

An Empirical Examination of the Importance of Defining the PHR for Research and for Practice

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ABSTRACT

Objective

Recent discourse surrounding PHRs conflates definitions of the technology and confuses both novices and experts. This matter assumes critical importance when research subjects are asked to respond to questionnaires in which the specific definition of the PHR is not given. We conducted this study to demonstrate that people have very different mental models of what a PHR represents and this affects their attitudes related to privacy and choice of specific PHR forms.

Design

Using data collected from a survey of both HIT stakeholders and a general population, we conduct descriptive and statistical analyses to demonstrate that various conceptualizations of PHRs exist. We use regression analysis and analysis of variance to test our hypotheses.

Results

We find that the nature of concerns regarding privacy and security of PHRs differ based on the individual's prior knowledge about and involvement with PHRs. We find that education influences choices regarding the type of PHR form-factor preferred but age does not. Beliefs are also dependent on the source of distribution of the PHR and as trust in an entity declines, consumers' choices regress towards isolated PHRs such as paper- or home PC-based solutions.

Conclusion

This study demonstrates that research related to PHRs must be very explicit in terms of defining the type of PHR. It also provides evidence of relationships between demographic characteristics leading to variations in PHR beliefs and choices. This work highlights some pitfalls of conducting research on PHRs and also presents new evidence about people's perceptions of PHRs. This study can be informative for both the design of PHRs and also for policy makers by surfacing barriers to adoption which could potentially slow the diffusion of this technology.

Keywords: PHR, EHR, Personal Health Record, Electronic Health Record, Beliefs, Attitudes

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I. INTRODUCTION

In a recent article by Kevin Featherly (1), the author extols the virtues of a portable electronic health record that is managed by the patient. In the same article, he quotes Rishel and Tiazkun who claim that portable records, while spurring the growth and understanding of electronic records, are not substitutes for a national information infrastructure and interlinked information systems. This point was reinforced at the AHIC (American Health Information Community) conference in November 2005 when Dr. David Brailer, the former National Coordinator for HIT, stated that the PHR and EHR were not overlapping sets of data and that it was important to empower the patient before focusing on integrating the two currently disparate systems. Thus it is very timely for a detailed discussion of personal health records and the perceptions that people have about their use.

Although there is broad agreement that HIT can help ameliorate health care delivery, most of the research conducted to date has focused on the use of HIT by physicians and other providers (2, 3). Overall, the general conclusion that can be drawn from these and other studies is that there are clear benefits realized from *physician* use of HIT. In contrast, the use of HIT by *patients* is less explored and researched. Today, the technological capability of providing patients access to electronic records is widely available. A review examining the effects of promoting patient access to medical records (4) concluded that in light of increasing patient involvement with their personal health information, it is important to conduct additional research examining the implications of such access. A report issued by the Markle Foundation (5) provided extensive detail on a PHR definition and established consumer and clinician

readiness for PHRs, however, it did not investigate the impact PHRs can have on the health care system.

Some research has been conducted examining the effects on patients of PHR use (6), on the doctor-patient relationship (7), and on the medical practice (8). Examples of such studies that include both interventional and non-interventional research are reviewed in Ross and Lin (4). The main findings of their review are that patient-accessible medical records offer modest benefits, particularly with respect to improving doctor-patient communications, subjective improvements in patient understanding of medical conditions, and generally increased participation by patients in their own long-term care. However, we have observed that many of the studies reviewed are limited in various research design elements including sample size, use of controls, validated assessment tools, and limited exposure periods. Thus, much still remains to be done to examine the effects of providing patients access to their medical records. As Tsai and Starren (9) state, the most profound impact of personal health records may lie in their ability to encourage patients to become more active in managing their own care. This so called ‘patient-empowerment’ is a key theme of the Nationwide Health Information Network, which focuses on the patient as a critical partner in the flow of information (10).

