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## Article

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## MANAGEMENT | RESEARCH ARTICLE

# Phenomenological study of decline of personal health records: Empirical evidence from thematic analyses of blogs' content

Ravi Chinta<sup>1\*</sup> and Vijay V. Raghavan<sup>2</sup>

**Abstract:** This study examines the current state of personal health records (PHRs) in electronic health care. Surveys report that the PHR usage is generally increasing, and yet, even an influential organization such as the Google decided to end its “Google Health” venture. If the potential for use and future growth is high, why are there so many obstacles to the adoption of PHRs? We analyze comments to articles and blogs related to PHRs in order to identify the current status, barriers to adoption, and future potential of PHRs. This study identifies issues of PHRs clustering mainly around certain key ideas: trust, communication, markets, standards, usability, politics, usefulness, and data ownership. It appears that disparity among the multiple stakeholders as to the expected benefits is the main barrier to its adoption.

**Subjects:** Healthcare Administration and Management; Healthcare Management; Management of Technology

**Keywords:** electronic health records; personal health records; Google health; barriers to sharing health records



Ravi Chinta

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### PUBLIC INTEREST STATEMENT

Using electronic media to document patient health records is now commonplace in health care institutions (hospitals, doctor office, same-day surgery centers, nursing homes, etc.) where health care is delivered. Google, Inc., the vanguard company in the cyber world, recognized that personal health records (PHRs) in the public cyber space would be a new growth area and started a PHR venture within Google. However, the lack of enthusiasm in adoption of PHRs has perplexed many stakeholders including organizations such as Google who at one time thought PHRs will become popular, but subsequently abandoned their presence in the PHR marketplace. Our study examines the barriers that impeded PHR adoption and led to their eventual decline. We recommend different PHR systems ranging from clinical to non-clinical dissemination of health information for use by patients, policy-makers, providers, payers, employers, and others who have increasing interest in using PHRs to improve health care outcomes, costs, quality, and efficiency.

## 1. Introduction

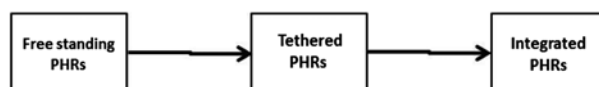
Personal health record (PHR) systems are more than just static repositories for patient data; they combine data, knowledge, and software tools, which help patients to become active participants in their own care. When PHRs are integrated with electronic health record systems, they provide greater benefits than would stand-alone systems for consumers (Tang, Ash, Bates, Overhage, & Sands, 2006). PHRs are patient-centric tools that can strengthen consumers' ability to actively manage their own health and health care. PHRs provide many benefits to the users. While their main goal is to record health profiles of users, PHRs can be used to track and assess users' health goals, make the most use of office visits to doctors, or simply getting organized by keeping records of appointments, vaccinations, surgeries, and preventive care treatments. They also have the potential to incorporate features such as prescription renewals and other communication tools for patients to connect with various health care providers. There have been contradictory indications as to whether PHR usage is really increasing and what benefits does it really confer to the patients. It has been reported that in California's Kaiser Plan (KP), of the plan's 8 million enrollees, 3 million use KP's *My Health Manager*, the plan's PHR (Sarasoehn-Kahn, 2010). There are others who claim that PHRs are a new concept to most people, and early users have found them difficult to use. IDC Health Insights, a research firm, found that only 7% of health care consumers had tried online PHRs, and fewer than half of those continued to use them (Lohr, 2011). Additional evidence is available for lack of adoption of PHRs as indicated by closing of PHR services such as the ones from Google and Revolution Health. And yet, a leading survey (Markle Foundation, 2011) suggests that PHR adoption is trending upward, from 3% in 2008 to 10% in 2011.

According to a PHR executive who had considerable experience with Google Health, the future of PHRs depends on a host of issues that need to be resolved before PHRs can enjoy wider adoption. Health is paternalistic and consumers are generally blind to both cost and health care data. Health information is generally boring and not social enough. PHRs of today strive to do too much and as a result lack enough functionality to be appealing to a large volume of users as they are generally designed to store structured medical data that come from the established medical industry. Medical archiving that PHRs are designed to achieve is not appealing to users.

