

# Helping Consumers Select PHRs: Questions and Considerations for Navigating an Emerging Market

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by the AHIMA Personal Health Record Practice Council

*HIM professionals can help consumers evaluate the multiplying choices in personal health records and select the one that's best for them.*

Consumers are taking a more active role in their healthcare. They are paying a larger portion for services, reviewing provider quality through Web sites, and researching the increased availability of health information online. There is growing momentum to encourage consumers to take another step: to maintain their own health records.

The idea behind the personal health record (PHR) is that the more consumers know about their health, the more control they will take over it and the healthier they will be. PHRs also encourage consumers to collect and share more health-related information with each of their providers. For this reason, healthcare providers, employers, insurers, vendors, and the federal government are all interested in promoting PHRs. Consumers will hear much more about the personal record in the months and years ahead.

And they will need some help sorting it all out. Recent statistics show that consumers are just beginning to be aware of PHRs and their usefulness. A study by Health Industry Insights in late 2005 found that of consumers surveyed, 83 percent had never used a PHR.<sup>1</sup> Of those, half had never heard of a PHR (see [results](#) below). We can conclude that consumers will need education to help them understand the PHR's uses and to choose and use the product that best fits their needs.

Consumers already have many choices when selecting a PHR. They must be aware of the benefits and risks of each type. They should be cautious when selecting a PHR product to ensure that the product they select allows them to maintain all of the information needed to provide a complete and comprehensive compilation of their health history. Consumers should consider ease of use, security, comprehensiveness, and accessibility.

HIM professionals have a unique opportunity to step up to this role of consumer educator. They can raise awareness of PHRs and their benefits, and they can help consumers choose the PHR model that is best for them. Consumers should be able to turn to HIM professionals in their community to learn about PHRs, including the types of PHRs, the providers, the important questions to ask when evaluating a PHR product or service, and how to create their own PHR.

## Didn't Know, Waiting to Be Asked

**What is the primary reason you have never used a PHR?**

	Percent of Total Answering
I have never heard of a PHR.	52%
I would if my physician or other healthcare professional recommended it to me.	18%
I do not seek much care and don't see the value.	10%
I do not trust the security of the currently available Internet-based sites.	10%
I do not want a written record of sensitive personal health information.	4%
I do not want to spend the time to initially input and update the information.	3%
Other	3%

Source: Health industry Insights, 2006

## Great Interest, Little Consensus

The encouraging news is that consumers are likely to make a receptive audience. Research suggests that when consumers learn about PHRs, their response is positive. Sixty percent of adults responding to a Markle Foundation survey in late 2005 said they would support the creation of an online PHR service that would allow them to check and refill prescriptions, get results over the Internet, check for mistakes in their medical record, and conduct secure and private e-mail communication with their doctors.<sup>2</sup> Only 19 percent indicated that they would not use a PHR service for any of the stated uses.

Healthcare providers, insurers, and employers are developing PHRs and online services that give consumers this kind of access. Vendors offer an array of products and services to maintain personal records. The federal government is actively promoting health IT that encourages the flow of information between consumer and provider. The American Health Information Community (AHIC), formed to help the government advance health IT adoption, charged its consumer empowerment work group with developing a plan that brings a quick health IT benefit to consumers. The group's short-term goal is prepopulated electronic registrations and medication histories that save consumers from writing out the same basic personal information at each doctor visit. That short-term goal will work toward the group's broader charge to promote widespread adoption of personal health records.<sup>3</sup>

AHIMA published one of the first PHR definitions in 2005:

The personal health record (PHR) is an electronic, universally available, lifelong resource of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the individual determining rights of access. The PHR is separate from and does not replace the legal record of any provider.<sup>4</sup>

While this definition has been well-received, it is important to note that nationally there is still debate and the industry has not yet agreed on one single definition. We are still in the infancy of the PHR, and HIM practitioners should monitor this carefully over the next few years.

Accordingly, there are different PHR models in the marketplace. The medium, or type, differs depending on the format-for instance, paper or electronic, desktop application or Internet-based service. PHRs are influenced by the organization sponsoring them, also. A PHR's provider may be a hospital, physician, vendor, employer, or insurer.

## Types of PHRs

PHRs can be kept on paper or electronically. Electronic records can be kept via a software application on a personal computer or through an Internet-based service.

