What It Takes: Characteristics Of The Ideal Personal Health Record

Wider adoption of PHRs will require greater computer competency, Internet access, and health literacy.

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**ABSTRACT:** There is a gap between today’s personal health records (PHRs) and what patients say they want and need from this electronic tool for managing their health information. Until that gap is bridged, it is unlikely that PHRs will be widely adopted. Current barriers to PHR adoption among patients include cost, concerns that information is not protected or private, inconvenience, design shortcomings, and the inability to share information across organizations. However, in the future, when these concerns are addressed, and health data are portable and understandable (in both content and format), PHRs will likely prove to be invaluable. [Health Affairs 28, no. 2 (2009): 369–376; 10.1377/hilthaff.28.2.369]

A **PERSONAL HEALTH RECORD (PHR)** is a tool to use in sharing health information, increasing health understanding, and helping transform patients into better-educated consumers of health care. As defined by the National Alliance for Health Information Technology in a report to the National Coordinator for Health Information Technology (NCHIT), “a PHR is an individual’s electronic record of health-related information that conforms to nationally recognized interoperability standards and that can be drawn from multiple sources while being managed, shared and controlled by the individual.” This defines an idealized PHR. Several recent publications document the high degree of interest in PHRs for sharing health information such as health finances, diagnoses (problem lists), allergies, immunizations, insurance information, and medications in an easy way to help people manage their own health.³

PHRs are generating interest because they offer tremendous new opportunities to influence health and provide tools to assist consumers as they make treatment decisions.
“The mobile phone may serve as an important entry point for consumers to access their PHRs.”

choices. More than 60 percent of people participating in a Deloitte 2008 Survey of Health Consumers wanted online access to their medical records. In this paper we discuss the numerous challenges to PHR adoption and the policy changes that could overcome those challenges.

**Challenges Contributing To Slow PHR Adoption**

In 2006 President George W. Bush and Health and Human Services Secretary Mike Leavitt revealed a vision that “would create a personal health record that patients, doctors and other healthcare providers could securely access through the Internet no matter where a patient is seeking medical care.” The National Committee on Vital and Health Statistics responded with support for PHRs, but PHRs have not yet been widely embraced.

- **Technical barriers.** A nuanced discussion of the reasons for the slow adoption includes issues of cost, access, and interoperability, security concerns, and data ownership. However, in our opinion, slow PHR adoption may be linked to a failure of engineering, which has led to products with limited value to the end users. The best example of this is that because health information such as financial or clinical data does not flow freely among multiple organizations, PHRs do not automatically receive data. This means that the data must often be entered manually by consumers—a time-consuming and error-prone process. For most consumers, this lack of safe and reliable automation makes it problematic to maintain a PHR, and a PHR that is not up to date is not useful and thus will not be used.

- **Policy barriers.** Delays with federal rules and with the implementation of national policies have also contributed to the lack of PHR development and subsequent adoption. The engineering challenges were magnified by regulations that were only partially implemented and a framework for information technology (IT) that was not prepared for the dramatic changes induced by the World Wide Web. For example, the financial and clinical data held by provider organizations are not well linked even within an organization. This limits the kinds of tools that could be developed for a PHR to help consumers understand their treatment options within their own health plans. In addition, major challenges associated with creating national standards for electronic transactions for health care (established by the administrative simplification provisions of the Health Insurance Portability and Accountability Act [HIPAA] of 1996) resulted in evolving and even fragmented standards. The delayed development of standards contributed to slow development cycles of PHRs, and without the benefits of standards, PHRs often functioned as islands in a vast sea of collected health data. As a result, consumers had PHR options but no PHR that did everything they needed to manage their health and wellness. In
the future, the ideal PHR will receive health data from multiple sources of information, integrating the data that are necessary to manage health.

**Computer Competency, Internet Access, And Health Literacy**

Wider consumer adoption of PHRs will require attention to at least three important but non-technology-based areas: computer competency, Internet access, and health literacy. If these are not made policy priorities, PHRs risk becoming a tool that is limited to groups of people who are already linked to the Internet with high health literacy and computer skills. Improving health literacy is a national priority identified in *Healthy People 2010* as a key objective in improving the public's health. The relationship between literacy and health is complex. Low health literacy is associated with being poor and with engaging in fewer activities that influence good health. The groups with the greatest limitations for health literacy include people older than age sixty-five; minority, immigrant, and low-income populations; and people with chronic mental or physical conditions. The skills to increase health literacy will be critical for PHR adoption by a diverse population.