## 2. Types of PHR

An important objective of a PHR is to provide its users control over their health data. The extent to which this goal can be achieved can depend on how and where exactly they host their data. *Stand-alone PHRs* such as Microsoft's Healthvault allow users to store their health data without any commitment to any health care organization other than the ones hosting the PHRs. One of the main disadvantages of such stand-alone PHRs is that they often require users to enter their own health data manually. Another disadvantage is that health care providers often distrust the data stored in stand-alone PHRs. At the other end of the PHR spectrum is the *Completely Integrated PHRs*, which theoretically could draw from any number of sources ranging from pharmacy data to insurance claims, although patients could enter data into specific areas to manage their own health care. It appears that while there are no true completely integrated PHRs available, some do exist to manage specific illnesses with narrow clinical scope (Detmer, Bloomrosen, Raymond, & Tang, 2008). *Tethered PHRs* are PHRs provided by health organizations such as hospitals or insurers for their subscribers to maintain their health information. In the Markle survey, 62% of respondents say their doctors or hospitals offered their PHR. These are often referred to as the tethered PHR and it is possible that there may be increased adoption from the tethered side. At the other end of the spectrum, as shown in Figure 1, exist free-standing PHRs that dynamically change in terms of content with very loose links to clinical

Figure 1. Taxonomy of PHRs showing depth of clinical data.



data sources such as pharmacy data and insurance claims. A shift along the spectrum is evident from non-clinical information focused on preventive care and general health maintenance to clinical information focused on specific disease-based data.

When PHRs are viewed from the substantive content maintained in them, it becomes evident that there are a variety of PHRs in existence (Jones, Shipman, Plaut, & Selden, 2010). Lack of standards, a point discussed later in our thematic analyses, could make information sharing across PHRs more difficult (Shortell, Rundall, & Hsu, 2007; Young & McClean, 2008). There is a gap between the wide variety of PHRs and what patients say they want and need from this electronic tool for managing their health information (Kahn, Aulakh, & Bosworth, 2009). That gap can be bridged only by tailoring each type of PHR to the specific needs of the targeted participants. Blogs on the Internet provide a forum for expressions by participants with regard to PHRs. Kim, Jung, and Bates (2011) trace a historical trend in PHRs that were originally patient centered and clinical data focused to PHRs that have come to address mixed uses that are not necessarily patient centered and clinical data focused. Mixed uses of health records include such activities as analysis, research, quality and safety measurement, public health, payment, provider certification or accreditation, marketing, and other business applications, including strictly commercial activities (Safran et al., 2007). The proliferation of different types of PHRs as shown in Figure 1 substantiates this historical trend leading to the birth of diverse PHRs. Research by Pang and Lee (2008) suggests that broader issues such as health care privacy laws could deter wider proliferation of individual PHRs, despite the growth of social media.

### 3. Research method

Eight articles and blogs that were directly related to PHRs were selected based on the presenting organizations' reputation, authors' credentials, and the popularity as indicated by the number of response comments. The presumption is that those who write about and comment on these web pages belong to certain interest group stakeholders studying the evolution of the personal health care records. Opinion leaders are those who carry information across social boundaries between groups. Diffusion research confirms how opinion leaders play their role of brokering information between groups (Burt, 1999). The role of opinion leaders facilitating adoption in the domain of health care has also been recognized (Veith et al., 2001). There was no judgment involved in identifying the idea clusters as the comments were directly related to one or more of the idea clusters. Since the goal of the study is to simply identify the idea clusters surrounding the adoption of PHRs, but not their relative importance, there is no author bias introduced in classifying the ideas. Direct recitation of the comments throughout the article was done to minimize the author's rephrasing bias. We used the "tm" text analysis package in R to first create a corpus of the eight blogs as separate texts, and followed frequently used steps in text analyses (Feinerer, Hornik, & Meyer, 2008). We first removed numbers and punctuation, and then stripped white spaces using the built-in functions of the package. We then converted all words to lowercase and removed the stop words. These stop words are common English words such as a, an, the, that, etc. that do not have semantic relevance to the context. We then performed a stemming operation using the "tm" package to treat all the words of a root the same. We removed the sparse terms—terms occurring only in a few documents (Table 1).

