

Realizing the Transformative Potential of Personal Health Records

KEY POINTS:

- The PHR is a critical tool for engaging consumers in improving the quality and efficiency of their own health care.
- All PHRs are not equal: The transformative potential of PHRs requires that they be able to integrate and exchange data with other health care information systems.
- Policymakers have critical roles to play in enabling the widespread use of PHRs.

DEFINITION

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

The Markle Foundation's Connecting for Health Collaborative

Why Policymakers Need to Know About PHRs

Widespread adoption of electronic Personal Health Records (PHRs) is a key component of strategic plans for a national health information infrastructure, which experts consider essential to achieving significant improvements in health care quality and efficiency. PHRs are increasingly relevant to policymakers because:

- PHRs can serve as a tool to engage and empower consumers to play a larger and more active role in wellness, self-care, and disease management, with important dividends in quality improvement and cost containment.
- PHRs can collect and consolidate health information from both consumers and providers across the care continuum, including the home.
- Lessons learned from recent natural disasters highlight the importance of portable personal health information in response and recovery efforts.
- The full potential of PHRs and other consumer empowering tools cannot be realized without policy intervention.

This issue brief explores the potential of Personal Health Records (PHRs) to transform the way care is delivered and received. It examines how consumer-centric health records and related technologies can improve the quality, efficiency, and effectiveness of health care. It examines the definition of PHRs, the variety of existing PHR technologies, their functionalities, and the requirements for realizing their transformative potential.

What is a PHR?

The definition of a PHR is open to interpretation by its various sponsors, vendors, and users. While existing PHRs differ in functionality and degree of integration with other health information systems, they share several common characteristics:

- They allow individuals to manage their personal health information.
- The individual patient is the primary user.
- They contain information provided by the individual.
- They are portable, meaning they can be accessed anytime, anywhere via the Internet, or carried with the individual in a digital media storage device.
- They are tools for managing information relevant to lifelong health and wellness.

Types of PHRs

Personal Health Records have origins in low-tech paper-based solutions that individuals and families have used for many decades because they needed one place to record and store their personal health information. Today, there are two dominant PHR models:

Standalone or free-standing PHRs are often PC-based and require manual data entry to populate and update the record.

Integrated, interconnected, or networked

PHRs can be populated with patient information from a variety of sources, including electronic health records (EHRs), insurance claims, pharmacy data, and home diagnostics. This model provides consumers with a more complete view of relevant health information. **Tethered** PHRs are a form of the integrated model that connect with a single provider-based EHR system or other institutional database, offering patients access to parts of their electronic health records or claims data via web portals.

Types of PHRs		
	Standalone (Does not connect with other systems)	Integrated (Connects with potentially unlimited sources of health data)
Media	<ul style="list-style-type: none"> • Paper-based • PC-based • Data storage device • Web-based 	<ul style="list-style-type: none"> • Web-based
Value to Consumer	<ul style="list-style-type: none"> • Helps organize and store medical data • Provides anytime/anywhere access • Enables information sharing with providers 	<ul style="list-style-type: none"> • Includes all "Standalone" values, plus: • Provides access to provider-based records • May eliminate manual re-entry of data • Enables an additional patient-provider communication channel • May reduce medical errors, eliminate duplication, and improve quality • Enhances efficiency and convenience with online transaction tools • Promotes a more comprehensive view of health status and health care activity

Beyond the Basics

Most standalone PHRs provide basic tools that help people collect, organize, and store their health information. These include: medical history, medical and emergency contacts, outpatient and hospital visits, immunization tracking, insurance records, and health related alerts and reminders. More advanced PHR systems, particularly those that are integrated with other information systems, offer additional online functionality. The box to the right lists examples of advanced PHR functions and their benefits.

