Healthcare Consumers' Voluntary Adoption and Non-Adoption of Electronic Personal Health Records

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Abstract

The use and ready availability of electronic health records is broadly purported to have the potential to improve health outcomes for individual healthcare consumers, providers and the healthcare system as a whole. Unlike electronic health records that are created and managed by providers, personal health records (PHR) are controlled by the individual consumer and the persons/entities to which they choose to grant access. Studies show while more healthcare consumers have access to PHRs, their voluntary adoption is lagging. Yet, our understanding of adoption lag is also lacking. In this qualitative study, we investigate: (1) how individual healthcare users in Connecticut currently manage their personal health information, (2) whether they have adopted an electronic PHR and the considerations that influenced the volitional adoption or non-adoption of a PHR. Initial findings casts new and surprising understandings including how healthcare consumers would like to use PHRs.

Keywords electronic health records (EHR), personal health records (PHR), personally controlled electronic health records (PCEHR), technology adoption, consumer healthcare

1   Introduction

A report by the National Committee on Vital and Health Statistics (NCVHS) attributed more than 30 benefits to PHR systems including "the ability to strengthen disease prevention, improve population health, and expand health education opportunities" (Wynia and Dunn 2010). Yet, some researchers and policy experts continue to puzzle over whether PHRs will ever gain the necessary adoption rates to make the systems effective. PHRs have been around for some time now, and by many estimates, in the United States for example, a over 70 million consumers have access to PHRs (Studeny and Coustasse 2014) that are either tethered to their healthcare provider's electronic health record (EHR), or that or the payer (health insurance company or employer). Yet adoption rates remain low. The barriers to adoption noted have included concerns for information privacy, patient awareness and or interest. In Australia, by late March 2015, approximately 9% of Australians had registered for MyHealth Record (Lehnbohn, Douglas, and Makeham 2016), the national initiative promoting the adoption of personally controlled electronic health records (PCEHR) as a key part of the national health care reform agenda (Australian Digital Health Agency 2016).

Consumer electronic health records are differentiated into those that are owned and controlled by the consumer, and those that are owned controlled by healthcare providers. Formally defined, an electronic health records (EHR) is created, maintained, owned and controlled by HIPAA regulated covered-entities e.g. physicians, hospitals, pharmacies and health insurance companies. The EHR tracks healthcare consumer encounters with their providers as well as other healthcare information. However, the healthcare consumer typically sees the contents of the EHR when a provider issues printed or PDF copies of portions of the record. An electronic personal health record (PHR), on the other hand, is a private and secure electronic record of an individual's health information through which the consumer controls access to the information. (Jones et al. 2014; Kaelber et al. 2008; Tang et al. 2006). A PHR can imbue the individual with the ability to manage, track, share and participate in his or her own health care (Jones et al. 2014; Kaelber et al. 2008; Tang et al. 2006). Thus the design intent behind PHRs is: patients or healthcare consumers maintain control over the healthcare record, and not the provider. A PHR may, nevertheless, be directly linked to an electronic health record (EHR); it may include partial information contained in the electronic health record as well as information entered by the consumer, his/her health providers (doctors, pharmacies and labs) (Jones et al. 2014; Kaelber et al. 2008). Some PHRs are even tied to the patient's medical librarians. Purveyors of PHRs include health care organizations such as hospitals, health insurance companies, employers and private vendors who may or may not charge a use fee (Jones et al. 2014).

The purpose of this study is to get an in-depth understanding of (1) how individual healthcare users in New England, USA currently manage their personal health information, (2) whether they have adopted an electronic personal health record (PHR) and the factors that influenced the voluntary adoption or non-adoption of a PHR. The study uses semi-structured interviews with two core open-ended questions as the basis of the interview between investigator and research participant.

2   Background Literature

In general, the drive to implement electronic health records is motivated by multiple potential benefits for consumers, healthcare providers as well as the broader healthcare system. Specifically, the benefits of using EHRs include: increased revenues for providers through the better capture of charges and reduced billing errors, and averted costs, e.g. reduced printing costs and supply (Menachemi and Brooks 2006). Such cost savings can translate into improved health for the broader system through negative effects on healthcare cost inflation. For consumers, the benefits include: better overall patient care, helping alert physicians to potential medication error and critical lab values, and better facilitated communication with patients (King et al. 2014), patient engagement in their own care and health (Ancker et al. 2015)

