CLINICIAN GUIDE TO A PERSONAL HEALTH RECORD

INTRODUCTION

For consumers (individuals), their caregivers and clinicians, a Personal Health Record (PHR) can be a valuable electronic tool for managing, storing and sharing health and medical information. The quality of healthcare can be improved when more complete health and medical information is available to caregivers and clinicians. Better informed consumers may be more engaged and able to make better health-related decisions through the use of information available in their PHR. When a consumer cannot give it, a PHR may provide treating clinicians with the important information they need in an emergency. A PHR also can provide caregivers with information they need to make healthcare decisions on a loved one’s behalf.

PHRs may be available through several sources, including:

• A PHR sponsor such as a health insurance company or a healthcare facility.
• A PHR sponsored by an employer.
• An independent PHR service provider like Microsoft HealthVault or WebMD.
• Software programs that support a PHR on a personal computer.

The health information for some PHRs may be sent from a health insurance company or healthcare facility such as a hospital, physician practice, laboratory or imaging center, while other information may have to be entered by the consumer or their PHR designee. PHR sponsors can choose what information to include in the PHR they offer. Depending on the sponsoring organization, the PHR may be free to the consumer or available at a low cost.

Security for a PHR

Most PHRs are web-based and can be viewed from almost any computer with an Internet connection. PHR information is stored electronically and, in general, is backed up periodically. Consumers should be able to find out how their PHR information is stored and backed up so that access always can be available, especially when traveling, in times of an emergency or a natural disaster.

PHRs allow PHR account holders to share their health information to authorized individuals through the use of privacy and security measures. PHR account holders or their designated caregivers and clinicians can visit the PHR website for secure access to the information through a login or Web ID process. To help minimize the opportunity for unauthorized access to their PHR, consumers should keep health information safe and secure by always protecting their login and password.
IMPORTANT REASONS FOR HAVING A PHR

A PHR can give consumers the peace of mind of knowing that medical conditions, such as allergies, current medications and diagnoses are kept in one convenient and secure place online, ready when needed.

PHR Contents

PHRs contain consumer demographic, contact and emergency contact information, possibly including information regarding family members. It also keeps the names and contact information for treating clinicians, caregivers, healthcare facilities, laboratories and pharmacies all in one easy-to-find, secure location. A consumer's advance directives or other similar healthcare decision instructions also may be documented in a PHR. Documenting this will help clinicians and caregivers know what medical procedures or interventions should or should not be given if they can't speak for themselves. PHRs vary, so it is likely that not all of them will contain a place for each piece of information that may be available from the clinician or the consumer.

Through a PHR, access to the consumer's medical history, medical records and family medical history may be available in times when emergency or urgent care/aid is needed. In the aftermath of a fire, flood or natural disaster, a PHR may be the only medical record available to consumers, their designated caregivers and clinicians. Additionally, a PHR may list over-the-counter medications, immunizations and allergies, as well as travel destinations that may be subject to health precautions.
BENEFITS OF ACCESS TO A PHR

The availability of a PHR can help clinicians coordinate care by making extensive patient data available to them. This could help reduce medical information errors and eliminate duplicate medical tests or procedures by consolidating this data in one easily accessible location.

The information found in a PHR can help clinicians to better manage medication dosage and frequency, how a medication is being prescribed (intended and/or off-label use, etc.) and the related medical condition that triggered the prescription. This information also may help clinicians learn whether adverse drug interactions are present or whether adverse drug interactions could exist among current medications and those to be prescribed.

In an emergency medical situation, important health-related information may be available to treating clinicians or family members by appropriately accessing the consumer’s PHR. Having a PHR may help provide peace of mind by knowing the ability exists to reconstruct medical records electronically should paper medical records and documents be damaged or destroyed.

