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Personal Health Record Interoperability

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ABSTRACT

Personal Health Records (PHRs) is a software application that allows patients to review their medical information remotely through a secure domain. There are four forms of PHRs which are; 1) self-contained Electronic Health Record (EHR), 2) self-contained EHR, 3) PHRs integrated care EHR controlled by health provider and partially by the patient/consumer, 4) PHRs integrated care EHR controlled by the patient/consumer. The methodology for this study was a literature review and semi-structure interview with a specialist in health information technology. Electronic databases used included PubMed, Academic Search Premier, EBSCOhost, LexisNexis and Google Scholar. A total of 38 sources were referenced. Currently, most PHRs are not integrated with other systems. Interoperability exists and has continued to grow steadily, but few individuals perceive the potential benefits of a PHR system including cost and quality of care. Regardless, the review has shown increased PHR use as well as MU adoption. Based on previous literature PHRs, although there has been imported accesses for patient portal as well as major saving for health care providers, the success rate of adoption is still low. The information gathered through semi-structure interview identified PHRs lack of interoperability in the nation and interoperability will not be achieved until the implementation of MU stage 3 by 2019. PHR interoperability has been presented to have significant ability to transform the way individuals have been able to access their PHRs and allowed for increased patient autonomy in the US.

INTRODUCTION

Personal Health Records (PHRs) are applications that have enabled patients to access personal health information remotely, in a secured domain and permit them to engage in their own health management (Yamin, et al, 2011). The PHR has been considered in at least four different forms: 1) self-contained Electronic Health Record (EHR) maintained and controlled by the patient/consumer, 2) self-contained EHR maintained by a third party such as a web service provider, 3) a component of an integrated care EHR maintained by a health provider and controlled at least partially by the patient/consumer, 4) component of an integrated care EHR but maintained and controlled by the patient/consumer (Maloney & Wright, 2010).

The PHRs has two main models: the stand-alone and the tethered (HealthIT.gov, 2016). The stand-alone models main characteristics have been that information has been filled by a patient and data exchange between external sources, such as other providers and laboratory, and the patient had the autonomy to add and share the information with providers (HealthIT.gov, 2016). A tethered, or connected, PHR has been linked to a specific health care organization's EHR system or to a health plan's information system (HealthIT.gov, 2016).

The Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH) core purposes focused on quality, safety, and efficiency of healthcare information exchange through support of technical providers and staff training to ensure proper operations (HealthIT, 2014). The major goal of HITECH has been promoted to providers and healthcare institution to adopt the EHR through Meaningful Use (MU) (CMS, 2010b). The HITECH act has offered reimbursement incentives through Medicare and Medicaid to enhance this adoption and in 2012, only 72% of physicians who had implemented the basic EHR system met the requirements of the MU stage 1 (Hsiao & Hing, 2012).

The Centers for Medicare and Medicaid Services (CMS), took the lead to create the principals of patient portals under MU, which has been an incentive program. Meaningful use created a specific characteristic of patient

portal functions which included a summary of outpatient visits, exchange information with a provider in a safe domain, patient's ability to download and transfer health data, provided educational material for patient and alert system for preventative services and order medication (Irizarry, Dabbs & Curran, 2015). Additionally, MU has evolved in three stages in a five-year timeframe, starting 2011-2012 for stage 1, which have been the year of capturing and sharing the data. The criterion for stage 1 was to automate the health information data collection to improve the coordination process among providers and engage the patient and patient's family in the healthcare process (HealthIT, 2013). In 2014, performance measures data showed over 50% of patients who visited Eligible Professionals (EP) were able to access health information within 4 days and over 50% of discharged patients found health information within 36 hours of discharge (IHS, 2014).

MU stage 2 was scheduled in 2014 with the focus on clinical procedure advancements which included Health Information Exchange (HIE), expanded e-prescription requirements, and increased exchange information between providers and patients (HealthIT, 2013). In 2013, only 10.4% of hospitals had provided online access for the patient to view, download and transmit information. Among those functions, the most used one was the view of health information by 39.3% hospital adoption (Adler-Milstein, *et. al.*, 2014).