A recent article by Tang et al. (2006) highlighted the importance of PHRs, in particular the contingency of adoption rates on individual perceptions of ease of use and realized personal benefits. However, a key barrier identified in prior work suggests that people have not formed complete mental models regarding the design, functions, and features of a PHR (11) and therefore, similar to any emerging innovation, adoption has been hindered by cognitive confusion. Simply put, if an individual does not fully understand what the functionality of a PHR is and how it operates, he/she is unlikely to adopt it.

The mental model of consumers has been confounded for many reasons. First, there has been very little public education or promotion given to the use and benefits of PHRs. Most healthcare consumers are not even aware of the initiatives currently underway to digitize and make interoperable their medical information. A recent nationwide opinion-poll found that a striking 70% of people were not aware of the federal government's initiative to make electronic health records available to all Americans by 2014 (12). With limited knowledge of these initiatives, it is difficult for people to conceptualize the technology and its value. Even for people with some knowledge of PHRs, there is confusion about the boundaries of the technology. For example, does a medication list constitute a PHR? Does a PHR have to span multiple providers? Must there be an element of continuity of care in the PHR? There is also the dilemma that there are numerous stakeholders involved in healthcare and many claim to possess the ability to provide PHR-like features and functions. For example, if a payor provides Internet-based access to a beneficiary's claims data, does this constitute a PHR?

Finally, the most challenging and troubling issue is that many people do not understand why they would want nor need a PHR. Its use only becomes more salient when tragedy strikes in the form of an accident, illness, or medical error. Within this study, we found that 26% of people believe their doctors maintain their medical information electronically, and 38% were not sure how the information was maintained or stored. To the extent that these people believe that their doctor possesses a complete electronic record of their health history, they are likely to be less interested in having this information themselves. In contrast, the reality is that by most accounts, less than 35% of hospitals (13-16) and less than 20% of primary care practices use electronic medical records (17-19). Therefore, it is critical to educate the public that in most cases, their historical electronic health record does not exist.

Some have argued that unless a clear vision for the Personal Health Record becomes informative and distinct, interest from potential stakeholders will wane. We believe that in order to facilitate the adoption and diffusion it is important to equip consumers and stakeholders with the necessary vocabulary and framework to build a robust, commonly understood, and widely accepted mental model of the PHR. Without this conceptualization, consumers will not know what they are being asked to adopt, researchers will struggle to tap into key barriers, and policy makers will make decisions based on incomplete or erroneous information.

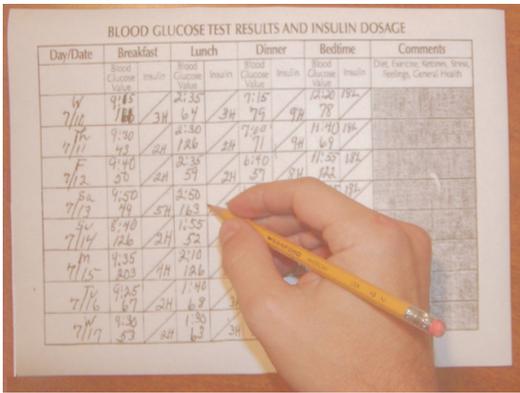
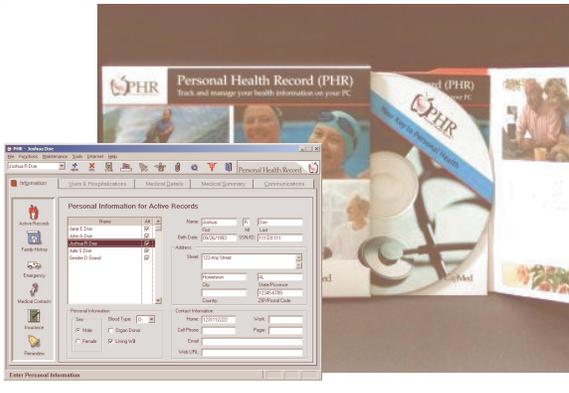
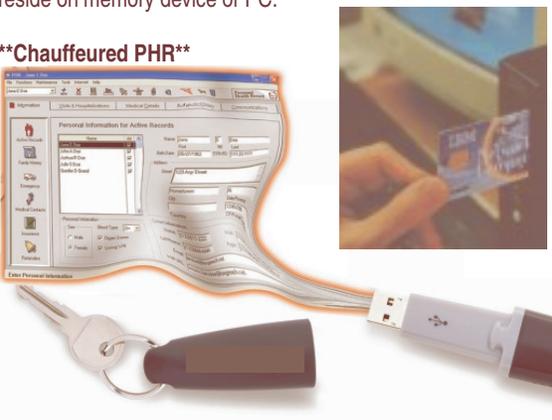
A. Description of the PHR

