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# Patient Access to Electronic Health Records: Strengths, weaknesses and what's needed to move forward

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It is becoming increasingly ubiquitous to be able to access personal information of all types online: banking, billing, course grades and resumes, to name a few. One type of information that has been slower to adapt to the digital realm is the personal electronic health record (EHR). The National Alliance for Health Information Technology defines a personal health record as: “an individual’s electronic record of health-related information that conforms to nationally recognized interoperability standards that can be drawn from multiple sources while being managed, shared and controlled by the individual” (2008). This paper reviews the literature relating to EHRs, and discusses the key factors for the successful universal implementation of personal EHRs. Potential benefits of EHRs to patients and physicians include reduced costs for patients, hospitals and insurance providers, patient empowerment, fewer errors in records and better health outcomes, but security and privacy concerns, cost of implementation and poor electronic records management system (ERMS) design have proved barriers to adoption.

A personal health record is not a new concept. Many individuals keep their own paper-based health records organized and stored at home (Detmer, Bloomrosen, Raymond & Tang, 2008). However, these are only based on part of the health information that exists about an individual, as many more pieces of information like doctor charts, mental health notes and test results are not always released to the patient. Paper-based records are also prone to misplacement, poor preservation or misinterpretation without the knowledge and input of a doctor. Equally problematic is the fact that doctor and patient will each have a different set of information gathered over the years. There lacks a central location where all of this information can be compiled and accessible to both physicians and consumers alike. The EHR is the missing piece to this puzzle.

## **EHR Models**

There exist three main models of EHRs (Detmer et al., 2008). The first, and most primitive, is the *standalone* or *free-standing* EHR. This model relies entirely or nearly entirely on consumer’s data input. This model has limited efficacy because consumers can enter data incorrectly, and this data may not be as reliable as medical records kept by physicians and hospitals. A more advanced EHR model is the *integrated* model. This model compiles not only a consumer’s medical records, but also pharmacy information about prescriptions, insurance information, and additional resources for patients. It is a two-way communication tool between doctors and consumers, in contrast to the traditional unidirectional stream of information from physician to patient. A more limited version of the integrated model is the *tethered* personal health record. This record is limited to information provided by the healthcare provider, and may not include entire records from previous providers included. These are called *web portals*.

The ideal model for complete access and control thus far is the integrated model. However, this ideal solution poses a host of barriers to its implementation. Money and time are always issues of concern for any project, and grappling with new technology is a difficult change for most users. Additionally, as the circle widens for those that have access to personal information, security concerns grow (Magid, 2012). Despite these obstacles, personal EHRs pose an array of benefits—reducing time (Cauldwell et al., 2007; Detmer et al., 2008) and costs (Hillestead et al., 2005; Stanberry, 2011) in the long run, patient empowerment (Bonander & Gates, 2012; Hannan, 2010), better health outcomes (Pascal et al., 2013) and error reduction (Stanberry, 2011; Hannan, 2010)—that far outweigh the risks. Physicians and consumers express a desire for control over records, and the needs of healthcare stakeholders should be considered a priority in the healthcare field.

## **The existing need for EHRs**

Although an increasing number of personal EHRs are offered for consumers, there still exists a need in the healthcare industry to make this privilege universal. Physicians perceive potential benefits from implementing an IT system capable of handling EHRs (Anderson, 2007; Cauldwell et al., 2007). Despite perceiving benefits, physicians doubt vendors' abilities to design an effective system for managing this (Anderson & Balas, 2006). Doctors feel that current ERMS options take more time than paper-based records and detract from time better spent elsewhere (Hensley, 2014). It appears that a major factor in the slow rate of EHR adoption is not simply the unwillingness of physicians to transition to a new way of working, but dissatisfaction with ERMS functionality thus far (Kahn, Aulakh & Bosworth, 2009).

Physicians are not the only stakeholders that have expressed interest in EHRs. Despite privacy concerns, consumers in the U.S. express their desire for access to their personal medical records online. Ninety percent of Americans would like to look over their medical records, and 65% want to do so online (Markle Foundation, 2006). When given a scenario like moving or switching doctors, the percentage of those interested in EHRs jumps to 84% (Markle Foundation, 2006). Patients also appreciate having record of their prescription history online and accessible (Montelius, Astrand, Hovstadius & Petersson, 2008). Sixty-five percent of consumers in one study stated that access to their medical records was important, but only 17% of those respondents had Internet access (Ricciardi et al., 2013). Thus consumers have expressed interest, but are unable to connect to their personal health information because of existing barriers. Lack of access, not lack of interest, is a factor of a slow uptake of electronic EHRs.