In 2017, the requirement of stage 3 has been the EHRs incentive program to promote interoperability. In addition, CMS has selected specific metrics to evaluate the performance of providers based on quality and Health Information Technology (O'Neill, 2015). The providers and health institution that have been participating in MU stage 3 had the option of 90-days reporting period per CMS. However, reporting for a full year started by 2018 for providers unless it was the first year of joining the Medicaid incentive program (HIMSS, 2018).

The interoperability has consisted of three-level known as foundational, structural and semantic (HIMSS, 2013). The foundational level is where data is exchanged between different systems within a secured domain. At the structural level, information of a similar format is exchanged without any alterations. Lastly, the semantic level has been the highest level of interoperability that is fully structured with the ability to exchange data from more than one system and grant data interpretation (HIMSS, 2013).

The purpose of this research was to evaluate the PHRs to determine if the implementations of PHRs had assisted in achieving interoperability as well as the benefits and challenges of adoption focusing on implementation of MU.

METHODOLOGY

The primary hypothesis of this study was the implementation and process involved in using PHRs for health information exchange has increased patient autonomy in the US.

The methodology for this study was a literature review and semi-structure interview with a specialist in health information technology. The interview was approved through IRB and was conducted by the authors and recorded. Majority of the information obtained during the interview was used in the result and discussion section of the paper. The research followed a systematic search approach conducted in stages. The research approach and conceptual framework is illustrated in Figure 1 and followed the framework implemented by Yao, Chu, & Li (2010). The current study's use of this conceptual framework is appropriate because its original application was to explore how PHR achieved interoperability of information exchange. The framework elucidates the issues of transition and view of information between providers and patients, which suffer from lack of interoperability.

The suggested solution is the adoption of PHRs, a system that integrates information from EHRs. There has been significant need for health information integration which will assist to recognize benefits and challenges that exist. The process of this study consisted of a development method which defines the problem, determines the needs, and finally implements the solution.

The search was conducted by utilizing the online databases such as EBSCO host, PubMed, LexisNexis, Academic Search Premier, and Google Scholar. Keywords searched were "PHR" and "Meaningful Use" and "Interoperability" OR "HIE" OR "Autonomy" OR "Benefit" OR "Adoption" and "U.S.". This literature review yielded 38 articles which were significant resources for this research. To ensure the utilization of current material,

all sources referenced were articles published between 2008 and 2018 in English. Further, a semi-structured, face-to-face interview with an expert in information systems and well versed in the utilization of PHRs added to the data collected.

The results were categorized in the following research subheadings: *Implementation of PHR Interoperability, HIEs and Patient Autonomy, Benefits of Adoption, PHR Adoption Rate, Meaningful Use and PHRs, and PHR Challenges.*

RESULTS

Implementation of PHR Interoperability

Adoption of national standards has been a necessity as it is crucial for interoperability, transportability, and security, features that would likely be mandated by legislation (Jones, Selden, Shipman & Plaut, 2010). Interoperability has referred to the standards that have made it possible for diverse EHR systems to work compatibly (AHIMA Work Group, 2013). To drive interoperability, the adoption of standards has been primarily driven by regulation (AHIMA Work Group, 2013).

The Center for Information Technology Leadership (CITL) reported that PHR could result in an annual net value of \$19 billion, for direct cost savings to healthcare providers and payers, based on a 10-year implementation period and an 80% adoption rate by the US population (Jones, *et. al.*, 2010). Another study integrated a 10-year roll-out period into their analysis and found that all PHRs demonstrated initial net negative value, as shown in Figure 2 (Kaelber & Pan, 2008). Figure 3 has shown the steady state net value and the minimum number of patients per PHR installation to obtain a steady state net positive value (Kaelber & Pan, 2008). Figure 3 also indicated that interoperable PHRs have had the earliest breakeven point. According to the expert interview, the cost of PHR implementation has varied between \$15,000, for smaller systems, and \$100,000, for the larger systems.

Another factor that has driven interoperability challenges have included the fact that the different medical device and health IT manufacturers each had their own proprietary interface technology, so there has been no way to connect the disparate part. Also, there has been no overarching architecture for creating interoperability (CMI, 2016). Architecture has been the key for identifying standards and facilitated sessions to achieve the requisite degree of interoperability (TOGAF, 2015).

