

Research Article

Uptake and Effects of the e-Vita Personal Health Record with Self-Management Support and Coaching, for Type 2 Diabetes Patients Treated in Primary Care

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We studied the use, uptake, and effects of e-Vita, a personal health record, with self-management support and personalized asynchronous coaching, for type 2 diabetes patients treated in primary care. Patients were invited by their practice nurse to join the study aimed at testing use and effects of a personal health record. Patients were followed up for 6 months. Uptake and usage were monitored using log data. Outcomes were self-reported diabetes self-care, diabetes-related distress, and emotional wellbeing. Patients' health status was collected from their medical chart. 132 patients agreed to participate in the study of which less than half (46.1%) did not return to the personal health record after 1st login. Only 5 patients used the self-management support program within the personal health record, 3 of whom asked a coach for feedback. Low use of the personal health record was registered. No statistical significant differences on any of the outcome measures were found between baseline and 6 month follow-up. This study showed minimal impact of implementing a personal health record including self-management support in primary diabetes care. Successful adoption of web-based platforms, as ongoing patient centered care, is hard to achieve without additional strategies aimed at enhancing patient motivation and engaging professionals.

1. Introduction

Type 2 diabetes mellitus (T2DM) is a chronic metabolic disorder characterized by hyperglycemia and an increased risk of developing micro- and macrovascular complications [1, 2]. The estimated world prevalence of 387 million T2DM patients is rapidly increasing [3]. To deal with the increasing number of people with T2DM, and burden on diabetes health care, alternative treatment options are being considered. Successful treatment of diabetes builds on empowering patients in their daily self-management of the disease, with a focus on healthy eating, being active, and taking medication as

recommended [4–6]. A patient centered approach is called for to improve both medical and psychological outcomes [7–10]. Patient centered care is characterized by shared decision making between patient and professional, guided by the preferences, needs, and values of the patient [11]. One way of supporting patient centeredness is by using a personal health record (PHR) [12, 13]. In general, PHRs are web-portal environments with which patients can get an overview of their health outcomes, communicate with their care provider, and read information regarding their disease. PHRs support a patient centered approach by allowing patients to get more involved in their own disease management and decision

A pilot study to evaluate the magnitude of association of the use of electronic personal health records with patient activation and empowerment in HIV-infected veterans

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ABSTRACT

The HITECH Act signed into law in 2009 requires hospitals to provide patients with electronic access to their health information through an electronic personal health record (ePHR) in order to receive Medicare/Medicaid incentive payments. Little is known about who uses these systems or the impact these systems will have on patient outcomes in HIV care. The health care empowerment model provides rationale for the hypothesis that knowledge from an electronic personal health record can lead to greater patient empowerment resulting in improved outcomes. The objective was to determine the patient characteristics and patient activation, empowerment, satisfaction, knowledge of their CD4, Viral Loads, and antiretroviral medication, and medication adherence outcomes associated with electronic personal health record use in Veterans living with HIV at the San Francisco VA Medical Center. The participants included HIV-Infected Veterans receiving care in a low volume HIV-clinic at the San Francisco VA Medical Center, divided into two groups of users and non-users of electronic personal health records. The research was conducted using in-person surveys either online or on paper and data abstraction from medical records for current anti-retroviral therapy (ART), CD4 count, and plasma HIV-1 viral load. The measures included the Patient Activation Measure, Health Care Empowerment Inventory, ART adherence, provider satisfaction, current CD4 count, current plasma viral load, knowledge of current ART, knowledge of CD4 counts, and knowledge of viral load. In all, 40 participants were recruited. The use of electronic personal health records was associated with significantly higher levels of patient activation and levels of patient satisfaction for getting timely appointments, care, and information. ePHR was also associated with greater proportions of undetectable plasma HIV-1 viral loads, of knowledge of current CD4 count, and of knowledge of current viral load. The two groups differed by race and computer access. There was no difference in the current CD4, provider satisfaction, Health Care Empowerment Inventory score, satisfaction with provider-patient communication, satisfaction with courteous and helpful staff, knowledge of ART, or ART adherence. The use of electronic personal health records is associated with positive clinical and behavioral characteristics. The

