

A Novel Approach for Improving Chronic Disease Outcomes using Intelligent Personal Health Records in a Collaborative Care Framework

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Abstract.

Background- Effective management of chronic diseases is highly important to improve health outcomes of chronic disease patients. Emerging initiatives on online personal health records (PHR) have provided an opportunity to empower patients living with a chronic disease to take control of their own health data management. Online PHR solutions also provide data-driven intelligent analytics capability that can provide an effective view of the patient's health data to the patients themselves as well as to their consented clinicians and carers such as family members fully engaged in their routine care. Research suggests a tendency among chronic disease patients of using self-managed care without as well as with some support to monitor and manage their chronic disease. The rising usage of online solutions enable chronic disease patients store their physical as well as mental health information in self-managed online PHR. There are a variety of such online PHR mechanisms that are available via desktop computers, mobile smartphones, smart TVs as well as biometric devices. However, the main problem of disparate data sources and lack of a universal view of patient's health data still exists. These problems needs a novel way of integrating various types of PHRs in an efficient way and provide effective insights about the patient's health to empower and engage the patients in active management of their chronic condition. **Objective-** To describe a framework to integrate various online PHRs for providing effective self-managed and collaborative care. **Methods-** Comprehensive research was conducted to analyse current trends of various PHR mechanisms. A series of discussions were held with the clinical as well as non-clinical end users of online PHRs to identify the current problems with accessing PHRs and their expectations about usage of PHR in managing chronic disease condition. The requirements analysis and emerging technology trends were utilized to develop a framework that provides intelligent capabilities for a collaborative online platform. **Results-** The requirements analysis and discussions with the end-user representatives showed that the proposed framework is considered novel and intuitive by the stakeholders thus confirming our findings. **Conclusion-** The results of this investigation specified a novel framework that can enhance the value of PHRs and thus may address usability challenges identified by the PHR developers as well as the end-users.

Keywords: Personal Health Record (PHR), Collaborative Care, Self-managed care

1 Introduction

A personal health record (PHR) is a record in a tangible document format (e.g. information recorded on a piece of paper and/or in an electronic document); in which an individual patient creates, maintains and controls his/her health related data [1]. The patient may access, modify as well as control the individual health information before using it for specific purposes such as self-assessment and sharing it with care providers through a consent process. The patients may also store a copy of data collected by their clinicians in their personal health record. The patient's PHR is a component of complete set of the patient's health related information as some information is also created, stored and managed in hospital and clinic health information systems.

Personal Health Records exist in paper-based (offline) format as well as electronic format (online). Some percentage of patients may regularly use offline PHR's to store and access their chronic disease specific health information. A certain section of patients may use various online PHR mechanisms (such as website-based tools and mobile applications provided by private vendors) to manage their health related information. The online PHR is an electronic record of an individual's personal health information stored securely in a central repository that can be accessed by an individual patient for self-managed care, self-monitoring of health conditions and can be shared with the clinicians for clinical use. The patients may choose to share the online electronic health record with clinical information systems used by their care provider to provide an accurate and a complete set of information required for providing point-of-care health services at various geographic as well as clinical settings [2, 3, 4].

1.1 Current State-of-the-art

The online personal health record is an emerging discipline of research. The current research in this discipline makes an attempt to improve value of the personal health records through application of innovative intelligent data processing methods [5]. The concept of Personal Health Record (PHR) has been evolved along with the advancements in web-based technologies. The current state-of-the-art suggests that intelligent PHRs are evolving to add more features such as data exchange, data sharing with clinicians, and family members. There are certain proprietary PHR solutions as well as open source PHR solutions. Each of the PHR solution offers common functions and features that can be accessed by the patients through a web-enabled device with a web browser. These solutions are evolving to add more features such as data exchange, data sharing with clinicians, families and carers. However, there are open issues in the intelligent PR especially in the area of functions provided by these solutions. Our review of the existing PHR solutions indicates that there is a lack of collaborative functions in the PHR [6]. This work attempts to address this gap by proposing a collaborative PHR platform.

1.2 Main Problem

There are certainly growing efforts both in private as well as public domains for adopting online PHR as a data recording and analysis tool for self-managed care, self-monitoring of disease conditions, as a preventative health intervention and clinical use. There is growing number and various types of private online PHR solutions that are available as a web-application and/or mobile application storing patient health data. The growing number of mobile health applications for tracking and monitoring exercise is a good example of this evolution (E.g. Nike+ app or the Fitbit app with optional weight scale and wrist fitness band). The various types of PHR's can be also categorised as per the devices that can be used to access the PHR. The types of online PHR are shown in table 1.

Table 1. Types of Online PHR

No	Online PHR Type	Access Devices
1	Web-based PHR	Desktop Computer, Smart phone, tablet device
2	PHR in Mobile App	Smart phone, tablet device
3	PHR in wireless monitoring device	Smart phone + portable device such as blood glucose monitor

The advances in web-based and mobile apps online technologies as well as rising use of online data recording and analysis solutions has led to the development and launch of private and public online PHRs. The broad categories of online PHR systems are illustrated in Figure 1 which links with the relationship illustrated in Figure 1.

