An Overview Of Consumer Perceptions And Acceptance As Well As Barriers And Potential Of Electronic Personal Health Records

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ABSTRACT

Healthcare industry leaders, government agencies and the general public are beginning to see the value that Electronic Health Records (EHR) systems bring through increased quality, reduced medical error rates, and improved care coordination. One subset of the EHR, known as the electronic personal health record (PHR), is gaining in popularity. Before PHRs will be widely adopted, many barriers to their use must be overcome. These include the costs to the developer, host, and patient. Patient access to electronic resources is a concern. Interoperability is another problem. It is not practical for physicians to convert different data formats so that different PHRs may be adopted. Finally, privacy and security concerns also impact EHR adoption. Patients want assurance that their data is secure and not used for marketing purposes. Despite these barriers, there is high consumer interest in PHR products. In future, it is expected that PHR programs will be certified, security and privacy will be enforced by legislation, and standards for interoperability will be developed. PHR will also incorporate additional decision support aids and may become part of a social network that promotes peer support for positive behavior change. This paper will provide an overview of all these issues pertaining to PHR.

Keywords: Electronic Health Records

INTRODUCTION

The United States healthcare industry is frequently criticized for its high costs, high medical error rates, inconsistent quality and poor care coordination systems. Electronic health records (EHR) are frequently publicized by government and healthcare industry leaders as potential remedies for these challenges. They bring highly touted benefits including improved documentation, increased information access for patients and providers along with the potential to reduce healthcare costs. They can improve care coordination because all providers, from nurses to physicians to pharmacists, can access the electronic record in real time. Electronic health records and the electronic personal health record promote patient involvement and help empower patients to be better consumers. Despite these benefits, EHRs still face many obstacles. Development and implementation costs, physician acceptance, and patient involvement are just a few of the concerns. Some EHR systems are being now being developed to address the last concern, patient involvement. The main subject of this research is to study industry trends in the development of electronic personal health records, explore barriers to their use, and identify future opportunities for their development.

One subset of the EHR, known as the electronic personal health record (PHR), is gaining in popularity. The PHR is intended to be managed by the patient, be portable in that it can be accessed from most personal computers (PC) in almost any location, and can be "read" by any provider who has capabilities for handling electronic medical information. The ultimate goal of a PHR is to give the patient a sense of ownership in the care delivery process and represents a transition from physician-centered to interactive patient-centric care

documentation (Wynia and Dunn 2010). However, there are many technical and ethical challenges to be overcome. Currently, there are few standards governing the use, format, data coding, or access of PHR's. In addition, there was little national coordination in developing the existing standards to ensure compatibility or interoperability (Hammond 2005). Numerous privacy and security concerns exist, with both EHRs and PHRs. The possibility of health records access from a mobile device raises a host of other concerns because advertisers, cellular service providers and other third parties could link to a person's phone GPS and discover sensitive health information based on their movement (Conn 2010). Over the coming pages, these topics will be discussed in greater detail. First, general public attitudes towards the PHR will be discussed. This includes barriers to their use, as well as the current status of the EHR & PHR. Second, provider concerns with PHRs will be outlined and explained.

TYPES OF PERSONAL HEATH RECORDS

Many differentiators exist between the current PHR products currently available. PHR offerings vary in the sources of data, people served, degree of interconnection and others. Data can be entered directly by the patient, it can be derived from professional sources, or it can come from a monitoring device. They vary by the population served. Some PHR software targets patients who are managing a specific chronic condition and are tailored for treatment of a specific disease state. Others are available for the general public to use. PHRs also vary by the level of integration (Lemieux, Nicholson, Lansky, & Shirky 2006). It is this third dimension, level of integration, that is used the most frequently and is most relevant. For the purposes of this study, three main definitions will be used:

