

Consumer Attitudes Toward and Benefits of Personal Health Records

by

Elizabeth J. Horn, Ph.D.

A CAPSTONE PROJECT

Presented to the Department of Medical Informatics and Clinical Epidemiology

and the Oregon Health & Science University

School of Medicine

in partial fulfillment of

the requirements for the degree of

Master of Biomedical Informatics

May 2007

School of Medicine
Oregon Health & Science University

Certificate of Approval

This is to certify that the Master's Capstone Project of

Elizabeth J. Horn, Ph.D.

*Consumer Attitudes Toward and Benefits of Personal
Health Records*

Has been approved



Paul Gorman, M.D.

TABLE OF CONTENTS

Acknowledgments.....	ii
Abstract.....	iii
Overview of Personal Health Records.....	1-8
Introduction.....	1
Definitions of Personal Health Records.....	2
Table 1: Characteristics of EHRs and PHRs.....	3
Table 2: Roles of the EHR and PHR.....	4
Types of Personal Health Records.....	5
Providers of Personal Health Records.....	6
Table 3: Twelve questions consumers should ask when choosing a PHR..	7
Consumer Attitudes Toward Personal Health Records.....	8
Recommendations for Personal Health Records.....	11-13
Attributes of Personal Health Records.....	11
Data Elements of Personal Health Records.....	13
Consumer Benefits of Personal Health Records.....	14
Barriers to Adoption of Personal Health Records.....	18
Conclusion.....	20
References.....	22

Acknowledgements

I am grateful to Dr. Paul Gorman, my advisor, for introducing me to the exciting field of personal health records and expanding my ability to think critically. I acknowledge Andrea Ilg for her guidance and support throughout my journey. I appreciate the interactions I have had with faculty, fellows and students of the Department of Medical Informatics and Clinical Epidemiology.

Abstract

Personal Health Records (PHRs) are gaining attention within the greater medical community. PHRs give consumers a platform to compile health information from multiple sources and provide a vehicle for this information to be stored in one place. PHRs can take many forms, but a common feature is that the individual is the custodian of the information, often responsible for collecting, entering, storing and distributing the information. PHRs are being championed by many stakeholders including medical providers, government and insurers, and experts are providing suggested content and best practices for these tools. Consumers have expressed interest and excitement in PHRs, but these tools have not yet been widely adopted. Research shows that individuals perceive benefit from PHRs, but there are few good examples that PHRs alter health outcomes. This paper provides an overview of PHRs, examines consumer attitudes toward and benefits of PHRs, and recommends additional studies be conducted demonstrating that PHRs can change behaviors and alter health outcomes. These studies are necessary for stakeholders to continue to invest in PHR development, maintenance and utilization, and to justify widespread adoption of PHRs.

Overview of Personal Health Records

Introduction

Information is the currency of modern health care suggests the Markle Foundation's Personal Health Work Group (PHWG).¹ Information is essential to an individual's health care, however, a challenge exists as this information is scattered among multiple health care providers seen over an individual's lifetime: in medical providers' offices and hospitals, in multiple paper and electronic systems and in human memories. Currently there is no coordinated system that integrates all health information in one place.¹ This niche could be filled by the Personal Health Record (PHR), bringing all the information from fragmented systems together in a single location.² PHRs can contain relevant health information across the individual's lifetime from multiple sources, providers and health care systems. The PHR can aid the individual in remembering important medical information, such as names and doses of medications and dates of medical provider visits, screening tests and immunizations.³ The more comprehensive the data is, the more useful it will be to both the individual and caregivers. However, PHRs "are much more than static repositories for patient data." They provide an opportunity for consumers to become active participants in their health care.²

Much attention has been placed on the need for PHRs. PHRs have been identified as a priority by multiple stakeholders, and recent events, such as Hurricane Katrina in 2005, have demonstrated a need for the public to access their healthcare records in times of crisis.² President George W. Bush and Health and Human Services Secretary Michael Leavitt outlined a vision that "would create a personal health record that patients, doctors, and other health care providers could securely access through the Internet no matter

where a patient is seeking medical care.”⁴ However, in a 2005 survey, 83% of consumers had never used a PHR, and of those approximately half (52%) had never heard of a PHR.⁵ Hence, for this vision to be realized, PHRs must gain a wider acceptance.

