

PHR CONSUMER GUIDE¹

A. UNDERSTANDING PERSONAL HEALTH RECORDS

The use of a personal health record (PHR) is much like the use of an online bank account. A PHR is a secure and private place to store and track information about your health. You can type or scan or have another person enter health information into your PHR. Some types of PHRs can have information added from other sources like your hospital's *electronic health record* (EHR) system or a *home health monitoring device*. Depending on the type of PHR you may select, a PHR allows you to decide who can view the information stored in it.

1. What is a PHR?

Many companies and organizations provide PHRs, and there are many different types of PHRs. This document will help you think about which one might be best for you.

A PHR is a tool that gives you the opportunity for collecting, storing, tracking, and sharing important, up-to-date information about your health, so that you, and others whom you permit, can use the information to better manage your care. In addition, a PHR may assist you if you need to know the health information about someone in your care.

A PHR allows you to:

- Easily and quickly communicate your health information to others, because it has been collected in one place
- Choose who is able to view this information
- Keep your information in a complete, accurate, private and secure way.

2. How can having a PHR benefit you and your family?

Currently, your health information may be stored in many different places, including:

- doctors' offices
- hospitals
- pharmacies
- laboratories
- dentists' offices
- eye doctors' offices

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- and other places where you receive health services

A PHR is designed to hold all of this information in one place. Having a complete summary of your health information makes it easier for you and your healthcare providers to make good decisions about your health. It can also make it easier, faster and safer for your doctor to treat you.

Also some PHRs contain sections to store your insurance information and other important information for your care, for example, the list of your providers. If you are managing a chronic condition such as diabetes or high blood pressure (hypertension), a PHR can be extremely valuable because it can contain your entire health history. PHRs may help coordinate care across many different doctors or if you are traveling away from home or moving to a new community. PHRs may also be helpful if you are responsible for taking care of someone else's health care such as an aging parent or a child.

3. What are basic PHR features and how do PHRs handle health information?

- PHR products come in different formats:
 - Some PHRs are software applications for your personal computer or for a removable thumb drive.
 - Others are web-based services (accessed through the Internet) that store your information in a central place (sometimes called a "repository").
 - Hybrid PHRs allow you to do both – store the information on your personal computer (with or without a thumb drive transfer of data to carry around), and transfer the information to a web-based account; hybrid types are useful for emergency situations.
- PHR products can be simple or complex:
 - **PHRs can be a stand-alone product.** A standalone or independent PHR has no links to other information sources. With a stand-alone type of PHR all the information in it must be entered and kept up-to-date by you.
 - **A PHR is called "tethered" if it is linked to another system, such as your hospital's electronic medical record system.** Usually, tethered PHRs are sponsored by an organization, such as your insurance plan, or your physician group or hospital, and sometimes, are offered by your employer. These other organizations contribute information that can appear in your PHR.

For example, the Department of Veterans Affairs offers a tethered PHR to its patients called MyHealthVet.com. Patients may view selected health information from the VA's medical record system as well as enter their own information, such as family history.

4. Frequently Asked Questions

If I have a "patient portal" do I have a PHR?

The answer to this question is "sometimes". You are considered to have a PHR if you can enter information that you have gathered, for example, blood sugar values that you have with an in-home device. Some large hospitals, medical centers, and physician

practices offer patients access to see their medical record through a “patient portal”. Patient portals are helpful because they allow you to see test results and other information without having to call the doctor’s office. Beth Israel Hospital in Boston, Massachusetts and its doctors have this kind of system, called *PatientSite*; this is available for patients who have physicians who are part of the CareGroup system. Partners Healthcare Systems in greater Boston also has a patient portal for its patients and caregivers called *Patient Gateway*.

How do I use and make changes to my PHR?

A tethered PHR allows you to enter your own information, but also receive information from different sources like your doctor’s office, a lab, or a hospital that you were in. The most convenient type of PHR is the tethered type. With this type of PHR, you can have the most complete, accurate, and up-to-date record possible with information from you and all of your care providers in one place.

Who can see my PHR and is the information private?

PHRs are controlled by you. A PHR’s most important feature is your ability to control who sees it.

- With stand-alone PHRs, you store your information on your personal computer and you are in control of who accesses it. You’ll want to create a password that only you or a trusted family member or friend knows.
- Web-based PHR products must include a secure way for you to access and to allow others to view your information once you have provided permission. *For example, if a family member is managing your care, you would most likely want that person to have the ability to log-in to your PHR via the Internet and view your health information.*
- One factor to consider when selecting a PHR is whether or not the company offering the PHR uses the information included for any other purpose.

B. UNDERSTANDING THE BENEFITS OF USING A PHR

The greatest benefit of the PHR is its ability to help collect and store all of your health information from different doctors and facilities in one place so that is available when needed.

