

A Study Of Healthcare Consumers' Voluntary Adoption and Non-Adoption of Electronic Personal Health Records in Connecticut

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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 (PHR), personal health records (PHR), technology adoption, healthcare consumer.

Introduction

Consumer health records have historically been paper-based, and many remain this way today. The migration from paper to electronic records has increased demand for greater access to health information. In the domain of healthcare and healthcare governance, 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 like 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 Connecticut 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.

Related Literature

In general, the drive to implement electronic health records is motivated by multiple purported benefits for individual consumers, healthcare providers as well as the broader healthcare system. Specifically, the benefits of implementing and using EHRs are relatively well-documented; they 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 by helping curb healthcare cost inflation. For consumers, the benefits are best articulated in a national study assessing the clinical benefits of using electronic health records for patients; they 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).

PHRs and EHRs are not the same thing, as explained above, yet the personal health information they contain can 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 concept of patient self-management and the 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 Senior 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 behaviors (Saparova 2012). However voluntary adoption rates among PHRs remain low. Tang et al (2006) suggested that there are two main mechanisms for understanding

and unraveling 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).

The purpose of this study is to get an in-depth understanding of (1) how individual healthcare users in Connecticut currently manage their personal health information, (2) whether they have adopted an electronic personal health record (PHR) and the considerations that influenced their 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.

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 conduit of information (DiCicco-Bloom and Crabtree 2006). The semi-structured interviews are the only data source for the study.

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 semi-structured interviews were conducted in the December of 2014. We note that this was prior to the January 2015 Anthem data breach that affected 80 million healthcare consumers. Researchers interviewed 30 healthcare consumers. Subjects ranged from 21 years of age to 60 years old and were nearly evenly split with respect to gender. Interviews were recorded for subsequent transcription with the subject's consent. Each interview lasted between 30 minutes and 1 hour.

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

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

Data Analysis

The interviews are transcribed in the Nvivo 9 software application environment. Transcripts are then analyzed, coded and labeled thematically for sense making. Thematic analysis is being done both manually and using the coding capacity of the tool. 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.

Question 1	
<i>Use of PHR less than 20%</i>	
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.	<i>Guardians of patient personal health data</i>

Table 1 Some Emerging and Surprising Responses for Question 1

Question 2	
Incenting Considerations:	
If it would reduce my <i>insurance premiums</i>	Financial benefit or Price Value
It reduces my <i>premiums</i>	
\$50 offer from insurance company	
It may benefit <i>overall health</i>	Health benefit
<i>If my physician asked me to.</i>	Professional Influence
If PHR <i>use</i> was <i>growing</i> or <i>widespread</i> in the United States.	Social Influence
“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 he may want to do or something like that...”	<i>Permanent record of provider consultation instructions, and/or underlying reasons</i>
“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”	<i>Permanent record of provider consultation instructions and/or underlying reasons</i>
Disincentivizing Considerations:	
I don’t visit the doctor nearly often enough for the hassle, perhaps when I’m older	<i>[Degree of wellness or relative wellness]</i>
Risks associated with stolen social security number and financial information. Less worried about personal health information. “Faking results”	Security
“I need to better <i>understand</i> what a PHR is.”	Education
“I’m lazy, I wouldn’t update it.”	Habit?

Table 2 Some Emerging and Surprising Responses for Question 2

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, healthcare consumers may have access to personal health care records through health insurance and employer services, however actual use is significantly less than access (Agarwal et al. 2013). Relatively healthy consumers perceive the PHR as cumbersome to update, and thus are less likely to keep it up to date; they believe as their health worsens with age, they will be

more likely to track their personal health record. The predominant position is to let health care providers (doctors, pharmacies, hospitals) be the custodians or watchdogs of this information, notwithstanding (even the experienced) risk of inaccurate information-keeping. 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. Nevertheless, healthcare consumers would rather deal with data inaccuracies as they discover them, rather than take more active control of their personal health data through a PHR.

Security is a very important disincentive for adoption. Surprisingly, consumers were not particularly concerned about the health record itself, but rather personally identifying information such as one's social security number and financial information.

Other surprising considerations include, the belief that PHRs could better help patients understand conversations and directives from their encounters or consultations with physicians. 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 go back and re-listen to it 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 it with follow-up questions. This 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.

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