Definition of Personal Health Records

There is an ongoing debate over the accepted definition of the PHR.^{4,5,6} In its simplest form, the PHR is an individual’s documentation of their health through medical provider visits, medications, insurance claims and other information.⁴ A common theme is that health information is owned and managed by the individual.⁷ This trait separates the PHR from the provider’s record, the paper chart or electronic health record (EHR) that is managed by the clinician or healthcare institution.² Proposed definitions include the following.

The PHWG describes a PHR 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.”¹ Similarly, the American Health Information Management Association (AHIMA) defines a PHR as “an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.”⁵ Not all groups agree that it is important to define the PHR. In 2005, the National Committee on Vital and Health Statistics (NCVHS) stated “NCVHS concluded

that it is not possible or even desirable to attempt a unitary definition at this time.

However, the Committee believes it is possible as well as useful to characterize [PHRs] by their attributes”.⁶ Attributes can include the nature of the contents, the sources of information and the functions they offer including accessibility and availability of the data.⁶

Given these definitions of the PHR, it is important to understand the distinctions between the characteristics and roles of EHRs and PHRs (Table 1, Table 2). The EHR is a system to serve the information needs of providers driven by episodes of illness. The PHR is a system for the individual to capture their health information - a lifelong record that includes both wellness and illness of the individual.^{1,2} The EHR is often limited to a single organization or provider and rarely has information provided by the individual. In contrast the PHR can encompass multiple organizations and providers and relies on data entered by the individual.¹

Table 1: Characteristics of EHRs and PHRs

Characteristic	EHR	PHR
Information system for providers	X	
Information system for individuals		X
Captures episodes of illness	X	X
Captures episodes of wellness		X
Data from single provider or organization	X	
Data from multiple organizations or providers		X
Data entered by provider	X	
Data entered by individual		X
Record maintained by provider	X	
Record maintained by individual		X
Lifelong record		X

Table 2: Roles of the EHR and PHR¹

	HER	PHR
Control of information stored in the record	Provider or institution determines content	Individual controls content
Access	Any authorized clinical or support staff in the doctor's office or institution as part of routine "treatment, payment, and operations" may access the EHR under HIPAA	Can only be accessed with individual's consent (with possible exceptions for emergencies)
Origin of information in the record	Primarily from one practice or institution	Cross-institutional
Individual's entries into the record	Rare	Common
Users	Professionals in the office or institution; may be shared with patients	Used by the individual for self-care and record keeping. May be shared with medical providers for continuity of care
Integration with decision support tools	Provider-centered medical management	Person-centered self-care
Source of information for other systems	Important source of individual's data for the PHR	Important source of individual's data for the EHR

Despite these distinctions, there is great potential for the complementary use of EHRs and PHRs. For example, while an EHR might state that a doctor wrote a prescription, the PHR could capture if the individual filled the prescription, took the medication and if the treatment worked.¹

Types of Personal Health Records

The above definitions assume that the PHR is electronic. However, these records can be stored on paper. Paper systems are often folders filled with information from providers, pharmacies, hospitals and others collected and kept by the individual.

Templates exist to prepare the information but are not required, and the record may be as simple as handwritten notes. The benefits include a good snapshot of the individual's health history and an easy way for the individual to keep records, as paper records are portable and familiar and do not rely on technology or infrastructure. Drawbacks include the effort required to edit, update and duplicate the record, inability to link to other sources of information and limited accessibility, as the paper record is only available if the individual is carrying it.⁵