**Table 1. Source blog characteristics**

Article	Total words	Unique words	Number of comments	Mean frequency
Krasner (2011)	7,058	1,944	42	3.63
Goldstein (2008)	6,456	1,722	37	3.75
Grohol (2011a)	2,206	811	13	2.72
e-patients.net (2011)	1,890	746	15	2.53
Kuraitis (2007)	9,370	2,339	34	4.01
Grohol (2011b)	2,608	940	10	2.77
Chase (2011)	4,426	1,364	31	3.24
Schrage (2011)	8,198	2,267	50	3.62

#### 4. Idea clusters

One of the authors read all articles and comments to identify whether the writer was a physician, patient, member of a PHR provider organization, or health care provider other than a physician. A word cloud of the words in all the articles together is provided in Figure 2 to give the reader a flavor of the current discussion on PHR. Higher the frequency of occurrence of a given word, bolder is its representation in the word cloud. For example, the words “patient” and “information” appear to be prominent in Figure 1 because they have high frequencies of occurrence in the verbiage. Likewise, the words “social” and “current” have low frequencies of occurrence and hence show up in very small or insignificant size in the word cloud. Prima facie the word cloud may not reveal statistically significant interrelationships among conceptual constructs, but it does uncover some thematic roots in the conversations’ verbiage.

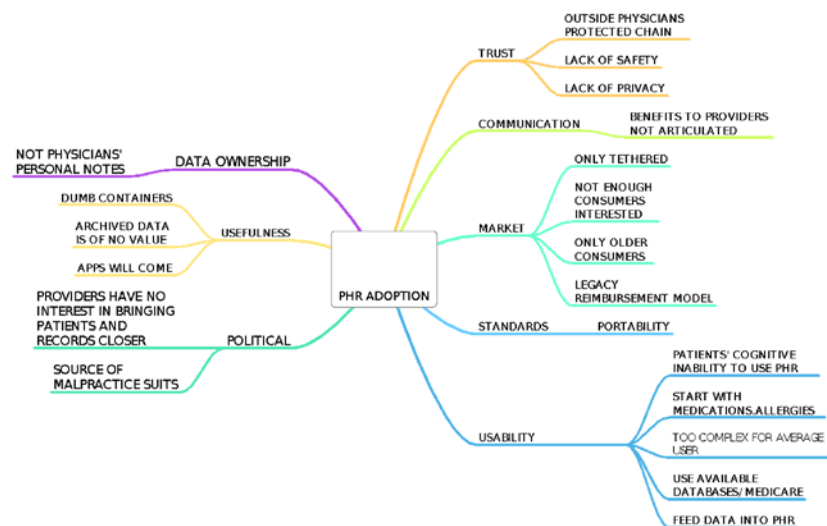
If a Martian (or someone who has no prior knowledge about the phenomenon under study) were given the word cloud and asked to write a narrative on the dominant themes to reconstruct the phenomenon, like an archaeologist does with excavated fragments, then some logical research hypotheses may emerge from a closer scrutiny of the word cloud. Ideas are then clustered and a mental map of the phenomenon emerges from the word cloud. The phenomenon of PHRs is described in a mental map shown in Figure 3. Like an archaeologist, we are surfacing the latent story that underlies the use of PHRs. Our reconstructive writing based on the mental map in Figure 3 elucidates the prospects and use of PHRs. The notes based on the key ideas of the write-up are described in the mental map presented in Figure 2 and are presented in the discussion that follows. In developing the narratives through thematic analysis, the synonymous words and phrases were woven together to make meaning for each of the idea clusters. Specific quotations from the blogs that are relevant to each theme are also highlighted for each of the revealed themes.