## **Barriers to EHR implementation**

One significant barrier to implementing a patient-accessible EHR is a slow shift to digital in the healthcare professionals that are charged with creating the records. Doctors view EHRs unfavorably because they take up much more time than the previous method of physically writing notes. A survey of over 400 doctors showed that 37% of doctors stated that EHR creates somewhat less free time, while 22% state that it creates much less free time (Hensley, 2014). This could be due to its poor user design, as one doctor in the survey noted that many of the boxes he had to tick when filling out records were about billing information, which is not something that a doctor should be filling out during a patient visit. A lack of ERMS functional design means that the systems that physicians and consumers are supposed to use are not designed with them in mind. This, in turn, leads to limited value to the stakeholders for whom it was created (Kahn, Aulakh & Bosworth, 2009). For faster implementation in the medical field, an ERMS will need to cater to design requests from the users so that medical professionals feel they are worth investment.

Provider resistance may not merely be due to resistance to digital changes, but also a lack of time set aside for interpreting the plethora of information now accessible to each patient via their EHR. When patients don't have access to their medical records freely, they can't query about what each note means that a doctor has hand-written. However, once this information becomes accessible to a consumer, a new wave of questions may arise. While this may reduce time in the hospital or clinic in the long run, physicians still will need to answer patient emails, a part of their day for which time is not currently factored into (Detner et al., 2008). Serious adjustment in time management and workflows will need to take effect in order to ensure physicians are not overworked as a result of personal EHR implementation.

Equally as challenging as a physician's inability to properly create records is the patient's potential inability to access these records. In a survey of Canadian hospital CEOs, patient computer literacy was one of the top three identified barriers to implementing EHRs (Urowitz et al., 2008). Without computer literacy, or access to the Internet, patients won't be able to view their records even if they exist. For them it would make no difference whether or not their EHRs were available online because they may not have Internet or the skills to navigate an EHR if they do have Internet. If the issue of computer and information literacy is not addressed, this poses a risk to have only computer-savvy individuals benefit from EHRs, a population that already possesses higher than average health literacy rates (Kahn, Aulakh & Bosworth, 2009). Addressing this issue can prevent the widening of the already great digital divide.

Another barrier to the technological advancement of EHRs is a combination of funding and IT capabilities. In a survey to Canadian hospital CEOs, financial resources were named the biggest barrier in providing patient access to EHRs (Urowitz et al., 2008). Without sufficient funds, hospitals and other healthcare providers are unable to invest in a suitable ERMS for patient access purposes. Only half of respondents in the same survey (54.2%) even had an ERMS in place, with hardly any having predominantly electronic records. Furthermore, a lack of interoperability between different EHR systems means that there could be difficulty compiling records from different providers (Detmer et al., 2008). The lack of cohesion means individual health data will inevitably be lost when switching providers or insurance companies, a fact that could dissuade users from committing to a EHR altogether (Kahn, Aulakh & Bosworth, 2009). Funding for more advanced IT options and expertise should be a priority for a successful ERMS implementation.

As with any personal information available online there are privacy concerns. Americans worry that putting this information online will make it more easily accessible to people other than themselves. Eighty percent worry that online access to this information will increase identity theft or fraud, and 90% have concerns about medical information being accessed and used by marketers (Markle Foundation, 2006). Discrepancies between Health Insurance Portability and Accountability Act (HIPAA)'s privacy standards and consumer's personal privacy preferences need to be resolved, as medical record sharing between health professionals that have no role in a consumer's care is explicitly prohibited by HIPAA, yet possible in a medical ERMS (Stanberry, 2011). As it turns out, consumers have justified concerns about privacy and security. In 2012 it was revealed that medical providers disclose certain patient medical information to those willing to pay enough money for it, among which are drug companies, employers and insurance companies (Magid, 2012). Justified consumer fears about information security has lead to a slow adoption rate of this technology out of fear of exploitation.

### **Benefits of EHR implementation**

Some steps to grant patient access have been implemented in limited capacities. The Patient Access to Electronic Healthcare Records System (PAEHRs) in the UK allowed patients to access their medical records in the waiting room of a surgery office, but only once they had checked in (Cauldwell et al., 2007). Even access to their records in this limited capacity provided shorter consultation times according to patients, possibly because they were better informed during their wait-time compared to if they had not had access to their records beforehand. Online consultations for minor issues can reduce in-house clinic or hospital visits, greatly reducing time on both the part of patients and physicians (Detmer et al., 2008). Time is money in any

profession, thus reducing wait time and healthcare provider appointments can save both hospitals and patients money.