There are two major differences between the formats. The first is the convenience with which they can be updated and maintained. The second is their accessibility-how easily consumers can make them available to their healthcare providers. All types require that the consumer monitor and update information as appropriate.

**Paper.** Some current products on the market provide the paper forms required to prepare a PHR. Consumers also create their own homemade paper-based PHRs. These are the folders filled with information from doctors, pharmacies, and hospitals that many consumers keep as reference. Since not all information may be available in an electronic format, some consumers may find the old-fashioned file folder or three-ring binder the easiest and most inclusive format when first compiling a PHR.

If completed properly, paper forms provide a good snapshot of one's health history. The drawbacks, however, are the effort required to keep the forms current and the limited accessibility of the information. A file folder will not be available in an emergency unless the consumer happens to be carrying it at the time.

**Personal Computer.** Some current PHR products are kept on personal computers. Consumers load a PHR program onto their home computers and input their health information directly into electronic forms or by scanning documents from their providers. This information can be easily updated and printed in a health history report. The consumer stores the PHR information locally on the computer, a CD, or a flash drive. The consumer controls the access to the information. The major drawback is the lack of accessibility in the event of an emergency, unless the consumer makes a habit of carrying a CD or a flash drive copy of the current information.

**Internet.** A majority of newer PHR products are Internet-based. Through these services, consumers access private PHR accounts by connecting to the Internet and logging in with a unique user name and password. Once logged in, this solution, like a PHR on a personal computer, allows organization of health information in an electronic format. The consumer's information can be easily updated, and consumers and approved caregivers alike may access various health reports online. The major advantage to this type of PHR is the availability of the information in both emergency and nonemergency situations.

**Hybrid Personal Computer-Internet.** The typical hybrid PHR allows the consumer to maintain his or her health information on a personal computer and transfer that information to an Internet account for use in the event of an emergency. In most cases individuals can upload all or part of their medical information as they choose.

## PHR Providers

Consumers also have many choices when selecting a PHR provider. Their healthcare provider, employer, or insurer may offer them a PHR at little or no cost. They may select a vendor who offers a software application or online service.

As with PHR format types, consumers should understand the advantages and disadvantages of each type of provider. Asking the right questions is important in determining which provider type is best for the individual. Questions should center on record completeness, data rights, access, security, portability, and cost (see "[12 Questions Consumers Should Ask When Choosing a PHR](#)," below).

**Employer Sponsored.** Many employers such as Dell and IBM believe that supplying PHRs for their employees is a good way to introduce responsibility and wellness in healthcare. Examples of benefits of an employer-sponsored PHR may include a reduced or low cost, a link to the employer-sponsored health plan, and the ability to add or input information not related to the consumer's health plan. A disadvantage may be that if the individual leaves the employer for another company, the PHR may remain behind.

**Insurance Sponsored.** The insurance industry is very interested in the PHR. As part of a goal to further IT adoption, the Blue Cross and Blue Shield Association has launched a consumer empowerment program featuring PHRs.<sup>5</sup> An advantage to insurer-based PHRs is often cost: insurers are likely to offer PHRs for free with enrollment. Disadvantages might include the inability to use the PHR should the individual change insurers and the use of the individual's information by the insurance company. For instance, the Blue Cross Blue Shield of Illinois Web site informs members in the privacy disclaimer that information supplied may be used to better understand healthcare needs.

**Provider Sponsored.** Some major providers, such as the Department of Veterans Affairs, offer PHRs to their enrollees and staff. As providers begin to implement electronic health records, we can expect to see physicians and health systems offer more applications to consumers. These will include what might also be called a patient portal, a view of some or all of the individual's information in the provider's electronic health record. Depending upon the amount of input and review the consumer has, the portal may or may not be a true PHR. If consumers cannot add their own information or information from other care providers, then it is not a PHR by definition, it is a view-only information source.

An advantage to a provider-sponsored PHR might be that much of the data collected by the provider would be automatically downloaded in the PHR; the consumer would not need to input it. However, a disadvantage might be that the consumer would not be able to include information from outside providers not connected or in practice with the ones offering the PHR.