Electronic records can be kept using stand alone applications on a personal computer, using a Web-based system, or a combination of the two. Portable devices are gaining popularity where PHR information can be stored on a smart card, PDA, mobile phone or USB memory device.³ In the personal computer scenario, the individual enters information directly into an electronic form or scans documents from a provider. This information is used to generate reports. Benefits include that the individual controls access to the information and information can be updated and new reports generated. The major drawback is lack of accessibility unless the individual always carries a copy of the information.⁵ There are hybrid models where the primary PHR is kept on a personal computer and information is transferred to a secondary Internet location for access in emergencies.⁵ Another option is Internet or Web-based PHRs where private accounts are kept on the Web accessible through a user name and password. Benefits include

information can be updated easily and the individual may approve access to the information for others, making the information more accessible.⁵

The above scenarios are stand alone PHRs that do not connect or integrate with other health information systems. Some believe the full potential of PHRs will not be realized until they can exchange information with other systems containing health data.⁴ In an integrated model, the PHR could connect with the EHR, allowing individuals to view their personal health information and also use advanced EHR features such as scheduling appointments, renewing prescriptions or communicating with their provider.² While the EHR is maintained by the provider organization, the PHR has components that allow the patient to view specific parts of their record as well as capture some additional information and features often through a secure Web portal.⁶ When the PHR is maintained and controlled by others, such as the health plan, employer or provider, it is considered a “tethered” record, and the biggest disadvantage is the lack of portability.⁶ Tethered records are not considered true PHRs by some, as they may just be a view of provider data and not allow the individual to enter their own data.³

Providers of Personal Health Records

Consumers will likely have a variety of choices in selecting a PHR provider, and there are advantages and disadvantages for each type. PHRs sponsored by employers offer benefits such as free or reduced cost, a link to the employer sponsored health plan and the ability to add or input additional information not related to the health plan. When the employee leaves, the PHR stays with the employer, and this is the key disadvantage. In provider-sponsored PHRs, benefits may include a portal for the individual to view

information in their EHR. A disadvantage is that information from an outside provider may not be included. Insurer-sponsored PHRs often use a model similar to the provider PHR.⁵ It is important to note that to be a true PHR, the individual must also be able to input information. Another scenario is the independent product, which could be free or have a monthly charge. The major benefit is that the individual controls the content, additions and access to their record. The disadvantage is the cost and that the individual is responsible for maintaining and updating the record.⁵ To assist individuals in choosing a PHR, AHIMA has developed 12 questions that include areas like content, ownership and use, access and security, portability, and cost (Table 3).⁵

Table 3: Twelve questions consumers should ask when choosing a PHR (from AHIMA⁵)

Content	
1	Will the PHR provide all the information I need for a complete health history?
2	Will information be automatically added to the PHR from any other records (e.g., insurance, employment, or care)? If so, what information will be added, and how will it be added? Is the information transfer audited?
3	Do I have the opportunity to delete, correct, or add information? How will I do this?
Ownership and Use	
4	Does the PHR sponsor have any ownership rights to the collected information?
5	Can the PHR sponsor sell my information to anyone or for any reason? If so, how can I protect my privacy? Can I specify that my information not be sold?
6	Will my information be used for employment or insurance coverage decisions (e.g., to determine insurance eligibility)?
Access and Security	
7	Who has access to the information in my PHR?
8	Can I choose to give my doctor, dentist, and other caregivers access? How do I control the sharing of my information?
9	How will my information be protected from unauthorized use?

Portability	
10	If I am no longer employed/insured by you, can I still continue to use the PHR?
11	How can I transfer my information to another PHR sponsor (e.g., a new insurer or new vendor)?
Cost	
12	Will there be any cost for me to have a PHR with you? (For instance, are there fees if I give my doctor, dentist, and other caregivers access to my PHR?)

