

Viewpoint Paper ■

A Research Agenda for Personal Health Records (PHRs)

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Abstract Patients, policymakers, providers, payers, employers, and others have increasing interest in using personal health records (PHRs) to improve healthcare costs, quality, and efficiency. While organizations now invest millions of dollars in PHRs, the best PHR architectures, value propositions, and descriptions are not universally agreed upon. Despite widespread interest and activity, little PHR research has been done to date, and targeted research investment in PHRs appears inadequate. The authors reviewed the existing PHR specific literature (100 articles) and divided the articles into seven categories, of which four in particular—evaluation of PHR functions, adoption and attitudes of healthcare providers and patients towards PHRs, PHR related privacy and security, and PHR architecture—present important research opportunities. We also briefly discuss other research related to PHRs, PHR research funding sources, and PHR business models. We believe that additional PHR research can increase the likelihood that future PHR system deployments will beneficially impact healthcare costs, quality, and efficiency.

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Introduction

Today, an estimated 70 million people in the US have access to some form of personal health record (PHR). Such access in many cases comes through patients' health insurers or healthcare providing institutions, even though most patients may not be aware of it.¹ Patient surveys suggest that patients want to use PHRs and believe that they will be valuable. One survey found that about 75 percent of Americans report they would communicate electronically with their physicians if given the means to do so,¹ while another study found that 60 percent of patients said they would look up test results and track medication use through PHRs if these records were available.²

Many healthcare information technology vendors and healthcare providers already have the tools available to offer PHRs to their customers and patients. For example, an estimated 50 million patients see healthcare providers who use the EPIC EHR (Electronic Health Record) software

system, which includes a tethered PHR product. The EPIC "MyChart" application provides a Web-based portal that allows patients access to a variety of PHR functions, such as reviewing test results and scheduling appointments. The Department of Veterans Affairs (VA), with its approximately 25 million veterans, has a Web-based PHR called MyHealtheVet, which allows US veterans to obtain authoritative health information, link to federal and VA benefits and resources, access a personal health journal and request prescription refills online.³ A number of health plans and employers also offer or are planning to offer PHRs to their members and employees in the near future. For example, the Blue Cross and Blue Shield Association has teamed up with American's Health Insurance Plans to offer a PHR to the more than 200 million members covered by these organizations by the end of 2008.⁴ In the Dossia project, launched in 2006, large employers Intel, Wal-Mart, Applied Materials, British Petroleum, Pitney Bowes, and others, have committed millions of dollars to create a web-based framework that will supply over 5 million of their employees with access to personal health data through a common open-source architecture framework.⁵ In the second half of 2007, Microsoft[®] debuted HealthVault[™] which allows anyone with internet access the ability to search for health information, store their own health information, and upload their health information from home health devices.⁶

Interest and investment in PHRs can have multiple motivations. Some organizations have implemented PHRs to try to create "stickier" relationships with their patients or enrollees through improved patient satisfaction,⁷ while others may be motivated by goals of efficiency, increased patient empowerment, or improved disease management.⁸ Almost all the investments in PHRs have focused on product development and implementation, and not on evaluation or research, as demonstrated by the low publication rate in this field. Ultimately, PHRs will succeed if patients use them enough

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Table 1 ■ Categorization of Existing PHR PubMed Citations

Category	# of References	%*
PHR Adoption and Attitudes	16 (18, 19, 22, 25, 27, 33–43) (44–47)	24%
PHR Architecture	2 (27, 48, 49)	3%
PHR Function Description (without evaluation)	4 (13, 22, 44, 50, 51)	6%
PHR Function Evaluation	15 (12, 14–17, 36, 39, 40, 52–59)	22%
PHR Position Statement/ Editorials	19 (34, 46, 47, 58, 60–96)	28%
PHR Privacy and Security	8 (26, 97–105)	12%
Other	10 (106–133)	15%

*- 10% fell into more than one category.

and they provide some combination of improved quality, increased safety, enhanced efficiency, and/or better patient satisfaction both for acute and chronic conditions, along with a reasonable ease of use. These attributes are valued by various healthcare constituencies—patients, providers, payers, employers, and others—and may generate healthcare cost savings to some or all of these parties. The PHRs might conceivably achieve widespread acceptance and use if patients demand and employ them even, if the PHRs do not deliver measurable value. However, under such circumstances, patients might have to pay for PHRs directly. In any case, we believe the lack of evaluation and the current rudimentary understanding of how PHRs can specifically contribute to healthcare quality, safety, efficiency, and patient satisfaction threatens the viability and sustainability of these systems.