At the most basic level, a PHR is a health record for an individual. The semantics of a PHR are open to debate based on the interpretation of who should manage, enter, store, and update the information. At a macro level, the PHR is a tool for patients to self-manage their health and aggregate medical information. At a minimum, it should allow patients to view a copy of their provider-based information (20). The more pragmatic approach states that while it is a patient-centric form of the electronic medical record, the PHR itself is only a data set, and perhaps functions simply as a tool to see the data (21). A recent definition drawn from the Markle Foundation and extended by the Centers for Medicare & Medicaid Services is very comprehensive and reads:

“...a PHR is an electronic, universally-available, lifelong resource of health information to be used by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from health care providers, health plans, and the individual himself or herself. The PHR is maintained in a secure and private environment, with the individual determining rights of access to the information. The PHR is separate from, and does not replace, the legal record of any provider (22).”

While it is apparent that the industry is attempting to converge on a discrete definition, it is troubling that we are currently in a position where multiple interpretations and extensions occur. In our opinion, the conceptualized form of the PHR determines how well any of the proposed definitions apply. In the exhibit below (Figure 1), we label and define five form-factors for the PHR spanning from the most basic form of patient record – a paper-based document – to a fully digitized, electronic, interoperable PHR.

Figure 1. PHR Form-Factors.

PHR Form-Factors									
<p>OPTION 1. <i>Paper Entry.</i> Patient enters, updates, and manages health information on paper and stores it in binders, folders, or filing cabinets.</p> <p>**Primitive PHR**</p> 	<p>OPTION 2. <i>PC-based software.</i> The software is installed on a home computer where the patient enters, updates, and manages health information. Note: this may interface with the Internet in a "Quicken®" type model.</p> <p>**Detached PHR**</p> 								
<p>OPTION 3. <i>Device-based.</i> Patient can enter, manage, and transport entire record on the device. Participating providers will accept the device and populate it through a USB port or card reader. Software can reside on memory device or PC.</p> <p>**Chauffeured PHR**</p> 	<p>OPTION 4. <i>Internet Portal.</i> The software resides on the Internet and patients access it using a username and password from any computer with Internet access. Participating providers can populate the record and patients can grant access to others.</p> <p>**Tethered PHR**</p> 								

OPTION 5.

Hybrid - Internet Portal with Device. The software can reside on the memory device or Internet, allowing the patient to communicate with the repository utilizing Web services. This ensures the data synchronization and backup. Patient can either logon to the portal and access the information or use the memory device to login and access the information from the device in a secure and encrypted environment. Participating providers populate the patient's record through the device and/or the patient can link to the Internet to send and receive information.



****Networked PHR****

The five options represented above describe the PHR form-factors known to date, yet we acknowledge that there are variations and nuances to each that are viewed by vendors as competitive advantages. Along with several other issues, these structural forms do not identify who provides the PHR, who has access and who does not, how the data are coded and transferred, what should be contained within the PHR, and how barriers to adoption should be addressed. These questions are beyond the scope of this study, but it is extremely important that more research be conducted related to these topics. These form-factors will provide us an opportunity to be more explicit in our operationalization of the PHR and to proceed to more interesting questions about the uses and benefits. Our goal in creating the taxonomy for the PHR is to demonstrate the importance of identifying the PHR form-factor for future research; we do not seek to assess the advantages and disadvantages of each, but rather to use them as a basis for addressing our research questions.

