

White Paper ■

## Personal Health Records: Definitions, Benefits, and Strategies for Overcoming Barriers to Adoption

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**Abstract** Recently there has been a remarkable upsurge in activity surrounding the adoption of personal health record (PHR) systems for patients and consumers. The biomedical literature does not yet adequately describe the potential capabilities and utility of PHR systems. In addition, the lack of a proven business case for widespread deployment hinders PHR adoption. In a 2005 working symposium, the American Medical Informatics Association's College of Medical Informatics discussed the issues surrounding personal health record systems and developed recommendations for PHR-promoting activities. Personal health record 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. This paper summarizes the College Symposium discussions on PHR systems and provides definitions, system characteristics, technical architectures, benefits, barriers to adoption, and strategies for increasing adoption.

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The 2005 Hurricane Katrina disaster exposed the fragility of America's health information infrastructure. When confronted by a hurricane, an avian flu pandemic, or a bioterrorism attack, the public needs to be able to depend on reliable access to their health information. Lack of a robust health information infrastructure undermines any attempt to establish a coherent and reliable plan to deal with natural or other disasters affecting the public's health. Fortunately, large-scale catastrophic disasters are rare, but that does not diminish the need for a robust health information infrastructure that significantly improves both personal and public health care delivery.

Over the past several years, there has been a remarkable upsurge in activity promoting the adoption of electronic health

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This paper summarizes the discussions that occurred at the 2005 Symposium of the American College of Medical Informatics in Key West, FL. Although the authors led many of the discussions, the comments summarized here reflect the in-depth knowledge and years of hands-on experience developing, testing, implementing, and evaluating PHR and EHR systems by over 50 fellows of the College. It is our privilege to report them. We greatly appreciate the many helpful suggestions of the editor and reviewers.

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records (EHRs). All levels of government—federal, state, regional, and local—as well as the private sector, have encouraged EHR adoption. By contrast, personal health record (PHR) systems have not received the same level of attention. While EHR systems function to serve the information needs of health care professionals, PHR systems capture health data entered by individuals and provide information related to the care of those individuals. Personal health records include tools to help individuals take a more active role in their own health. In part, PHRs represent a repository for patient data, but PHR systems can also include decision-support capabilities that can assist patients in managing chronic conditions. Most consumers and patients receive care from many health care providers, and consequently their health data are dispersed over many facilities' paper- and EHR-based record systems.<sup>1</sup> A fragmented system of storing and retrieving essential patient data impedes optimal care.

The U.S. Secretary of Health and Human Services, the National Coordinator for Health Information Technology, and the Administrator of the Centers for Medicare and Medicaid Services (CMS) have all identified PHRs as a top priority. In order to advance the discussion of PHRs, the American Medical Informatics Association's College of Medical Informatics (hereafter called "the College," whose formal legal name is the American College of Medical Informatics), composed of elected fellows from the United States and abroad, held a symposium on PHRs in February 2005. Participants discussed aspects of PHR technology and the potential individual and societal implications of PHR availability. The symposium addressed the following questions: What is a PHR? Who are the intended beneficiaries?

Who uses it? What is its relationship to EHRs? What is the technical architecture to connect PHRs? What strategies can be employed to overcome the technical, societal, and organizational barriers that impede dissemination and use of PHRs? This paper summarizes the discussions that occurred at the symposium.

## Definitions and Characteristics of a Personal Health Record

The Markle Foundation's Connecting for Health collaborative, a public-private endeavor working toward an interoperable health information infrastructures defined PHR in their report on the subject as:

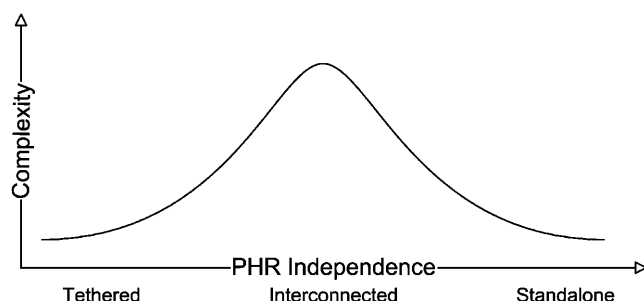
"An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment."<sup>2</sup>

Although this definition represents a good starting point, more clarity is necessary to understand how PHRs might function to benefit individuals, their caregivers, and their health care providers.