In this paper, we propose a research agenda for PHRs, in the same spirit as past frameworks for other areas of clinical informatics.^{9,10} If carried out, the suggested research agenda could provide important insights that would increase the likelihood that PHR implementation will lead to better, more efficient healthcare, and improve patient outcomes.

PHR Description

One of the challenges in delineating a PHR research agenda is the absence of a consistent description of what a PHR actually entails. Although many descriptions and definitions exist, for our purposes, we have used a relatively broad description, put forward by the Markle Foundation. A PHR is:

“a set of computer-based tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it.”²

We recognize that the Markle Foundation description is one of many PHR descriptions, that many definitions are evolving, and that the dominant future PHR description remains unknown.¹¹

Existing PHR Research

To assess the published research focused on PHRs, we performed a PubMed search of the terms “personal health records” and “PHRs” from 1950 through 2007 and found 100 unique citations related to PHRs. By comparison, an equivalent PubMed search under the terms “clinical decision

support” yielded 17,396 citations and under the term “asthma” yielded over 100,000 citations.

We reviewed each of the 100 citations and grouped the citations into seven main categories (Table 1). Overall, 10% fell into more than one category. Most of the citations fell roughly equally into the PHR adoption and attitudes, PHR function evaluation, and PHR position statements/editorials categories. Of the seven categories, four appear to offer significant research opportunities:

- PHR Function Evaluation
- PHR Adoption and Attitudes
- PHR Privacy and Security
- PHR Architecture

Approximately 60% (24 of 41) of the citations in these four categories included original primary research (Table 2).

PHR Function Evaluation

At this stage of development and deployment, PHR function evaluation may be the most important area of PHR research. Ultimately, PHR functions are likely to drive data, infrastructure, and interoperability requirements, as well as adoption.

The crucial areas for PHR research are better delineation of their functions and of their impact on care. Primary PHR functions fall into four general categories, based on use of information from the patient's perspective:

- Information Collection—PHR functions that help patients to enter their own health information and to retrieve their information from external sources.
- Information Sharing—PHR functions that allow patients to engage in one-way sharing of their health information with others.
- Information Exchange—PHR functions that allow patients to engage in two-way data exchange with others.
- Information Self-Management—PHR functions that allow patients to better manage their own health/healthcare. Examples of PHR functions in this category include those functions that allow patients to record, track, and edit information about their own health/healthcare, as well as obtain relevant patient oriented disease information and decision support.

Based on our literature review, most previous PHR research focused on the areas of information self-management and information exchange. In these areas, PHRs have the potential to dramatically improve the patient-provider relationship, enhance patient and shared decision making, and enable the healthcare system to evolve towards a more

Table 2 ■ Categorization of Primary Research PHR PubMed Citations

Category	# of References	%
PHR Function Evaluation	10 (12, 14, 15, 17, 36, 39, 40, 52–55, 59)	8%
PHR Adoption and Attitudes	13 (18, 19, 22, 25, 33, 35–41, 43, 45)	19%
PHR Privacy and Security	0	0%
PHR Architecture	1 (48)	1%

personalized medicine model through the integration of more individualized healthcare information in patient care.^{12–17}

Numerous research opportunities exist to evaluate each area of PHR functionality with respect to the outcomes of healthcare quality, safety, efficiency, cost, and patient and provider satisfaction. The impact of PHRs on care for patients with chronic conditions represents a particularly important research priority given the extremely high associated costs and the potential to improve quality and efficiency. Research should quantify the overall value derived from composite PHR systems—not just the value of individual functions or impact on individual patient-provider pairs.

PHR Adoption and Attitudes

Understanding and addressing attitudinal and physical adoption barriers among patients and healthcare providers represents an important key to achieving widespread implementation and use of PHRs. As noted earlier, patients have expressed willingness to use PHRs, at least for certain functions such as viewing test results and tracking medications.² Less information is available about provider attitudes toward PHRs. Nevertheless, some studies suggest that physicians may be more reticent to adopt PHRs than other health professionals, due to concerns about whether adoption of PHRs will create additional work that is not reimbursed.^{18–21}

Studies of adoption generally show relatively low adoption rates among patients who have been offered access to a PHR, which have typically been free to them. This might be unexpected, given the high reported desire for this technology by patients, but is perhaps not so surprising given the lack of use cases that demonstrate proven value and the lack of proven business models for PHRs. Studies also report low use among providers,²² and routine, monthly use among patients is generally well below 10% of users who have access to a PHR.^{23,24} While it is unclear what benchmarks for PHR use are appropriate, without substantiated PHR use cases for patients, providers, and other constituents, and business models that clearly articulate the value of PHR, PHR adoption will not reach its full potential.