PHRs and EHRs are not the same thing, as explained above, yet the personal health information they contain may be allowed to intersect to a greater or smaller extent. The potential benefit to consumers of using, even the simplest PHRs, in a readily accessible and central location for storing and managing medical history is important. One of the primary benefits is greater patient access to a wide and customizable array of credible health information, data, and knowledge (Tang et al. 2006). Patients with serious and/or long-term illnesses especially benefit most from these systems (Mitchell and Begoray 2010). Yamin et al. (2011) found patients with comorbidity, i.e. those with two simultaneous chronic conditions, were more likely to use a PHR system. Patients are able to timeously and actively

participate in their own care-related information tracking, such as blood sugar and blood pressure data from home, medications and reactions, diet and exercise information. They can verify and optionally share information with health care providers, medical librarians, care givers, and researchers. In addition, so-called mobile personal health records (mPHRs) that are accessible via mobile phones, tablets, personal digital assistants can help in case of emergencies when a patient presents to a new provider or where the EHR is not accessible or interoperable with the new provider's systems (Bouri and Ravi 2014).

Web-based social networking and the Health 2.0 movement, with the attendant concept of patient self- management and web-based personal medical home model have enabled the popularity of PHRs (Jones et al. 2014). By some accounts over 70 million Americans have access to a PHR (Studeny and Coustasse 2014), however the rate of voluntary adoption and use by patients themselves has been low (Agarwal et al. 2013). Prior studies show multiple factors adversely affect the adoption of electronic health records. These include: privacy and security concerns (Abramson et al. 2014; Carrion et al. 2011; Carrion Senor et al. 2012; Kaelber et al. 2008; Kavoussi et al. 2014; Patel et al. 2011) and the evolving challenges to regulatory standards and health privacy protection (Terry 2014); the rate of adoption of electronic health records and the variances in physician willingness to use technology in managing patient care (Archer et al. 2011); the interoperability problem, a technical challenge for both PHRs and EHRs (Studeny and Coustasse 2014); the digital, racial/ethnic and income divide (Yamin et al. 2011); and the usability of PHR applications (Cruz Zapata et al. 2014) especially amongst middle-aged and older patients (Taha et al. 2013). Yet some studies have shown that many existing patients believe using PHRs can help them better manage their health (Studeny and Coustasse 2014) and that this belief is also prevalent in groups with low income levels, and minority racial/ethnic groups (Patel et al. 2011; Turvey et al. 2012).

Some researchers have postulated that the adoption of PHRs would be subject to "captology" (Saparova 2012). Captology is a theoretical framework established in Human-Computer Interface (HCI) research. The framework holds computers as persuasive technologies that can motivate, influence, and persuade users toward the adoption of target behaviours (Saparova 2012). However voluntary adoption rates among PHRs still remain low. Tang et al (2006) suggested that there are two main mechanisms for understanding and unravelling the barriers to PHR adoption, namely, education and research. They argued that we "do not know enough about health care consumers' need for, and potential use of PHRs" (Tang et al. 2006).

3   Research Questions and Methodology

The study is a qualitative study whose data collection strategy is semi-structured interviews, where the study participant (interviewee) participates more in the meaning making than in merely as serving as a conduit of information (DiCicco-Bloom and Crabtree 2006). The semi-structured interviews are the only data source for the study.

3.1   Data Gathering

The study was carried out at a liberal arts college in New England, however interviewees or study participants were not restricted to college students; we sought to specifically diversify the age-range of participants interviewed. The first round of semi-structured interviews was conducted in the December of 2014; The second and third round of interviews were conducted in the Spring and Fall of 2105, with the last round conducted in the Spring of 2016. For each round, subjects ranged from 21 years of age to 65 years old and were nearly evenly split with respect to gender. In each round, we interviewed approximately 30 subjects. Interviews were recorded for subsequent transcription with the subject's consent. Each interview lasted between 20-60 minutes.

Two primary questions were the basis of the inquiry. Healthcare consumers were asked the following questions with the necessary follow-up questions.

   i.   How are you currently managing all your healthcare data (prescription data; medical bills, test and lab results, historical medical data)

   ii. Do you use a personal health record (PHR)? What considerations incent or would incent you to use a personal health record? What considerations discourage or would discourage you to use a personal health record?

3.2 Data Analysis

All the interviews are transcribed. Transcripts are then analysed, coded and labelled thematically for sense making by two interviewers independently. Thematic analysis is being done both manually and using the coding capacity of the coding tool, Nvivo 9. The latter is useful for repeating emerging themes, however is not ideal when data is surprising, be it in support of the literature or in substantiating the reasons behind existing findings. Tables 1 and 2, below, show some of the emerging themes for both research questions. (We note that the analysis of the data is at this stage still ongoing).

First, we note that a majority of our subjects considered themselves to be in good health, only five of our 85 subjects explicitly referred to a chronic health condition that required ongoing treatment, e.g. anxiety, Type I and II diabetes, thyroid disease, and severe sinusitis.

