

# Personal Touch

## Personal Health Records for Consumers of Healthcare

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### KEYWORDS

Personal health records, consumer, PHR, health information, empowerment.

### ABSTRACT

Personal health records (PHRs) consist of medical records that the consumer collects from each of their healthcare providers, plus any health information that the consumer adds. Sharing information from the PHR with providers enables the consumer and provider to work together. Use of data in the PHR can help reduce or eliminate duplicate procedures or processes. This helps save time and healthcare dollars. It can help the consumer receive better, more coordinated healthcare. In addition, PHRs will eventually have the impact of empowering consumers as never before to make informed healthcare choices and have a positive impact on the overall cost of healthcare.

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### CONSUMER EXPECTATIONS: A PHR PATIENT USER PERSPECTIVE

Like many baby boomers, Bob has had an increasing number or health issues over the last few years, including some chronic conditions. He is a frequent patient at his primary care physician or specialists, with a current treatment regimen including six ongoing prescription medications plus periodic testing, combined with treatment by specialists in five different medical specialty areas over the last two years. Recalling details correctly can be a challenge for him, and repeatedly giving the same basic information to hospitals and doctors in written and verbal form is source of frustration. This frustration is exacerbated by his knowing there is an easier and more accurate way to share this information.

The mix of providers he has used in the last three years includes:

- Two primary care physicians. After moving several years ago he switched from his long time personal physician to a new physician located near his new home.
- Two heart specialists. Upon his primary care physician's discovery of an irregular heartbeat, he began seeing a cardiologist, who in turn referred to a specialist in cardiac electrophysiology

- Gastroenterologist, for routine colonoscopy
- Orthopedic surgeon for knee problems
- Chiropractor for chronic back and neck pain
- Sleep specialist

Treatment by these doctors involved having tests and procedures done at four different hospitals. Chronic conditions include high cholesterol, allergic rhinitis, enlarged prostate, sleep apnea and back and neck pain.

In addition to six ongoing prescriptions for these conditions, he uses some over the counter drugs/treatments.

Having worked in the healthcare information technology (IT) arena for 30 years, it is probably not surprising that Bob was an early adopter of PHR. He has been using one for over four years. His relocation about three years was a motivation for him to use the PHR better since it necessitated changing his primary care physician and he wanted to have his health information well organized for his new doctor. His PHR experience has yielded mixed impressions. On the one hand, it has been personally positive and helpful. On the other hand—it is still far from fulfilling its potential.

Here's what he wants from a PHR:

- A helpful and easy way to organize his medical history.
  - An easier and more accurate way to share it with physicians – both to avoid responding to the same questions/requests for information, and to share it accurately with healthcare providers. At the top of that list is prescription information – recalling precise name, spelling and dosage of drugs can be a challenge, as can simple information such as names and contact information.
  - Do the same for other family members.
- To date, his PHR has proven helpful in the following areas:
- Organizing key portions of his personal medical record – specifically medications, immunizations, provider contact information, and listing of conditions, diagnosis and major procedures.
  - It is easier to share the information than relying solely upon his memory and writing or verbally responding to routine questions every visit. The current means of sharing information is to print it out and hand it to the provider during physician visits.
  - He can carry a printed or electronic copy (such as a CD or a flash drive) of the record with him when he travels – especially for out of country travel where there may be a big language barrier and immunization records can be vitally important.

Bob clearly states he does not want to minimize the value and importance of these benefits – they are certainly worth the cost (none in his case, but there can be costs for other PHRs) and effort (manual entry via web site)—and he will continue using it. However, he feels it could do much more. Frustrations in using the PHR include:

- Information can only be manually entered - by him. There is no mechanism to scan data, import from other systems, or permit providers to enter data. Data sets are limited – for example he cannot enter test results, physician notes/recommendations, radiology transcriptions etc.
- It is not always easy or intuitive to enter data – and can be time consuming. There are no edits to validate accuracy of entered information, though, unlike when he is at a physician office, he has the luxury of having his prescriptions and other records in front of him, making the source of his information much more accurate than memory alone.>

- Despite the PHR vendor claiming to have one of the largest physician user bases in the country, none of his personal physicians uses this PHR. To his knowledge none of them use any PHR. Hence, they are not interested in electronically accessing his records. All data is exchanged with them by printing out records from the PHR.
- There are certainly other products out there claim they can do these things, but there has been no compelling evidence to suggest they do it well enough to warrant the time, effort and possible cost of switching.
- Other family members do not share his enthusiasm for PHR, and are not currently taking advantage of it.