A review of PHRs in cancer care concluded that, while patients welcome PHRs, they do not yet use them effectively.¹⁶ These trends mirror research in paper based PHRs, which show high support for PHRs, but relatively low utilization.²⁵ This suggests that until PHRs provide valuable functions that improve care on some level, or in other ways promote “stickiness,” adoption rates will remain low.

Research on adoption and attitudes should focus on:

- specific populations, including the underserved, elderly, and patients with chronic illnesses, including what can be done to improve adoption in these populations and what reasonable adoption benchmarks may be, though these will likely vary by population.
- trends in adoption to determine when uptake might be approaching a tipping point.
- factors associated with attitudes, adoption, and use, ranging from basic usability testing to patient-level factors (i.e., age, education, health literacy, accessibility, etc.) to organizational factors (i.e., PHR from providers versus

payers) to structural features (i.e., PHRs tied to an EHR versus free-standing PHRs).

- ways to improve provider attitudes toward PHRs, and
- barriers to the use of these systems by patients and providers.

PHR Privacy and Security

Patients’ greatest concern about nearly every type of electronic healthcare applications, including PHRs, is security and privacy. Ninety-one percent of people report they are “very concerned” about the privacy and security of their personal health information.² While the Health Insurance Portability and Accountability Act (HIPAA) of 1996 outlines the legal protections for PHR privacy and security, it does not address all the issues involved, especially because HIPAA only applies to “covered entities” including health plans, healthcare clearinghouses, and healthcare providers. Organizations like Dossia, Microsoft®, and Google® are not covered entities. Potentially, PHRs (as with EHRs) could protect patient privacy and security in ways that are much more secure than traditional paper-based patient records, such as password protecting and audit tracking. On the other hand, the security provided by paper-based records existing in only a small number of physically accessible places makes the risk of multi-site unauthorized PHR access seem greater. Despite the potential technological privacy and security advantages of PHRs, the general public appears more concerned about these issues for electronic records than for paper-based records. This is not surprising, given a number of recent highly publicized thefts and inadvertent disclosures of personally identifiable electronic information.

Several important issues regarding PHR privacy and security need better evaluation. The first involves who controls sharing and accessing of the information in a PHR. This is critical when many organizations and individuals are sharing data within the PHR. For example, patients may include children or others who do not have legal control over their healthcare information in their PHR record, and patients may want to share their PHR with others not in healthcare. The privacy and security interoperability issues with PHRs have many parallels to privacy and security issues associated with regional health information organizations (RHIOs). Clear tradeoffs exist between privacy, security and access, even for patients.

A second concern is how to optimally design PHR systems in order to allow patients to maximize the security of their PHR. For example, patients may have difficulty remembering or finding their passwords when it is time to use them. If password recovery is too difficult, it may diminish use, while if it is too easy, it increases the likelihood of security breaches. A third related issue of who controls information in a PHR (privacy) and how it is controlled (security) is authentication methods which ensure both privacy and security yet in doing so do not present a major barrier to access. Authentication is vitally important both in terms of people accessing the PHR and data entering the PHR. Although robust authentication methods have been worked out in the financial services sector and other areas, it remains to be seen how well these models will work for PHRs.

PHR issues around control over sharing and access to PHR data present even more complex issues, especially consider-

ing a patient controlled PHR and patient proxies. For example, determining appropriate permissions for parents' accesses to their children's records, or for caregivers' access to mentally compromised patient's records, is extremely complex. The perception of PHR privacy and security (and data reliability) will depend on who is hosting the PHR. Many people may think of privacy and security issues differently for a PHR hosted by their provider than for one hosted by their employer, health insurer, or a for-profit corporation. Some PHR designs, such as hardware-based, "pocket" USB PHRs, appear to have inherent privacy and security issues of their own.²⁶ All of these issues around PHR privacy and security present opportunities for research.

PHR Architecture

As with many other types of health information technology, a PHR consists of three primary components—data, infrastructure, and applications. Data are the types and elements of information that are exchanged, analyzed, and stored by different information technologies. Examples of data include healthcare claims information, laboratory and imaging results, medication history, and lists of patients' medical problems. Infrastructure is the computing platform(s), usually software package(s), functions or websites, which exchange and process healthcare data. Lastly, applications are the capabilities and outputs of health information systems themselves, and are enabled through data and infrastructure. Applications include data exchange and transactional capabilities such as appointment scheduling and medication renewals; analytical capabilities such as patient decision support; and content delivery capabilities such as patient-oriented care guidelines or disease education materials. All three components are critical for effective health information systems and interoperability between health information systems also represents a critical issue. The PHR functions exist in the PHR infrastructure and applications and process data used in the PHR.