**Figure 2. Word cloud of the text in all source files.**





**Figure 3. Mind map of the idea clusters.**



## 5. Trust

A user can painstakingly maintain a PHR, but if a health care provider is unwilling to use it, it may not provide its intended benefits. Lack of trust by physicians seems to be a factor contributing to a poor adoption of PHRs. The information from PHRs is outside of the protected chain for a physician, so the doctors are going to repeat the tests, even though the results are available through a PHR and are done by another trusted health care provider. While many writers generally acknowledge this lack of trust, occasionally some disagree. One blogger commented,

I use a PHR to help me manage all the details about my medications, and I use it to keep track of my insurance information. Now my children (who care for me) all have access to the same information to help me manage my medications. When I go to the doctor's office, I simply hand them my customer card, and they print off my list of medications. I cannot remember them all to fill out all their forms. You're telling me the doctors don't trust it? (Grohol, 2011a)

Another writer questioned the very term protected chain on the grounds that the physicians do not verify with the protected chain when you personally tell them the medication that you are currently using; secondly, the health care system has not been able to provide a protected chain that patients can participate in (Goldstein, 2008). Aside from the distrust of the physician who may not trust the PHRs, many patients themselves do not trust the PHR due its lack of privacy and safety (Becker & Sewell, 2004).

### 5.1. Lack of privacy

The word "privacy" was mentioned 44 times in our text entries. Many lamented how PHRs are vulnerable to privacy violations and it was mentioned frequently as a reason for non-adoption. McGraw, Dempsey, Harris, and Goldman (2009) suggest that privacy is an enabler, not an impediment to building trust into health information exchange. Thus, an open systems design for PHRs can be expected to fail compared to proprietary systems design for PHRs, especially when the health data relate to clinical information such as procedures done, etc.

A writer expressed an interesting dimension of how privacy is viewed in the context of PHRs. Most privacy laws govern the sharing of data between health enterprises and support the right of patients to obtain their health information and use it as they wish. So, if the data that might usefully flow between health enterprises used the patient (or patient-controlled agent) as an intermediary, then the patient would have control over his/her health information flow. This would eliminate the typically complex decision about whether sharing the data was permitted under law. Generally, it seems

that the question for a health enterprise would turn from “Can I release this data without risking violation of a privacy law/regulation?” to “Is there a solid rationale for me to resist releasing this data?” While such a model would move some power from health care enterprises to their customers (and so they may resist), it seems to be consistent with the idea of a patient-centric model generally and seems to solve the sharing problem to most customers’ satisfaction (Kuraitis, 2007).

A user articulated privacy concerns: “... an online PHR service provider can have access and steal private information of patients and sell it to insurers in spite of the privacy policies and security measures. Personally, I too feel that privacy risks of PHRs outweigh the potential benefits especially at the current level” (Goldstein, 2008).

### **5.2. Lack of safety**

Federal Trade Commission (FTC) has instituted a breach notification rule for PHRs, which requires covered entities to report the FTC’s breach notification rule. This rule mandates reporting of incidents involving unauthorized acquisition of unencrypted PHR information that contains personal identifiers. The FTC has posted a list of 13 incidents affecting 15 individuals in 2009. All were reported by Microsoft Corp., which offers the HealthVault PHR platform. Each case involved lost or stolen credentials, and none of the cases involved is known to have resulted in inappropriate use of patient information (Anderson, 2010). Yet, security remains an important reason for non-adoption because the information maintained could be directly stolen from the storage devices (Li, Yu, Ren, & Lou, 2010). The use of the Internet as an interface appears to have contributed to this concern. The term “security” was used 26 times and the term “safety” was mentioned 5 times. There is a sense that consumers want to use PHRs not in the same fashion as social networks; they want the data to be secure and private. Abbas and Khan (2014) conclude that storing the patient health data in the third-party servers also entails serious threats to data privacy and lends itself to unauthorized usage of health data for uses other than patient care. Privacy-preserving approaches classified into cryptographic and non-cryptographic approaches will be increasingly employed in varying degrees based on the type of PHRs (Mandal, Sarkar, & Chaki, 2015).