In our study we found (Table 1) that a small minority indicated they maintained some paper records of their health information. The majority of our subjects relied on their healthcare providers to manage their health information. In other words, their various healthcare providers acted as surrogate guardians of documented patient health information. This is not withstanding federal law (HITECH Act) granting individuals the right to receive an electronic copy of their medical records for free from their healthcare providers.

Almost 65% of our subjects were unaware of what a personal health record was, meaning they did not understand the potential benefits of a PHR. The interviewer would explain and show what a PHR is using Microsoft HealthVault.

Question 1	
How are you currently managing all your healthcare data (prescription data; medical bills, test and lab results, historical medical data)	
SAMPLE SUBJECT RESPONSES	THEME
"I keep some paper records."	
"I rely on my healthcare provider… doctor, pharmacist, hospital, health insurance company to track my personal health data. When I need it, I ask them to provide it."	*Guardians of patient personal health data*

Table 1. Some Emerging and Surprising Responses for Question 1

Having established some understanding of a what a PHR is, the interviewer then explored the second question, whether the subject has access to and/or uses a PHR, and considerations that would encourage/discourage them from using a PHR. We found that the adoption of PHRs was less than 20% of our subject population.

When asked to consider factors that would incent(ivize) them to use a PHR (Tabl2 2), several themes emerged. For example: [1] If they were offered some *financial benefit*, e.g. a rebate on healthcare premiums. [2] If primary-care physician indicated there was a need or reason to use one (physician influence); this was tied to if it was demonstrable that using a PHR would benefit one's [3] *overall health.* Some felt if other people were using it, or if PHRs were widely used, they were more likely to use it [4] *social influence.* A number of our subjects felt the ability to easily integrate information about their [5] *dietary and exercise* habits into the PHR would for various reasons be an incentive to adopt a PHR.

[6] The user interface and relative ease of use was a feature that the majority of subjects were concerned about, positively and negatively. There was general perception that these systems

would not be easy to use. There we interesting suggestions regarding what would render them easy to use. For example, being accessible in similar ways to how they use other technologies, i.e. through mobile apps; and allowing for voice data input from the individual.

[7] Among those that indicated having a health condition that required regular and ongoing treatment, the PHR offered the possibility of revisiting provider instructions, explanations, and suggested actions post-encounter with the healthcare provider.

Question 2	
Do you use a personal health record (PHR)? What considerations incent or would incent you to use a personal health record? What considerations discourage or would discourage you to use a personal health record?	
Incentivizing Considerations:	
SAMPLE SUBJECT RESPONSES	THEME
"If it would reduce my *insurance premiums*" "It reduces my *premiums*" "$50 offer from insurance company" *"I believe a financial incentive would convince me"*	Financial benefit or Price value
"If my physician asked me to." *"If my doctor gave me reason for concern to use one."* *"If my doctor suggested it, I would do it"*	*Primary-care physician influence*
"It may benefit overall health"	*Overall Health benefit*
"If PHR *use* was *growing* or *widespread* in the United States."	Social influence
"I think that if they (PHRs) focus a little bit more on wellness and getting fit" "If it was something other than like storing like my medical information, or stuff like diet and exercise stuff would be nice, so that I could kind of get a full picture of my health, not just what was diagnosed on a piece of paper, the medications that I pick up at a pharmacy. It would be nice to get like a well-rounded feel of it I guess, and then maybe if it included like warnings or when I needed more of something like fruits, vegetables, whatever stuff like that would be cool to have." "Definitely my diet and exercise, I think that would help a lot because if I ever have any problems, doctors can understand what I've been eating and what could change in my diet."	Integrate diet and exercise health information
"...depending on how easy the doctor made this (PHR)for me to understand, or how accessible he made this (PHR) to me" "It would depend on how hard it is to use, but I probably would use it." "I would want it to be user friendly. I would want to be able to manipulate the information entry format if I needed to, I'd want to be able to speak my information rather than type..."	Relative ease of use; user interface
"There are times when you go doctor's office and you think you understand what they told you and you go home and you realize you didn't understand it, or some questions have occurred to you about a drug interaction, or a procedure that	*Permanent record of provider consultation instructions, and/or underlying reasons*]

he may want to do or something like that…"	
"It's very overwhelming in the doctor's office sometimes. Particularly, when you are getting information that you weren't expecting. When you sort through everything and you realize you still have a bunch of questions about what happened. What she wants you do, why she wants you to do it"	*Permanent record of provider consultation instructions and/or underlying reasons*

Table 2. Some Emerging Responses for Question 2 (Incentivizing Considerations)

Table 3 below, captures the emerging themes arising from considerations disincentivising use of a PHR. The primary factor was [1] relative wellness and the [2] perceived time and effort required to upkeep a PHR. Most of our subjects thought they had no health issues to warrant what they perceived as the time and effort required to upkeep a PHR. Even the subjects being treated for a disease did not necessarily use a PHR. (Lack of) ease of use was a related disincentivising factor. [3] Security and privacy concerns were the next most important issue. Then [4] E*ducation*: about 50% feel they better needed to understand what a PHR was before they would decide whether to use it.