Clinician and Caregiver Access

In the future, consumers may be able to choose to allow their caregiver or clinician to have access to some or all of the information contained in their PHR. This consumer-approved information may be able to be electronically transferred from the PHR to the system utilized by healthcare facilities and/or clinicians; referred to as an Electronic Health Record (EHR).

This electronic transfer of PHR information could allow clinicians to access the patient’s information in their EHR system. Additional patient information from the PHR into the EHR may have workflow impacts and raise liability concerns for clinicians related to access to this new information. However, there is general industry agreement that the additional information will be valuable input to improving the quality of patient care. To that end, the industry is seeking to address the privacy and information access concerns of patients and clinicians in this area.

If caregivers and clinicians are allowed access to information from a consumer’s PHR, a separate secure login and password may be required. Improved care coordination is anticipated as one of the benefits when caregivers and clinicians have access to more information, helping to reduce gaps in patient care and broad-based, multi-clinician information from varied sources, including PHRs. Using a PHR could help consumers, their clinicians and caregivers make better healthcare decisions. This may also help consumers spend their healthcare dollars more wisely.
CONTROLLING DESIGNATED ACCESS TO A PHR

Consumers control their PHR and can decide who can access their health information. Designated caregivers and/or family members can be given access to a consumer’s PHR. In some cases, treating clinicians may be given access to a consumer’s PHR prior to a medical appointment or consultation.

Under certain medical emergency circumstances, such as when an unconscious person is brought into the emergency room, the “break the glass” feature (if authorized by the consumer) could be activated. This would allow clinicians to access PHR information without requiring prior consent from the consumer, allowing clinicians to give the appropriate care.

Opting in or opting out of information sharing

If the sponsored, independent or web-based PHR is populated with information from clinician, healthcare facility or payer-provided clinical data from a health insurer, consumers may need to give authorization or request this information to be included in their PHR. Payer–provided clinical data may be automatically populated in a consumer’s PHR. Whether this data is filled in on a consumer’s PHR or not is likely to be the result of the processes known as “opting in” and “opting out”.

Opting in generally occurs when a consumer, or their designee, specifically requests that information be sent to the PHR. Opting out occurs when the consumer or PHR designee specifically requests that information not be included into the PHR. The procedures for opting in and opting out vary among PHR sponsors. Consumers should check with their PHR sponsor or service provider to learn about the opting in or opting out procedures that are in place for their specific PHR.

PHR privacy and security

Privacy and security are important aspects of protecting personal health information. Using a secure login and password when accessing a PHR helps protect personal health information. In addition, a secure login and password make certain that PHR information can be available to appropriate individuals when it is needed. Access to information contained in a PHR is controlled by the consumer or the consumer’s designee.

Typically, consumers can choose to allow their caregivers or clinicians to have access to some or all of the information contained in their PHR. If a caregiver or clinician is allowed to access information from a consumer’s PHR, a separate secure login and password may be required for those individuals.

Consumers may have the option of allowing authorized clinicians to access their PHR information without requiring prior consent under certain medical emergency circumstances, such as when an unconscious person is brought into the emergency room. Timely access to this information will help clinicians give the appropriate care.

Since most PHRs are web-based and the PHR information is stored electronically, in general, the data is backed up periodically. Consumers should be able to find out how their PHR information is stored and backed up so that access always can be available, especially when traveling, in times of an emergency or a natural disaster.
PHRs AND OTHER ELECTRONIC HEALTH INFORMATION SOURCES

Improved access to health information can lead to better communication among consumers, their caregivers and clinicians. With greater access, consumers and caregivers can more easily find, review and manage their health information or the health information of those in their care. Better informed consumers may be more engaged and able to make better health-related decisions through the use of information available in their PHR.

A consumer’s PHR is not the same as clinician’s EHR system that may be utilized by healthcare facilities and/or clinicians (also referred to as an Electronic Medical Record, or EMR). These electronic record systems may contain a consumer’s health and medical information that is created, gathered, managed, and accessed by authorized clinicians or their staff within or across more than one healthcare organization. The use of electronic record systems by clinicians and healthcare facilities is growing and over time, could become a significant source of information for PHRs.

