

PERSONAL HEALTH RECORDS

A True “Personal Health Record”? Not Really ... Not Yet.

Author: Erica Drazen

Personal Health Records (PHRs) have long held appeal as a way to empower patients by providing them with lifetime access and control over comprehensive and accurate information about their health. During the peak of the e-health boom ten years ago, it was difficult to pick up a healthcare IT publication without being reminded of the key role that PHRs were going to play in transforming healthcare.

PHRs were again in the news with the announcement that Google will discontinue their Google Health PHR in January 2012. Even though it can be argued that Google’s failure underscores some of the inherent challenges with PHRs, the buzz surrounding PHRs continues to grow. A few large integrated payer and delivery systems like Kaiser Permanente are offering patients access to increasingly sophisticated patient portals. Microsoft HealthVault, the primary competitor to Google Health, continues to roll out new capabilities and features. The federal government has clearly made PHRs a priority. The Office of the National Coordinator for Health Information Technology (ONC) hosted a day-long public roundtable on PHRs in December 2010, and the recommendations from the HIT Policy Committee on Stage 2 meaningful use requirements would hold hospitals and eligible professionals (EPs) accountable for ensuring a minimum percentage of patients view their health information online.

Unfortunately, despite the continued buzz and some well-publicized initiatives, the reality is that we are still no closer to a **true** personal health record than we were 5 or 10 years ago. Fundamental barriers still exist, and without major changes in behavior and dramatic increases in adoption of technology, a true PHR – and the benefits associated with it – will not be possible.

The purpose of this white paper is to look at the current market and identify what needs to change in order for the healthcare system to realize the benefits of a true PHR.

The *True* Personal Health Record

The goal of a PHR is to empower patients so they can make the most informed decisions possible about their health. There is no widely accepted definition for what specific capabilities a PHR needs to include, but at a minimum any true “personal health record” needs to at least possess the following four characteristics: the PHR needs to be **comprehensive, interactive, patient-controlled** and **secure**.

Table 1. Characteristics of a True Personal Health Record

<p>Comprehensive</p> <p>The PHR includes accurate and complete data from all settings of care. This includes any data required to make a healthcare-related decision: clinical information from a primary care physician or hospital, data uploaded from a device in the patient’s home, details on health insurance coverage, notification of upcoming appointments, etc.</p>	<p>Interactive</p> <p>Information flows both to and from the PHR. Patients are provided with proactive and timely feedback based on the information provided; authorized physicians can be automatically notified of important changes or new information.</p>
<p>Patient-Controlled</p> <p>The patient has lifetime access to any information in the PHR and decides which stakeholders can access the information.</p>	<p>Secure</p> <p>The information in the PHR is accessible only by the patient or third parties authorized by the patient.</p>

Realities of the Current PHR Landscape

Given the siloed nature of healthcare and limited adoption of technology in many care settings, no “personal health record” on the market today possesses all the characteristics of a true PHR. There are certainly organizations that have had success providing patients with access to portions of their health information, but in most communities in the United States, actual PHR use is low and any potential benefits are limited by the amount of clinical information available electronically.

A closer look at four realities of the current PHR landscape:

1. The current PHR market remains fairly fragmented with multiple models still in use.

Virtually all of the PHR solutions on the market today fall into one of the following three categories:

- a) **Payer-populated PHRs.** A PHR tethered to a payer or employer that is populated with claims information. PHRs in this model rarely include any clinical information directly from providers, but some allow members to enter basic information such as height and weight, known allergies or any over-the-counter medications taken. Payer-populated PHRs can also include decision support tools designed to help members improve their health or manage a chronic condition; for example, sending a reminder for an overdue test or screening.

Specific capabilities vary, but most large health plans such as Aetna and Cigna offer some type of payer-populated PHR. Large employers are increasingly looking at payer-populated PHRs as well. Dossia, a nonprofit consortium founded by Fortune 500 companies, offers a PHR that can be populated with claims information. In late 2008, Walmart became the first member company to roll out the solution to their employees.¹

- b) **Provider-populated PHR.** A PHR tethered to a hospital, physician practice or other health delivery organization that is populated with data from the provider’s clinical or financial information system. Patients typically have access to medications, immunizations, allergies and lab results, and in some cases even the problem list. Provider-populated PHRs often include transactional services as well, such as the ability to email with providers, request a prescription refill or schedule an appointment.