B. Research Questions

With notably few exceptions (4-7, 10, 23-27), much of what we know about PHRs is a result of opinion poll data (12, 28-30). When national opinion polls are conducted, people respond according to their personal interpretation or mental model of a PHR. Our objective is to demonstrate that people's mental models of PHRs are very different and this incongruence

in conceptualizations affects attitudes and behaviors related to acceptance of the technology. For example, if a person believes a PHR is a Web-based software product that stores and manages personal health information, he will likely have a greater concern about privacy and security than he would if he conceptualized a PHR to be a PC-based software package.

Through our analysis, we will show that variations in conceptualizations of the PHR artifact will result in sharp and statistically discernible differences in perceptions. Much of the research thus far has been conducted on one specific type of PHR, namely the Tethered PHR (7, 10, 23, 26), and little is known about attitudes towards the other form-factors. Specifically, we address the following broad research questions:

RQ1: Do attitudes about PHRs vary depending upon the type of PHR form-factor conceptualized?

RQ2: Do attitudes about PHRs vary depending upon who is providing and maintaining the PHR form-factor conceptualized?

In the remainder of the paper, we develop our hypotheses, discuss the methods employed to investigate our research questions, present the results of the study, and discuss implications for practice and research.

II. Hypothesis Development

Prior literature has demonstrated that certain demographic characteristics are key covariates of IT adoption. For example, older people typically are not early adopters of IT (31) while highly educated individuals are usually early adopters (32). We argue that demographic characteristics will also affect the mental model of individuals and influence their conceptualizations and subsequent attitudes toward PHRs. This leads to our first two hypotheses:

H1: Older people will choose a more primitive PHR form-factor.

H2: People who are more highly educated will choose a more advanced PHR form-factor.

Recent research in the information systems literature has examined people's concern for information privacy (33, 34). Although that work focuses on people's attitudes about information privacy in a business setting; the survey items are highly relevant to any industry or organizational setting, including healthcare. The Concern For Information Privacy (CFIP) instrument is a multi-dimensional latent construct consisting of multi-item factors labeled by Smith, Milberg and Burke (33) as privacy concerns associated with *Collection*, *Errors*, *Unauthorized Access*, and *Secondary Use*. We adapted this validated instrument to our research context by replacing the word 'companies' with 'health care entities.' In order to understand beliefs about privacy, we also draw from the attitude and persuasion literature. Extant research reveals that people form stronger attitudes about 'attitude objects' as they gain more information (35). Research in social psychology also indicates that when individuals view an innovation as personally important or relevant in the near term, they will evaluate its use and value more thoroughly (36-39). Because uncertainty and confusion about the artifact are diminished when evaluation and knowledge of PHRs are greater, it is likely that those who are more involved in the use of electronic health records will be less concerned about privacy issues than the general population. We therefore test the following:

H3a: The general population (GEN) will be more concerned about *Secondary Use* of personal health information than those (MED) with more extensive understanding of electronic medical records.

H3b: The general population (GEN) will be more concerned about *Unauthorized Access* of personal health information than those (MED) with more extensive understanding of electronic medical records.

H3c: The general population (GEN) will be more concerned about *Errors* of personal health information than those (MED) with more extensive understanding of electronic medical records.

H3d: The general population (GEN) will be more concerned about *Collection* of personal health information than those (MED) with more extensive understanding of electronic medical records.