1. Using a PHR has many benefits

- Care providers can make better treatment decisions with up-to-date and accurate information. *For example, if you have diabetes, you can provide information that your care providers may not have, like changes in diet and information uploaded from your glucose monitoring device.*

- Avoid repeating unnecessary tests. Adding or posting your test results to your PHR with authorization to other doctors or hospitals, saves healthcare costs, your time and your doctor's time.
- Ease of sending your medical history to new doctor or hospital for an appointment rather than having to re-create it each time, on the spot.
- Typically, and importantly, if privacy policies and security measures are in place, your information will be private and secure.
- It may increase your safety and improve your quality of care, if your care providers are better informed about your health.
- It can help you to take a more active role in managing your care and your family's care.

2. Benefits for Handling *Sensitive* Information

- Your providers benefit with the availability of information such as mental health medications or diagnoses for treatment can result in:
 - Better patient care, when a provider has a full picture of key aspects of your condition, risk for errors is reduced
 - Better quality and safety of care, when a provider does not have to guess about medications, diagnoses or allergies
 - Critical time saved in the emergency room.

C. UNDERSTANDING THE CHALLENGES OF USING A PHR

There are many issues regarding PHRs as they are a new tool for patients and their providers. Therefore, the marketplace has many different products, and identifying the best product for you can be confusing.

One current challenge with using a PHR is collecting all of your health information and filling in the questions on your PHR forms or pages. Patients will find maintaining a PHR easier if it can link to their provider's electronic medical record system.

However, a tethered PHR – one that includes information from other health care organizations - requires provider use of an electronic health record (EHR) system and the technical ability to share information between EHRs and PHRs. Less than half of all provider organizations have electronic systems. Most providers still rely on paper medical charts. As providers start to use EHRs, patients may be able to upload or transfer their information from their providers' EHR to their own PHR.

The ability for your care providers to import your PHR information into their EHRs may be further off in the future. For now, printing your PHR information in preparation for a

provider visit offers the easiest solution, but again--if it is all on one PHR, it is much easier to do.

Another way to start filling in your PHR, is having one that is a part of your health plan's web site. Many health plans have built the capability to download some of your health information from its *database* (sometimes called a "claims database"). From this claim database, your health plan can provide some limited information to get your PHR started.

D. UNDERSTANDING THE CHALLENGES OF CHOOSING A PHR

A more serious challenge is the PHR creator's commitment to patient privacy.

For many PHRs, this requirement is not yet in place to fully protect patient information. Unless your PHR is sponsored by your healthcare provider or health plan, your health information is not protected under the federal *Health Insurance Portability and Accountability Act of 1996* (HIPAA) Privacy and Security Rules. (Even if your PHR is protected under HIPAA, your information within your provider's medical record or health plan's database can still be accessed without your consent for the purposes of treatment, payment, and health care operations.)

There is no federal oversight of independent PHR companies, and they could potentially use your information without your explicit permission. If your PHR is not sponsored by your health plan or a provider, you must be very certain that privacy protections are in place so that your information cannot be used for product marketing to you or to discriminate against you.

For those PHR vendors that not required to follow the HIPAA Privacy and Security Rules, they are not required to gain your explicit consent to share or sell your information. The risk to you and your family is that your sensitive health information could potentially get into the wrong hands. For example, if your PHR is sponsored by your employer and it contains sensitive information about your health which could impact the way you are treated at work or the cost of your coverage, you should check that strong privacy protections are in place.

The lack of privacy protections governing information uploaded to PHRs is currently one of the greatest barriers to their mainstream usage. This is a risk you need to consider as part of a balanced decision when electing to use a PHR. Another barrier is that PHR use is new and it is currently a growing market. The benefits of having a PHR could potentially far outweigh the risk. For example, a patient may be taking medications for behavioral health as well as physical health conditions. The medications for each may not work well together (sometimes called "contraindicated") and may actually have bad combined effects. A provider needs to have access to the best information available to make the best decisions for treatment.

When your sensitive information gets into the wrong hands it is called a "breach" and can be un-intentional or intentional. An intentional privacy breach could occur for example, in child custody battles, when the non-custodial parent wants to prove the custodial parent is not competent. In this case, the non-custodial parent may try to get

an unauthorized copy of the custodial parent's history of medications or mental health visits. Un-intentional human mistakes can happen when someone who does not need or want to know your health information finds it in their hands or in front of their eyes. While this situation does not occur "on purpose", your privacy has still been breached.

One Approach to Privacy Challenges

One way that experts are approaching this privacy challenge is vendor certification by independent, unbiased healthcare groups that have developed model policies for health privacy. For example, in July of 2009 the Certification Commission for Healthcare Information Technology (CCHIT), a private, non-profit organization that certifies different health information technologies will begin to certify PHR products according to a set of consensus-based and reviewed criteria. Vendors who meet these criteria will receive a seal of approval from CCHIT. The criteria will include such safeguards as requiring your explicit consent or authorization before your PHR information can be released or disclosed to others, and allowing you to restrict or limit access to specific pieces of information within your PHR to persons that you permit access. These safeguards will keep you in control of your personal health information and establish a greater sense of public trust in PHR products. (For more information, see the CCHIT website, <http://phrdecisions.com>)

E. CHOOSING A PHR

1. How to Select the Right PHR for You

Selecting the right product for you can be difficult because there are so many different PHRs on the market. Each type has advantages and disadvantages. Here are some questions to ask of the PHR company and information to look for on a PHR website. You might also look for products that attain CCHIT certification, when available, to guide your selection process.