Many PHR supporters believe the individual needs a voice in participating in a PHR.⁶ While this is not an issue when the PHR is completely under the individual's control, in situations where the PHR is provided by the employer, health plan or provider, there is discussion on whether individuals should be asked to sign up (opt-in) or if all individuals should be included unless they have refused in writing (opt-out).⁶ The opt-in approach has the benefit of being in between yes and no as the individual could block certain categories of information. Others believe that the opt-out power does not exist, as health plans or employers could require the creation of a PHR to be eligible for benefits.⁶

Consumer Attitudes Toward Personal Health Records

Individuals appear to have contrasting opinions about storing health information online. A 2002 study by Masys showed that all respondents believed having their medical records online would be "valuable" or "very valuable."¹ In contrast, others have concerns about privacy and security of online health information, highlighted in a 2002 survey of online medical records in which nearly two-thirds of health seekers (63%) and Internet users (60%) believed that putting medical records online is a bad idea even if the site is secure and password protected. Only 38% of Internet users stated that they would access

their medical records online, but this was age dependent, as 70% of those 25-34 and only 35% of those over 65 wanted access to their medical records online.¹ Not surprisingly, those in poor health were less likely to be concerned about accessing their medical record online than those in better health.¹

PHRs have not yet been fully adopted, but interest in PHRs is growing. Research conducted by America's Health Insurance Plans (AHIP) suggests that at least 70 million Americans have access to a PHR offered by their health plan.⁶ A 2004 Harris Interactive poll found that 42% of adults keep personal health records. Of those who did not keep records, 84% thought it would be a good idea.³ The Foundation for Accountability surveyed 1246 online households and found that 70% of respondents would use one or more features of a PHR, and more than one-third (35%) would use seven or more features of a PHR. The greatest interest in PHRs was demonstrated by the chronically ill, frequent users of health care and people caring for elderly parents. The majority of respondents (91%) were concerned about privacy, but only 7% stated that they would not use any features of the record due to privacy and security concerns.¹ Respondents also desired to control their record, to limit access by others without their specific permission and to make choices about how their personal health information is used. In addition, respondents were most comfortable with medical professionals accessing their record and less comfortable with family members and insurance companies having access. Finally, respondents believed online medical record tools would improve the quality of health care and help prevent medical mistakes. Differences in responses were not found by age, income, education or gender.¹

Focus groups were conducted by the PHWG to understand attitudes towards PHRs. Focus groups saw benefits to using PHRs, such as once information was entered, this information became part of the record and they did not need to remember it. Participants also believed storing personal health information would give their children a more complete family health history, and online records were more credible than personal notes to medical professionals. Participants found it very difficult to consolidate their medical records from different providers for their complete health care record.¹ For the most part, participants would not hesitate to use PHRs because of privacy and security concerns. However, the focus groups desired control over who could access their record and had an expectation that they would provide permission for access. It was important that the PHR capture when the record was accessed, who accessed the record and what information was accessed.¹ In general, the groups thought access should be granted to their medical providers, their designated family members, hospitals and pharmacies for filling prescriptions. Emergency room personnel could access part of their record to treat them in an emergency. However, they did not want access by insurance companies, employers, wellness nurses at work, the federal government, pharmaceutical and medical equipment companies, marketing entities and legal professionals.¹ AHIP focus groups have also shown that consumers like the convenience of PHRs but have concerns over the security of their personal health information.⁶

It is important to acknowledge that consumer attitudes about PHRs are dependent on the sponsor of the PHR. In the Foundation for Accountability Survey, respondents trust their doctor to host, manage and access their PHR but not their insurance company, employer or the government.¹ This is confirmed by a study from the University of

Maryland showing that the physician is the more trusted source over employers.⁶ In studies sponsored by BlueCross BlueShield of America, respondents preferred that the PHR be sponsored by an insurer to the government or a third party vendor.⁶ PHR vendors recommend that PHRs should be sponsored and overseen by a group that the consumer trusts, such as the doctor's office, medical group or independent organization.¹

Recommendations for Personal Health Records

Stakeholders are excited about the potential for widespread adoption of PHRs, and are developing opinions, recommendations and standards for them. The American Medical Informatics Association College of Medical Informatics held a symposium on PHRs in 2005 to conceptualize the informatics view of PHRs.² The PHWG has identified core features that should be addressed in any PHR model and five policy areas that need to be addressed: privacy, national infrastructure, data standards, payment to providers for EMR adoption and federal agency leadership.¹ AHIMA has also developed recommendations for the scope, format, security and accessibility of PHRs.⁷ NCVHS has developed 20 recommendations for PHRs in the following categories: evolving practices, privacy, security, interoperability, federal role, and research and evaluation.⁴ Finally, the PHWG and AHIMA have developed suggested attributes, or characteristics, for PHRs.^{1,7}

