

Technology Profile: Personal Health Records

Overview

Personal Health Records (PHRs) refer to a set of technologies through which patients can access and manage their own health information. The contents of a PHR vary, but should include at a minimum diagnosis/ problems, medications, allergies, and past medical history. The PHR may include the clinicians visit notes, laboratory results and imaging reports. Some PHRs allow the patient to keep a narrative summary of events, to record blood pressures and blood sugars, and to track medications, diet, and exercise. Most PHRs contain generic health content or links for references, and self-management.

When discussed by source and relationship a PHR may be referred to as “tethered” or “untethered.” A tethered PHR is sponsored by an organization that is making available to the person his or her own health information. The record is automatically populated without the person having to enter information or arrange for the information to be transferred. The person may be able to add and/or correct the information. Tethered PHRs are usually sponsored by a health care provider and use information from the providers’ electronic medical records. Other sponsors might include payors, and employers. It may have other functions such as secure messaging, appointment scheduling or access to the person’s entire medical history. This may also be referred to as a patient portal. An untethered PHR is under the control of the person. The person controls access and must grant privileges to others for them to use the PHR. The person must enter all information or arrange for the information to be transferred from a specific source like a laboratory or pharmacy. Thus, the value of an untethered PHR is determined by a person’s willingness to manage and maintain their PHR information.

History

The PHR has evolved over time from a paper and pencil solution, to simple word processing and spreadsheet implementations, and finally to a specialized electronic system. In the late 1990’s some large medical groups began to offer their patients a tethered PHR as a service. Two examples would be MyChart at the Palo Alto Medical Foundation and Indivo at Boston Children’s Hospital. This was followed over the next several years by offerings from payors and commercial vendors. The payor systems were often limited in that they were interoperable only with the information systems of the organization that developed the system (e.g., the claims database and prescription information). The commercial vendors, whose systems were completely siloed, relied exclusively on the patient to enter health data.

The PHR market accelerated rapidly in late 2006 with the formation of Dossia (www.dossia.org), a non-profit organization formed by a consortium of large corporations to develop and host a comprehensive PHR. This was followed by PHR announcements from Microsoft, Google, large clinics, many hospital systems, online health information resources such as Revolution Health and WebMD, and many other smaller commercial vendors. These developments have coincided with an increasing focus on interoperability and information portability. For example, the Google system integrates with a number of information sources such as commercial laboratories, pharmaceutical suppliers, and devices. Microsoft is focusing more on connecting with typical service providers like the Cleveland Clinic. Both of these strategies are designed to populate the person’s record with some information from electronic sources, but still rely on the person to self-enter much of their information.

Technology	<i>Personal Health Record</i>
Applications	<i>Health and wellness, fitness, disease management</i>
Comparison Technology	<i>N/A</i>
Vendors	<i>Dossia, Microsoft, Google Health, MyMedicalRecords.com, Kaiser Permanente</i>
Drivers	<i>Demand for interoperability and portability of patient data</i>
Barriers	<i>Privacy and security, standards, closed systems, usability</i>
Cost	<i>Free or minimal cost</i>
Reimbursement	<i>N/A</i>

As PHRs are growing, standards and certifications are beginning to emerge. Common across many of these systems is support for the Continuity of Care Record (CCR) as outlined by the American Society for Testing and Materials (www.ccrstandard.com). The CCR is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare and is becoming a de facto data standard across implementations. Functional, communication, and data standards for PHRs are emerging from the other major standards bodies. HL-7 has released the Personal Health Record System Functional Model (PHR-S FM), which identifies a set of recommended functions and specifications for PHR's. In addition the Certification Commission for Healthcare Information Technology (CCHIT), the organization that certifies electronic health records, is currently developing a certification standard for PHRs.

Applications

PHRs remain first and foremost a tool to engage individuals in their own health management. There are numerous applications of all types and they are constantly evolving.

Current applications of PHRs tend to target the following key functions:

- Storage and viewing of parts or all of a person's medical history
- Access to health information
- Support for wellness activities
- Assistance with chronic disease management
- Secure patient-provider communication
- A portable repository for the CCR
- Medication management

Project Health Design is a national program of the Robert Wood Johnson Foundation that designs next-generation PHRs through grantmaking activities (www.projecthealthdesign.org). The program has funded a number of multi-disciplinary teams to work with users to design and eventually build prototypes of PHR applications. For example:

- *My-Medi-Health (Vanderbilt University Medical Center)*: A system that features a medication management assistant to help children with cystic fibrosis play a larger role in taking care of themselves. A device links in to help kids take the right medications at the right times, alert parents and caregivers if doses are missed, manage refills, and more.
- *Stanford University and Art Center College of Design*: A set of multimedia PHR tools to help adolescents with chronic illness communicate with their providers and others about their health as they transition to adulthood. By tapping into teen technology behavior, the applications help track progress and treatment in ways that fit seamlessly into their lives.

Barriers

- Limited value: People without special needs or chronic medical problems seldom need to access their health history and most are not inclined to regularly participate in structured wellness activities.
- Privacy concerns: Most patients guard their medical information as closely as their money. As more people use electronic systems to manage their money they gain trust in systems for both functions. The one privacy area that remains a challenge is the right of a parent to access an adolescent's PHR, thus most organizations with tethered PHRs don't provide PHRs for adolescents.
- Limited interoperability: Current standards do not allow information to flow easily from one health information system to another. This limits the usefulness of an untethered PHR to the small number of motivated persons willing to self-enter their important information.
- Lack of funding: At present there is no reimbursement for a PHR. Provider organizations that supply PHRs do so to project an image or because it improves their operating performance. Currently, only the integrated, tethered PHRs that are an extension of a provider's Electronic Medical Record (EMR) appear to improve an organization's operating performance, as Kaiser Permanente has shown.

The Future

In the near-term, tethered PHRs with the functions of a patient portal will increase at a rate that follows the implementation of ambulatory EMRs. This adoption could be further accelerated if the US Health and Human Services were to include PHR adoption with their EMR incentive plan for supplemental reimbursement followed by reimbursement penalties. Untethered PHRs will struggle and will be used mostly by persons with special needs and chronic diseases whose providers do not supply a tethered PHR, as well as the occasional person who is willing to self-enter the information.

In the long-term, all providers will have robust PHRs as an extension of their EMRs. Their EMR/PHR's will be able to accept CCR/CCD information from other providers on an automatic or on-demand basis. Even if an individual is healthy and receives only episodic care, he or she will have encounter information sent to a single site, most likely a primary provider. Most provider organizations will have added all of the portal functions to their PHR to provide improved access, self-service, continuity of chronic care, and remote care.

To access additional background, forecast, and policy materials, please go to www.childrenspartnership.org/HITInnovationForChildren

Health Technology Center and The Children's Partnership would like to acknowledge The California Endowment for its support of this project.

© 2009 Health Technology Center/The Children's Partnership.
Permission to copy, disseminate, or otherwise use this work is generally granted as long as ownership is properly attributed to Health Technology Center and The Children's Partnership.