Success with provider-populated PHRs has primarily been limited to large, integrated delivery organizations with high levels of electronic health record (EHR) adoption and longstanding commitments to provide patients with access to their data. The most well-known example is [My Health Manager](#) used at Kaiser Permanente, an integrated payer and delivery organization. The PHR provides users with access to their allergies, medications, lab results and information from their problem list from Kaiser’s EHR, and the ability to exchange messages with providers and request appointments. Kaiser reports that enrollment has increased from roughly 20 percent of eligible members in 2006 to almost 60 percent of eligible members through 2010. At this point in time, the PHR is only available to Kaiser members, but the organization plans to make the solution available to non-members as well in the coming years, so patients will continue to have access to their information after they leave Kaiser.²

- c) **Untethered/patient-populated.** Untethered PHRs are controlled by the patient rather than by the provider, employer or health plan. The patient can manually populate the record or authorize certain payers, pharmacies, providers or other organizations to do so with information from their systems (provided those organizations have an agreement in place with the PHR vendor). Untethered PHRs also allow users to integrate third-party solutions into their record. These can range from tools that help patients manage medications to tools that are specific to a certain condition or disease.

Until recently, the two most well-known entrants into the untethered PHR space were Microsoft HealthVault (launched in 2007) and Google Health (launched in 2008). In June 2011, Google announced it was discontinuing the Google Health service, indicating that although “there has been adoption among certain groups of users”, the company “hasn’t found a way to translate that limited usage into widespread adoption in the daily health routines of millions of people.”³ Microsoft continues to invest in HealthVault though, and recently rolled out a mobile version of the site as well as an option that would allow users to sign in using their Facebook credentials.⁴ As of mid-July 2011, the HealthVault website lists links to more than 100 data sources and tools.

Partnerships between untethered PHR vendors and provider organizations are limited to date, but a December 2010 survey of 120 acute care organizations from KLAS indicated that providers are at least considering integrating with an untethered PHR. Microsoft was mentioned most often by respondents, considered in 31 percent of potential PHR deals; Google Health was third, considered in 23 percent of deals.⁵

2. No PHR model in use today could accurately be described as having all the characteristics of a true PHR.

There are still inherent barriers to all three models. PHRs tethered to a provider or payer are typically populated with **accurate** information, but the information is usually just from a single source (i.e., the provider’s EHR or the payer’s claims system). A typical provider-populated PHR might not provide information related to care delivered by another physician; a typical payer-populated PHR might list the last time a test had been performed based on claims data, but not the actual result. Users usually have limited control over the information included, and access is often contingent on remaining a member of the health plan or patient of the provider.

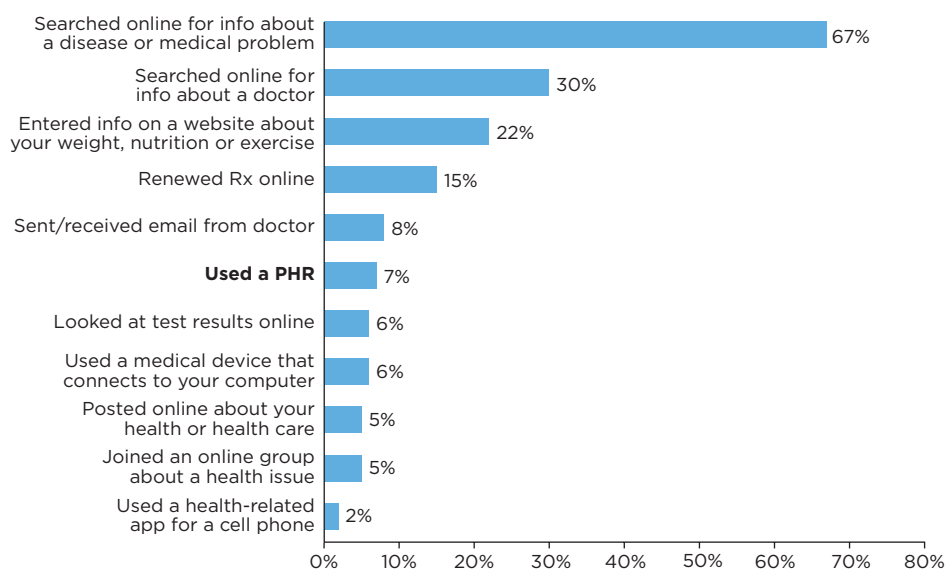
Untethered PHRs give the patient control over what information appears in the record and allow input from multiple sources, but the data may not be as accurate. The most reliable source of information is the provider’s EHR, but most provider organizations are still largely paper-based and only a fraction of organizations that have implemented an EHR have a partnership in place with a PHR vendor such as Microsoft HealthVault. As a result, most patients will need to manually enter clinical information, which historically they have been reluctant to do. Additionally, even when populated with accurate clinical data, it remains unclear how untethered PHRs will effectively support the most popular features of provider-populated PHRs, such as online refills, email communication and appointment scheduling, without requiring the patient to log in directly to the provider’s portal.

