# YOUR PERSONAL HEALTH RECORD

## INTRODUCTION

For you, your caregivers and doctors, a Personal Health Record (PHR) can be of value. A PHR can be used to manage, store and share your health data. When more health data is at hand for you, your caregivers and doctors, healthcare quality can be better. By having more information, you can be more involved and able to make better healthcare choices. A PHR may give doctors important data they need in an emergency when you cannot give it. A PHR also can give caregivers the data they need to make healthcare decisions.

PHRs may be found in several places such as:

• A PHR offered by a health insurance company or a healthcare facility.

• A PHR offered by an employer.

• A PHR service provider like Microsoft HealthVault or WebMD.

• Software that supports a PHR on a computer.

Health data may be sent from a health insurance company or healthcare facility into some PHRs. Healthcare facilities may include a hospital, doctor's office, lab or x-ray center. Some of your data may have to be added by you or your approved caregiver. PHR sponsors can choose what data to add to the PHR they offer. A sponsor may offer a PHR that is free or at a low cost.

### Security for your PHR

Most PHRs are on the web and can be viewed from almost any computer. PHR data is stored and is often backed up routinely. When data is stored on the web, PHR access is often easier, especially if you are traveling, having an emergency or in a natural disaster.

A secure login and password help keep your PHR information safe and lets you to share your health data when it is needed with people you choose. Each PHR is different and you should carefully decide if you want others to see it. You should take time to look at how to set it up for others to see your health data. You or your caregivers can visit the PHR website for secure access to the data. A secure login is needed. You can help lessen unwanted viewing of your PHR. You should keep your health data safe and secure by keeping your login and password private.

# WHY YOU SHOULD HAVE A PHR

A PHR can give you peace of mind. It is good to know that medical conditions, such as allergies and current drugs are kept in one secure place. It will then be ready when it is needed.

## PHR Data

PHRs have your address, phone number, and emergency contact data. Your PHR also may have data about family members. It also keeps contact data for doctors, caregivers, healthcare facilities, labs and drugstores in one, secure place. Your advance directives or other similar healthcare decisions also may be kept in a PHR. This will help doctors and caregivers know what healthcare actions or treatments you want to have or not have and when. This data is used by doctors when you are not able to speak for yourself. PHRs are not all the same. Not all of them will have a place for each piece of data from you or your doctor.

In a PHR, your medical history, medical records and family medical history may be ready when you need emergency or urgent care. After a fire, flood or natural disaster, a PHR may be the only medical record available. Also, a PHR may list over-the-counter drugs, immunizations and allergies, as well as travel areas that may have a health alert.

# BENEFITS OF HAVING A PHR

Having a PHR can help doctors manage care by making your healthcare data available to them. This could help reduce errors and stop duplicate medical tests or procedures by keeping this data ready.

The data kept in a PHR can help doctors better manage your drugs. It can also tell how a drug is ordered and list the medical condition it was ordered for. This data may help doctors learn if there are drug interactions or if there could be drug interactions for current drugs or new ones.

In an emergency, important health data may be available to doctors or family members who can see your PHR. Having a PHR may help give peace of mind by knowing your medical records are kept on the web. This is safer than paper medical records that can be damaged or destroyed—and safer than a computer lost in a tornado or hurricane.

## Doctor and Caregiver Access

In the future, you may be able to choose to let your caregiver or doctor view some or all of the data in your PHR. Your approved data may be able to be sent on the web from your PHR to the system healthcare facilities or doctors use. This is called an Electronic Health Record (EHR) system.

Moving PHR data on the web may let doctors see your data in their EHR system. Other data moving from the PHR to an EHR may affect workflows. It may raise liability concerns for doctors who see the data. Many in the healthcare industry agree that more data helps improve patient quality of care. The healthcare industry is looking at the privacy and data access concerns patients and doctors have.

If caregivers and doctors are given access to data in your PHR, a separate secure login and password may be needed. Better care management is one of the benefits when caregivers and doctors have access to more data.

# GIVING ACCESS TO YOUR PHR

You control your PHR and can decide who can see it. You can let caregivers and/or family members see your PHR. In some cases, doctors may be able to see your PHR before a medical visit.

In some emergencies, like when a person is unconscious, the "break the glass" feature (if approved by you) could be used. This would let doctors see your PHR without giving your prior consent. This will let doctors give you good care quickly.

## Opting in or opting out of data sharing

If the PHR can get data directly from a doctor, healthcare facility or health insurer, you may need to give approval or ask that this data be put into to your PHR. Health insurer data may be automatically added to your PHR by "opting in". Opting in happens when you or your caregiver ask that data be sent to your PHR. You can also opt out which happens when you, or your caregiver asks that data not be sent to your PHR. The rules for this are not the same for all PHRs. You should check with your PHR sponsor to find out about the opting in or opting out rules for your PHR.

## PHR privacy and security

Privacy and security are important parts of keeping your health data safe. You should read carefully the privacy and security rules for your PHR. You should make sure you understand how the PHR sponsor will keep your health data safe. Using a secure login and password when looking at a PHR helps keep the data safe.