### **PATIENT CONTROL OF PHR INFORMATION**

Who owns health information? While healthcare providers typically maintain health records, consumers must have the ability to control their own PHR. Consumers need to be aware of their rights regarding health information in general, regardless of whether they have a PHR. According to Lydia Washington, MS, RHIA, CPHIMSE in her 2007 article entitled *Protecting the Privacy of Your Personal Health Record*, Ms. Washington suggested the following:<sup>1</sup>

**Understand your rights as a healthcare consumer.** This includes the right to review and obtain copies of your medical information, the right to request amendments and corrections of information that may be erroneous, the right to know who has received copies and reviewed information and the right to complain about medical privacy practices or breach of privacy.

**Exercise information rights.** Consumers should obtain and maintain copies of their medical records and information so that personal care can be monitored and spot any errors in the information. Individuals are strongly encouraged to establish PHRs and monitoring the accuracy of the health information.

Once consumers decide to utilize a PHR, they should have the ultimate authority in deciding which sections of their PHR can be accessed, by whom, and for how long. This includes granting or retracting permission to view specific content by provider. The PHR must contain sufficient security features to authenticate users, their permitted level of access and their authorized purposes. For example, consumers must be assured that the data contained in the PHR will not be used for undisclosed purposes such as drug marketing or research, though they may elect to specifically permit such uses. Consumer health information should never be made available to an employer in the case of an employer-sponsored PHR.

Another important concern of consumers is the portability of their personal health data from insurer to insurer if they change plans. This is especially important if their PHR is sponsored by a health plan. There should be no restrictions (procedural or technical) imposed by the health plan, or PHR vendor, on easily moving one's own data from one PHR to another. Indeed, the industry should strive to develop standards and tools to make portability fast, efficient and easy.

As PHRs develop to empower consumers to make informed choices, consumers need to ensure that organizations protect their health information and ensure its privacy. Privacy and security are covered in more detail in the Privacy and Security Chapter of this white paper.

## PHR SPONSORS

In the November 2007 Continua newsletter, Dr John Halamka describes four types of PHRs currently available.<sup>2</sup>

- In the provider hosted patient portal to the clinician's Electronic Health Record (EHR), consumers have secured access to health information from the hospital and/or clinician's office.
- The payor hosted patient portal to the payer claims database allows for access to claims data such as discharge diagnoses and reim-bursed medications. Lab data may or may not be available through this model.
- Employer sponsored PHRs typically utilize a third party vendor to provide consumer access to both claims and benefits information.
- Vendor hosted PHRs allow for consumers to store, retrieve and manipulate their own data.

Consumers also have a fifth PHR option. Vendor software is available for the consumer to maintain and control their own PHR on their own computer. This type of PHR is not remotely hosted or supported by any vendor, employer or provider.

An example of an employer sponsored PHR recently in the news includes the Dossia project sponsored by companies including Wal-Mart, AT&T, Sanofi-Aventis and Intel.<sup>3</sup>

There are close to 100 vendor hosted products on the market today including products such as MEDEM and Microsoft's Health Vault.

The concern with any of these models except for the vendor hosted PHR, is portability. The consumer can lose access to a payer, employer or provider hosted PHR if they voluntarily or involuntarily change jobs, insurance companies, or providers for any of a number of reasons.

## PATIENT PORTALS IN ILLINOIS

Patient portals are similar in concept to PHRs in that they offer an electronic means of sharing information between patient and provider. However, they do not necessarily include the key attribute of a PHR—e.g., the ability for a patient to maintain and store their own clinical information, and often have capabilities that individual PHR products do not. As of an Internet search in the spring of 2009, Illinois has several examples of provider and payer-sponsored portals in existence. The portals vary in their offerings to consumers and may include some components of a true PHR.

**Decatur Memorial Hospital, Decatur, IL.** The online portal (<https://mydoctor.dmhhs.org/>) allows patients to view and update their medical record; request appointments; request prescription refills; and e-mail their physician office.

**Christie Clinic, Champaign, IL,** by InteGreat (<https://www.icmyhealthrecord.com/christieclinic/>) allows consumers to view health summaries and request an appointment.

**Methodist Medical Center, Peoria, IL,** by Geonetric (<http://www.mymethodist.net/>). The online portal "creates" a PHR for the consumer and allows patients to request an appointment; message their physician office; get prescription refills; request or view lab results; create a "Web" visit for non-urgent medical questions that the physician replies to after the consumer completes a specific questionnaire; and create a PHR that includes patient medications, problem list, allergies.

**Rush University Medical Center, Chicago,** by Intervent. The

Heart Health Portal (<https://www.interventathome.com/rush/>) is available in Cook, DeKalb, DuPage, Grundy, Kane, Kankakee, Kendall, Lake, McHenry and Will County; specific to heart health.

**BlueCross BlueShield of Illinois (<http://www.bcbsil.com/>).** PHR available to insurance subscribers

**IVF 1 (<http://www.ivf1.com/>).** A fertility medicine clinic in Chicago and Naperville provides both a patient and physician portal that allows patients to enter or update their personal demographic information; review laboratory results; review treatment flow sheets and past treatments; review prescriptions; send messages to office staff; and allow primary care and referring physicians access to medical data.