One paradigm for a PHR is to envision a PHR system as a hub and spoke model, with a patient-controlled PHR at the center connected to different stakeholders who exchange data and interact with patients (Figure 1). In this paradigm, the PHR becomes more valuable the bigger the hub (i.e., the more functions the PHR has), the more spokes it has (i.e., the more connected it is to other sources of health information), and the thicker the spokes are (i.e., the more complete the sources of health information are).

This PHR paradigm can be adapted to other PHR models.²⁷ For example, PHRs tethered to electronic health records (EHRs) might be considered in the hub and spoke model with just one thick spoke. A free standing PHR could be envisioned as a hub without any spokes. A claims-based PHR could have more data than a free standing PHR, but would be unlikely to have as much as a provider-tethered PHR linked to a patient's primary care provider. The relative advantages and disadvantages of different types of PHRs and how a complete hub and spoke PHR system would be developed vary depending on how specific patients receive care and have not been rigorously evaluated from a research perspective. Regardless of the PHR paradigm, as with other types of health information technology, interoperability rep-

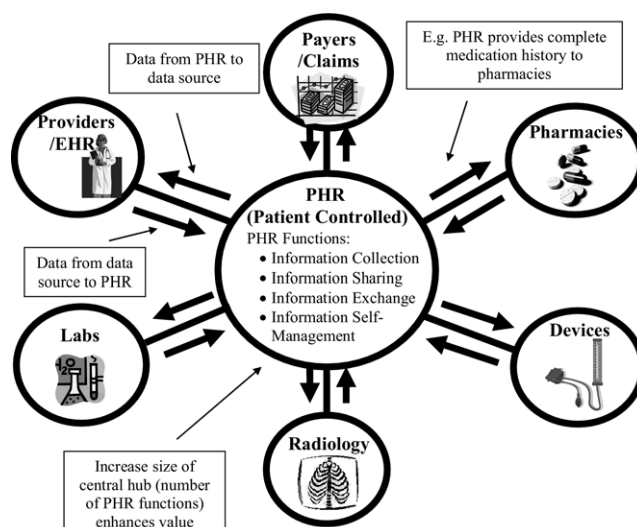


Figure 1. Idealized hub and spoke concept of a PHR system.

resents a key component of PHR architecture. Many people see PHRs as an important catalyst toward achieving meaningful health information exchange. Even more so than with EHRs, if PHRs are to be viewed as central data repositories of a patient's data, then interoperability, both in terms of importing information into a PHR and exporting information from a PHR, is critical. The core importance of interoperability poses significant challenges and research opportunities, including assessment of the limitations of specific standards and data reliability.

Research evaluating the relative benefits and costs of different PHR architectural models represents a key research priority. In particular, it is important to determine the relative benefits of free-standing and third-party PHRs, EHR tethered (i.e., provider-tethered) PHRs, and claims or payer-based (i.e., payer-tethered) PHRs, depending on patient-specific circumstances. The value proposition for different PHR architectures may vary based on the type of healthcare delivery system in which a given patient and provider operate in. In addition, how well interoperability works with the various architectures should be examined.

Non-PHR Research Related to PHRs

Although the cumulative research literature on PHRs is modest, other areas of healthcare research may have direct applicability to PHRs. This research generally involves functions and features which were studied outside of a PHR, but which could be incorporated into a PHR. For example, one study showed that secure e-mail between patients and providers improved the ease and quality of communication.²⁸ Although this study did not use a PHR, email communication is a generally accepted function of many PHRs. Another study showed that computer-mediated medical histories taken directly from patients prior to visits save clinician's time collecting information about family history, personal history, prior immunizations and other important historical data, and may even improve patient candor about sensitive subjects, such as substance abuse and sexual behaviors.²⁹ Such data are directly applicable to PHRs because patient entered data represent an element in many PHRs.

Although data from these studies may extend to PHRs, at least some of these results should be replicated in an actual PHR environment.

PHR Business Case

Another critical issue for PHR research, which must be assessed if PHRs are to be widely adopted, is the business cases for PHRs. Whoever the owner or at least the sponsor of the PHR is must have a valid business case to support it. Each constituency—patients, providers (physicians and non-physicians), payers, pharmacies, labs, etc.—must have sufficient incentives in order for them to be willing to participate in a PHR, either through direct use or data exchange.