A PHR includes health information managed by the *individual*. (Often the term *patient* is used when referring to stakeholders of PHRs, but we prefer to use the term *individual* to emphasize that the PHR is a tool that can be helpful in maintaining health and wellness as well as a tool to help with illness that the term *patient* implies.)

This can be contrasted with the clinician's record of patient encounter-related information (a paperchart or EHR, also known as an electronic medical record or the computer-based patient record), which is managed by the clinician and/or health care institution. Over time, we envision an environment in which health information about an individual can flow seamlessly among systems used by authorized health professionals, caregivers, and the patient, when the patient authorizes such sharing.

There are several possible approaches to creating a functional PHR (Fig. 1).<sup>3</sup> In the first approach, an individual may create his or her PHR using commercially available applications, ranging from stand-alone systems to Web-based applications. The patient can enter and access his or her health data through such systems. In its simplest form, the PHR is a stand-alone application that does not connect with any other system. At the other end of the spectrum, PHR functionality can be provided by allowing patients to view their own health information that is stored in their health care provider's EHR. The EHR-based



**Figure 1.** Range of complexity in various approaches to personal health records (PHRs).

systems may include additional functionality, such as allowing the patient to request appointments and prescription renewals and providing a communication channel to clinicians.<sup>4-7</sup> In some cases, patients may add supplemental information that may or may not subsequently be incorporated into the provider's EHR. Although there are not good data available that quantify current use of PHR systems, we believe that the majority of consumers using a PHR today use one that is integrated with the provider's EHR in some way. Some hybrid PHR systems can connect to various health care data sources to acquire and transmit data. This latter approach overcomes the limitations that result from using a PHR integrated in a single health care provider or organization, but is much more complex. Figure 1 illustrates the spectrum of PHR models. As part of the symposium agenda, the College conducted a formal debate to discuss the relative advantages and disadvantages of each model.

In the discussions following the debate, symposium attendees considered the merits of stand-alone PHRs, including those supplied on "smart cards," USB drives, and CDs. Although the stand-alone nature of such devices provides more individual control over access to the data contained in the PHR, the attendees were concerned that, except for the most highly motivated, it is unlikely that individuals would keep records in a stand-alone PHR up to date. In addition, it is unlikely that a stand-alone PHR that depends solely on patient input can act as a trusted conduit for transmission of medical record data among clinician offices or health care institutions. A PHR system must serve as more than a repository for an individual's health information. While patient-entered segments are desirable for some information and only patients can provide some types of health data, clinicians must also have access to their own past considerations and interpretations, as well as reliable objective data, if they are to depend on records for clinical decision making. The reliability of patient-entered data depends on the nature of the information per se, the patient's general and health literacy, and the specific motivations for recording the data. For example, patient reports are usually reliable for symptoms and easy-to-measure objective parameters, such as height, weight, and temperature by thermometer. However, most patients cannot reliably report specific laboratory values such as their specific cholesterol level or hemoglobin A1c.<sup>8</sup>

Although there are specific advantages for each type of PHR, symposium participants concluded that PHRs integrated with EHRs, either through tethering or interconnectivity, provide much greater benefits than stand-alone PHRs. The integrated PHR-EHR approach can convey much more relevant data to the patient. In addition, because EHRs generally are equipped with more robust backup systems, in a natural disaster such as that experienced during Hurricane Katrina, it is more likely that patient data in PHR-EHR systems will survive. The ability of the Veteran's Health Administration to restore patient data within days illustrates this benefit. In addition, the business case for such integrated systems is easier to make (see discussion below). The remainder of this paper considers the integrated PHR model as the preferred model.

## Data Sources

Ideally, the PHR should include as much relevant data as possible over the individual's lifetime, from multiple sources, including health care facilities as well as the individual. The

**Table 1** ■ Sample PHR Data Types and Potential Sources

Data Type	Source
Problem list	Patient, EHR
Procedures	Patient, EHR, or claims
Major illnesses	Patient, EHR, or claims
Provider list, potentially linked to problems	Patient, EHR
Allergy data	Patient, EHR
Home-monitored data (eg., BP, glucose, peak flow)	Patient, automated interface with equipment
Family history	Patient, EHR
Social history and lifestyle	Patient, EHR
Immunizations	Patient, EHR, immunization registries
Medications	Patient, EHR, claims history (partial data)
Laboratory tests	Patient, EHR, commercial laboratories

PHR = personal health record; EHR = electronic health record.

specific data source of each item should be labeled and visible to the user. The more comprehensive the data contained in a PHR are, the more useful the data will be to patients and care providers. Although there are no conventions for what data should be contained in a PHR, symposium participants suggested that the items listed in Table 1 should be included in any PHR. A number of different sources may furnish the data outlined in Table 1.