Health Information Exchange

In some parts of the country now, and expected to be widespread in the future, health information can be securely exchanged through a Health Information Exchange (HIE). This type of information exchange allows a consumer’s electronic health and medical information to be moved safely and securely between authorized participating clinicians and facilities – and may include healthcare industry stakeholders such as payers, labs, radiology centers and pharmacy benefits managers. Clinicians’ electronic record systems are anticipated to be part of the HIE, and will help expand the information available for the consumer’s PHR.

The use of PHRs can be an important tool for improving safety, communication, care coordination, quality outcomes and efficiency for consumers. Leveraging this information technology in healthcare includes the process of securely sharing health and medical information while protecting the confidentiality of that information.
ADDITIONAL INFORMATION ON PHRs

For more information about PHRs, visit these sites:

- Centers for Medicare & Medicaid Services PHR website.

- Agency for Healthcare Research and Quality “Creating a Personal Health Record” video.
  http://www.ahrq.gov/video/personalrecord/indivrecord.htm

- Information from the AHIMA Foundation on PHRs and how to choose and start a PHR.
  http://www.myphr.com/StartaPHR/quick_guide.aspx

- The Robert Wood Johnson Foundation highlights and background on PHRs.
  http://www.rwjf.org/pr/product.jsp?id=49988

- An article on 15 Mobile Apps for Better Health.
TESTIMONIALS

From a member:

Jennifer Freeman, Arkansas

“As a teacher, my time is often divided among many areas and the PHR allows me to follow my family’s healthcare, from my children’s immunization to my husband’s diabetes easily.”

From a physician:

Jim Clark, MD, ER Physician, Conway, Arkansas

“The access to medical and pharmacy data available within this tool has been very beneficial for me as an ER physician. It is as though the patient has a voice, even when they don’t know they need one.”

From healthcare industry organizations:

American Osteopathic Association Medical Informatics (AOAMI):

“The time is now for individuals to partner with their physicians and other healthcare providers to manage the coordination of care for themselves and their families,” said Carl G. Bynum, DO, MPH, president of the American Osteopathic Association of Medical Informatics. “Our members believe that PHR’s form the basis for this critical partnership that will streamline healthcare delivery and improve patient outcomes.”

MedStar Diabetes Institute:

Diabetes is the nation’s costliest disease, affecting over 24 million Americans. Diabetes is a complex medical condition that requires a high level of daily self-management by the patient and sharing of personal health information with providers. MedStar Diabetes Institute (MDI) provides programs of excellence in diabetes care and self-management education. MDI’s PHR, eHealth2go, program has been recognized as a 2011 winner of the Microsoft Health Users Groups (HUG) Innovation Award, and was also a 2008 Microsoft HealthVault “Be Well Fund” winner.

“We believe that PHRs have tremendous potential to bring diabetes self-management into the home, where most diabetes care takes place.” said Michelle Magee, MD, MDI Director. “It’s a great way to harness health information to your benefit 24/7 when and where it is needed. For example, a PHR can make it easier for you to monitor your own blood sugars and blood pressure trends allowing for timely adjustments to medications and diet and exercise routines to help improve diabetes and blood pressure control and long-term health.”
Introduction ..........................1
Important reasons for having a PHR ..........2
Benefits of access to a PHR .................3
Controlling designated access to a PHR ........4
PHRs and other electronic health information sources ....5
Additional information on PHRs ...6
Testimonials ..........................7
PHR Screen Examples ...................9
Glossary .............................13
Participating organizations.............14

From a health insurer:

Ob Soonthornsima, Senior Vice President and Chief Information Officer, Blue Cross and Blue Shield of Louisiana

“When Hurricanes Katrina and Rita struck Louisiana, more than 300,000 customers and providers lost everything, including their medical records. During that time, Blue Cross and Blue Shield of Louisiana began offering a vital service to our customers and their doctors – claims-based health records. For customers who must evacuate and seek medical care from unfamiliar doctors, the claims-based health histories give the new doctor an overview of the patient’s medical conditions and care received. They have a record in their hands of every healthcare procedure, surgery performed and prescriptions filled in the last three years.”