### **6. Communication**

Many believe that the benefits of PHRs are not clearly articulated to potential users as well as to providers. There is a sense that Google might have given up on its PHR venture too soon. Some health care providers believe that the data recorded in a PHR are static or even erroneous, and PHR is meant to be just a data repository. The possibilities in a correctly implemented PHR must be communicated to all parties clearly. Communications make clear the vision and purpose of PHRs as being beneficial to all participants (Lorenzi, Kouroubali, Detmer, & Bloomrosen, 2009). The emerging themes from the blogs reveal a lack of clear articulation of benefits of PHRs. Even a suspicion of errors in PHRs would make them unreliable instruments as data repositories (Nanji et al., 2011; Slight et al., 2013).

### **7. Market**

Younger consumers of health care really do not care about PHRs. Only older adults and people who have chronic illnesses have the need to think about PHRs. This is often cited as the reason for Google not being able to monetize PHRs in the way they hoped to. Google’s reason for closing its PHR was stated as, “Google Health is not having the broad impact that we hoped it would. There has been adoption among certain groups of users like tech-savvy patients and their caregivers, and more recently fitness and wellness enthusiasts. But we haven’t found a way to translate that limited usage into widespread adoption in the daily health routines of millions of people” (Brown, 2011). A frequent criticism of PHRs is that it is a static repository of data with no meaningful applications to make use of the data. Health care providers are not interested in making these applications, as the providers will not get paid unless there is a face-to-face visit by the patients. This flawed reimbursement model contributes to the lower than potential market for PHRs. Different markets require different products. Likewise, there is a distinction between electronic health records and electronic medical records (Garets & Davis, 2006).

## 8. Standards

PHRs are not portable since there are no commonly accepted standards of how the data are collected, what data are collected, and how they are stored. Since the general use of PHRs is at a nascent stage, users often experience the need to try different systems or they are forced to adopt different systems due to changes in the providers. The lack of standards means that the data that were collected painstakingly suddenly become unusable since the providers have changed. A user expressed concern about the inaccurate statements on the lack of HIT standards. He argued that the problem is that the standards were not yet widely adopted. The specs for “Consumer Empowerment” including exchange of the data included in CCR (using the APPROVED, not future, HL7 CCD XML specification) have existed for nearly a year, were created through an open multi-stakeholder public process (not unilaterally), and were accepted by ANSI, HITSP, and HHS. HITSP’s interoperability specs include the coding standards. Those accepted standards are in existence and in process of being implemented. Thus, rallying around those standards would help both providers who have EHRs, as well as patients who have PHRs to all be interoperable without divergent and wasteful efforts (comment in Kuraitis, 2007). The role of standards in the rapid adoption of electronic health records in hospitals has been well documented (Boonstra, Versluis, & Vos, 2014; Hayrinen, Saranto, & Nykanen, 2008). Interoperability of data elements is essential for wider adoption of electronic health records.

## 9. Usability

A general criticism of PHRs is that they are too complex to use and many PHRs require patients to become data-entry clerks. Some users feel that providers should be mandated to feed data into a PHR of patients’ choice who can share it with whoever they want to share it with much in the same fashion as social networks. Some highlight the need to educate users to make them more prudent users of health care and at the same time advocate the need for being portable and not be tied to providers.

Suggestions have been made to start with simple and immediately useful areas such as inclusion of medication and allergies. One possible way to improve their usability is to automatically feed data into it from source systems that collect data. Available databases such as Medicare have vast amounts of data that can be fed into PHRs to improve their usability. A common source of complaint appears to be the fact that users have to enter data into it. Weiner, Kfuri, Chan, and Fowles (2007) coined the term e-Iatrogenesis to refer to the problems of data entry burdens and errors that can impair the data quality in PHRs.