Attributes of Personal Health Records

As stated above, a common theme in PHRs is the individual, the primary user of the PHR.¹ The individual is usually responsible for creating, collecting, updating and controlling their personal health records.⁶ The PHR has distinct attributes that support the

individual in managing their personal health information. Here the seven PHWG recommended attributes are explained in detail.¹

1. **Controlled by the individual.** Each person controls his or her own PHR. The individual determines access to the PHR, including who has access, what components may be accessed and for how long the information can be accessed. It is expected that security measures will be used to prevent unauthorized use of the data by others

2. **Longitudinal.** PHRs contain information from one's entire lifetime. The PHR is an ongoing, longitudinal and lifelong record of information that includes both wellness and illness.

3. **Inclusive.** PHRs contain information from all health care providers. This includes the individual's entire lifetime of health information from all health care providers entered by the individual.

4. **Accessible.** PHRs are accessible from any place at any time. Information can be accessed by the individual at any time they need it, even at the point of care.

5. **Private.** PHRs are private and secure. The Health Information Portability and Accountability Act (HIPAA) ensures that individuals can control access to their health information. Consumers should be able to access an "audit trail" that lists who has accessed their record, what was accessed and when it was accessed.

6. **Transparent.** PHRs are transparent. Individuals should be able to see information about each piece of data, including who entered the data, where it was transferred from and who has viewed it. With each new piece of information, the data and source should be verified.

7. **Interoperable.** PHRs permit easy exchange of information across the health care system. Exchange of information with other information systems and professionals is essential, and standards are needed to ensure interoperability, including a minimum data set.

Data Elements of Personal Health Records

As PHRs have many possibilities for the types of data that can be entered, many groups have recognized the need for common data elements and a minimum data set. The American Medical Informatics Association College of Medical Informatics has recommended the following data be entered into the PHR: problem list, procedures, major illnesses, provider list, allergy data, home-monitored data, family history, social history and lifestyle, immunizations, medication laboratory tests.² AHIMA and the PHWG have also suggested minimal data sets.^{1,5,7,8} In addition to common data elements, standards for data fields are essential if the PHR is to be used across multiple care settings and providers. Data sources (pharmacies, physician offices, hospitals, clinical systems and monitoring devices) need to capture and store information in a standard format that can be used to exchange information easily with appropriate permissions.¹ PHRs must also be standardized to integrate with EHR systems, and standards must be developed to document and exchange this self-reported data.¹

If data fields are standardized, it must be recognized that the individual is often responsible for the maintenance of the PHR, and not all individuals will keep their information up to date.⁶ Even if the information is kept current, the quality of data depends on a variety of factors including the type of information to be entered, the individual's general literacy and health literacy and the individual's motivation for

recording the data.² Studies of patient reported data have shown mixed results. In a study of the accuracy of medication information in an outpatient record, patients caused more than one-third (36%) of reported errors.⁹ In another study, involving the patient increased the completeness of the medical record problem list by almost one-third (28%).⁹ Patient reports are usually reliable for symptoms and easy to measure objective parameters such as height, weight and temperature. However, most patients are unable to reliably report laboratory values (*e.g.* cholesterol levels).² In addition, patient entered data may not be trusted by all parties, such as the medical provider.⁶