3. Adoption by consumers remains limited and current activity consists largely of niche uses of silos of information.

Given the lack of a widely accepted definition for what constitutes a “personal health record”, actual adoption by consumers is difficult to pinpoint — but recent data suggests that outside of a few well-known initiatives, use is low. A 2010 study sponsored by the California HealthCare Foundation found that only 7 percent of adults nationwide have ever used a website from a doctors’ office, health plan or other company to get, keep or update health information, such as lab test results, medicines, doctors’ visits.⁶ Fifteen percent of all survey respondents nationwide said they have renewed a prescription online, 8 percent said they have sent or received e-mail from a doctor, and 6 percent reported they have looked at lab results online. A 2011 survey sponsored by the Markle Foundation suggested similarly low rates of PHR adoption, with only one in ten U.S. adults saying they have a PHR.⁷

Table 2. Consumers' Use of Health IT

"Have you ever done any of these things online?"



n= 1,849
 (Source: "Consumers and Health Information Technology: A National Survey", California HealthCare Foundation, April 13, 2010)

There are large integrated delivery organizations that have had some success with PHRs though. At Beth Israel Deaconess Medical Center (BIDMC) in Boston, Massachusetts, patients can use [PatientSite](#) to view medication information and test results, renew prescriptions, request appointments and securely message with providers. According to BIDMC, between April 2000 and March 2004, 18,435 patients registered on the site and logged in at least once.⁸ By 2008, BIDMC reports that more than 35,000 unique patients were "actively using the site."⁹ The most popular features as of March 2008 were provider messaging (27.8 per month per 100 patients), prescription refills (3.1 per month per 100 patients), appointment scheduling (2.6 per month per 100 patients) and referrals (2.1 per month per 100 patients).¹⁰

On the payer side, estimates of PHR use vary. A November 2009 report from Forrester cited in the May 2010 issue of *Health Management Technology* found that 22 percent of U.S. consumers said they have a PHR from their health plan — but Forrester themselves questioned the results, saying it was not in line with what they are hearing from health plans, especially as it relates to use.¹¹ Low adoption of payer-populated PHRs was also reported in a *Health Affairs* study based on interviews conducted in 2008 with 35 executives at health insurers offering PHRs. While most participating health plans were not willing to provide company-specific information, they reported that PHR enrollment was "in line with the national estimate of one percent."¹²

Limited information exists on how many people have an account with an untethered PHR, but it appears that the number is far fewer than those who are using PHRs sponsored by a health plan, employer or provider organization. For example, the November 2009 report from Forrester cited in the May 2010 issue of *Health Management Technology* indicated that 2 percent of U.S. consumers use a PHR from WebMD, 1 percent use HealthVault, and 1 percent use Google Health.¹³ The 2010 survey sponsored by the California HealthCare Foundation did not ask about specific products, but only 6 percent of PHR users indicated the solution they used was from a source other than a health plan, employer or provider.¹⁴

Google's decision to phase out Google Health further underscores just how limited actual use of PHRs is in most communities today. It can be debated whether Google would have been successful with a different strategy, but the fact that consumers did not use a PHR from a company known for literally changing the way people access information on the Web is telling.

4. There remains no evidence that outside of specific niche uses, PHRs actually represent a value proposition in the eyes of most patients.