Finally, to more fully elaborate the first research question, we explore the relationship between attitudes and each PHR form-factor proposed above. Prior research informs us that people will err on the side of caution if they do not have a well-formed conceptualization of an innovation and will resist adoption (40). In addition, people have been shown to reject innovations they do not believe to be useful (41) or compatible with their beliefs, values, or preferred practices (42). To the degree that knowledge and understanding of PHRs is low, we argue that individuals will choose a simpler PHR form-factor.

H4: Respondents who have less general knowledge of PHRs will tend to choose a more primitive form of PHR.

To answer the second research question, we test the differences in a respondent's attitude about PHRs when various entities – employers, doctors, pharmaceutical companies, etc. – provide, sponsor, and/or maintain the individual's PHR. We hypothesize that differences in attitudes will result depending upon who provides the PHR and this difference will be driven by the perceived security or trust of each group.

H5a: People will choose a more advanced PHR form-factor when their *primary care physician* versus their *employer* provides, sponsors, and/or maintains the PHR.

H5b: People will choose a more advanced PHR form-factor when their *primary care physician* versus a *pharmaceutical company* provides, sponsors, and/or maintains the PHR.

III. METHODS

A. Study Design

To address some of the research hypotheses, we needed to examine two distinct groups of people in this study. One group is a random selection of healthcare consumers from a wide

range of backgrounds as a representation of the general population (GEN). A second group is a sample of people who had a more extensive knowledge of electronic medical records (MED), thus allowing us to test differences in attitudes across groups. For the latter group, we were provided access to an EMR user-group of 102 individuals who identified themselves as involved in the use of electronic medical records or having broad knowledge of them. The first group consisted of respondents from a random sample of people who had opted-in to an online survey sample list provided by ZoomerangTM. We collected data from 264 subjects through Zoomerang. In total, our sample size was 366 subjects and all completed a Web-based survey. We primarily used regression and analysis of variance techniques to evaluate our hypotheses.

IV. RESULTS

Prior to presenting the results of our hypotheses, we first present descriptives and demographic properties of respondents (see Table 1 and 2, respectively). Our dataset was slightly biased toward middle aged (between 35 and 60) females and more heavily weighted toward a high income population, relative to national statistics. Of note in the table are the significant differences between the general population (GEN) and EMR-savvy group (MED) on several variables such as PC experience and skill, and self-assessed health status. Consistent with prior research (27), we did not find any statistical evidence that chronic illness leads to a significantly increased desire for use of a PHR. That research showed that there were mediating factors, such as perceived value, that were directly related to intent to use PHRs.

Table 1. Sample Characteristics (Descriptives)

Variable	Description	Mean		Missing
		GEN	MED	
Age (Years)	Years	46.6	45.1	2
PC experience (Years)	Years	12.5*	16.0	4
Self-rated PC skills	1=None to 5=Very Extensive	3.54*	3.88	2
Health Status	1=Poor to 5=Excellent	3.58*	4.01	4
Information Privacy Concern (1=Strongly Disagree to 7=Strongly Agree)	Secondary Use	6.41*	6.07	10
	Unauthorized Access	6.20*	5.82	9
	Errors	5.80*	5.50	11
	Collection	4.70*	4.26	14

*Statistically significant difference ($p < 0.05$) between general population (GEN) and those knowledgeable of EHRs (MED).

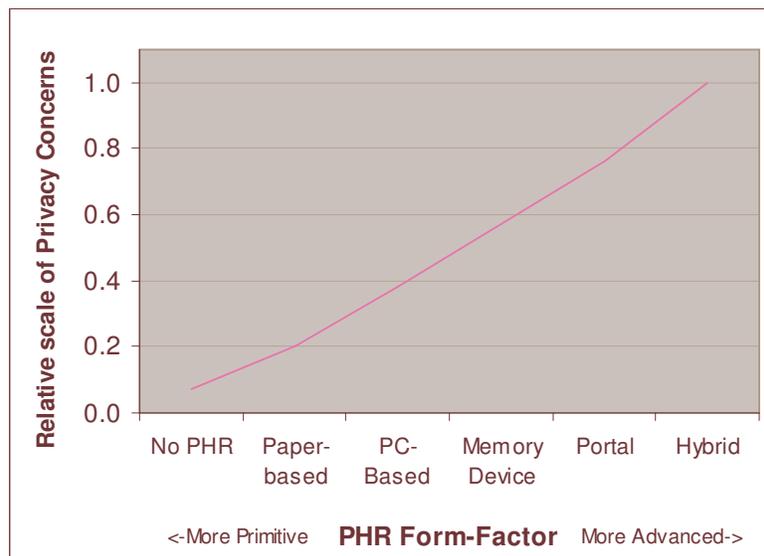
Table 2. Sample Characteristics (Demographic Properties)