**Evanston Northwestern Healthcare.** The online portal (<https://www.northshoreconnect.org/>) allows patients to schedule appointments, view test results, renew prescriptions, secure message their physicians; pay their medical bills; manage their children's health; and review their medical record.

**Adventist Health System, Illinois.** This includes Adventist Hinsdale Hospital, Adventist Glen Oaks Hospital, Adventist Bolingbrook Hospital and LaGrange Memorial Hospital. The online portal (<https://patient.ahss.org/#Illinois>) allows patients to request appointments; pay bills; pre-register for an appointment; and access personal health records.

## PHR CONTENT

Ideally, a PHR will serve the healthcare needs of both the patient and provider community. Most providers of healthcare collect certain elements of a patient's history almost universally at the time of an initial encounter and at subsequent visits to the same provider. Consumers of healthcare are repeatedly asked to respond to the same questions. As a result, errors of omission in recollection can result. A PHR can readily serve as a source of information assisting patients in collecting and presenting health information easily.

Components commonly requested by providers during patient encounters that are also important to the consumer, and should be included in a PHR include:

**Health history,** including surgical, family, psychiatric, social history. Part of most new patient visits to primary care providers and specialists include delineating a basic medical, surgical and psychiatric history. A history is important even if a medical condition is no longer current. By recording a list of active and past medical, surgical and psychiatric problems within a PHR, the patient does not need to continually recall this information with every new provider. The patient can make additions and modifications to the PHR.

**Allergies.** Every provider of healthcare requires this element. Once recorded within a PHR, it helps to prevent omissions due to recall.

**Medication list (current and past/inactive).** Who best to record what medications they are taking than the patient? The PHR serves as a central record for prescribed and over the counter medications. JCAHO has mandated medication reconciliation across all patient care encounters. Consumers could facilitate this process by furnishing this information from their PHR to providers of healthcare. The PHR in turn could assist patients by making drug information and interaction checking available.

**Immunizations and preventive care.** A listing of completed

and pending routine vaccinations and preventive care screenings.

**Insurance information.** Consumers know when this information changes and can readily track modifications within a PHR.

**An emergency contact section.**

What is the difference between an EHR and a PHR? A basic PHR could be merely an extract of EHR data or a summary from multiple provider EHRs and other sources of data. To personalize its use beyond that of an EHR, it needs to include components that would benefit the consumer in managing their own personal care plan. The components that would benefit the consumer, and are typically not part of a single EHR, include:

- Health maintenance and preventive care reminders geared toward the patient – To encourage consumer participation in healthcare management the PHR needs to be “smart” enough to recommend goals and provide tools unique to that patient. For example, a PHR could be used to track peak flow readings for asthmatics, and make recommendations based on values entered.
- The ability to track information for family members in addition to themselves.
- Tools for journaling activities such as recording an exercise log or food diary.
- A schedule of past and future appointments – what better place for a consumer to keep track of their own appointment history across the healthcare system than in a PHR.
- A listing of current and past providers – the consumer is the best source for knowing the names of healthcare providers. The PHR can serve as a central source for recording the contact information of providers and facilities visited.
- Dental and eye records.
- Store medical data from multiple providers in a single place, making it easier for the consumer to access and easier to share with other providers when the consumer wishes to.
- Living wills and advance directives—the actual content of a living will or advance directive is appropriate to store within a PHR.

### **DISEASE MANAGEMENT TOOLS**

Without the incorporation of disease management tools, the PHR serves only as a static repository of consumer data. To be truly beneficial to the patient it must also be interactive, allowing for self-management of diseases.

To effectively manage diabetes, patients need to record and track home blood glucose readings and understand their medication regimen. While some glucometers can download readings to computers or specialized software applications, uniform standards for transmission of data from a medical device to the PHR do not exist. Hence, consumers must either hand enter values from their glucose monitors, or copy/manipulate data files in order to get the data into their PHR. Ideally standards would allow for data transmission between home monitoring devices, the PHR and the EHR. Once blood glucose readings were available in the PHR they could be displayed in a graphical format along with instructions for self-adjustment of medication dosages, allowing for improved self-management in care for the consumer. Improved diabetes management would result in fewer emergency room and office visits, and would ultimately reduce diabetes complications and overall healthcare costs.

Another example where a PHR could serve in consumer disease self-management is for the asthmatic population. A consumer could record home peak flow readings within the PHR and adjust medication use accordingly. Specific trigger events, such as exercise, could be plotted along with its associated peak flow reading. A parent could readily use a PHR for management of their asthmatic child. Patterns of medication use and peak flows recorded within a PHR would provide invaluable information to the provider treating the consumer in changing medication therapy.