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Personal Health Record Sharing Scheme using Blockchain Technique

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ABSTRACT

In this article we offer a new safe EHR sharing system with verified data integrity based on blockchain and cloud computing. The new system uses symmetric encryption and attributes-based encryption techniques to achieve privacy protection and fine-grained access controls in the process of personal health record sharing, aiming at the issues of data protection and loss of control rights during personal health record sharing. Compared with current systems, the new system enables patients to give private key attributes to users, which prevents many security issues.

In addition, the new scheme utilises blockchain to handle scheme keys. The original strategy saves the hash upsides of encoded individual wellbeing data in blockchain and save the related file set in a savvy agreement to additional upgrade the effectiveness of confirmation of information respectability.

Keywords:- Data security, data integrity, blockchain, cloud computing.

INTRODUCTION

It is very important to share the personal health records, as it may enhance the effectiveness of the assessment of the doctor and assist in clinical research development. As a general rule, individual wellbeing records are regularly moved to different gatherings, for example, the cloud specialist co-op to save information support costs.

But the cloud service provider may manipulate or disclose personal health data in this scenario. Sustaining the privacy of personal health data and implementing fine-grained access controls are thus key challenges in the sharing of personal health records. As a distributed architecture with decentralized and manipulative characteristics, Blockchain offers new ways of protecting the sharing system for personal health data. The most probable way of reducing security and privacy concerns is for data storage servers

such as mail servers and encrypted file servers [1].

The growth of networking informatics and cloud computing has changed people's lifestyles enormously in recent years. The development of a system for personal health data sharing related to electronic data and cloud computing allows patients to easily, effectively and correctly store, manage and exchange their health information. Since the patient may enter and maintain his or her health information, personal health records offer a consistent and objective personal medical record, accessible online and shared effortlessly.

These personal health data are important and handy resources. Individual health records are frequently externalised to other parties, such as cloud providers. In the conditions, one of the main problems is how to guarantee the safety, privacy and management of personal health data. The

MENINGKATKAN LITERASI KESEHATAN MELALUI INOVASI PERSONAL HEALTH RECORD

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Abstract: *Personal Health Record (rekam kesehatan personal/pribadi, PHR) adalah salah satu model Health Record (rekam kesehatan) yang dikelola secara individual, merupakan sumber informasi kesehatan primer yang memuat kumpulan informasi/knowledge kesehatan seseorang. Manfaat personal health record memungkinkan seseorang melakukan analisa riwayat, dan mengidentifikasi ancaman terhadap kesehatannya (individual's health profile), sehingga dapat memudahkan dalam pengambilan-pengambilan keputusan kesehatan (health decisions). semua ini akan mempengaruhi budaya literasi kesehatan dan pada akhirnya akan berdampak pada peningkatan derajat kesehatan seseorang. Peningkatan literasi kesehatan melalui inovasi personal health record baik manual maupun berbasis elektronik tentu tidak semudah yang dibayangkan, karena selain literasi kesehatan dan personal health record relative kurang dikenal oleh masyarakat luas, juga sangat dipengaruhi kondisi individual masyarakat, kultur, norma, dukungan dan keterlibatan para pemangku kepentingan, serta kebijakan dan sistem kesehatan yang diterapkan. Untuk menjamin agar peningkatan literasi kesehatan dapat terlaksana secara efektif selain diperlukan konsep, kebijakan pemerintah, program dan sasaran literasi kesehatan yang jelas dan terukur, juga harus didukung oleh para pemangku kepentingan termasuk masyarakat yang merupakan subjek penting pada literasi kesehatan.*