For provider groups which develop PHRs, there must be sufficient revenue or other return on investment to justify implementing and providing support for the PHR. Third-party vendors such as Microsoft[®] and Google[®] may rely on advertising revenues to generate revenue; it is unclear in this structure what the incentives are for providers to participate, and how information from these PHRs will make its way back to providers. Insurers who develop or sponsor PHRs will have to be able to demonstrate sufficient return on their investment as well.

Overall, many of the incentives for PHRs do not seem well aligned. For example, non-visit care is not generally reimbursed, so strong incentives exist for providers to delay PHR implementation, even if they already have an EHR with PHR functionality. Patients are generally not yet incentivized to use any type of PHR. Legislation may be needed to help create the appropriate incentives, with one example being the proposed Personalized Health Information Act of 2007 (HR 1368) (<http://www.govtrack.us/congress/bills/110/1368>). Key questions include the value to a variety of stakeholders of PHR implementation, and the business case for PHR adoption and use. In considering reimbursement reform, policymakers need additional information about the benefits of non-visit care to determine how best to compensate providers for it.

Although current incentives are not well aligned, consumer demands and needs should also play a major role in the development of PHRs. Because patients are the ultimate end consumers of PHRs, broad demand from consumers could obviously have a dramatic effect on overall PHR adoption and use rates, although this has not occurred to date. For patients to have a significant motivation to adopt PHRs or even catalyze rapid PHR implementation throughout the U.S. health care system, patients must perceive that PHRs provide value to them in some qualitative or quantitative way.

Research Support

To date, private foundations, especially the Markle Foundation (<http://www.markle.org/>) and the Robert Wood Johnson Foundation (<http://www.rwjf.org>) have provided the majority of targeted funding for research into PHRs. These foundations have had specific initiatives and funds directed at PHR research. Government funding sources, including the National Library of Medicine, the Agency for Healthcare Research and Quality, and various National Institute of Health institutes have also provided some funding for

research related to PHRs. These investigator initiated grants are generally not from PHR designated funds. These investigators compete for their PHR funding with all other investigator initiated grants to these funding sources.

In other clinical research areas, the typical sources of research support include governmental, commercial, and foundation support. Usually, governmental and commercial support constitute upwards of 90% of clinical research funding.³⁰ This is far from the case for PHRs. In order to ensure that more fundamental PHR research is conducted, both governmental and commercial sources of funding should increase their support of PHR research through programs that designate funds specifically for PHR research. Even though governmental spending on research has been flat, and despite the general woes of the economy, the high costs of healthcare represent a top priority, and PHRs represent one of the areas that should receive top priority for research given their potential for reducing costs and improving care. If funding cannot be increased, at least a portion of existing PHR funding should be directed into the areas highlighted above. Additionally, for PHRs that are already being developed, an evaluation component should be integrated into their development and results from that evaluation should be published and presented.

Several governmental organizations have identified PHRs as a growing priority for research. The National Library of Medicine in its 2006–2016 strategic plan identified PHRs and personal knowledge bases as one of its nine areas of strategic visions.³¹ The American Health Informatics Community (AHIC) formed its Personalized Healthcare Workgroup in the fall of 2006, although it has focused primarily on other issues such as standards for genetic test reporting to date.³² Hopefully, the increasing governmental interest in PHRs will result in increasing funding for PHR research.

Given the relative lack of clarity of many aspects related to PHRs outlined above, additional research investment is warranted to help maximize the return on the enormous investment currently being made into PHRs. This research on PHRs will be challenging, since PHRs have a broad range of functions and implementations, and any individual study may or may not be generalizable to other PHRs. However, today the evidence base about what key features a PHR needs to improve care and deliver value remains remarkably scanty. Because PHRs mostly involve software development costs, as opposed to hardware costs, if benefits are achieved, the returns on this research investment could be great.

Conclusions

We spend nearly \$2 trillion annually in healthcare in the US with a high cost per person and an unacceptable variability in the quality of care. It is clear that PHRs have the potential, if designed appropriately and adopted widely, to reduce costs and simultaneously improve quality and safety of care. This potential has led to enormous public enthusiasm for PHRs and large investment. However, the existing knowledge base that underpins this work is surprisingly limited and most of the fundamental issues remain unresolved. For PHRs to realize their future potential, additional research is essential, but it is unlikely to be performed unless substantial additional financial support is committed to PHR

research and evaluation, especially from federal and commercial sources. If these additional investments are not made, much time and money may be wasted and the potential value of PHRs will remain unrealized.

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