Data within PHRs can be subjective or objective. Table 2 illustrates objective and subjective PHR data types by their potential source(s). Representative sources may include patient-entered data, home diagnostic equipment data, or data from the provider-maintained medical record. Subjective data may include symptom scores, qualitative descriptions of symptoms or medical problems, and responses to questionnaires.<sup>9</sup> These data would generally originate directly from the patient, although they might be collected either through the PHR or in a health care setting. The PHR should also capture objective data, such as blood pressure. These data might be measured and manually entered by the patient or transmitted directly from home-based monitoring devices. Blood pressure could also be measured in the clinician's office and transmitted electronically as part of a shared medical record. The system may acquire some data electronically from insurance claims or pharmacy records.

In order to be useful to the patient, the PHR must present data and accompanying tools in ways that enable the individual to understand and to act on the information contained in the record. This is challenging because of patients' widely varying levels of general literacy and of health literacy.<sup>10</sup> For many individuals, health literacy may be more amenable to improvement than general literacy. For example, individuals may have little interest in understanding health-related terminologies or test results until they develop a chronic or life-threatening illness. Typically, such individuals then become more engaged in their health and attempt to understand a wider range of knowledge and information related to their disease processes. Both terminology and data presentation must be adapted to the individual using the PHR, so that they realize optimal benefits.

**Table 2** ■ Objective and Subjective PHR Data Types by Source

Data Source	Data Type	
	Subjective	Objective
Patient	Manual entry or results of online data capture (e.g., symptoms scores, qualitative descriptions)	Manual entry (e.g., blood pressure, weight)
Home instrumentation	N/A	Automated interfaces (e.g., blood pressure from interfaced home blood pressure monitor)
Clinicians	Automated interface with medical records	Automated interface with medical records
Claims databases	N/A	Automated interfaces

N/A = not applicable.

### Adoption of Personal Health Records

While PHRs have many potential benefits to patients, caregivers, and institutions, the supporting evidence of specific benefits and the business case for PHR adoption are limited. Furthermore, the technology supporting PHRs is still evolving. Widespread adoption and use of PHRs will not occur unless they provide perceptible value to users, are easy to learn and easy to use, and have associated costs (both financial and effort) that are easily justified related to the PHR's perceived value.

### Benefits of Personal Health Records

For consumers, PHRs have a wide variety of potential benefits. One of the most important PHR benefits is greater patient access to a wide array of credible health information, data, and knowledge. Patients can leverage that access to improve their health and manage their diseases. Such information can be highly customized to make PHRs more useful. Patients with chronic illnesses will be able to track their diseases in conjunction with their providers, promoting earlier interventions when they encounter a deviation or problem. Collaborative disease tracking has the potential to lower communication barriers between patients and caregivers. Improved communication will make it easier for patients and caregivers to ask questions, to set up appointments, to request refills and referrals, and to report problems. For example, communication barriers are responsible for many adverse drug events in the outpatient setting.<sup>11</sup> In addition, PHRs should make it easier for caregivers (proxies for the patients) to care for patients, which is difficult today. A critical benefit of PHRs is that they provide an ongoing connection between patient and physician, which changes encounters from episodic to continuous, thus substantially shortening the time to address problems that may arise.

To date, there is limited evidence supporting these hypothetical benefits; however, many consumers have high satisfaction levels with existing early versions of PHRs.<sup>3,7,12,13</sup> In particular, consumers place value on easy access to test results and better communication with clinicians.