PENDAHULUAN

Setiap orang tentu menyadari bahwa kesehatan merupakan kebutuhan primer dalam kehidupan manusia, untuk hal ini pemerintah dalam upaya pencapaian sasaran pembangunan kesehatan telah mencanangkan berbagai kebijakan dan program, agar pelaksanaannya dapat berjalan efektif masyarakat yang merupakan subjek dari

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Intelligent Health Diagnosis Technique Exploiting Automatic Ontology Generation and Web-Based Personal Health Record Services

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This work was supported by the National Research Foundation of Korea funded by the Ministry of Education, Science, and Technology through the Basic Science Research Program under Grant NRF-2016R1D1A1A09918271.

ABSTRACT Growing interest in healthcare has promoted the use of symptom checkers, which are online health applications that provide diagnostic information on users' health. However, their diagnostic accuracy remains low because the existing symptom checkers rely on manually constructed knowledge models through labor-intensive processes or perform diagnoses based on simple pairwise relationships between diseases and symptoms without considering personal health conditions. In this paper, we propose an intelligent health diagnosis technique that exploits automatically generated ontology and Web-based personal health record services. The proposed technique first automatically generates a human disease diagnosis ontology by exploiting two well-established ontologies for diseases and symptoms: a large-scale medical bibliographic database and an open biomedical repository. When a user enters the symptom-based queries, possible diagnoses are identified by analyzing the user's queries and their health record data via semantic inferences of the automatically generated ontology. Subsequently, the ranked diagnostic results are provided to the user via ranking methods that consider the user's symptoms, personal health attributes, and multi-level diagnosis. The proposed technique also provides the user's diagnostic progress information, which can be used to track or monitor the progress of diseases by considering changes in symptoms over time. The proposed technique was evaluated through a comparison with the existing well-known symptom checkers and other related approaches. The evaluation results show that the proposed technique can feasibly help to improve diagnostic accuracy and deliver appropriate diagnostic information for healthcare action by users.

INDEX TERMS Health information retrieval, healthcare, human disease diagnosis ontology, intelligent health diagnosis, personal health record.

I. INTRODUCTION

In today's e-health era, the internet has become a common means of acquiring knowledge on personal health. However, most healthcare consumers primarily use search engines to retrieve health information based on their symptoms without precise consideration of their personal health conditions [1], [2]. Thus, they can easily confuse or misunderstand their health status by reviewing only high-ranked search results without filtering out irrelevant or unreliable health information. This can result in social issues such as *cyberchondria*, which is the unfounded escalation of concerns about common symptoms based on search results [3].

To acquire more reliable information, there has recently been a proliferation of online health applications called

symptom checkers. Symptom checkers are sophisticated health applications that attempt to more effectively provide potential diagnostic information regarding a user's symptoms. Thus, they can help users who lack proper medical knowledge to more easily understand their individual health concerns (i.e., what the symptoms could mean) and direct them to the appropriate care settings or inform them as to whether they should seek care at all [4].

However, despite the benefits and proliferation of symptom checkers, concerns have been raised in many recent studies regarding their diagnostic accuracy. These studies expressed skepticism regarding the usefulness of diagnostic results suggested by symptom checkers due to their low diagnostic accuracy [5]–[7]. For example, one study evaluated the

INTEGRATED, RELIABLE AND CLOUD-BASED PERSONAL HEALTH RECORD: A SCOPING REVIEW

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ABSTRACT

Personal Health Records (PHR) emerge as an alternative to integrate patient's health information to give a global view of patients' status. However, integration is not a trivial feature when dealing with a variety of electronic health systems from healthcare centers. Access to PHR sensitive information must comply with privacy policies defined by the patient. Architecture PHR design should be in accordance to these, and take advantage of nowadays technology. Cloud computing is a current technology that provides scalability, ubiquity, and elasticity features. This paper presents a scoping review related to PHR systems that achieve three characteristics: integrated, reliable and cloud-based. We found 101 articles that addressed those characteristics. We identified four main research topics: proposal/developed systems, PHR recommendations for development, system integration and standards, and security and privacy. Integration is tackled with HL7 CDA standard. Information reliability is based in ABE security-privacy mechanism. Cloud-based technology access is achieved via SOA.