- Standalone PHR. In the Standalone model, the patient enters their own data into the electronic record. This model includes relatively simple records such as word processing or spreadsheets that the consumer creates himself or herself and ranges up to internet-accessible programs such as Google Health. The standalone PHR is sometimes referred to as the independent PHR because it does not readily connect to outside data sources (Lemieux, Nicholson, Lansky, & Shirky 2006).
- Tethered PHR. The tethered PHR, also referred to as the patient portal, is tied into a provider's network. The patient can log into a tethered PHR and access data that is uploaded by a provider. Patients can view prescription information, lab results, and medical images. Some tethered PHRs even allow patients to set up appointment reminders, communicate electronically with providers, renew prescriptions online, and track billing or claims information. Unlike the standalone model, where the patient controls what data is in the record, the tethered PHR is populated by health professions. Another drawback to the tethered PHR is that it is linked to a limited network of providers, for example a hospital system or physician practice network (Jones, Shipman, Plaut and Selden 2010).
- Ideal PHR. The ideal PHR is a record of health related information that conforms to national interoperability standards, can be drawn from multiple sources, and still be managed, shared and controlled by the individual (Kahn, Aulakh, and Bosworth 2009). Currently few PHR products meet this definition. Tethered PHR, if they allow consumers to manage information and connect to an interoperable health information exchange, may meet this definition (Lemieux, Nicholson, Lansky, & Shirky 2006).

CONSUMER AND PROVIDER PREFERENCES

Healthcare consumers would like to use electronic health records to support their care. U.S. consumers already use the Internet to support a variety of activities from banking to shopping. They generally want online access to tools to help manage their health information as well (Kahn, Aulakh, and Bosworth 2009). Many individuals would like to integrate the billing and claims information from their insurers into the PHR, although some still have fears about how an insurer might use data obtained in a PHR (Grossman, Zeyas-Caban, and Kemper 2009). Secure messaging, set up through a PHR or a tethered EHR portal, is a feature desired by many patients. PHR applications that can link to a provider may facilitate other communication as well. The ability to schedule appointments and renew prescriptions offer value to many consumers, especially those who have or care for someone with a chronic illness (Wynia and Dunn 2010). Most consumers want to control who can access data in the PHR, and want the ability to hide sensitive data from either physicians, insurers, or employers (Grossman, Zeyas-Caban, and Kemper 2009). Consumers demand easy to understand privacy policies, and want assurances that their data is secure with any organization that they chose to host a PHR with. Without strong privacy protections, both providers and patients are unlikely to contribute information to a PHR (Wynia and Dunn 2010).

Healthcare providers look for several desired features to reduce their reluctance to accept PHR data from their patients. Interoperability is a key. Physicians want to quickly and easily assimilate data from a PHR into their own records system. The records also need to be complete, in that they incorporate data from other healthcare providers and thus offer a more complete history for their patients. Physicians are most concerned with obtaining data on hospitalizations, surgical procedures, lab results and a complete medication history (Grossman, Zeyas-Caban, and Kemper 2009). Ease of use is another desire in any health record system. Physicians commonly complain about EHRs because they are not very user-friendly (Conn 2011). Both physicians and patients alike are interested in mobile applications. Smart phones such as the iPhone, Blackberry, and the devices running Android operating system are becoming more prevalent and PHR/EHR access is desired on these devices (Conn 2011 and Jones, Shipman, Plaut and Selden 2010).

ACCEPTANCE OF PERSONAL HEALTH RECORDS

Electronic health records, and especially electronic personal health records, are advertised as a beneficial product that will transform healthcare and have few drawbacks once they are fully implemented. Further study indicates that this may not be the case. Many physicians and other healthcare providers are skeptical. So are some patient and consumer groups. However, according to one study, there are two groups uniformly in favor of Personal Health Records: policy makers and payers in the health system (Wynia and Dunn 2010). One aim of this study is to evaluate the interest of potential future PHR users. It seeks to understand whether people want to use electronic personal health records. For patients who do not want a PHR, the author will explore what barriers prevent them from utilizing a PHR product. Second, it seeks to better understand the preferences that various healthcare stakeholders have regarding what model of PHR to use and how they will use it.