Consumer Benefits of Personal Health Records

It is expected that consumers who take an active role in their health care and increase their knowledge about their health will enjoy better health outcomes.⁵ Because of this and other expected benefits, great effort is going into the development of PHRs by a variety of stakeholders. The NCVHS has described benefits by key stakeholder groups, and although the greatest benefits were to the consumer, other groups including healthcare providers, payers, employers and society could benefit from PHRs.⁴ Today's electronic PHRs have evolved from paper health records. Tang and colleagues (1998) evaluated a paper system that was provided to the patient after visiting with the physician. In the evaluation, the paper record was rated as uniformly positive by patients using it. Patients perceived value because it was a permanent record of their health, provided customer satisfaction and helped them adhere to therapy.¹ In another study, MedicaLogic (2000) evaluated an online health record system for patient value. Patients reported value in not having to remember what was said during a visit, being better

prepared for visits, and printing relevant information to distribute to their doctor. After the study, nearly three-quarters (74%) reported that they would “definitely” use the record, believing that being more involved in their care would improve their quality of care.¹

The theory that taking an active role in your healthcare improves your health may be especially relevant in chronic disease management. In a study of patients with congestive heart failure expressing an interest in using a patient-accessible electronic medical record, more than three-quarters surveyed perceived benefits from using the record.¹ Many (89%) believed it would help them prepare for appointments, increase their understanding, and reassure them; 85% believed it would clarify their physician’s instruction; 76% believed it would improve their compliance; and 68% believed it would increase trust in their physician. Despite these perceived benefits, congestive heart failure patients also had concerns. Sixteen percent believed the lab data would confuse them, 5% believed it would make them worry and 3% believed they would take offense at viewing a PHR.¹ Patients with chronic conditions were more focused on benefits of electronic PHRs than risks of privacy invasion.

While studies have shown that users of PHRs perceive benefit, studies are also needed to indicate if measurable benefit is actually achieved. Many stakeholders want to know if the introduction of PHRs will change behaviors and improve quality of care. This is an important issue to be addressed as the PHR field moves forward. Nine of 14 studies (60%) using educational material (mostly through passive distribution) to modify health behavior showed no significant changes in health behaviors.¹⁰ In some instances, all elements needed to be effective may not be provided. Kim and colleagues examined the

function and utility of 11 Internet PHRs by examining elements that would provide a complete clinical history to diagnose and treat a medical problem. Overall the PHR tools provided Web access to personal health information, but had limited functionality, and only one incorporated all the elements needed to provide a complete history.¹¹ Three studies are highlighted below that examine the use of paper health records, the use of PHRs by individuals and the use of PHRs combined with a visit to the healthcare provider.

Newell and colleagues examined the effects of Personal Health Record Booklets (PHRBs) containing both educational and recording features on cancer screening behaviors.¹⁰ PHRBs were postulated to be a cost-effective way to improve cancer prevention behavior and utilization of screening tests. This study used a randomized controlled trial design involving 10 matched pairs of rural towns in New South Wales, Australia. PHRBs were mailed to adults aged 20- 60 in the town. Each packet included an introductory letter describing the need for preventive and screening behaviors relative to cancer, a better health booklet that provided information about cancer and cardiovascular disease including recommendations for screening and reducing risks, and a better health diary with areas to record health information customized by gender. Outcomes measured were Pap smears, mammograms and skin operations for five years prior to distributing the PHRBs and at three months and one year following the distribution. Significant increases were not seen in utilization of Pap smears, mammograms or skin operations in the short or long term follow-up periods following the distribution of PHRBs. The authors concluded that communicating this information to the general public is unlikely to change behaviors. The study did not examine other reasons why there were no

increases in cancer screening behaviors, such as cost of tests, access to tests, education about cancer screening and motivation of individuals in the community. The authors were hopeful that targeting the materials to high-risk groups may be more likely to change behaviors.¹⁰

Denton and colleagues asked the question, “will patients use electronic personal health records?”¹² In this study of individuals with spinal disorders, a PHR program was offered with a disc containing information exported from the practice EHR. The participants were given a survey 10 months later. Of the 1000 patients offered the PHR, only 330 (33%) took advantage of the offer. Of the 136 individuals who responded to the survey, almost all (90%) reported that they should keep personal health records. However, only 50 respondents (37%), 5% of those who were originally offered the PHR, reported they continued to use the PHR after 10 months. Of those not using the PHR, 46 planned to use the PHR at a later date.¹²