KEYWORDS

Personal Health Record, Electronic Health Record, Integration, Privacy, Cloud Computing.

1. INTRODUCTION

Nowadays healthcare delivery model is changing from institution-centered to a more patient-centered model [1]. The past fragmented patient health information [2] is changing to patient-centered that enables patients to store and access to their health information ubiquitously in a personal health record (PHR) [1]. PHR is defined as a set of computer-based tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it [3,4]. There is not agreement or standard on what information a PHR should store [5]. Some shared information supported by PHRs are problem lists, procedures, major illnesses, provider lists, allergy data, home-monitored data, family history, social history and lifestyle, immunizations, medications and laboratory tests [6].

When patients assist to different healthcare centers, their health information remains distributed across the healthcare centers visited. An integrated health record will provide a global and complete view of a patient health state that can lead to a better decision support by physicians during consultation, or even in emergency situations [7].

Cloud computing is a model for enabling ubiquitous and on-demand access to a shared pool of services [8]. Ubiquitous access to information not only benefits to patients but also, to healthcare professionals. Due to the high level of mobility physicians experience, ubiquitous access to relevant and timely patient data would help to make critical care decisions [9], even save lives

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Exchanging personal health data with electronic health records: A standardized information model for patient generated health data and observations of daily living

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RESEARCH ARTICLE

Open Access



Client perceptions of the mental health engagement network: a qualitative analysis of an electronic personal health record

Cheryl Forchuk^{1,2*}, Jeffrey P. Reiss^{1,3,4}, Tony O'Regan¹, Paige Ethridge¹, Lorie Donelle^{1,2,5} and Abraham Rudnick^{1,6,7}**Abstract**

Background: Information technologies such as websites, mobile phone applications, and virtual reality programs have been shown to deliver innovative and effective treatments for mental illness. Much of the research studying electronic mental health interventions focuses on symptom reduction; however, to facilitate the implementation of electronic interventions in usual mental health care, it is also important to investigate the perceptions of clients who will be using the technologies. To this end, a qualitative analysis of focus group discussions regarding the Mental Health Engagement Network, a web-based personal health record and smartphone intervention, is presented here.

Methods: Individuals living in the community with a mood or psychotic disorder ($n = 394$) were provided with a smartphone and access to an electronic personal health record, the Lawson SMART Record, for 12 to 18 months to manage their mental health. This study employed a delayed-implementation design and obtained both quantitative and qualitative data through individual interviews and focus group sessions. Participants had the opportunity to participate in voluntary focus group sessions at three points throughout the study to discuss their perceptions of the technologies. Qualitative data from 95 focus group participants were analysed using a thematic analysis.

Results: Four overarching themes emerged from focus group discussions: 1) Versatile functionality of the Lawson SMART Record and smartphone facilitated use; 2) Aspects of the technologies as barriers to use; 3) Use of the Mental Health Engagement Network technologies resulted in perceived positive outcomes; 4) Future enhancement of the Lawson SMART Record and intervention is recommended.

Discussion: These qualitative data provide a valuable contribution to the understanding of how smart technologies can be integrated into usual mental health care. Smartphones are extremely portable and commonplace in society. Therefore, clients can use these devices to manage and track mental health issues in any place at almost any time without feeling stigmatized.

Conclusions: Assessing clients' perspectives regarding the use of smart technologies in mental health care provides an invaluable addition to the current literature. Qualitative findings support the feasibility of implementing a smartphone and electronic personal health record intervention with individuals who are living in the community and experiencing a mental illness, and provide considerations for future development and implementation.