Computer competency and Internet access are necessary to facilitate information retrieval and online communication. The issue of Internet access is important because it disproportionately affects those with limited resources and limited health literacy. Most studies that have evaluated Internet applications for health suggest that patients are ready to use these tools, and the most-anticipated Internet applications include access to information on new treatments, e-mail communication, and medication information. Some research groups also identified the importance of sharing information through social networking and the value of learning from people like themselves. If policies are to be fair for everyone, especially for populations with a history of poor Internet access, they need to focus on improving access to the Internet.

Training for computer competency goes beyond turning a computer on and off. Competency includes understanding how to navigate the Web and complete simple functions such as searching for information, saving information, and sending e-mail. Acquiring and mastering the skills necessary to work with online applications also become important as consumers increasingly turn to online tools and sources of health information. Another opportunity to improve Internet access is through mobile phones. It is clear that mobile phone use is much higher than Internet access in underserved communities, especially among Hispanic youth. As devices become more sophisticated and application providers design mobile-ready solutions, the mobile phone may also serve as an important entry point for consumers to access their PHRs. The mobile phone also introduces an important opportunity to support consumers in behavior change through direct and customized text reminders.
Different PHRs For Different Functions

Health organizations often build PHRs to improve patients' access to their clinical information and engage patients in improving their health, reducing administrative costs, encouraging brand loyalty, and influencing patients' behavior. However, PHRs become even more valuable to consumers once their functionality matches the NCHIT's idealized definitions for PHRs and clinical, financial, and other personal information can be automatically integrated into one record. This requires consumers to gain information from various providers and organizations including employers, health plans, providers, and, potentially, family members to plan for their health. When consumers have access to their data, they will be able to use the information in health applications on the Web, obtain second opinions, or discuss their concerns with others who may have similar conditions. In the future, these idealized PHRs may represent an important tool to use in improving health and wellness.

For some organizations, the cost of the PHR may be offset by improved health activities and reductions in administrative fees that might translate into reduced health care costs. For patients who remain in the same location with the same organization over a lifetime, a PHR tied to an organization would be valuable, especially if it could help improve health through reminders or alerts and reduce health costs to the organization. However, it is rare for consumers to stay within the same health organization for their lifetimes. For the majority of consumers who are mobile, receive care from providers in different organizations, and change (or lose) insurance, the relative lack of PHR interoperability between health organizations and the resulting problems with poorly accessible health data may lead to frustration and inefficiency and could act as a disincentive for using current versions of PHRs. That is why the NCHIT's definition for the ideal PHR includes the notion that a PHR can be "managed, shared and controlled by the individual." Making PHR data portable for consumers when they move among health organizations represents a key factor in wider and more rapid PHR adoption.

Principles For PHR Health Data

PHRs are evolving; however, fundamental principles for Web-based PHR development may accelerate consumer adoption. These principles highlight the importance of interoperability, data security, consumer control, and fair access. Although others have examined these issues, the principle of including disadvantaged populations has not been stressed.\(^{17}\) Online PHRs have the potential to improve health, and boosting Internet connectivity has the added advantage of improving associated Internet skills for many new users.\(^{18}\) A common technology like the Internet may be used to help connect individuals to their health information and may reduce the participatory divide by bringing relatively inexpensive online technology to those with limited financial means.\(^{19}\)
“Privacy issues are complex in part because new PHRs are not necessarily covered by the HIPAA regulations.”

- **Behavioral change.** Consumers’ behavior may influence PHR adoption, and PHR adoption may influence consumers’ behavior. Often the most crucial impact on health will involve relatively simple behavior changes that are difficult to achieve. Examples include strategies that lead to less use of tobacco, regular exercise, dietary changes, and improvements in medication adherence. Individual efforts to change behavior are important; however, in a group setting, social network development and support are critical to bringing about behavior change. Developers of Internet-based PHRs are beginning to consider how to connect with or construct social networks to help support behavior change. The power of peer support in behavior change, which has been solidly documented, may be important for people seeking to improve their health.  

- **Types of PHR Interactions.** There are four types of interactions between idealized PHRs and consumers, and each one has the potential to affect consumers’ adoption of PHRs. PHR-to-consumer interactions include ways for the system to interact with individuals using automation for alerts, reminders, information, and education. Consumer-to-PHR connections enable patients to update their records with new data such as a new allergy or information from a home monitoring device such as a glucometer. Consumer-to-consumer connections promote applications such as e-mail, social networking, and online group participation. This might be important as consumers obtain “experience” from other patients or connect to support groups for information and other practical understandings. Finally, PHR-to-PHR connections allow for the transfer of health information needed to maintain consumers’ accurate and up-to-date health information. Provider group and health plan organizations emphasizing PHR adoption highlight the value of using the PHR focusing on consumer-to-PHR and PHR-to-consumer interactions as levers to improve health and reduce costs.