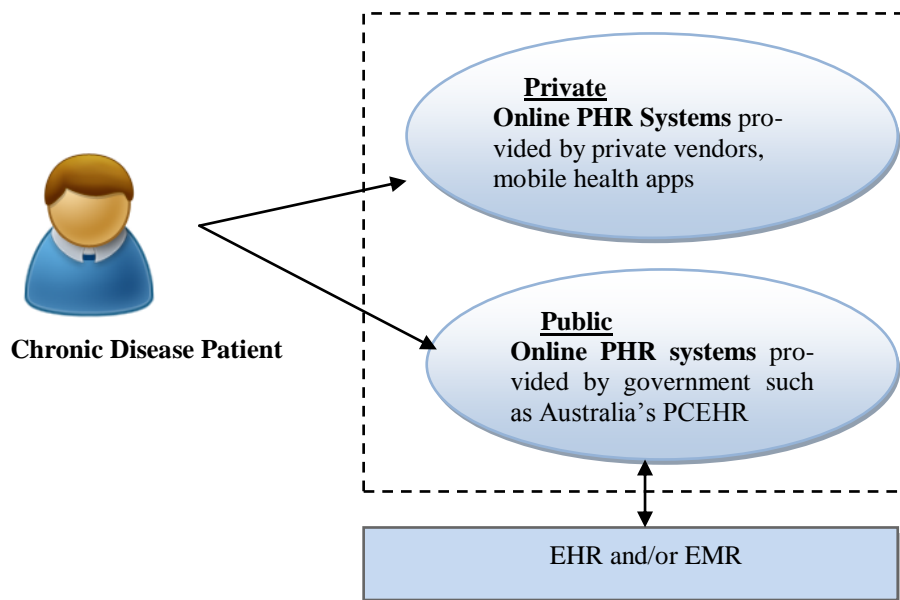


Fig. 1. Types of Online PHR Systems

Due to the widespread use of web-based PHR solutions, the patient’s health data is stored in various disperse data sources. Thus, despite advances in online solutions, the core issue of “Health Information SilOs” (HISO) still exists and thus the issue of accurate information for self-managed care as personalised decision support is still largely unresolved. We propose an approach in the form of a framework that attempts to address this issue with a new design proposal for an intelligent PHR framework.

2 Methods

This research was undertaken for an initiative that aims to improve journey of chronic disease survivors. The following main steps were undertaken for our research.

- **Expert Interviews:** A group of clinical experts, patient representatives as well as technology experts was engaged to understand the real-life issues of chronic disease survivors. A series of expert interviews were conducted to understand the main drivers as well as requirements for developing an online technology approach to leverage advances in PHR, established as well as emerging industry trends in health information technology. A key challenge of providing a seamless experience for the patients to manage their own health data was identified during these interviews. The challenges of adoption by the chronic disease patients with limited health and information technology literacy were also identified. The inputs from the interviews were used to specify requirements of our proposed platform. The specifications aimed to propose an innovative design of a PHR-based solution using a vendor-provided PHR platform with customization.
- **Online Solution Investigation:** A comprehensive research was conducted to investigate global landscape of emerging online PHR solutions including desktop as well as smart devices (smart phones and tablets) based solutions. The results of the comprehensive research are summarized in the table below-

Table 2: Online PHR status around the world

Country	PHR Solution	Roll Out	PHR Standards	Current Status
Australia	PCEHR [7]	July 2012	NEHTA PCEHR	Active Adoption in progress
UK	NHS Healthspace [8,9]	2010	HL7 and others	Closed in De- cember 2012
Canada And US	Various Private Online PHRs[10], Big blue button[11], blue button+ as a public PHR in US	Since 2009	Proprietary and open source	Active Adoption in progress

- **Proposed Approach Development:** The investigation resulted into recommendation of our technology platform that can address the issues of HISO in an online PHR context.

3 Proposed Approach for an Integrated PHR

Our investigation resulted into identifying key challenges and critical needs for providing a single platform that can provide a holistic view of the patient’s PHR. We propose a platform that can not only record critical data but also provide intelligent analysis of patient’s health data to patients as well as their carers. A schematic representation of our approach is shown in figure 2.