Another striking benefit is the lowered costs for hospitals and patients alike. In 2005 it was estimated that hospital-adoption of ERMS in the U.S. would save over \$371 billion (Hillestead et al., 2005). Even insurance providers would save from this shift. Medicare would save over \$20 billion a year (Stanberry, 2011). When patients have better access to their medical records, they are better informed and more proactive in their own personal health. Eighty-eight percent of Americans feel that access to medical records online would reduce the unnecessary tests and procedures they would have to undergo (Markle Foundation, 2006). This, in turn, would reduce costs for hospitals, patients and insurance companies. Patients taking better care of themselves with preventative measures means less money spent on emergency procedures and treatments.

When patients are more in control of their medical records, they feel more empowered in their health choices. Web-based programs for tobacco-cessation and diabetes self-management are some ways that EHRs can be used for public health purposes (Bonander & Gates, 2010). Electronic health records can be incorporated into shared care plans between patients and physicians when devising long-term plans for managing chronic diseases like diabetes (Pascal et al., 2013). In this case, both patient and physician create a knowledge object together that exists in an ERMS. Consumers express positive thoughts about their ability to access his or her EHR: "I feel I am taking a positive step towards maintaining a healthy life, understanding my medical needs and doing it all on MY time, when it's CONVENIENT to me" (Hannan, 2010, p. 45-6). When control and information is placed in the hands of the consumer, the consumer feels better equipped to make their own decisions.

In addition to physicians' ability to provide patients with more resources through an integrated EHR, patients now have the ability to provide physicians with pertinent health information of their own. Bonander & Gates (2010) state, "this sharing also opens the door to a new kind of bidirectional relationship between individuals and public health, one not part of traditional public health monitoring activities" (p. 6). Now for the first time patients can relay information to their physician and update notes without needing to first schedule an appointment. EHRs can then provide personalized recommendations based on patient-entered data. Suggested physical activities near a patients home, menu suggestions based on particular restaurants and dietary restrictions are just a few of the potential recommendations a personalized EHR can provide using input from both patient and physician (Bonander & Gates, 2010). An EHR can help make each user's medical experience customized to their needs.

Other resources like online support groups, health assessments and reminders for routine check-ups are also possible (Detmer et al., 2008). "When [personal health records] allow iterative communication between patients and providers, export data to and import data from other information systems, and transform clinical measurements and observations into meaningful and actionable information, fundamental changes in health care delivery and self-care by patients are possible" (Detmer et al., 2008, p. 4). Ninety percent of Americans feel they would gain more control of their health by better tracking their health history online, and 82% of parents say they would like to track their children's medical history online (Markle Foundation, 2006). By opening the communication channel in both directions, EHRs have the power to transform consumers' lifestyles and develop healthier habits.

EHRs can promote better record-keeping practices and reduce errors. Since EHRs are able to connect to multiple different information sources, they are able to consolidate an individual's disparate medical history into one central location. Having a structured way of entering information can also lead to a more coherent patient history since there will be a

universal method of entering and displaying each type of data, to some extent. EHRs can reduce physician error with computerized physician order entry, which verifies instructions about prescriptions that the physician can then relay to the patient (Stanberry, 2011). In a case study by Hannan (2010), the physicians state they “have not had a single problem resulting from patients having gained access [to health records], though errors in records have been found and corrected” (p. 44). Allowing a second, more personal set of eyes on medical records provides the added benefit of proofing.

Not only are patients proactive about their own health, but they are completing the circle by further educating the medical community and their peers about their experiences with EHR access. In an updated version of the PAEHRS program previously mentioned, U.K. patients who were given full online access to their medical records educated medical students about the benefit of EHRs (Hannan, 2010). Patients from the same study have presented at national and international conferences on their experiences of patient-accessible EHRs. Patient-created resources have also been posted on the online web portal from which the EHRs are accessed. Patients, students and clinicians can learn from each other and work together by exchanging information to improve both sides of the ERM process.

### **The next steps needed for EHR adoption**

Several adjustments need to be made in order for the concept of EHRs to become a habitual part of life for both physicians and consumers. One of the more worrisome challenges is how to make data more secure. This is one of the primary obstacles needed to overcome low levels of participation from the public. There need to be tighter controls on who can access what information, and there should not be any money exchanged for personal health information. This would be frowned upon for paper-based records and the same should apply for electronic records. If this is in some way not possible, then the next best option is providing full transparency to the consumer about the possibility of how their information may be used. Consumers need to have the right to opt out of any health information-sharing options that they feel uncomfortable with. The Office of National Coordinator (ONC) has developed a concept of a “Model Notice,” which healthcare companies can use to display security information in terms widely understood by the public (Ricciardi et al., 2013). EHR sharing control needs to be in the hands of consumers more than hospital administration.