**Independent Product.** There are many PHR products offered in the marketplace at many different price levels from free to a monthly charge. Generally, the customer of this service is the individual, and he or she controls the content, additions, and access to the record. The advantage of the independent product is the total control the consumer wields. The disadvantage might be the cost and the total responsibility the consumer has for making sure the PHR is current and updated. Other companies are developing and testing PHR prototypes connected to the nation's 911 system, for use in the automotive industry, providing immediate medical data to emergency medical service responders.

## 12 Questions Consumers Should Ask When Choosing a PHR

Asking the right questions is important in determining which PHR product is right for the individual. Following are some questions that consumers should ask. In most instances, these questions should be asked regardless of who

provides the product (e.g., healthcare provider, employer, insurer, vendor). However, several questions are specific to PHRs offered by employers and insurers.

## Content

- Will the PHR provide all the information I need for a complete health history?
- Will information be automatically added to the PHR from any other records (e.g., insurance, employment, or care)? If so, what information will be added, and how will it be added? Is the information transfer audited?
- Do I have the opportunity to delete, correct, or add information? How will I do this?

## Ownership and Use

- Does the PHR sponsor have any ownership rights to the collected information?
- Can the PHR sponsor sell my information to anyone or for any reason? If so, how can I protect my privacy? Can I specify that my information not be sold?
- Will my information be used for employment or insurance coverage decisions (e.g., to determine insurance eligibility)?

## Access and Security

- Who has access to the information in my PHR?
- Can I choose to give my doctor, dentist, and other caregivers access? How do I control the sharing of my information?
- How will my information be protected from unauthorized use?

## Portability

- If I am no longer employed/insured by you, can I still continue to use the PHR?
- How can I transfer my information to another PHR sponsor (e.g., a new insurer or new vendor)?

## Cost

- Will there be any cost for me to have a PHR with you? (For instance, are there fees if I give my doctor, dentist, and other caregivers access to my PHR?)

## PHR Best Practices: Emerging

Best practices for an HIM system describe the generally agreed-upon best ways of developing, designing, implementing, and using the system. Identifying best practices for a PHR or a PHR system is premature because the industry has not yet agreed on a single PHR definition and many stakeholders are currently experimenting with various models, policies, and procedures. In short, there are no generally agreed-upon best practices to reference at this time.

However, for the past few years national groups and organizations have been exploring the potential attributes of a PHR. The National Committee on Vital and Health Statistics recommended that the Department of Health and Human Services support the development of framework for characterizing PHR systems through public-private consensus. The framework was to include, but need not be limited to, the scope and nature of content, information sources, features and functions, record custodianship, data storage, technical approaches, and party controlling access to the data.<sup>6</sup>

The chart "Emerging PHR Attributes" [[below](#)] plots the initial work of four groups-the Markle Foundation, AHIMA, the AHIC Consumer Empowerment Work Group, and Health Level Seven-against the framework. More organizations have indicated an interest in the concept of the PHR but have not yet published recommendations. Though many PHR-like products are already

available for use by consumers and providers, the chart illustrates that the concepts of a PHR and PHR systems are still very much works in progress.

<b>Emerging PHR Attributes</b>				
<p>Many PHR products are currently being offered to consumers, but a single definition of a PHR has yet to emerge. This chart compares the PHR descriptions of four organizations against the NCVHS framework characterizing the attributes of PHRs and PHR systems. NCVHS intends the framework as a starting point for building consensus on a PHR definition, not as a definition itself. The four groups represented are the Markle Foundation, AHIMA, the American Health Information Community's consumer empowerment work group, and Health Level Seven (HL7). Other organizations are involved with PHRs but have not published recommendations.</p>				
<b>PHR Attributes</b>	<b>Markle</b>	<b>AHIMA</b>	<b>AHIC</b>	<b>HL7</b>
<b>Content</b>				
Contains information for one's lifetime (longitudinal)	X	X	X	
Contains registration summary and prepopulated medication history			X	
Provides for entry and display of PHR holder's demographic information				X
Provides for entry and display of contact information				X
Provides for entry and display of insurance information				X
Features common set of data elements		X		X
Contains standard data terms and vocabularies		X		
<b>Sources</b>				
Allows for patient-approved download of provider electronic health information into the PHR		X		X
Enables the holder to self-report symptoms or concerns in a chronologically sortable diary				X
<b>Features</b>				
There is no widely accepted standard definition or functional specification for the features of a PHR.			X	
PHRs should have data integrity: data sources and age of data should be cited.	X	X		X
Consumers can annotate but are not permitted to change or destroy data electronically supplied by other systems.	X	X		
Consumers and permitted providers can access PHRs at any place at any time.	X	X		
Individuals own and and manage the information in the PHR.		X		
<b>Functions</b>				
Serves as a resource of health information needed by individuals to make health decisions		X		X
Captures, stores, and processes the data		X		X
Allows for interaction with others involved in the holder's healthcare (e.g., physicians, to make appointments; pharmacies, to refill prescriptions; health insurers, for claims data)		X		X
<b>Technical Approach</b>				