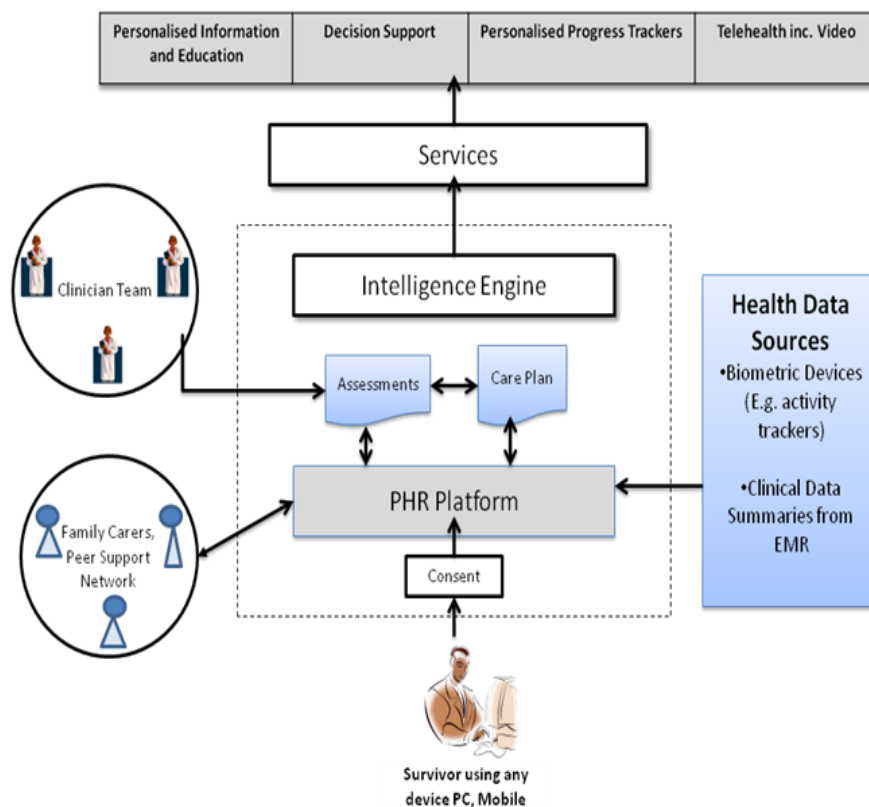


Fig. 2. Schematic Representation of Our Proposed Approach

One of the central components of our proposed platform is the intelligence engine. The intelligence engine component will execute algorithms driven by the personal health data stored in the PHR. The specific details of the algorithms will be reported

as the research progresses. Our proposed platform also provides intelligent analytics of the patient’s health data which improves patient’s own understanding of their health data. The intelligent analytics also improves monitoring of key health indicators such as weight, mood, and nutrition in a personalized visual dashboard.

Our proposed approach is in the form of a collaborative PHR platform addresses the issue of disperse health data sources. It allows the patients as well as their care providers a universal view of patient’s health data governed by the consent process. The clinicians also have the ability to view as well as add clinical notes to the patient’s PHR. The patient’s can collaborate with their clinicians as well as similar patients through the platform which can integrate with patient-driven social network. The patients can connect with their carers through video, voice as well as text communication methods enabling different communication mediums. Our platform also improves patient engagement as it enables collection of their physical health data through wearable health monitoring devices that seamlessly integrate with our platform. This integration with biometric devices improves efficiency in data recording.

3.1 Challenges

Our proposed approach has the potential to support care models that deliver better health outcomes. However, the successful execution requires understanding of the challenges involved in online PHR integration. The challenges are -

- **Adoption:** The adoption rate for mobile health applications for health monitoring and health tracking for self-management among healthy population is increasing over the last decade. [12]. However, the Australian and worldwide research shows that the adoption rate for online PHR based solution among adults with chronic disease conditions is less than expected [13, 14, 15]. Our proposed solution aims to improve the uptake rate by providing a simple and yet highly effective solution.

The challenges in adoption of online PHR mechanisms are not only applicable to the patients but clinicians and carers as well.

Table 3. Adoption Challenges by online PHR users

Online PHR User Category	Challenges
Chronic Disease Patients	IT Literacy, Technology device preferences, Ability to record and understand own data (health literacy)

Online PHR User Category	Challenges
Families	IT Literacy, Interpretation of data
Primary and Specialist Clinicians	Quality of concern Patient recorded data for treatment decisions, Time to access patient reported data in online PHR
Nursing Staff	Data Quality, Time to access patient reported data in online PHR
Allied Health clinicians (E.g. Physiotherapists)	Quality concern of Patient recorded data, Lack of instant physical interaction with men
Care coordinators	Quality concern of Patient recorded data for care plan development and implementation

- **Data Quality:** The data quality in the PHR should be endorsed by the clinicians.
- **Cost-effectiveness:** The evidence suggesting online PHR as a cost-effective tool to manage personal health information is not clearly established [16, 17, 18, and 19].
- **Health Outcomes:** There is also no clear evidence about better health outcomes due to online PHR [20].

The above challenges can be addressed through a careful implementation of the proposed platform. The implementation of the proposed platform is under progress and the evaluation of the platform will be undertaken in a randomised clinical trial settings. The proposed approach has received positive feedback from the patient as well as clinical community representatives.

4 Conclusion

This research has made an attempt to address the current issues of disperse personal health data sources. The proposed platform aims to provide a single view of the patient's PHR that can empower chronic disease patients and improve collaboration with the clinicians for self-managed care. The proposed platform will be implemented and evaluated as this research progresses in future.

Limitations

The author acknowledges that the research is a work-in-progress. The proposed platform is not evaluated with a sample data yet. The concepts proposed in this paper are specified strategic perspective. The research does not provide real-life evaluation of the proposed PHR platform as well as core design of the intelligent PHR.

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