## 10. Political

Other objections to PHR are political in nature, as can be discerned from the data provided through the blogs. Providers, in general, have no interest in bringing the patient and data together. One medical practitioner commented in a blog, “Unfortunately medical records are also the underlying source of ‘facts’ that frame medical malpractice claims. In medicine today, the medical record is the doctor’s, with patients having the right to access it and under some conditions amend it. If a medical record is no longer 100% accessible to the physician, at risk for unintended disclosures and/ or not guaranteed with respect to fidelity, there arise a number of very significant medical liability issues (James Knight MD in Wall Street Blog).” These political pressures can be alleviated either through mandates or through patients’ collectivism, either of which is tall order to expect to happen in the short run (comment in Goldstein, 2008). The legal implications of PHRs extend beyond changes in medical malpractice liability. Other important consequences include potential liability under privacy and confidentiality laws, disputes over ownership of health data, heightened vulnerability to Medicare or Medicaid fraud claims, and so on (Mangalmurti, Murtagh, & Mello, 2010).

## 11. Usefulness

The information flow in health care systems typically tends to either payment centric or claims centric. Unfortunately, there is a disconnect between this “payment centric information flow” or claims information and “clinically relevant information flow” or what is currently charted in paper format in the



medical care transaction, resulting in the lack of usefulness of automatic information in PHRs (comment in Kuraitis, 2007): small booklets that record well-baby appointments, with basic information such as weight and height being recorded, and most critical, with immunization records. Mothers have maintained such basic “Portable Health Records” over many years. Whereas these records were simple, they were typically accepted as legal proof of immunizations for school purposes. When a family moved, the next pediatrician or school nurse used these “patient records” quite happily. Some lament: Why is it hard to encourage more of the same in the mobile world? (comment in Dave, 2011). Like every other, EHR has to not only get the data, but it has to be reliable and available. Some of the most useful data are that which are not contained in the EHR, but those that are locked up in outpatient devices. Getting this data into the EHR for use in clinical interventions will make a huge difference in outcomes (comment in Kuraitis, 2007). Consequently, integrated PHRs are thus seen to be much more useful than free-standing PHRs, as noted in Figure 1 (Buntin, Burke, Hoaglin, & Blumenthal, 2011).

## 12. Data ownership

“A key issue in this debate is the flawed mindset that a medical record is the physician’s personal notes, not the patient’s record. The medical record should be viewed as a team document, intended to be shared with others as the patient navigates the health system. Physicians are not yet incented to collaborate in this manner, so variability in documentation style and structure make information sharing difficult.” Doctors resist the secondary use of health data because of a diverse set concerns that are complex, ethical, political, technical, and social since they view health data ought to be patient centered and private (Safran et al., 2007).

## 13. Conclusion

Our phenomenological study of the decline through a thematic analysis of blogs revealed several barriers that impeded PHR adoption and led to their eventual decline. Patients, policy-makers, providers, payers, employers, and others have increasing interest in using PHR to improve health care costs, quality, and efficiency. The lack of enthusiasm in patient adoption of PHRs has perplexed many stakeholders including organizations such as Google who at one time thought PHRs will become popular, but subsequently abandoned their presence in the PHR marketplace. And yet, it appears that adoption of PHRs can be very beneficial to patients. It is not only the job of participating organizations but also the responsibility of those who are engaged in health care research to study the usefulness of PHRs and explore the reasons for its lack of an enthusiastic adoption. It is a socially responsible thing to encourage the adoption of meaningful use of PHRs. Our study identified many barriers for PHR adoption and in particular avers that PHRs lack standardization which is impeding their adoption. This article highlighted several areas in which future research could be conducted by exploring the comments of various stakeholders in the domain of PHRs, adding to the scope of new research suggested by Kaelber, Jha, Johnston, Middleton, and Bates (2008) and Archer, Fevrier-Thomas, Lokker, McKibbin, and Straus (2011). The comments that were qualitatively studied included a variety of participants such as doctors, patients, and software vendors providing multiple perspectives of the adoption of PHRs (Schrage, 2011). We predict that integrated PHRs will proliferate with standardization and free-standing PHRs will gradually wane into the oblivion. Google Health’s move to exit PHRs buttresses our view of the future of PHRs.

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