Question 2
Do you use a personal health record (PHR)? What considerations incent or would incent you to use a personal health record? What considerations discourage or would discourage you to use a personal health record?

Disincentivising Considerations:	
"I don't visit the doctor nearly often enough for the hassle, perhaps when I'm older"	*Relative wellness*
"Honestly I don't have time for that" "I'm lazy, I wouldn't update it." "I'm not in the habit of keeping journal and record of any kind"	Required Time Effort (Perception)
"Risks associated with stolen social security number and financial information." "Less worried about personal health information." "Faking results" "I'd want it to be very secure"	Security and privacy concerns
"I need to better *understand* what a PHR is."	Education

Table 3. Some Emerging Responses for Question 2 (Disincentivizing Considerations)

4   Preliminary Discussion of Results

In the initial analysis of the data, we are finding some results that are consistent with the literature, some surprising and new insights. For example we found, subjects may have access to personal health care records through healthcare providers, health insurance and employer services, however actual use is significantly less than access (Agarwal et al. 2013; (Lehnbohn, et al 2016). Relatively healthy consumers perceive the PHR as cumbersome to update (even though they have not used it, and thus are less likely to keep it up to date); a majority believe as their health worsens, they would be more likely to track their personal health record, even though five of our subjects had a chronic disease, had access to a PHR and were not using it. The predominant attitude is to let health care providers (doctors, pharmacies, hospitals) be the custodians of this information, notwithstanding (even the experienced) risk of inaccurate information-keeping; one of our subjects had experience of inaccurate

record-keeping by a provider. Those who have not experienced erroneous information keeping do not think about the quality of information kept by the custodians. Yet, for example studies conducted in the USA, report dispensing error rates of up to 24% in community pharmacies, and 12.5% in hospital outpatient pharmacies (Beso et al. 2005; Kistner et al. 1994) and that these errors are difficult to discover.

Security is a very important disincentive for adoption., Subjects were not particularly concerned about the health record itself but rather personally identifying information such as one's social security number and financial information, information that would put them at risk of financial fraud. The relative lack of concern for the health record itself deserves further study; less than 6% of population indicated the presence of a chronic disease. It may be that individuals with chronic or socially embarrassing conditions feel differently, or that the privacy of the health record itself is highly contextual.

There are surprising and interesting findings emerging from the study. These relate particularly to features that healthcare consumers assert would encourage them to use a PHR and/or features they would like to see in PHR. wish a PHR. For example, the belief that PHRs could better help patients understand conversations and directives from their encounters or consultations with physicians, presupposes that the PHR would record this information. For instance, if a patient could record the conversation with their physician and be able to upload the audio of the consultation, or related instructions on his/her PHR, they could subsequently go back and re-listen to the conversation at home, when they are more relaxed, as they seek to process and better understand, or clarify their earlier interaction with the physician. They could also update the record with follow-up questions that a physician could later respond to. Such a feature however would require a PHR to technically allow for the integration of voice or audio. This is an understanding that is new with respect to how patients would like to be able to use a PHR. On the other hand, such a feature would require the support of the healthcare provider community. Yet, a feature such as this may also reduce or simplify the note-taking process for the physician when integrated with reliable audio-to-text automated transcription. In cases, where a healthcare provider needs to demonstrate say a proper technique for application of care, e.g. in physiotherapy, the demonstration could be uploaded as video.

The perception that the personal health record would require a burdensome amount of upkeep coupled with facilitating user interface design or inconvenient access were a dominant disincentive for adoption. First, targeted educational initiatives are required. Currently providers encourage and give access to tethered PHRs, it would seem those discussions ought to correctly reflect the burden of upkeep. Healthy subjects incorrectly imagined a PHR as a journaling (daily) effort. Second, the user-interface design for the PHR may need look and feel like the technologies consumers use regularly through their mobile devices. For instance, incorporating the ability to enter one's data through voice, or automatically linking data entry to diet and fitness apps.

It is an open matter whether in countries, such as the Australia where the national PHR initiative is directed and developed through government policy (Andrews, Gajayanake, and Sahama, 2014) such feature enhancements may be more feasible in a systemic manner. Or, whether in places like the United States where PHR rollout, with the exception of the Veterans Administration, remains in the private sector will yield feature enhancements that better address healthcare consumer needs..

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