- 1) *Is it easy to keep the PHR complete, accurate and up-to-date?*
 - Will the PHR allow me hold all the information I need for a complete health record?
 - How difficult will it be for me to keep the information current?
 - Can information be automatically added from other sources, such as my provider, health insurance plan, pharmacy, laboratory or home health monitoring device?

- 2) *Is the PHR accessible and secure?*
 - Do I control who sees my PHR information?
 - How is my PHR protected so that only the people I permit have access to view it?
 - Does authorization require only a user ID and password or are more rigorous security measures in place?
 - Is my PHR information stored in a secure location and backed up frequently? What protections does the sponsor or vendor have in place to prevent medical identity theft or hackers from stealing my information?

- 3) *Is the PHR private?*
- Does the PHR sponsor or vendor have a posted privacy policy?
 - Does the PHR sponsor or vendor have the right to use, sell or share my health information?
 - Does the PHR sponsor or vendor (especially if sponsored by my employer) provide privacy protections around sensitive information, which I do not want anyone to see (called an “audit log”)?
 - Does the PHR allow me to see a list of people who viewed my PHR?
 - Is the PHR sponsored by my provider or health plan and therefore protected by the federal HIPAA privacy and security law?
- 4) *Is the PHR portable?*
- Can I access my PHR from anywhere via the Internet?
 - Can I carry my PHR with me on a CD, USB key (thumb drive), cell phone or smart card?
 - Will I be able to transfer my PHR information to another PHR sponsor or vendor if necessary in the future?
- 5) *Is there a Cost for the PHR?*
- What are all the fees associated with the PHR product?
 - If the PHR is offered to me for free, does the sponsor have the right to sell or share my health information, place targeted advertising within my PHR, or customize Internet search results based on my information?

2. How Does a PHR Work?

Your health information is located in a number of places, because you may visit many healthcare providers and organizations. Since no one doctor, hospital or healthcare organization has a complete picture of your health status and healthcare services, a PHR can pull all your separate health information together. It can store and organize all the information about your health in one place, so that you, and others you allow, can use the information to better manage your care. When you select the PHR for your needs, you will enter some information yourself, and other information may have to come from your physicians, other providers, hospitals and healthcare organization. Information from other sources may have to be entered by you but sometimes it can be added automatically or manually by other sources. Some PHRs can receive information directly from your hospital’s electronic medical record system or be sent (sometimes called “uploaded”) from a health monitoring device.

The American Health Information Management Association (AHIMA) has created the following list of information that a PHR should contain:

- Personal identification, including name and birth date
- People to contact in case of emergency
- Names, addresses, and phone numbers of your physician, dentist, and specialists
- Health insurance information
- Living wills, advance directives, or medical power of attorney
- If you want to be an organ donor.
- A list and dates of significant illnesses and surgical procedures
- Current medications and dosages

- Immunizations and their dates
 - Allergies or sensitivities to drugs or materials, such as latex
 - Important events, dates, and hereditary conditions in your family history
 - Results from a recent physical examination, conditions and diagnoses
 - Opinions of specialists
 - Important tests results; eye and dental records
 - Correspondence between you and your provider(s)
 - Current educational materials relating to your health
- Any information you want to include like your exercise regimen and any herbal medications you take.

3. Starting a PHR

To begin filling out your PHR, there will be questions you can answer and for others, you will need to request copies of your health records from each of your healthcare providers.

Most likely, the provider organizations that you ask for health information, like your hospital, will ask you to complete an *authorization form*, show proof of your identity (such as a driver's license), and pay a fee to cover the cost of copying and mailing the information to you. Some provider organizations may be able to provide your information in electronic form, such as on a CD, which can make it easier for you to copy the information into your PHR. Others that provide PHRs or are affiliated with PHR vendor products may be able to download your information from their EHR directly into your PHR that you have already started. With linked PHRs and patient portals, sponsor organizations have determined the types of information that they will add to your PHR or display on your portal.

4. Keeping Your PHR Up-To-Date

To keep your PHR up-to-date, you can periodically enter your own information. For example, you may want to track symptoms, exercise routines, blood pressure or other vital signs (if the PHR you selected has these functions). Or you may choose to keep a sleep diary, diet log, or the results of home tests, such as glucometer, peak flow, or heart rate monitor readings in your PHR.

ADDITIONAL RESOURCES

The organizations and websites below offer more information about PHRs and their evolution in the marketplace.

- AHIMA
http://www.myphr.com/your_record/what_include.asp
- Markle Foundation
<http://www.markle.org/archives/library/>
Search the website for "PHRs"
- AHIC Consumer Empowerment Work Group
http://www.hhs.gov/healthit/ahic/materials/10_08/ce/bell_files/textonly/slide2.html

- National Committee on Vital and Health Statistics
<http://www.ncvhs.hhs.gov/pvcmemb.htm>
- The Certification Commission for Healthcare Information Technology
<http://www.cchit.org/phr/>
- PHR Decisions
<http://www.myphr.com/>