The value proposition for patients remains unclear. Surveys have long suggested that patients are interested in the **idea** of a PHR, but data continues to suggest that few act on that intention when capabilities are made available. For example, a June 2010 Harris Interactive Poll found that even though the **number** of patients who use typical provider-populated PHR capabilities has increased since 2006, the **percentage** of people who use those capabilities has actually changed very little among those who have access.¹⁵

Table 3. Patients' Use of Typical Provider-Populated PHR Capabilities

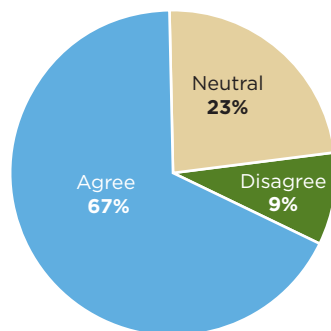
<i>"To what extent do you use, or have access to, the following?"</i>	Year	% saying "I use it now"	% saying "It's available to me but I don't use it"	Adoption rate among users who have it available*
An electronic medical record to capture medical information	2006	2%	3%	40%
	2010	7%	8%	47%
Email to communicate directly with my doctor	2006	4%	4%	50%
	2010	9%	12%	43%
The ability to schedule a doctor's visit via the Internet	2006	3%	4%	43%
	2010	8%	11%	42%
Receiving the results of diagnostic tests via email	2006	2%	3%	40%
	2010	8%	10%	44%
A home monitoring device that allows me to send medical information — like blood pressure readings or blood tests — to the doctor's office via the telephone or email	2006	2%	3%	40%
	2010	3%	8%	27%
Reminders via email from my doctors when you are due for a visit or some type of medical care	2006	4%	3%	57%
	2010	11%	10%	52%

n= 2,035
 *not part of study; numbers based on CSC calculation from results to survey
 (Source: Harris Interactive, June 2010)

The 2011 survey sponsored by the Markle Foundation suggested a similar disconnect. Although more than two-thirds of respondents agreed with the statement "doctors should make a patient's information like lab results available electronically to the patient as soon as the information is available", only 2 percent said they actually ask for their information electronically with any kind of frequency.¹⁶ More than eight in ten patients said they never ask for copies of their health information electronically.¹⁷

Table 4. Public Opinion on Control of Electronic Patient Information

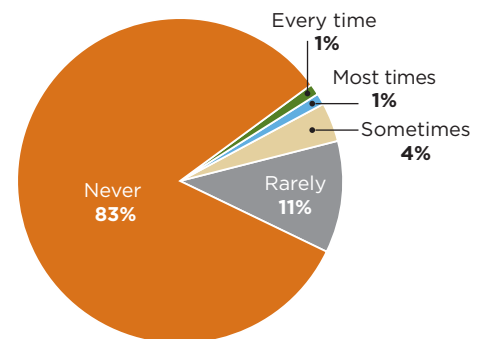
"Doctors should make a patient's information like lab results available electronically to the patient as soon as the information is available."



n=1,582
 (Source: "Survey on Health in a Networked Life", Markle Foundation, January 31, 2011)

Table 5. Actual Action Taken by the Public to Obtain Electronic Health Information

"How often do you ask for copies of personal health information or medical records in electronic format?"

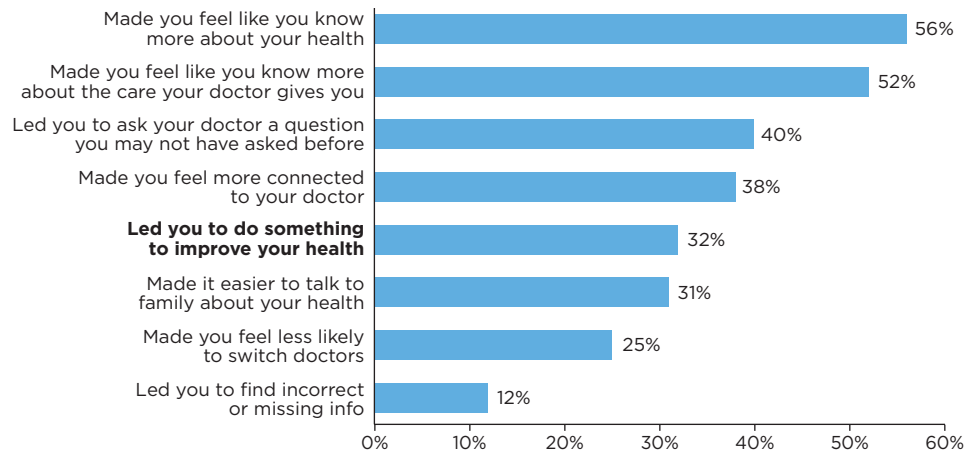


n=1,582
 (Source: "Survey on Health in a Networked Life", Markle Foundation, January 31, 2011)