- **Security issues.** Data security and identity protection are critical issues and are central for widespread consumer acceptance and adoption of PHRs. Ongoing vigilance by consumers, correct system use and viewing privileges, compliance with laws and regulations, and the vigorous prosecution of those who violate the law will always be needed. Privacy issues are complex in part because new PHRs are not necessarily covered by the HIPAA regulations, as many new PHR developers are not covered entities as defined by HIPAA. There is a clear need to address the gap in the current HIPAA regulations and to establish additional legal protections to reach these new PHR developers and hosting organizations. An important policy implication is the protection of online health information and developing the tools for secure data exchange.
PHR Development At Home And Abroad

- **U.K. efforts.** The United Kingdom recently launched two different online health records. The summary care record (SCR), a centrally stored summary of health information populated from the electronic records of general practitioners (GPs), contains patients' current medications, their known adverse reactions, and their known allergies. This record is available at multiple health venues. It is hoped that this system will assist patients when they seek care during emergencies. HealthSpace is a separate initiative allowing patients to have access to the information in the SCR. HealthSpace allows patients to share their health information with whomever they choose and to enter data into the application themselves. These programs have encountered slow adoption and remain highly polarizing. It is too early to speculate on the outcome of this national experiment; however, the National Health Service (sponsors of SCR and HealthSpace and guardians of the information) is attempting to create a free, interoperable national health database that will be accessible by health professionals and consumers alike. In our opinion, it is not technology that will limit this experiment but the culture that resists change. The policy implication from this experience is not whether an electronic health record (EHR) allowing patient access is desirable or not; rather, it will be the lessons learned to facilitate needed “culture” change among providers and the pace of system implementation.

- **U.S. efforts.** The culture change required for PHR implementation in the United States might not be as daunting. Important efforts are already under way to provide people with access to their health data online. U.S. consumers generally desire online access to their health information and want tools to help them manage their health. A secure and ambitious effort to support PHR adoption has been launched in the Veterans Health Administration (VHA) system. Identified as My HealtheVet, the tool is being rolled out with a focus on appointments, medication requests, protecting the identity of the users, and helping veterans obtain a variety of services. Another example is the Epic system, which provides a PHR that is being used by Kaiser Permanente, the Cambridge Health Alliance, and others. These systems are widely used by consumers because they provide important functionality, which could lead to improved health.

The Case For Optimism

New entries into the PHR realm will likely contribute to PHR adoption, because these applications promote sharing of data at multiple sites for multiple purposes. The tools launched by Google (Google Health) and Microsoft (HealthVault) represent an opportunity for consumers to gain access to their health information via the Internet without new technology development or even organizational agreements. Additionally, in the future, consumers will have the option to use various health applications linked to the PHR. For example, a pa-
tient with diabetes, elevated cholesterol, and hypertension can use applications that influence behavior changes to decrease their blood glucose, reduce their cholesterol, and lower their blood pressure. This may include a check to determine if the patient is receiving recommended guideline-based care and text or phone messages. PHRs that use this new model for data sharing and portability offer an interesting solution to help address some of the engineering problems inherent in the complex data-standards environment that fragments health care. The value to drive PHR adoption will be accelerated as consumers receive expert advice, consultations, and guidance as a result of sharing their securely stored data. Then the PHR may become a critical component for how consumers manage their health, and consumers may become the stewards of their health data.28

Policy Implications

The policy changes that will likely lead to improved consumer adoption of PHRs include expanding PHRs' functionality; establishing standards for PHR information; facilitating the unencumbered, secure exchange of health information; improving consumers' access to PHRs; and helping consumers improve their understanding of the information contained in a PHR.

Consumers who adopt PHRs will require that the information be protected and private; that ownership lie solely with the consumer; that storage and use of the data be approved by the patients; and that the data be easily portable and in a format that is understandable. The value of an idealized PHR with these components will be enhanced by the development of tools to help consumers obtain advice and receive information to determine their best health options. A PHR that adheres to these concepts will provide extraordinary value for consumers and will accelerate the changing of patients into partners for health.

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