The PHR can benefit clinicians in many ways. First, patients entering data into their health records can elect to submit

the data into their clinicians' EHRs. Having more data helps clinicians to make better decisions. The PHR may also become a conduit for improved sharing of medical records. Patients who are more engaged in their health are more active participants in the therapeutic alliance, for example, when patients with chronic conditions collaboratively manage their illnesses with clinicians to reduce pain, improve functional outcomes, and improve medication adherence. Finally, asynchronous, PHR-mediated electronic communication between patients and members of their health care teams can free clinicians from the limitations of telephone and face-to-face communication or improve the efficiency of such personal contacts. Notably, all the advantages of PHRs for providers depend on the PHR being integrated with the provider's EHR.

Potential benefits of PHRs to payers and purchasers of health care include lower chronic disease management costs, lower medication costs, and lower wellness program costs, although none of these has been well studied. The greatest area of benefit relates to the chronic disease management, where costs are typically high.<sup>14</sup>

### Who Should Pay for Personal Health Records?

Determining who will pay for PHRs is key to establishing a business case for adoption. Because health care payers and purchasers are the primary beneficiaries, they should probably be the primary ones who bear the cost of PHRs. However, the evidence supporting the rationale for payers to provide PHRs is not mature, and they may be reluctant to do so. Perhaps providers will recognize that paying for PHRs may give them a competitive advantage in the marketplace. Small incentives to health care providers may be enough to encourage them to adopt EHRs that link to PHRs. Many of the putative financial benefits of PHRs only occur when PHRs are tightly integrated with EHRs, so that seed funding of PHRs in practices that operate an EHR might advance PHR adoption to the "tipping point." Patients may be willing to pay a small amount, for example, \$60 a year, for the physician-communication component of the PHR. However, this model is unlikely to cover the full costs of PHR licensing or development, physicians demands for remuneration may be higher, and some patients who might benefit most from PHRs might not use the service if they had to pay for it.

### The Roles of Key PHR Stakeholders

Government can play a number of important roles in increasing PHR use. At the infrastructure level, the federal government could catalyze development and adoption of data and interchange standards for key PHR content areas. Relevant federal agencies such as the Agency for Healthcare Research and Quality and the National Library of Medicine should sponsor research to assess the clinical and health behavior benefits of PHRs.

Although legislators have introduced a number of bills relating to health care information technology in Congress, none focuses on PHRs. There are a number of possible legislative actions that would promote the adoption and use of PHRs. For example, a tax deduction for PHR-related expenses may promote adoption. Such a deduction might also benefit providers. Payers should experiment with monetary incentives to providers to implement PHRs. The CMS should sponsor demonstration projects in this area.

Providers should participate in research efforts evaluating early experiences with PHRs, including how PHR use changes the way that clinicians relate to their patients. Research should investigate different platforms for providing PHRs, such as using cell phones or personal digital assistant devices as an adjunct to PHRs. Personal health records could connect with home-monitoring instruments, especially when reimbursed by payers. Providers and payers should work together to develop pay-for-performance contracts that provide incentives for PHR use. Furthermore, PHRs must link to information from multiple EHRs across networks. One potential key for moving ahead with EHR adoption in the United States is for the CMS to provide incentives for EHR use<sup>5,15,16</sup>; if this occurs, it will be possible to subsequently link PHRs to EHRs to obtain the benefits previously described.

### Personal Health Record Technical Architectures

If they cannot exchange data with other health care systems, PHRs will become "information islands" that contain subsets of patients' data, isolated from other information about patients, with limited access and transient value. As a result, integrated PHR systems will have to interoperate with other systems throughout the entire health information environment. At a minimum, PHRs must export data to and import data from other systems in a standardized way. More advanced PHRs will at some future time function as seamlessly integrated, interoperable "components" of other health systems.

To provide interoperability, PHRs must support the same communications, messaging, and content encoding standards as other health information systems. Because the public rather than medical professionals will use PHRs, we will have to develop "lay" representations and explanations of the encoded data.

Beyond an individual's personal data, PHRs may include relevant information about family members, caregivers, and home and work environments that are important to the individual's health. A PHR might, for example, interact with EHRs to obtain information about contagious diseases detected among family members, allowing a provider to factor a sibling's recent diagnosis of "strep throat" into the differential diagnosis of fever and coryza in the index individual. A related concern is how to allow individuals to specify which of their own data they will allow to be shared with other health information systems.