Variable	Description	Count		Missing
		GEN	MED	
Gender	Male	84	60	4
	Female	176	42	
Chronic Illness	No	165	60	0
	Yes	99	42	
Preferred PHR Form-Factor	None	7	2	2
	Paper Entry (Primitive)	17	7	
	PC-based Software (Detached)	36	11	
	Device-based (Chauffeured)	51	18	
	Internet Portal (Tethered)	68	25	
	Hybrid, Portal & Device (Networked)	84	38	
Race	American Indian or Alaskan Native	2	1	1
	Hispanic	4	1	
	Black, not of Hispanic origin	19	2	
	White, not of Hispanic origin	224	86	
	Asian or Pacific Islander	7	7	
	Mixed racial background	6	1	
	Other	2	3	
Education	Some high school or less	2	2	1
	Completed high school or GED	31	3	
	Some college	90	9	
	Associates degree	20	9	
	Undergrad/bachelors degree	71	25	
	Masters degree	32	29	
	Beyond masters	18	24	

Industry employed	Healthcare and/or social services	0	72	6
	Not employed/retired	36	2	
	Homemaker	30	1	
	Student	24	0	
	Education	21	2	
	Retail trade	17	2	
	Professional, scientific, mngmt srvc.	15	3	
	Finance, insurance, real estate	15	2	
	Other	101	17	
	Annual income	Less than \$20,000	24	2
\$20,000 - \$29,999		20	5	
\$30,000 - \$49,999		51	6	
\$50,000 - \$74,999		61	12	
\$75,000 - \$99,999		20	16	
\$100,000 - \$124,999		15	14	
\$125,000 - \$174,999		8	11	
\$175,000 or more		3	17	
Decline to answer		59	18	

The relative perceived privacy and security of the various types of PHRs (as assessed by the respondents) is presented in figure 2 below. We normalized the data such that the privacy concerns associated with the hybrid form (Networked PHR) were considered to be equal to 1 and the other forms were calculated relative to the hybrid form. It is noteworthy that the privacy concerns associated with the use of a hybrid (Networked) are almost double that of the memory device (Chauffeured PHR).

Figure 2. Privacy Concerns Relative to PHR Form-Factor



A. Hypothesis Tests

We tested the impact of age on PHR form-factor in two ways. First we assigned each form-factor a relative scale ranging from 0 (primitive) to 5 (advanced), with ‘No PHR’ and ‘Hybrid PHR,’ respectively, anchoring the scale. We then simply regressed this ‘PHR complexity’ value on age. The second method we used was to conduct multiple planned comparisons using each form-factor as a single category and calculating the mean age for each category. We then compared age across each category. Interestingly, we did not find age to be a significant predictor of the preferred PHR form in either case: Regression $F(1,309)=.812$, $p=0.37$ and ANOVA $F(5,309)=0.598$, $p=0.70$). We discuss reasons for this contrary finding in the discussion section below.