Maintains interoperability between PHRs and EHRs	X			X
Complies with interoperability requirements, such as those required by certification bodies	X	X	X	
Is portable	X	X	X	X
Is accessed via a portal			X	
<b>Privacy and Security</b>				
Systems for the electronic health data exchange must protect the integrity, security, privacy, and confidentiality of an individual's information.	X	X	X	X
All entities that provide or manage personal health information, whether defined as covered entities under HIPAA, should follow the privacy and security rules that apply to HIPAA covered entities	X	X		X
<b>Access</b>				
Enables the holder to control the PHR and decide who can access each of its parts	X	X	X	X
Includes a "break the glass" capability that permits providers under very strict circumstances (e.g., when an individual is brought unconscious into an emergency room) to access the PHR without the individual's prior authorization.	X	X	X	X
Is transparent, allowing the holder to view who has accessed each part of the PHR	X	X		X

## The Information to Include

To begin compiling their PHRs, consumers will need to request copies of their health records from all of their healthcare providers: internists or family physicians, eye doctors, dentists, and any specialists they have seen. Some providers may already have a plan for helping patients create PHRs. HIM professionals in physician offices and facilities can assist by helping consumers determine which documents to gather (since not all records will be pertinent to a PHR).

Information does not need to be gathered all at once. It may be more manageable for consumers to build their PHRs incrementally. They could begin with the next visit to their doctors and ask for recent records, and then do so each time they visit a healthcare provider. It may be helpful for HIM professionals to review with consumers the process of requesting their records. Some facts are shown in the sidebar above.

## What Consumers Should Expect When Requesting Records

When consumers set out to collect their records from their providers, it may be helpful for them to know the following facts about records requests:

- They will be asked to complete an "authorization for the release of information" form for each provider. The form varies slightly from facility to facility and from state to state. (A sample form is available at [www.myphr.com/rights/disclosure\\_authorization\\_frm.pdf](http://www.myphr.com/rights/disclosure_authorization_frm.pdf).)
- They may be required to show proof of identification, such as a photo ID.
- They will likely be charged a fee. Most facilities charge for copies. The fee can only include the cost of copying, which includes supplies, labor, and postage, if the copy is to be mailed.
- They may not receive their records immediately. By law, facilities are allowed up to 60 days to provide records.

A PHR should seek to contain all of an individual's relevant health information. In addition to important medical information such as test results and treatments, a PHR can include diet and exercise logs. At the same time, it is important that consumers clearly understand that a PHR is separate from and does not replace the legal medical record of any provider.

At a minimum, a PHR should contain the following elements:

- Personal identification, including name, birth date, and Social Security number
- Next of kin or people to contact in case of emergency
- Names, addresses, and phone numbers of physician, dentist, and specialists
- Health insurance information
- Living wills and advance directives
- Organ donor authorization
- A list and dates of significant illnesses and surgeries
- Current medications and dosages
- Immunizations and their dates
- Allergies
- Important events, dates, and hereditary conditions in the family history
- Recent physical examination
- Opinions of specialists
- Important tests results
- Eye and dental records
- Correspondence with provider(s)
- Permission forms for release of information, surgeries, and medical procedures

HIM professionals have demonstrated strong leadership with PHRs. AHIMA launched the consumer Web site [www.MyPHR.com](http://www.MyPHR.com) to inform and educate the public. AHIMA members have represented the association well in the Markle Foundation's work and in advising the AHIC work group on consumer empowerment. AHIMA also was one of the first organizations to publish a definition of the PHR. HIM professionals have a role, a vested interest, in monitoring the developments industry-wide and in the development of consumer education.

## Notes

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