Carrie Corona, Blue Cross and Blue Shield of Louisiana

In the days after Hurricane Katrina struck, Carrie Corona, then Call Center Manager at BCBS Louisiana, was working in the lobby of the Baton Rouge headquarters, just talking to and helping evacuees from New Orleans as they came in. Blue Cross stayed open in Baton Rouge throughout the aftermath of the storm, and a lot of evacuees came through the office on their way to safety. The Plan usually has one member advisor on “lobby duty” each day, but in those first few days after Katrina, they had almost “permanent” lobby duty. Advisors were helping members find their doctors, get their prescriptions refilled, find out about surgery that had been scheduled, etc.

“So many of the customers couldn’t remember their prescription names – just the color of the pill. And then those who had just seen the doctor the week before and knew that his office was destroyed. Those certain phone calls still tug at my heart strings today. I guess they will forever! One customer said, ‘This is such a blessing.’ I remember another who told me, ‘Now I don’t have to repeat myself over and over again to my physician.’ And this one: ‘My memory is not so good, so having everything in writing is PERFECT.’” – Carrie Corona, Manager, Special Accounts, Blue Cross and Blue Shield of Louisiana
PHR SCREEN EXAMPLES

As PHR users enter their PHR, in many cases, their personalized health summary is displayed first. As shown below, the health summary page(s) may list information on key areas like conditions, medication, allergies and tests. The PHR account holder or an authorized user, such as a designated caregiver, can click on any of the links to get more detailed information.
PHR Screen Examples (Continued)

With just a click of a mouse, individuals can see details about their health history. As shown below, they can see the details on each of their medications, including the name, dosage, and frequency taken.

On the next screen, patients or their authorized caregivers can see details on each of their current conditions, such as the name, diagnosis date or last date of service, status (still active or present).
PHR Screen Examples (Continued)

For chronic conditions, effective care coordination and communication can be supported by the PHR. As shown in the two screen samples below, the health summary in the PHR can highlight when chronic conditions or risk factors are present, and the related “medical history” detail can highlight the relevant results of any health risk assessments, as part of the “Personal History.”
Introduction ..........................1
Important reasons for having a PHR ..........2
Benefits of access to a PHR .................3
Controlling designated access to a PHR ..........4
PHRs and other electronic health information sources ....5
Additional information on PHRs ..6
Testimonials .................7
PHR Screen Examples ...............9
Glossary .....................13
Participating organizations ..........14

A PHR can be an excellent tool for patients and their caregivers to track chronic conditions and ongoing metrics. These metrics may include lab values and screening results. As an example, weight management can be a key factor for effective diabetes management and control.

In the examples below, the PHR tells the user which health information is being tracked on the first screen, and it graphs the weight results over several months on the second screen. This data may be self-entered, captured by home-based, web-enabled scales or from the EHR information gathered from a clinic visit and/or hospital stay.