As discussed earlier, an increased level of education typically leads to a higher innovation adoption rate. We tested the impact of education on the preferred PHR form and found marginal support for this hypothesis using the same methods as proposed above. Using a simple linear regression, our results showed that more highly educated people chose a more advanced PHR form-factor ($p=0.060$). We also conducted ANOVA with planned comparisons between each form-factor and found the largest differences in education level occurred between the Primitive PHR and the Hybrid PHR ($M_{educ_prim}=3.76$, $M_{educ_hyb}=4.68$, $p=0.09$), again demonstrating marginal support.

Our next set of hypotheses directly tapped into the differences in attitudes between the general population and those who are knowledgeable in the area of electronic health records. We tested H3a-H3d by statistically comparing the means of each form of privacy between the general population and the EMR-knowledgeable population. In all cases we found support that the general population was more concerned about privacy and security associated with

electronic medical records than the knowledgeable population (see Table 1; $p_{su}=0.01$, $p_{ua}<0.01$, $p_e=0.03$, $p_c=0.01$). Interestingly, we found that across both samples, people are more concerned about their privacy associated with secondary use of their data than they are with collection of the data.

With hypothesis 4, we tested whether self-assessed knowledge of PHRs led to different selections of PHR form-factors. We posited that respondents who had less general knowledge (see Appendix for survey item) of PHRs would tend to choose a more primitive form of PHR. Our results demonstrated marginal support for this hypothesis ($F(1,328)=2.794$, $p=0.10$). Finally, in hypotheses 5a-5b we posited that people’s preferred PHR form-factor would vary depending upon who provided, sponsored, and/or maintained the PHR. Our results conclusively supported these hypotheses. Using the same coding scheme for the form-factors as described earlier, we found that when primary care providers (PCP) provided the PHR, people chose more advanced PHRs ($M_{pcp}=3.60$). When the PHR was to be provided by their employer or a pharmaceutical company, people chose more primitive PHRs ($M_{emp}=2.01$, $M_{pharma}=2.17$). Using multiple planned comparisons, we found these differences to be statistically significant ($M_{pcp}>M_{emp}$, $p<0.001$; $M_{pcp}>M_{pharma}$, $p<0.001$), thus supporting H5a and H5b. Results of our hypothesis tests are summarized in Table 3 below.

Table 3. Hypothesis Testing - Results

Hypothesis	Description	Result
H1	Older people choose more primitive PHR	Not Supported
H2	More highly educated choose more advanced PHR	Marginal Support
H3a	General population more concerned about <i>secondary use</i>	Supported
H3b	General population more concerned about <i>unauthorized access</i>	Supported
H3c	General population more concerned about <i>errors</i>	Supported
H3d	General population more concerned about <i>collection</i>	Supported
H4	Less knowledgeable will choose more primitive PHR	Marginal Support
H5a	If PCP vs employer provides PHR, people will choose more advanced PHR	Supported
H5b	If PCP vs pharma provides PHR, people choose more advanced PHR	Supported

V. DISCUSSION and CONCLUSION

Our findings suggest that people's conceptualizations of PHRs determine their attitudes and beliefs about their use. Several interesting findings emerged; one of which was contrary to our original hypothesis. It was encouraging to find that age is not a significant predictor of PHR form-factor. We had argued, based on prior research (43), that older people would be resistant to the most advanced form of PHR because of the technological challenges it poses. In addition, we presented data showing that the most advanced PHR is perceived to create the most risk for privacy and security breaches. Thus, we had expected to find that older people would prefer a less advanced form. We explain this contrary finding by recognizing that older people require more healthcare services, which may be a stronger driver than age in regard to innovation acceptance. In simple terms, people might accept more advanced innovations if they believe their health can be improved by using the innovation, even if use is perceived as a privacy risk or as technologically challenging. There is also some evidence indicating that older people who have used a PC in their past, at work for example, are no more concerned than the average user about the privacy and security of their information (31).