HIEs and Patient Autonomy in PHRs

According to one survey reviewed, amongst 117 respondents, the majority supported physicians' use of HIE (83%) or expressed interest in potentially using PHRs (76%) (Patel, Dhopeswarkar, Edwards, Barrón, Sparenborg, & Kaushal, 2010). Consumers' comfort sending personal information electronically over the Internet and their perceptions regarding the potential benefits of HIE were independently associated with their support for HIE (Patel, *et. al.*, 2010). Individuals with higher levels of ability to manage their own health (self-determination) are more likely to adopt PHR systems since they have more positive perceptions regarding the use of such systems (Assadi & Hassanein, 2017). Further, such self-determination is fueled by autonomy support from consumers' physicians as well as the consumers' personality trait of autonomy orientation (Assadi & Hassanein, 2017).

Fifty-six percent of PHR users stated they knew more about their own health because they had used these tools, 40% said they had asked a question they would not otherwise ask, 38% had felt more connected to their physicians, and 32% had taken measures to improve their health (CHCF, 2010). However, in three other studies, communication between providers and patients were examined and no improvements were reported in patient satisfaction with communication or with information provided to patients (Archer, *et. al.*, 2011).

Benefits of PHR Adoption in the US

According to Dimick (2008), The CITL proposed that based on a 10-year roll-out of infrastructure, the interoperable PHR could save \$19 billion annually in healthcare costs. Based on another study reviewed, the annual benefits of the PHRs functions ranged from \$9 million for the entire medication lists to \$7.9 billion for complete test results (Kaelber & Pan, 2008). Overall, the projected annual savings for interoperable PHRs has been \$21 billion (Dimick, 2008).

Furthermore, most participants wanted to view immunization records (89%), a list of providers visited (88%), lab test results (87%), history of prior medical visits and surgeries (87%), and medication history information (87%); another interest had been the possibility to access family member's healthcare information (71%) (Pushpangadan & Seckman, 2015). E-visits, replacing face-to-face visits, have had the potential to address a wide range of chronic and acute (non-emergent) healthcare issues, and therefore represent a large area of potential PHR benefit (Kaelber & Pan, 2008).

PHR Adoption Rate in the US

Approximately 8 million individuals had been using the two basic PHR functionalities, which included storing data on the Internet and communicating electronically with a clinical provider, in 2008 (Joshi, Thorpe, & Waldron, 2019). In 2013, PHR users exceeded 31 million (Joshi, *et. al.*, 2019). Despite the increased adoption rates, studies reported low PHR usage among providers and routine, monthly use among patients had been generally well below 10% of users who had access to a PHR (Kaelber, Jha, Johnston, Middleton, & Bates, 2008).

The PHRs used by the low-income elderly have been limited due to poor technical skills and low physical/cognitive abilities (Kim & Kim, 2010). The younger and affluent populations have used the web-based PHR system, which is much easier and efficiently compared to the older and low-income group (Kim & Kim, 2010). The best-performing model has been estimated to show PHR adoption exceeding 75% by 2020 (Jones, *et. al.*, 2010).

Meaningful Use and PHRs

According to Bates, *et. al.*, (2013), in May 2012, a total of 62,226 EPs had attested to MU under the Medicare program. To qualify for Stage 1 MU incentive payments as of 2012, EPs must have had completed 15 core objectives, 5 objectives out of 10 from menu set and 6 total clinical quality measures (CMS, 2010). Two of the new core criteria addressed patient engagement: providing patients with online access to their health information and providing secure messaging between patients and providers (Rowley, 2012).

Meaningful use required 5% of patients to use patient engagement tools for Stage 2 MU and 10% for Stage 3 MU (Ford, Hesse, & Huerta, 2016). Stage 3 MU recommendations, originally scheduled for implementation in 2017 but under policy reconsideration in 2016, stated that patients should be able to communicate electronically using secure messaging, access patient education materials on the Internet, generate health data into their providers' EHRs, and view, download, and transmit their provider-managed EHRs (Ford, *et. al.*, 2016). According to these authors, the PHR products available as of 2014 had been likely to meet and exceed MU stage 3 targets before 2020 without any incentive.

