swiftly processed. [4].

Other applications of integrated ePHRs

When discussing ePHR policies, conversations have concentrated mainly on ways in which the use of health information technology could impact the quality and value of healthcare services. Nevertheless, progressively digitised health information offers additional novel, and possibly extensive, chances for other applications of electronically available health information [18]. Other applications, which from this perspective entails other uses, instead of the basic use of personal medical care, vary and include research, public health, enhancement of healthcare quality, and commercial marketing.

In view of ethical issues, there are strong ethical traditions and governing frameworks that underline the confidentiality of this data, as well as the rights healthcare consumers need to be aware of before they consent to

the use of ePHRs [39]. Nevertheless, in some cases, privacy tends to be superseded by development of community interests, as is the case with transmissible or reportable diseases. Those advocating for ethics, as well as the controllers, have discussed various situations where the balance between individual confidentiality and public good is not clear [40]. For instance, a relative success study could, in a big way, improve scientific comprehension of health and healthcare if it could be carried out on medically thorough and widely representative information from interoperable PHRs. The social advantages of such a study could be considerable, in that it validates a more relaxed approach to consensus if unassailable aspects of personal privacy were safeguarded.

Conclusion

The implementation of computerised health record systems is moving from the present, health provider-centred capture and storage of information to a more patient-controlled information management system. Several countries have set the implementation of national or regional integrated ePHRs as a goal to enhance the safety, quality, and delivery of healthcare. While national approaches of implementing integrated ePHRs vary between top-down, bottom-up, and middle out, the latter has been demonstrated as the ideal method. Despite wide agreement on the advantages of ePHRs, adoption rates by health consumers have been low. Technical, individual, environmental, social, and legal factors need to be addressed to increase uptake and acceptance of ePHRs.

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