Liaw and colleagues examined the effect of a computer-generated patient held medical record summary (CHR) or a hand written PHR on patients’ attitudes, knowledge and behavior of health promotion.¹³ In the study, patients aged 25-65 in five practices received a questionnaire. Those who responded to the questionnaire received an invitation for a health check and one of the following types of records, a CHR plus PHR, CHR only, PHR only, or no personal record. At the health check, if the patient had a CHR, the nurse gave the patient an updated CHR. If the patient also had a PHR, the nurse referred to it for education as appropriate. If the patient had a PHR and no CHR, preventative care data was entered into the PHR and returned to the patient. A follow-up questionnaire was sent by mail six months after the intervention. Those patients who

received a CHR as part of the invitation were more likely to come in for a health check. Those who received both the CHR and PHR were more likely to keep and use the record. Those who received the PHR improved their knowledge of health promotion and were more likely to change their lifestyle. This study showed that the combination of a computer generated record with a patient health record were more effective in changing patient behavior than either alone. These were also used in conjunction with a health check, suggesting that interaction with a medical professional in cooperation with these tools is effective in changing patient behaviors.¹³

Barriers to Adoption of Personal Health Records

While consumers have favorable views of PHRs and believe they offer potential benefits, these tools are still underutilized. Multiple barriers exist that prevent adoption of PHRs.^{1,2,15} Technology barriers, privacy and security concerns, economic barriers, and research needs have been well documented. The California HealthCare Foundation described the following barriers to PHR adoption: the lack of a sustainable business model, the lack of research describing benefits of PHRs, privacy concerns and the lack of consumer demand.¹⁵

Less obvious barriers, including environmental barriers and individual barriers, must also be considered.² Environmental barriers exist because health information is spread across multiple organizations and platforms. Integrated PHRs must overcome the fact that many organizations use EHRs but most EHRs cannot communicate with PHRs. Economic barriers and market forces are also a barrier to adoption of PHRs, as many

vendors who have created PHRs have not been successful. Legal concerns of providers and privacy concerns of individuals may also inhibit adoption of PHRs.²

Individuals may not have access to a PHR, and individuals' economic barriers may prevent access. Consumers with lower incomes and lower levels of literacy often bear a disproportionate burden of disease, and PHRs may initially be available to those with higher incomes.¹ Individuals must also understand and accept roles and responsibilities related to their health care and understand the need to monitor their health.² Workflow models for individuals using PHRs must be understood, and workflow studies in homes and the community are needed. Finally it must be acknowledged that behavioral change is not easy. Individuals will have to change behaviors, and the relationship between the PHR and behavioral change must be studied.²

For widespread PHR adoption to proceed, it must also be determined who will pay for PHRs. A study by Sittig examined 27 PHR tools in November 2000, and by May 2003, only seven were still in existence, and the main reason for failure was the lack of the sound business model.¹ Since health care providers and purchasers have the most to gain, they are likely candidates to provide PHRs. However, the evidence for the benefits of PHRs is still lacking, and without this evidence, these groups are unlikely to take on the cost of PHRs.² As the PHR becomes a lifelong health record, the logistics of maintaining the record must also be determined.⁶

Experts believe that education and research can break down these barriers for PHR adoption.² Education about PHRs is necessary for all stakeholders, and well-designed studies to demonstrate the effect of PHR use on health outcomes are needed.^{2,5,14}

Conclusion

Many individuals have a positive attitude toward PHRs and believe there are benefits to keeping personal health information. Multiple stakeholders are supplying policies and recommendations on attributes, data fields and other aspects of this emerging field. The President has given his support along with the support of multiple government organizations. Despite all the enthusiasm about PHRs, these tools are not widely used by consumers. Barriers to adoption may partially explain this, but there is likely another reason holding back widespread adoption and the field of PHRs. It is still unknown if PHRs will change health outcomes. There are studies demonstrating perceived benefits of PHRs, but there are few studies in the literature evaluating PHRs and evaluating if the use of PHRs changes health outcomes. In order for all stakeholders to embrace PHRs, the evidence must exist that PHRs alter health outcomes.