Stage 2 of MU required that at least 5% of a practice's patients actually signed in and used their PHR at least once during the measured year (Rowley, 2014). Approximately 58,000 EPs had attested to meaningful use of a certified EHR in 2011 through the Medicare EHR Incentive program (ONCHIT, 2014). Of the 16% of providers that skipped their second year (2012), 43% returned to the program in 2013. Nine percent of the initial cohort skipped both 2012 and 2013 (ONCHIT, 2014).

PHR Challenges

In 2010, a national survey by the CHCF found that 75% of adults without PHRs had been concerned about the privacy of their health information if it were in a PHR (Kim & Nahm, 2012). Furthermore, a 2007 national survey commissioned by the Institute of Medicine found that only one percent of respondents had been comfortable having their health and medical information freely used by researchers without their consent (Detmer, *et. al.*, 2008). Another study had stated the omission of an assurance of security in a privacy statement may cause users to think that their personal data were susceptible to potential abuse, and this could discourage them from supplying the personal data needed to complete an online transaction (Señor, Fernández-Alemán, & Toval, 2012).

Additionally, some patient populations had been at a disadvantage when it comes to broadband access; this disparity had been referred to as the "digital divide" (Pirtle & Chandra, 2011). Non-Hispanic black population less likely compared to white people, 56% vs. 67% respectively have had used the internet or have had a home PC (Pirtle & Chandra, 2011). Eighty-seven percent of households with an income greater than \$75,000 had broadband internet access while fewer than 47% of households with an income less than \$30,000 had (Pirtle & Chandra, 2011).

Overall, challenges of PHRs had often been linked to little consumer involvement during planning, design, and implementation (Archer, Fevrier-Thomas, Lokker, Mckibbon, & Straus, 2011). Lack of trust in the provider has been an additional barrier, as have been poor computer and internet skills, fear of technology, inadequate access, low health literacy, and limited physical and cognitive abilities (Archer, *et. al.*, 2011).

DISCUSSION

The purpose of this research has been to examine the implementation and process involved in PHR interoperability and MU and whether it has improved patient autonomy. The literature review supported increased access to PHRs for consumers, by allowing e-visits to replace face-to-face visits for example, as well as significant savings for providers, but with the little research that has been done on PHR interoperability, there has not been much evidence of a success rate of adoption.

Perhaps the most significant information received was from the semi-structured interview with an expert in the field. This expert reinforced the lack of interoperability in the nation and also pointed out the potential drawbacks identified in the research. He, in fact, identified PHR interoperability as the wave of the future in healthcare. Meaningful use adoption had shown to be fruitful; however, interoperability will not be achievable until the implementation of Stage 3, taking place in 2019.

Based on the interviewee interpretation the percentage of PHR adoption nationwide has been 15% and this value has been minimal. This is because the PHR integration leaders in the country have included the Mayo Clinic, Cleveland Clinic and John Hopkins; who have made patient integration a part of their culture. However, for most institutions such as Cabell Huntington Hospital in West Virginia, they have not been there yet. The implementations of MU Stage 3, MIPS and MACRA in 2019 will allow PHR interoperability to thrive throughout the upcoming years. Additional research has been needed on the use of PHRs by consumer, family and caregivers; cost-effectiveness of PHRs use for consumers; and use of PHRs by consumers of different ages, cultural backgrounds, and health and computer literacy levels (Kim & Nahm, 2012).

The limitation of the research included the limited access to data as the paper was written based on studies from limited number of database and research papers as well as the search process by which the data was obtained. Also, there is a possibility of bias as the papers referred to have been evaluated to determine information that is relevant to the study being conducted.

CONCLUSION

This literature review has indicated that the adoption and implementation of PHR interoperability, as well as the effects it has had on patient autonomy, has been steady paced but has seen little value through limited amounts of research. However, the review has also shown increased PHR use, MU adoption, and indicated that the future is bright for PHR interoperability; thus, supporting the primary hypothesis introduced.

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