A secure login and password make sure that PHR data can be seen by the right people when needed. Access to the data in your PHR is given by you or your approved caregiver. You can decide if you want your doctor or caregiver to see all or some of the data in your PHR. If you let doctors or caregivers see your PHR data, they will need their own secure login and password.

In some emergencies, you may be able to let doctors see your PHR data without prior consent such as if you were unconscious. Fast access to this data will help doctors give the right care.

Most PHRs are on the web. The PHR data is stored and is backed up at times. You should be able to find out how your PHR data is stored and backed up so that it is always ready when traveling, in times of an emergency or a natural disaster. You should be able to find out from your PHR sponsor what they do if there is a security breach.

# PHRs AND OTHER HEALTH DATA

Better access to health data can mean better talks between you, your caregivers and doctors. With better access, you and your caregivers can find, review and manage your health data and your care more easily. By having more data, you may be able to make better healthcare choices.

Your PHR is not the same as a doctor's EHR system (also called an Electronic Medical Record). An EHR system may be used by healthcare facilities and doctors. These systems may have your health and medical data. This data may be gathered, managed and seen by your doctors or their staff in more than one healthcare facility. The use of electronic systems by doctors and healthcare facilities is growing.  In the future, this could be a main source of data for your PHR.

## Health Information Exchange

In some parts of the country now, health data can be securely moved through a Health Information Exchange (HIE). This is likely to increase in the future. This lets your health and medical data be moved safely and securely between approved doctors and facilities, such as health insurers, labs, x-ray centers and drug benefits companies. The doctors' electronic record systems are likely to be part of an HIE, and will help increase the data that can be added to your PHR.

Using this healthcare technology, including a PHR, means securely sharing health and medical data while keeping it safe. Your use of a PHR can be important for better results, communication, care management, healthcare quality and efficiency.

# ADDITIONAL PHR INFORMATION

For more information about PHRs, visit these sites:

- Centers for Medicare & Medicaid Services PHR website.
  http://www.medicare.gov/navigation/manage-your-health/personal-health-records/personal-health-records-overview.aspx

- 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.
  http://www.informationweek.com/news/galleries/healthcare/patient/227700177?itc=ref-true

# 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, M.D., 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 of 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, D.O., MPH, president of the American Osteopathic Association of Medical Informatics. "Our members believe that PHRs' 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 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, M.D, 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."

## 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, manager, special accounts, Blue Cross and Blue Shield of Louisiana
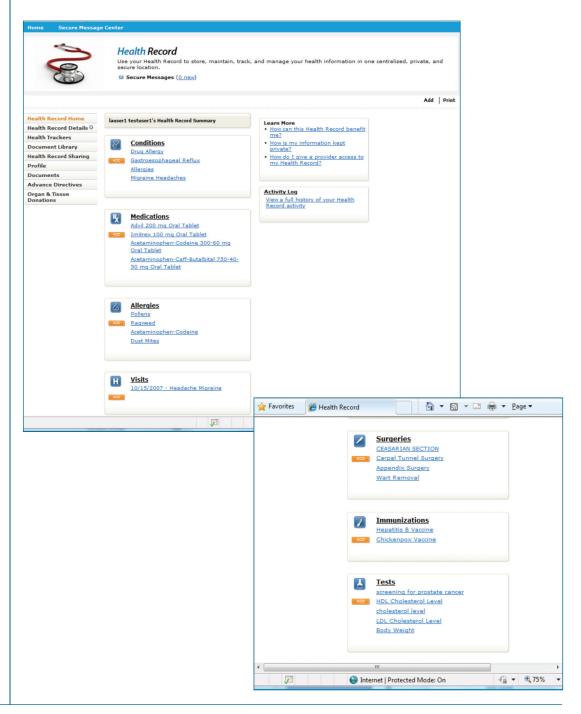
In the days after Hurricane Katrina struck, Carrie Corona, then Call Center Manager at BCBS Louisiana, was working in the lobby of the Baton Rouge headquarters, just talking to and helping evacuees from New Orleans as they came in. Blue Cross stayed open in Baton Rouge throughout the aftermath of the 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 there were 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.'"

# PHR SCREEN EXAMPLES

As you view your PHR, your health summary may be seen first. As seen below, the health summary page(s) may list data like conditions, drugs, allergies and tests. You or a caregiver can click on any of the links to get more data.
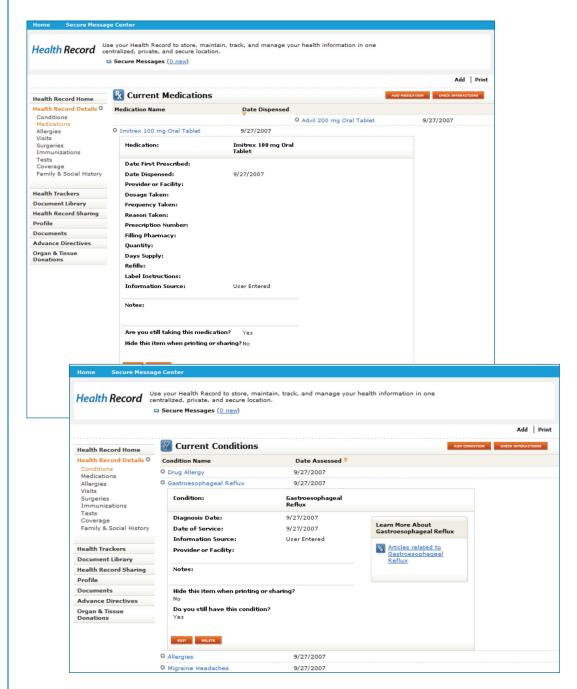
### PHR Screen Examples (Continued)