Authentication presents a particularly vexing problem for PHRs. A stand-alone PHR device may be safe if it is constantly under the control of the owner, unless its contents are unencrypted and the device is lost in a public area. However, as soon as the PHR becomes a component in an interoperable health care system, authentication becomes very important. Before another health information system shares data with a PHR, it will need to verify the identity of the PHR's owner. The College symposium participants could not identify a scalable solution to this problem for stand-alone PHRs. In addition, the difficulty of authenticating a patient in a stand-alone PHR creates a de facto unique patient identifier that may actually increase threats to the patient's privacy. In an integrated PHR, the provider's system might authenticate the patient. PHRs must also support and trust "designated caregivers," such as parents in the case of young children, or spouses in the case of incapacitated adults.

Although data provided by patients can inform providers' decision making, not all patient-supplied data will do so, and the

volume of “clinically irrelevant” information in their patients’ PHRs might become overwhelming for a health care provider to review. While providers routinely inspect and use the most recent blood glucose measurements in a diabetic patient’s logbook, reviewing complete documentation of patients’ daily activities, including detailed diet, exercise patterns, sleep patterns, and transient symptoms to find one crucial item of information becomes problematic. Either the PHR or the provider’s interacting EHR system should create useful summaries from voluminous PHR data. Ideally, the summarization tools would identify exceptions and important trends, presenting information via carefully crafted visual representations, statistical summarizations, feedback from clinical decision support systems, or, most likely, a combination of approaches. The architectural issues associated with PHRs overlap those found with other health information systems, but also include unique issues, such as transitive trust and the need to present information in a manner understandable to laypersons. Future PHRs will act as full peers in the health care systems environment, making their requirements more complex and sophisticated.

### **Organizational and Behavioral Barriers and Facilitators Related to Personal Health Record Adoption**

As with EHR adoption, the impediments to PHR adoption are not limited to technical ones. In addition to the economic and technological challenges, organizational and behavioral issues can delay PHR adoption. Barriers exist both at the environmental level and at the level of individual health care professionals and consumers. Education and research focused on the personal health record can facilitate adoption.

#### **Environmental Barriers to Personal Health Record Adoption**

Health information on each patient now resides in multiple locations; integrated PHRs must reach across organizational boundaries to interface with multiple EHR systems. The lack of ubiquitous EHR usage currently presents the greatest environmental barrier to such integrated PHR adoption. A related problem is that EHRs must not only exist in individual offices and hospitals but must also be able to communicate with PHRs. Nonetheless, lessons learned from early PHR usage can inform future PHR development. Understanding the types of patients and consumers who use PHRs, what functions they use the most, and what changes in health-related behaviors arise from using PHRs would contribute to productive future development.

Economic and market forces are obstacles to PHR (and EHR) adoption. Many vendors offering stand-alone PHRs have not been financially successful; numerous products and companies are no longer in existence. This may create a business climate that undervalues the potential of future, more ideal PHR systems and hinders their eventual development.

Other barriers to PHR adoption involve legal concerns on the part of providers and the privacy concerns of individuals. Providers are wary of the legal implications of PHRs. For example, courts might apply negligence standards in cases where practitioners rely on inaccurate patient-entered PHR information to make suboptimal decisions about care. While consumers appropriately desire protection of their

private health information, aggressive protection measures might hamper PHR access by patients and clinicians and impede optimal care.

#### **Individual-level Barriers to Personal Health Record Adoption**

At the level of the individual, health care consumers must understand and accept their roles and responsibilities related to their own health care. The developers and users of EHRs and PHRs must understand individuals’ and clinicians’ mental models of health care processes, and the related workflows. An individual’s PHR can only be useful if the person understands the importance of maintaining and coordinating health-related documentation and activities with health care providers. Consumer-related interface, technology, and access issues specific to PHRs are not yet well understood.

The workflow models for both providers and patients are poorly understood. While informaticians have studied clinical workflow models in some settings of care, evaluations of patient workflows in homes and in the community are rare. We will have to develop an understanding of how the PHR can fit into the flow of what individuals do on a day-to-day basis.

It is possible that PHRs will threaten the control, autonomy, and authority of some health care providers, based on traditional provider–patient roles. Providers and patients will need to develop different mindsets and levels of trust. Providers must learn to encourage patients to enter the information accurately and to trust that information appropriately. Consumers must trust that providers will only use the information for the individual’s benefit.