Even when patients do use PHRs, it is not clear that use of a PHR results in a change of behavior. According to the 2010 study sponsored by the California HealthCare Foundation, more than half of PHR users said that using a PHR made them feel like they know more about their health, but less than a third said using a PHR actually led them to do something to improve their health. Only 40 percent said using a PHR led them to ask their doctor a question they would not have otherwise asked.¹⁸

Table 6. Patients' Reactions to Using a PHR

PHR users who said "yes", using a PHR...



n=266

(Source: California HealthCare Foundation, April 2010)

Looking Forward

The failure of Google Health does not signal the end of other PHRs on the market today, but it certainly underscores many of the inherent barriers that still need to be overcome. Given the longstanding silos of data that exist in healthcare and the limited interest from patients to date, it is highly unlikely there will be any kind of true PHR on the market anytime soon. Niche uses clearly have value to many stakeholders though, and are likely to increase especially given the increase of social networking sites and the increasing availability of mobile health applications. But what needs to change before a **true** personal health record is possible?

- **Clinical information needs to be available electronically from a vast majority of providers.**

The best source of data for the PHR — the provider's EHR — is also the least prevalent today. A majority of hospitals and physician practices are still paper-based, and despite the incentives and penalties established under the HITECH Act, many remain years away from widespread EHR adoption. Until PHRs can be populated in real time with structured data from providers across all care settings (and integrated with coverage, billing and other health-related information), there are inherent limits to any benefits that can be achieved from a patient using the PHR.

- **Both patients and providers need to think of PHRs as more than just repositories for information.**

Today, PHRs are largely viewed as repositories of information that are more commonly used to record healthcare decisions than they are used to actually **influence** them. As capabilities continue to evolve, patients need to think of the PHR as an interactive tool that plays an integral role in how they make decisions about their healthcare. The PHR will need to provide timely, proactive information in a way that is a natural extension of the patient's daily life (e.g., access to their clinical information on a mobile device or condition-specific content integrated with their use of social networking). HealthVault recently announced initial steps in this direction, rolling out a mobile version of the site and allowing users to log in with their Facebook credentials.

The way that providers think about PHRs will also need to evolve. The PHR should be viewed as a vehicle to provide patients with health information, but also as a source of data. In order to help patients make informed decisions, providers need access to patient-entered information that might not be in the EHR (e.g., data from a device in the patient's home) as well as any information that is contrary to what is in the EHR (e.g., differences in medication or allergy lists).

- **PHR use needs to trigger an actual change in behavior.**

Some of the successful PHR initiatives to date have shown PHRs can increase patient satisfaction and make them feel more informed about their care. But happy, satisfied patients — while an important first step — are not necessarily **healthier** patients. In order to reap the benefits of a PHR, using the PHR must result in patients taking actions they would not have otherwise taken. This could be as simple as scheduling an overdue screening or as drastic as changing their entire diet — but without a majority of patients making some kind of change, the benefits of a PHR are limited.

A widespread change in behavior is the **expectation** of what will happen if patients have access to a true PHR, but it should not be viewed as a foregone conclusion. The PHR model needs to continue to evolve from a business model that largely benefits providers, payers and employers to one that is aligned with patients' needs and integrated with their lifestyle.

About the Author

Erica Drazen is the Managing Partner of the Global Institute for Emerging Healthcare Practices, the applied research arm of CSC's Global Healthcare Sector.

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Healthcare Group

3170 Fairview Park Drive
Falls Church, Virginia 22042
+1.800.345.7672
healthcaresector@csc.com

Worldwide CSC Headquarters

The Americas

3170 Fairview Park Drive
Falls Church, Virginia 22042
United States
+1.703.876.1000

Europe, Middle East, Africa

Royal Pavilion
Wellesley Road
Aldershot, Hampshire GU11 1PZ
United Kingdom
+44(0)1252.534000

Australia

26 Talavera Road
Macquarie Park, NSW 2113
Australia
+61(0)29034.3000

Asia

20 Anson Road #11-01
Twenty Anson
Singapore 079912
Republic of Singapore
+65.6221.9095

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