CURRENT STATUS OF ELECTRONIC RECORDS

At present, only 11.9% of healthcare providers are using an EHR system (Jha, DesRoches, Kralovec & Joshi 2010). However, there are incentives to increase their adoption. Recent studies by the Agency for Healthcare Research and Quality, and the journal Modern Healthcare indicate that providers can realize positive returns on investment if they implement an EHR (ARHQ 2006, & Conn 2011). In addition, the American Reinvestment and Recovery Act of 2009 in conjunction with the HITECH Act provides billions of dollars to spur the investment into electronic records. In the future, healthcare providers will be required to utilize an EHR that meets a number of "meaningful use" criteria in order to receive maximum reimbursements from CMS (Center for Medicare and Medicaid Services 2009). Many of these meaningful use criteria support the development of records electronically accessible by the patient. For instance the need to keep a longitudinal or, life-long, medication list lends to the integration of a PHR with the hospital's EHR. Another meaningful use core criteria dictates that eligible providers will make electronic versions of a patient's record available upon request. The electronic data could then be exported to the patient's PHR.

Unfortunately, electronic personal health record use is even more limited. In 2005, it was estimated that less than 1% of the population used some form of PHR (Tang 2005). By 2008, this had increased to 2.7% or six million adults in the United States using a PHR (Westin 2010). In contrast, over 87% of the population believe that electronic records could improve care quality and efficiency by allowing them to check for errors in their own medical records or track health related expenses respectively (Westin 2010). Nearly half of the U.S. adult population are interested in using one when asked about PHR systems. Some are even state that they are willing to pay for PHR applications, either directly or through increased insurance premiums or payments to providers (Vishwanath 2009).

BARRIERS TO PHR UTILIZATION

Privacy and security are commonly voiced concerns regarding PHRs, but very few policy makers or health experts have explored other potential adverse effects that they may have (Wynia and Dunn 2010). One of the first barriers to the use of any electronic record system is access to a computer. However, having a computer is not enough. In order to use most types of personal health record, be it a standalone product such as Google Health® or Microsoft Healthvault®, or a tethered product sponsored by a healthcare system or insurer, the patient needs to have a reliable broadband internet connection. Any PHR, unless typed in a standalone word processor and saved in some

form of hard media such as a CD or USB drive, requires an internet connection to access it. There are some patient populations who are at a disadvantage when it comes to broadband access, this disparity is sometimes referred to as the "digital divide" (Detmer, Bloomrosen, Raymond and Tang 2008). People of African descent are less likely compared to white people, 56% vs. 67%, to use the internet or have a home PC. Also not surprising, people of lower socioeconomic status are less likely to have reliable access to computers. 87% of households with an income greater than $75,000 have broadband internet access, while fewer than 47% of households with an income less than $30,000 do (Pew 2010). As the recession continues, low income households are expected to discontinue internet services because of costs. They are less likely to invest in a PC if they do not already have one. Geography is a factor as well. Citizens living in rural areas are less likely to have internet access. The reasons vary from lack of interest in the internet, to lack of infrastructure to support internet use. In addition, rural health providers are less likely to invest in health information technology. In turn, they are unlikely to promote PHR use among their patients. Reluctance of rural providers to implement EHR & tethered PHR is driven by physician resistance, cost, and a lack of trained IT personnel to support the investment (Harvard School of Public Health 2009). In addition to the digital divide, health illiteracy may be a bigger obstacle to more widespread PHR use. It is estimated that 50% of U.S. adults do not understand information that would enable them to make better health choices. (Institute of Medicine, Health Literacy: A Prescription to End Confusion).

Cost is another barrier to PHR adoption commonly cited in research. Even for so-called free PHR platforms, such as the ones sponsored by Google or Microsoft, consumers face an opportunity cost in the time it takes to set up and fill in the information. There is also a discrepancy between who bears the financial cost of setting up a PHR and to whom the benefits accrue. Most tethered PHRs, which are derived from a hospital system's EHR, are financed by the hospital or provider. The financial benefits, however, are directed to the patients and the payers (Vishwanath 2009 and Shekelle, Morton and Keeler 2006). Physicians derive no direct financial benefits from their patients adopting a PHR (Vishwanath 2009). Many stakeholders are unwilling to pay for a PHR; however, some patients may be willing to either directly or through slightly increased insurance premiums. Patients report a willingness to pay depending on how the benefits are framed. Similar benefits framing, in conjunction with education and reinforcement, may increase physician willingness to bear some of the costs associated with a PHR (Vishwanath 2009).