Keywords: Qualitative analysis, Personal health record, Smartphones, Tablets, Mood disorders, Psychotic disorders, Mental illness

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Adaptations of Personal Health Record Platform for Medical Research on Chronic Diseases

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Abstract

The article reports on experiences in e-Health platforms and services for supporting medical research into the causes and relationships among physiological parameters and health problems concerning different chronic diseases. The Personal Health Record (PHR) is a way of standardizing electronic management of medical information between patients and their physicians, including medical bodies collaborating in providing integrated medical care services. We describe roles and aims behind electronic health records, follow with applicable legal and standardizations frameworks and relevant European activities, leading to the presentation of common commercial and open-source implementations of such systems, concluding with the indication of specific adaptations enabling a use of stored personal health data for scientific research into causes and evaluation of chronic illnesses. We describe ethical and privacy concerns that are relevant to using and exchanging electronic health information.

Keywords: Personal Health Records; Chronic Diseases; Anonymity, Privacy.

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1. Introduction and motivation

Epilepsy, the propensity for recurrent, unprovoked epileptic seizures, is the most common serious neurological disorder, affecting over 50 million people worldwide. Epileptic seizures manifest with a wide variety of motor, cognitive, affective, and autonomic symptoms and signs and associated changes in the electrical activities of the brain electroencephalography (EEG), the heart electrocardiography (ECG), muscle electromyography (EMG), galvanic skin response (GSR), as well as changes in other important measurable biological parameters, such as respiration and blood pressure.

Their recognition and full understanding is the basis for their optimal management and treatment, but presently is unsatisfactory in many respects. Epileptic seizures occur unpredictably and typically outside hospital and are often

misdiagnosed as other episodic disturbances such as syncope, psychogenic and sleep disorders, with which they may co-exist, blurring the clarity of information presented to clinicians; on the other hand, costs of hospital evaluation are substantial, frequently without the desirable results, due to suboptimal monitoring capabilities.

Reliable diagnosis requires state of the art monitoring and communication technologies providing real-time, accurate and continuous multi-parametric physiological measurements of the brain and the body, suited to the patient's medical condition and normal environment and facing issues of patient and data security, integrity and privacy. The purpose of the FP7 projects "Advanced multi-parametric monitoring and analysis for diagnosis and optimal management of epilepsy and related brain disorders" (ARMOR) and StrokeBack is to manage and analyse large number of already acquired and new multimodal and advanced medical data from brain and

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A PRIVACY MANAGEMENT ARCHITECTURE FOR PATIENT-CONTROLLED PERSONAL HEALTH RECORD SYSTEM

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Abstract

Patient-controlled personal health record systems can help make health care safer, cheaper, and more convenient by facilitating patients to 1) grant any care provider access to their complete personal health records anytime from anywhere, 2) avoid repeated tests and 3) control their privacy transparently. In this paper, we present the architecture of our Privacy-aware Patient-controlled Personal Health Record (P³HR) system through which a patient can view her integrated health history, and share her health information transparently with others (e.g., healthcare providers). Access to the health information of a particular patient is completely controlled by that patient. We also carry out intuitive security and privacy analysis of the P³HR system architecture considering different types of security attacks. Finally, we describe a prototype implementation of the P³HR system that we developed reflecting the special view of Japanese society. The most important advantage of P³HR system over other existing systems is that most likely P³HR system provides complete privacy protection without losing data accuracy. Unlike traditional partially anonymous health records (e.g., using *k*-anonymity or *l*-diversity), the health records in P³HR are closer to complete anonymity, and yet preserve data accuracy. Our approach makes it very unlikely that patients could be identified by an attacker from their anonymous health records in the P³HR system.

Keywords: Health privacy, Personal health record, Healthcare service, Data sharing, Anonymization, Pseudonymization

1. Introduction

Electronic form of personal health records is both a problem and an opportunity. It opens new kind of threats to information leakage because electronic data are easy to

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