PHR Screen Examples (Continued)
### Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access</td>
<td>The possibility to retrieve medical information stored in a database or remote application. Access should be limited by security authentication mechanisms.</td>
</tr>
<tr>
<td>Advance Directives</td>
<td>Instructions regarding what healthcare actions or medical treatments an individual wants to have taken or not taken and under what circumstances. These instructions are used by medical personnel in the event that the individual is unable to speak.</td>
</tr>
<tr>
<td>Authorization</td>
<td>The process of giving someone permission to do or have something. In multi-user computer systems, a system administrator defines which users are allowed access to the system and what privileges of use (such as access to which type of files or, hours of access).</td>
</tr>
<tr>
<td>“Break the glass”</td>
<td>Access to a consumer’s Personal Health Record in an emergency situation; for example, by an Emergency Room physician during a heart attack, or by an emergency responder during a life-threatening injury.</td>
</tr>
<tr>
<td>Clinician</td>
<td>An expert clinical person, licensed, certified or otherwise authorized or permitted to provide healthcare, such as a physician, physician assistant or nurse.</td>
</tr>
<tr>
<td>Consumer (in relation to healthcare services)</td>
<td>A person requiring, scheduled to receive, receiving or having received a healthcare service; a patient.</td>
</tr>
<tr>
<td>Electronic Health Record (EHR)</td>
<td>A comprehensive set of clinical, demographic, environmental, social, and financial data and information in electronic form, documenting the health care given to a single individual.</td>
</tr>
<tr>
<td>Healthcare Provider</td>
<td>A person or entity that is licensed, certified or otherwise authorized or permitted to administer healthcare in the ordinary course of business or practice of a profession, including a hospital, clinic, physician, physician assistant or nurse.</td>
</tr>
<tr>
<td>Health Information Exchange (HIE)</td>
<td>The authorized entity facilitating the movement of health-related information among clinicians and healthcare facilities. This entity may be local, regional or statewide.</td>
</tr>
<tr>
<td>“Opting in”</td>
<td>When a consumer or PHR proxy specifically requests that claims, laboratory or prescription data from a health insurer be populated into the PHR.</td>
</tr>
<tr>
<td>“Opting out”</td>
<td>When a consumer or PHR proxy specifically requests that claims, laboratory or prescription data from a health insurer not be populated into the PHR.</td>
</tr>
<tr>
<td>Personal Health Record (PHR)</td>
<td>An electronic record of health information by which the individual controls access to the information and may have the ability to manage, track and participate in his or her own healthcare. A PHR should not be confused with an electronic health record (EHR).</td>
</tr>
<tr>
<td>PHR Account Holder</td>
<td>The owner who controls access to and the movement of data in and out of the PHR Account. Also referred to as the “patient” or “consumer.”</td>
</tr>
<tr>
<td>PHR Proxy</td>
<td>A person who is authorized to act on behalf of the PHR Account Holder.</td>
</tr>
<tr>
<td>PHR Service Provider</td>
<td>An organization that delivers a PHR application to PHR account holders. A PHR Service Provider may offer its application directly to PHR Account Holders or indirectly through contracted PHR Sponsors. Also referred to as a “PHR vendor”.</td>
</tr>
<tr>
<td>PHR Sponsor</td>
<td>Offers PHR Account Holders access to a specific PHR application. A PHR Sponsor may not be the same as the PHR Service Provider. Examples of PHR Sponsors include a physician office, health system, employer, pharmacy, health plan or direct PHR Service Provider.</td>
</tr>
</tbody>
</table>
14

CLINICIAN GUIDE TO A PERSONAL HEALTH RECORD

Introduction ..........1
Important reasons for having a PHR ..........2
Benefits of access to a PHR .....................3
Controlling designated access to a PHR ........4
PHRs and other electronic health information sources ...5
Additional information on PHRs ..6
Testimonials .............7
PHR Screen Examples ..........9
Glossary ..................13
Participating organizations............14

PARTICIPATING ORGANIZATIONS

American Cancer Society
American College of Physicians (ACP)
American Diabetes Association
American Health Information Management Association (AHIMA)
American Heart Association
American Osteopathic Association Medical Informatics (AOAMI)
Medical Group Management Association (MGMA)

This PHR brochure was created through a collaboration of the Blue Cross and Blue Shield Association, an association of independent Blue Cross and Blue Shield companies, and the American Cancer Society, American College of Physicians, American Diabetes Association, the American Health Information Management Association, the American Heart Association, the American Osteopathic Association of Medical Informatics and the Medical Group Management Association.