If PHRs can be shown to change behaviors and outcomes, it must also be demonstrated that PHRs will be utilized by consumers. While there is much data to suggest individuals have favorable opinions of PHRs and say they would use a PHR, more data is needed demonstrating actual PHR use. The study of individuals with spinal disorders showed that many did not accept the PHRs offered and few that accepted the PHR actually utilized the PHR. A PHR may be more successful if used in cooperation with a medical provider or EHR, and in one study, a PHR used with a visit to the health care provider was effective in changing behaviors and health outcomes. To ensure PHR utilization, strategies may need to be developed to encourage use and medical providers may need to take an active role.

To move the PHR field forward, additional studies must be conducted to demonstrate that PHRs change behaviors and health outcomes. These studies are necessary for stakeholders to continue to invest in PHR development, maintenance and utilization, and to justify widespread adoption of PHRs.

References

1. Markle Foundation. The Personal Health Working Group. July 2003. Available from: <http://www.markle.org/>. Accessed January 2, 2007.
2. Tang PC, Ash JS, Bates DW, Overhage JM, Sands DZ. Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *J Am Med Inform Assoc.* 2006;13:121-6.
3. Wolter J, Friedman B. Health records for the people. Touting the benefits of the consumer-based personal health record. *J AHIMA.* 2005;76:28-32.
4. National Committee on Vital and Health Statistics. Personal health records and personal health records systems. February 2006. Available from: <http://www.ncvhs.hhs.gov/>. Accessed January 2, 2007.
5. AHIMA Personal Health Record Practice Council; Burrington-Brown J, Claybrook D, Fox L, Gould K, Hall L, Hayman K, Jacobs E, Lang D, LaMoureaux L, Malchetske B, Morgan J, Olenik K, Peterson R, Williams L, Wolter J, Zallar B, Sweet D. Helping consumers select PHRs. *J AHIMA.* 2006;77:50-4.
6. Sprague, L. Personal health records: the people's choice? Issue Brief – No. 820 November 30, 2006. Available from: <http://www.nhpf.org/>. Accessed January 2, 2007.
7. Burrington-Brown J, Fishel J, Fox L, Friedman B, Giannangelo K, Jacobs E, Lang D, Lemery C, Malchetske B, Morgan J, Murphy K, Okamoto C, Peterson R, Robin D, Smith C, Sweet D, Thomas M, Wolter J, Zallar B; AHIMA e-HIM Personal Health Record Work Group. Defining the personal health record. AHIMA releases definition, attributes of consumer health record. *J AHIMA.* 2005;76:24-5.
8. Markle Foundation. Connecting Americans to their health care: a common framework for networked personal health information. December 2006. Available from: <http://www.markle.org/>. Accessed January 2, 2007.
9. Berner ES, Moss J. Informatics challenges for the impending patient information explosion. *J Am Med Inform Assoc.* 2005;12:614-7.
10. Newell SA, Sanson-Fisher RW, Girgis A, Davey HM. Can personal health record booklets improve cancer screening behaviors? *Am J Prev Med.* 2002;22:15-22.
11. Kim MI, Johnson KB. Personal health records: evaluation of functionality and utility. *J Am Med Inform Assoc.* 2002;9:171-80.
12. Denton IC. Will patients use electronic personal health records? Responses from a real-life experience. *J Healthc Inf Manag.* 2001;15:251-9.

13. Liaw T, Lawrence M, Rendell J. The effect of a computer-generated patient-held medical record summary and/or a written personal health record on patients' attitudes, knowledge and behaviour concerning health promotion. *Fam Pract.* 1996;13:289-93.
14. AHIMA e-HIM Personal Health Record Work Group. Practice brief. The role of the personal health record in the EHR. *J AHIMA.* 2005;76:64A-D.
15. California HealthCare Foundation. Personal health records: employers proceed with caution. January 2007. Available from <http://www.chcf.org/>. Accessed May 2, 2007.