With a click of a mouse, you can see data from your health history. As seen below, there is data on each of the drugs, including the name, dosage and how often taken.
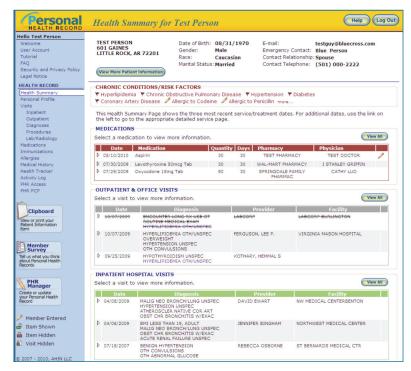
On the next screen, you or your caregivers can see data on each of your current conditions. This data may be the name, diagnosis date or last visit date and if it is still active or present.

### PHR Screen Examples (Continued)

For chronic conditions, care management and communication can be helped by your PHR. On the screens below, the "Health Summary" in the PHR can show when there are chronic conditions or risk factors. The "Medical History" data can show the results of any health risk assessment as part of the "Personal History."
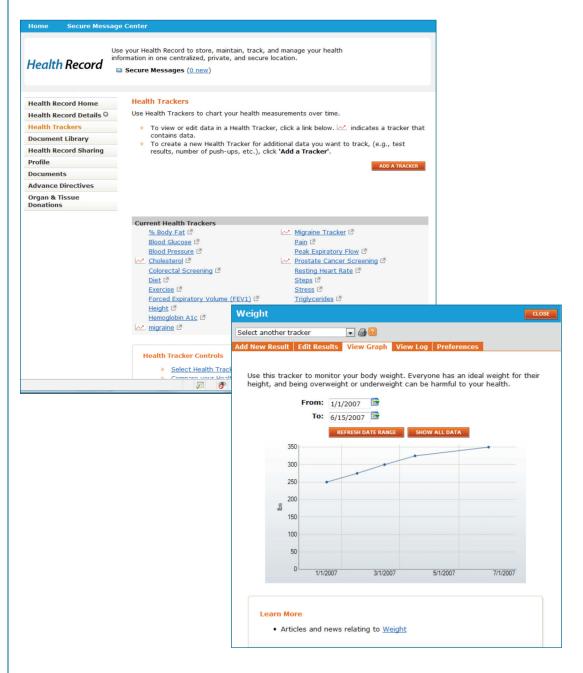
## PHR Screen Examples (Continued)

A PHR can be a very good way for you and your caregivers to look at your data and chronic conditions. This data may contain lab and test results. As an example, weight management can be a key way to control diabetes.

In the examples below, the PHR tells you which health data is being tracked on the first screen, and then shows it in graph form on the next screen. This data may be added by you or it can be from an EHR, and added after a clinic visit and/or hospital stay.

## GLOSSARY

| | |
|---|---|
| Access | Being able to see medical data that is stored electronically. Access should only be allowed by using a login and a secure password. |
| Advance Directives | Instructions regarding what healthcare actions or medical treatments you want to have done or not done and when. These instructions are used by doctors when you are unable to speak. |
| Authorization | Allowing someone to do or have something. In some computer systems, a designated person decides who is given access to the system and what they can see. |
| "Break the glass" | Access to your PHR in an emergency; This may be done by an Emergency Room doctor during a heart attack or by an emergency responder during a life-threatening injury. |
| Electronic Health Record (EHR) | Data showing the healthcare given to you. A system used by doctors and nurses. |
| Health Information Exchange (HIE) | The firm approved to move health-related data between doctors and healthcare facilities. This firm may be local, regional or statewide. |
| "Opting in" | When you or your caregiver asks that claims, lab or drug data from a health insurer or clinician be added to your PHR. |
| "Opting out" | When you or your caregiver asks that claims, lab or drug data from a health insurer or clinician not be added to your PHR. |
| Personal Health Record (PHR) | A system to store and manage your health data, where you control who views the data. |
| PHR User | The person who decides who can view a PHR and the moving of data in and out of the PHR. Also referred to as the "patient" or "consumer." |
| PHR Service Provider | A firm that makes a PHR available to PHR users. A PHR Service Provider may offer its PHR to PHR users, or offer the PHR through a PHR sponsors. Also called a "PHR vendor." |
| PHR Sponsor | Offers PHR users access to a certain PHR. A PHR sponsor may not be the same as the PHR service provider. PHR sponsors may include a doctor's office, health system, employer, drug store, health insurer or PHR service provider. |

# 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 of Medical Informatics (AOAMI)

Blue Cross and Blue Shield Association

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, the American College of Physicians, the 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.

N-11-358