Many providers, especially physicians, question the accuracy and reliability of PHR data. The idea behind a PHR, especially an ideal PHR or a standalone PHR, is that the patient controls both the data in the record and who can view it. Physicians are concerned that patients will use their PHR to intentionally hide data from them. Incomplete histories can adversely affect diagnosis quality. Some physicians even worry that the data in a PHR may expose them to additional liability or be used in a malpractice suit. (Wynia and Dunn 2010). The data is especially suspect when it is not tethered. Past diagnosis, treatments, or prescription medications may be subject to typos, typing or data entry errors, because the patient does not fully understand their health data.

LACK OF INTEROPERABILITY

Health information, both financial and clinical, is fragmented and does not flow easily between providers. Most providers are still using paper-based charting, and even the healthcare organizations that do use EHRs tend to have proprietary systems that do not easily import or export data. For consumers, this means that data has to be entered manually into a standalone PHR which is a time consuming and error prone task. The lack of automation makes is difficult to maintain a PHR (Kahn, Aulakh, and Bosworth 2009). The proprietary nature of current PHRs drives physician reluctance to use them. Physicians do not want their office staff to face the workload of converting PHRs from multiple vendors, each with a different format and containing potentially unverifiable information into the EHR that their practice uses (Wynia and Dunn 2010). Before PHRs can become interoperable, in other words compatible, with the applications that providers are using standards must be developed. In the United States, there is no clear plan for implementing health standards. Many different organizations are working to develop standards, but there is competition between these standard development organizations. For instance, the simple task of adding electronic prescribing to an EHR involves integrating data generated by conflicting standards. The prescription would be coded using National Council for Prescription Drug Programs, but much of the other data in an electronic record would be coded by Health Level 7 (HL7) standards. Additional standards are needed to export data from the provider's EHR to a PHR (Hammond 2005).

Privacy and security concerns round out the top barriers to PHR adoption. Many PHRs are not covered by the Health Information Portability and Accountability Act (HIPAA) which governs health information protection for healthcare providers. Some software developers and data hosts don't fit the definitions of covered entities under HIPAA (Kahn, Aulakh, and Bosworth 2009). Without strong privacy controls in place, physicians and providers alike are unwilling to contribute information to certain PHR providers unless they are tethered to a covered entity's EHR system (Wynia and Dunn 2010). The Markle Foundation survey also identified privacy concerns as a major barrier to public use of PHR applications. early 57% of the U.S. adult population are not interested in using a PHR; privacy concerns are the most frequently cited reasons why (Westin 2010). PHR designers must balance conflicting needs: they must respect the patient's desires to control their health information while respecting the business case for using data from PHRs for other benefits, most notably for marketing health services (Wynia and Dunn 2010). Finally, mobile health applications that are based on smart phone platforms raise a new set of privacy concerns: the phones can track a user's movement, and retain location data for a long period of time. The cellular service provider may be able to discover private health information based upon a subscribers movement patterns (Conn, 2010).

FINANCIAL RETURNS WITH PHR

Little quantitative data exists for evaluating returns on healthcare information technology investments. There is data to support cost savings and long term viability provider based EHRs. However, the payback period for such investments ranges between three and thirteen years for large healthcare systems (Shekelle, Morton and Keeler 2006). Long-term savings can be quite substantial. Partners Healthcare System was able to realize net savings of $86,400 per provider after implementing an EHR that included decision support, electronic prescribing and other features. The savings came from increased efficiency, reduced records keeping and transcription costs, and reduced utilizaton of laboratory and radiology services (Shekelle, Morton and Keeler 2006). More recent studies, involving physician practices rather than large institutions, are more promising. A recent survey by the Medical Group Management Association (MGMA) indicates that EHR systems boost productivity and help improve practice revenues (Conn 2011). Unfortunately, while there are many benefits to offering a PHR, no studies quantify the financial benefits to a patient or provider for offering a PHR.

GLOBAL PERSPECTIVES

Most developed nations are placing an increased emphasis on healthcare information technology. The United States, United Kingdom, and European Union all recognize the potential benefits of healthcare IT investment to improve quality, efficiency and safety in healthcare. The United Nations has even passed an eHealth Resolution, urging all member nations to adopt electronic health services. The UN Resolution calls for members to enact long term plans for electronic health technology adoption, investing in the infrastructure to support universal, affordable healthcare information access and establish national electronic health records databases (Car, Black, Ananden et. Al. 2008).