A shift also needs to occur in the realm of medical ERMS design as well. There exists a need for better-designed ERMS that cater specifically to medical professionals. In order to enable efficient record creation and maintenance through an ERMS, designers will need to incorporate users into their design and testing process. Without this key input they will be designing blindly. Taking stakeholder feedback and user experience testing into consideration will vastly improve the less-than-ideal systems reported by Hensley (2014) and Kahn, Aulakh and Bosworth (2009). A collaboration between The ONC, the White House and the Department of Veteran Affairs encourages technology developers to build e-health tools that would increase patient access to personal medical records (Ricciardi et al., 2013). This collaboration shows that health and technology professionals alike are becoming aware of the limitations of such systems.

Patients and physicians need to collaborate to make sure that EHRs are continuing to function satisfactorily for both parties. Ongoing patient-led education for medical professionals should be a priority. Online EHR education for medical students should be incorporated into their medical education, as suggested by patients participating in PAEHRS in the U.K. (Hannan, 2010). Patients are stakeholders in the EHR platform as well and their feedback should be taken

into consideration. After all, success of the program will not be possible without the satisfaction of the individuals accessing the records and on whom the information records are built.

A successful implementation of patient accessible EHR requires a strong support system from hospital staff with resources built into the EHR. Online web portals that allow EHR access should be designed as a “one stop shop” for a patient’s medical history and future, or what Detmer et al. call an integrated personal health record (2008). Patients should be able to schedule appointments, fill prescriptions and seek help through videos and articles in addition to accessing their medical records. Web portals should also be updated to reflect healthcare trends that may cause patients worry, like the H1N1 outbreak or, more recently, Ebola. These resources will better educate patients so that they can make more informed decisions. To provide EHR resources to those who don’t have consistent Internet access, computers should be available onsite during wait times for appointments so that they can at least have access prior to their scheduled visit. Doctors should be encouraged to remind patients that they have access to their EHR, as they may forget with a service this novel. The EHR should not be used as a replacement to doctor consultation and advice, but instead as a complement (Wiljer et al., 2008). Hannan (2010) notes a slow rate of patient adoption to online EHRs, and more education and gentle reminders should resolve this.

The EHR model of the future is an intelligent personal health record (iPHR), which is a concept that is still being developed. IPHRs will incorporate web search technology and existing medical information to anticipate patient needs and create individualized plans and resources. One such medical search engine, iMed, uses diagnostic decision trees that are designed by medical professionals that help the user (patient) form queries about their specific symptoms or diseases (Luo, Tang & Thomas, 2012). Using an extensive algorithm, iMed can search using the diagnostic trees to return related resources for the user. From these same methods an iPHR can suggest home nursing activities and home medical products. While this is an ideal model of an EHR, the basics previously discussed still need to be mastered before a complex model like this can exist. These concepts are promising to move toward a system that encompasses all of the desired facets of a successful EHR.

## **Conclusion**

Allowing patient access to personal EHRs empowers patients, minimizes physician error, and reduces patient, insurance provider and hospital costs. However, there still exist many barriers to effective EHR access. IT capabilities are lacking in hospitals, a resource that is desperately needed in order to implement and support the desired changes. There also exists a lack of funding, meaning there is a less likely chance for funding to be available to make IT changes. Physician attitudes of resistance to digital shifts may not be due entirely to a negative impression of digitizing workflows, but instead a call for more adequate ERMS design. If these obstacles are overcome, this will be a step in the right direction to make EHRs ubiquitous.

Future research should focus on incentivizing the adoption of EHRs for physicians, patients and hospital staff. Although benefits for patients are apparent from the analysis of the literature, these are long-term gains that will take some time for users to observe. More immediate rewards may be needed for universal adoption. The literature so far also suggests that there does not exist an ERMS that successfully complements the ways in which physicians work. Additional user studies should be conducted to understand the goals of the physician and integrate these with the goals of patients to create a cohesive ERMS. Incorporating patients into physician education is also a novel and interesting avenue that should be explored further, modeled off of the PAEHRS project. These future studies can contribute to the existing literature

and provide more well-rounded picture for how to improve the adoption rate and success of EHRs.

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