### **EASY EXCHANGE OF INFORMATION BETWEEN PATIENT AND PROVIDERS**

Ultimately it is the patient’s responsibility to maintain the PHR. No one healthcare provider or payer can capture all of the elements within a PHR. Dr. Daniel Sands describes his experience with patients using a tethered PHR in *Perspectives on the Future of Personal Health Records*.<sup>5</sup> Consumers are able to communicate with office staff via a secure email and can request appointments and prescription refills. Educational tools are available through the PHR and consumers can readily track their own health information. Per Dr. Sands description, “Patients who research health information, view their medical records, and track their own health and wellness make for much better care partners, take better care of themselves, and often have better outcomes.”<sup>6</sup> The PHR aids in open communication when both the consumer and physician embrace it.

### **BARRIERS TO CONSUMER ACCEPTANCE AND STRATEGIES TO OVERCOME THEM**

Perhaps the biggest barrier to consumer acceptance of PHRs is their relatively recent arrival on the healthcare scene. Like any new tool or technology, awareness of its existence and value are among the first hurdles to overcome. A variety of national organizations are committed to helping promote the use of PHRs in a secure and effective manner for consumers and other stakeholders. The American Health Information Technology Community (AHIC), which provides input and recommendations to the U.S. Department of Health and Human Services (HHS) on consumer impact of PHRs, is one such organization. Another is The Markle Foundation’s “Connecting for Health,”<sup>7</sup> a Public-Private Collaborative of over 100 organizations working to tackle the challenges of using information technology, specifically including PHRs, to improve healthcare.

There are numerous vendors involved in the design, implementation, and maintenance of personal health records. Fears about the privacy and security of health information are a persistent concern. This Markle foundation report found that “Almost all respondents (91 percent) are very concerned about their privacy and keeping their health information secure. However, most people believe that technology provides appropriate protections and would not be reluctant to use the PHR features that they value.”<sup>8</sup>

The National Committee on Vital and Health Statistics reports noted “public support ...depends on the confidence that personal health information is protected”<sup>9</sup> It goes on to say that any system of personal health information retrieval, collection, storage and dissemination requires the utmost trust of the public.

In a report from The Altarum Institute in January 2007 entitled *Report of the Personal Health Record Service Provider Market Privacy and Security*, regarding a review of existing PHR privacy and security policies, their research discovered a wide variation in the understanding of implementation of 30 publicly available privacy policies.<sup>10</sup> Not every PHR vendor Web site had a publicly available privacy policy. Because of these findings, the report made several recommendations which include the following:

- Privacy, in the context of PHR, should have a commonly understood meaning to all vendors, healthcare providers, and consumers.
- Consumers and vendors should agree or establish a forum as to the important components of PHR privacy policy, especially the transparency in secondary data used.>

Other practical concerns and barriers include:

**Low adoption by consumers.** A June 2008 news brief published by the Connecting for Health group and the Markle Foundation shows there is high consumer interest in PHRs, but very low adoption.<sup>11</sup> It states that “Almost half of the public - 46.5 percent - say they would be interested in using an online PHR service.”<sup>12</sup> It goes on to add that “Only 2.7 percent of adults have an electronic PHR today... Most (57.3 percent) do not keep any form of personal health records, and 40 percent keep some paper health records.”<sup>13</sup> One Chicago physician who is considered a leader and early adopter of PHR described his use of a PHR much the same as Bob experienced. He related that “I’m listed but haven’t received any patients using it (the PHR). A couple keep their “own” PHR on their computers. No importing yet for my patients. When the couple patients I have with their own PHR’s arrive, it assists with reconciling all their meds and ensures we’re always on the same page.”<sup>14</sup>

**Low adoption by providers.** As expressed by Bob in the above case study, he is frustrated that none of his doctors or hospitals are willing to accept information from his PHR in electronic form. What incentive does he have for continued use of it? Equally important, what incentives do physicians and other providers have to encourage, use and accept PHRs?

**Ease of use.** Use of the system, including data collection, shar-

ing with others, reporting, and disease management tools must be intuitive and quick.

**Interoperability.** The American Health Information Association (AHIMA) lists over 80 PHR products on the PHR sections of their Web site ([http://www.mypHR.com/resources/phr\\_search.asp](http://www.mypHR.com/resources/phr_search.asp)). With so many products available, the only way to assure quick and accurate sharing of patient information is by standards for “interoperability” of systems embraced by vendors and users of the PHRs. Without standards it can be tricky, cumbersome, or infeasible to share data, which will certainly encumber growth and productive consumer use. National standards are currently in development

**Trust issues.** Concerns about the motives and uses of providers, insurers, employers and vendors. Much of this ties back to privacy and security concerns. Development of national policies and standards is already underway to address this. **JHIM**

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