Our other hypotheses were supported. We found that attitudes associated with PHRs are similar to those of other technological innovations: more knowledge of PHRs will tend to cause a person to choose a more advanced form. We also found that more highly educated people felt more comfortable with more advanced PHRs. This study demonstrates that people's beliefs vary greatly depending upon the particular stakeholder group providing and/or maintaining the information. Primary care physicians are significantly favored over employers in regard to holding patient information. This has implications for stakeholders associated with the design and delivery of PHRs as well as for policy makers and legislators.

We believe that PHR adoption and diffusion is an extremely important topic and, as such, should be researched in greater detail. It is not difficult to comprehend the vision of creating electronic health records for all Americans; but to understand the intricacies of PHRs and their uptake can be considerably more complex. Yet, evidence has shown that electronic health records may be crucial to improving the healthcare industry. Given the emphasis placed on HIT in recent government initiatives and funding (44-48), it is important to understand the challenges that lie ahead. Although our study sheds important light on how barriers to adoption can be addressed, there is more work to be done.

It is important to acknowledge that there were limitations to our study. First, there is a pro-innovation bias in our work. This in no way affects the results of our study, however, our interpretation and explanation of findings assumes that adoption and diffusion of PHRs is a valuable outcome for individuals and society. Our sample was not representative of the demographic makeup of the US because our intent was not to make broad statements about society as a whole but rather to probe specifically at the variations in attitudes as a result of ambiguities surrounding the definition, structure, and delivery of PHRs. Our goal was to compare specific groups of people, and this was achieved because our sample size was robust enough to provide for a statistically rigorous and valid comparisons. We also acknowledge, because our survey was Web-based, that our results may not be generalizable to those in our population who do not use a computer or the Internet.

Finally, we note that privacy and security is a relative term: what some view as private and secure, others will not. Because we used a validated scale to assess concern for information privacy, we believe some clarity was brought to the ambiguity surrounding privacy.

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A small portion of this study was presented at the 2005 TEPR Conference in Salt Lake City, UT. The vast majority of the content of this study has not been published or presented elsewhere.

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APPENDIX: Survey Items

Knowledge of PHRs

KNOW_PHR How familiar are you with electronic Personal Health Records (PHR)?

- 1 Never heard of them before now
- 2 Heard of them, but not familiar
- 3 I know a little about them
- 4 I know quite a bit about them
- 5 I have extensive knowledge of them

Concern for Information Privacy (33)

This section of the study deals with your concerns regarding privacy and security of information in an electronic medical record. "Healthcare Entities" include any and all parties involved in the healthcare process.

- PRIV_SU1 Healthcare entities should not use personal information for any purpose unless it has been authorized by the individuals who provided the information.
- PRIV_SU2 When people give personal information to a healthcare entity for some reason, the healthcare entity should never use the information for any other reason.
- PRIV_SU3 Healthcare entities should never sell the personal information in their computer databases to other healthcare entities.
- PRIV_SU4 Healthcare entities should never share personal information with other healthcare entities unless it has been authorized by the patient who provided the information.

- PRIV_UA1 Healthcare entities should devote more time and effort to preventing unauthorized access to personal information.
- PRIV_UA2 Computer databases that contain personal information should be protected from unauthorized access no matter how much it costs.
- PRIV_UA3 Healthcare entities should take more steps to make sure that unauthorized people cannot access personal information in their computers.

- PRIV_E1 All the personal information in computer databases should be double-checked for accuracy—no matter how much this costs.
- PRIV_E2 Healthcare entities should take more steps to make sure that the personal information in their files is accurate
- PRIV_E3 Healthcare entities should have better procedures to correct errors in personal information.
- PRIV_E4 Healthcare entities should devote more time and effort to verifying the accuracy of the personal information in their databases.

- PRIV_C1 It usually bothers me when healthcare entities ask me for personal information.
- PRIV_C2 When healthcare entities ask me for personal information, I sometimes think twice before providing it.
- PRIV_C3 It bothers me to give personal information to so many healthcare entities.
- PRIV_C4 I'm concerned that healthcare entities are collecting too much personal information about me.