Behavioral change is difficult. For PHR adoption, change management issues involve providers, consumers, and regulators. First, there must be a motivation to change. While it is intuitive that PHRs can help to improve health by offering additional information when it is needed, better objective evidence of efficiency and effectiveness of PHRs may be required before consumers, providers, and regulators will move toward the goal of PHR adoption.

#### **Facilitators of Personal Health Record Adoption**

Cultural issues and trends can expedite the viewing of PHR adoption as a common goal. For example, a greater awareness of health issues and a greater availability of public-oriented health information resources (such as MEDLINE PLUS<sup>®</sup>) have led many individuals to use the Internet increasingly. Individuals, and especially patients with chronic illnesses, are more aware of the need to monitor their own health and to access health-related information. We know that patients who are ill, and their families, have “teachable moments” when they are especially receptive to educational interventions. Health care management tools are a relatively new form of PHR facilitators that may appeal to consumers by providing components of PHR systems: medication information, appointment information, care provider communication, and health care knowledge resources. These can eventually include reminders and decision support as they develop into more complete PHR systems.

#### **Breaking Down the Barriers to Personal Health Record Adoption**

The two main mechanisms for breaking down the barriers to PHR adoption are education and research. We do not know

enough about health care consumers' need for, and potential use of, PHRs. Behavioral research can identify optimal educational strategies.

### Personal Health Record–related Education

Individuals' education about health management techniques should begin early. Even in elementary school, the educational system can teach the importance of managing their health using simple tools. As previously mentioned, adults have teachable moments at a minimum when they are ill or concerned about illnesses in others. Reinforcement of the need to maintain the quality and accuracy of PHR information can occur as educational experiences unfold during the primary and secondary school years. Curricula promoting and explaining both EHRs and PHRs for health care providers should exist at all levels: medical schools, nursing schools, schools of the health-related professions, and in post-doctoral training programs (internships, residencies, fellowships, and in services). The curricula should teach providers how to educate their patients about PHRs in an ongoing manner.

For developers of systems, curricula about PHRs should include tools for PHR design and maintenance processes, approaches to integrating PHRs and EHRs, and advanced topics related to privacy, security, and authentication. We should base these curricula on up-to-date evaluations of what approaches to PHRs work and consumer satisfaction with different systems. For the purchasers and employers, educational efforts need to impart the value of the PHR for improving health and reducing total health care costs. Again, better research evidence documenting the benefits of PHR usage will help to convince these groups.

### Personal Health Record–related Research

Many PHR-related research opportunities exist for individuals and organizations studying sociotechnical issues. Provider sites that currently offer integrated PHRs offer a good starting point to determine which individuals tend to use the PHR, how frequently, for what purposes, and with what impacts on health and workflows. This research should then be expanded to users of stand-alone PHRs. We need additional research to detail the mental models that individuals and health care providers hold concerning patients' roles in their own care. As noted, privacy, security, and legal concerns of patients and providers should be investigated. More knowledge about how PHRs can meet the health information needs of individuals will help providers to deliver better care. We should study the relative weight or value that consumers and care providers place on the individual functions (components) of the PHR, including decision support capabilities. At the national level, support for a better vision of how genomic information might enhance the PHR is required. Insight into how PHRs can help with population health tracking is merited. Finally, many technical, interface, economic, vocabulary, and data issues need further investigation.

### Conclusions

There was widespread consensus at the College's symposium about the potential value of PHR systems. Participants elucidated the potential of PHR systems to transform patient–

provider relationships, especially when integrated with EHR systems. They also identified many challenges—technical, social, organizational, legal, and financial—that warrant further study.

Complex human and organizational factors can either hinder or accelerate adoption of PHRs. Many challenges to deployment of PHRs are similar to those for EHRs. More PHR-related research is required. Multiple stakeholders—patients, providers, employers, payers, governments, and research institutions—must play key roles in developing PHR technology more fully and to overcome the barriers to widespread adoption. With a better understanding of the needs and benefits of PHRs, we can develop better enabling policies. The opportunity costs for PHR deployment are measured in medical errors, dollars, and lives. If we are to realize the potential benefits for both routine health care and for responding to catastrophic disasters like Hurricane Katrina, these important PHR-related issues must be addressed.

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