Advanced PHR Functions	Benefits					
	Continuity of Care	Convenience	Access to Providers	Quality of Care	Quality of Service	Ubiquitous Access
Online Functionality						
Access to medical records	●	●		●	●	●
Make/change appointments		●	●		●	●
Patient-physician secure email	●	●	●	●	●	●
Reporting of laboratory and other tests		●			●	●
Refill prescriptions		●			●	●
Drug interaction checking		●		●	●	●
Interactive health risk profiling and patient education resources	●			●	●	●
Prevention and wellness reminders	●	●		●	●	●
View deductible/copay balance		●			●	●
Review eligibility and benefits		●			●	●

Integration with Other Systems Is Key to PHRs' Transformative Potential

Not all PHRs are created equal. In order for PHRs to realize their transformative potential in clinical practice, self-care, and wellness, PHRs must be able to integrate and exchange data with other health care information systems, such as provider-based electronic health records, insurance claims, pharmacy and laboratory data, and home diagnostics. The truly integrated PHR, populated with patient information from a variety of sources, can provide a comprehensive view of relevant health information for both consumers and providers.

The integrated PHRs' **transformative potential** includes:

Patient/Provider Interactive Communication—Internet-based communication tools available in many integrated PHRs give both patients and providers a convenient alternative to telephone and in-person communication.

Virtual Integration between Closed Systems—Integrated PHRs facilitate the sharing of patient and administrative information among otherwise closed health care systems. Allowing patients to manage the various sources of their health information may give providers a more comprehensive view of patient information at the point of care.

Care Management—Integrated PHRs connect clinical care managers with patients or their caregivers. For patients with chronic conditions, the innovations in online communication may result in improved treatment monitoring (including data capture from home monitoring devices and self-management), more efficient use of patient and provider time, and the option of online consultation instead of in-person visits.

Health Knowledge Promotion—Web-based knowledge bases, self-care content, and consensus clinical guidelines can be integrated with PHRs through Internet connectivity. Some PHRs feature tools designed to foster health education and lifestyle change (e.g., interactive health assessment, online support groups, reminders for preventive services).

Portability—The value to consumers of portable medical records and other personal health information lies in the ability to access a longitudinal view of relevant health information from a single interface accessible anywhere, anytime through the Internet. Integrated PHRs hold this potential.

Auto-population—Since many consumers will not have the skills, resources, or patience to compile their own health information, auto-population—the automatic insertion of information into the appropriate location in a record—is a key factor in making PHRs desirable and practical for consumers. The alternative (manual re-keying and transfer of information) is inefficient and error-prone. Auto-population of health information will increase the value of PHRs by ensuring more accurate, comprehensive, and timely content.

Data Sharing with Authorized Patient Proxies—Integrated PHRs offer an unprecedented means of supporting family members, informal caregivers, or other authorized individuals to communicate with the health care team and stay abreast of the patient's welfare, irrespective of their geographic location.

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.

Tang, PC, et al, J Am Med Inform Assoc. 2006;13:121-126

How Can Policymakers Help Realize the Potential of Personal Health Records?

Action in the following strategic areas can help move integrated PHRs closer to the health care mainstream:

- **Incentives for widespread adoption of PHRs**—incentives to encourage physicians and consumers to use PHRs can take many forms including financial incentives and access to desirable system features.
- **Standards for interoperability**—the key to integration and exchange of structured data between PHRs and the many entities involved in providing and financing health care.
- **Privacy and security standards**—identifying appropriate safeguards that instill public confidence in the privacy and security of personal health information without establishing unnecessary barriers to the legitimate uses of health IT.
- **Product certification**—the application of objective criteria against which health IT products can be evaluated to ensure consumer protection and compliance with data interchange standards.
- **Racial and socioeconomic disparity gap**—The difference in computer and Internet access to health care information is largely a function of race and socioeconomic factors, especially education.
- **Health illiteracy**—Programs to increase public understanding of health care information (health literacy) could help ensure that the information provided by PHRs is both useful and used to maximum effect.
- **Research**—Quantifying health IT value, including both tangible and intangible benefits, is no easy task. More research is needed to support the PHR value proposition.

In Focus is a series of briefs designed to bring key research findings on important health policy issues to the attention of health policy makers. This issue of In Focus is by Brian Raymond, senior policy consultant at Kaiser Permanente's Institute for Health Policy. For more information on this and related issues, please visit the IHP website at www.kpihp.org.

Resources on PHRs

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