The United Kingdom is currently experimenting with two national health databases. One, the Summary Care Record, is a central EHR that general practitioners around the country can access. It contains medication history, allergies, and other information that should assist in emergency care. The other is referred to as HealthSpace, and is a PHR. HealthSpace allows patients to access the data in the Summary Care Record, enter their own data into it, and share it with other parties as they choose. The goal of HealthSpace is to create a national, interoperable health database. HealthSpace has encountered slow adoption and utilization remains low. Cultural challenges need be to overcome before more providers or consumers in the U.K. will use the system. Unlike U.S. health consumers, those in the U.K. are less interested in online access to records (Kahn, Aulakh and Bosworth 2009).

FUTURE TRENDS

Efforts are underway to promote more widespread adoption of PHRs by healthcare consumers. Certification of PHR programs is likely in the future. Currently, the Certification Commission for Healthcare Information Technology has two panels addressing personal health records: the PHR Work Group and the PHR Advisory Task Force. Certification will probably be based on four attributes: privacy, security, interoperability and

functionality. Interoperability, transportability and security standards are likely to be mandated via federal legislation. Certification requirements may also spur development of data standards which are currently lacking (Conn 2011 and Jones, Shipman, Plaut and Selden 2010). Mobile device platforms are becoming more prevalent, and as previously mentioned more patients and providers alike are seeking access to health information on these devices. Mobile phones may start serving as an entry point for consumers to access a PHR (Kahn, Aulakh, and Bosworth 2009).

Shifts are also occurring in the field of medical informatics. Historically, informatics and decision support mechanisms were developed primarily for providers. Now, there is a shift towards patient empowerment. Evidence based medicine and a desire to make the roles of patient and provider more equal are helping drive this change. PHRs that incorporate consumer decision support features are becoming more common. Decision aids add value in that they help identify patient preferences and offer alternatives, rather than simply providing information. Consumer decision support systems also help engage the patient and keep them more involved in their health management (Eysenback 2000). Decision support tools are seen by some experts as a requirement in PHR development (Tang and Lansky 2005).

For PHR to be successful in helping improve the overall health of the population, they need to bring about behavioral changes. Examples of important, but difficult changes that people are reluctant to make include giving up tobacco, incorporating regular exercise into their routines, and improvements to medication adherence. Peer support is critical to bringing about lasting behavoir change. PHR developers are seeking tools to connect with social networks to help support behavior change (Kahn, Veenu, and Bosworth 2009).

CONCLUSIONS

Consumer interest in electronic records, coupled with the economic incentives from the ARRA, will increase both demand for PHR software products and the number of PHR applications that are offered to consumers. Investments will need to be made in broadband networks, and computer costs must continue to decrease in order to bridge the digital divide and bring PHR access to more people. Health literacy education will be a challenge to overcome as well. Certification of these systems, development of privacy regulations, and data standards that ensure interoperability will make PHRs more attractive to healthcare consumers and providers. While there are many potential benefits to adopting and utilizing PHRs on a wider scale, further studies will need to be conducted to assess their economic costs, including development and implementation costs, and benefits to the appropriate stakeholders. Use of PHR data on a national level could be most beneficial if data mining is allowing for public health research and also for marketing purposes. However, privacy policies and information disclosure practices need to inform consumers that their data may be used for these purposes, or allow them to opt out of such disclosures in order to overcome a major obstacle preventing more widespread PHR use. Value of PHRs will increased if they bring about positive behavior changes among users. Adding decision support aids and allowing the PHR to be a piece of the patient's social network may provide reinforcement for practices that improve health choices.

Many organizations, including hospital networks, large physician practices, insurance companies and other software companies not typically associated with healthcare continue to develop and offer PHR programs to the healthcare market due to the fact that consumers, as technology improves and costs reduce, are interested in using a PHR and understand the benefits. For this reason, PHRs will continue to emerge in prominence and prevalence in the healthcare industry.

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