Janie Appleseed

The Janie Appleseed Personal Health Record (PHR) Guide to Getting Started

*How to **Safely** Grow a Personal Health Record*

Edition 2.0

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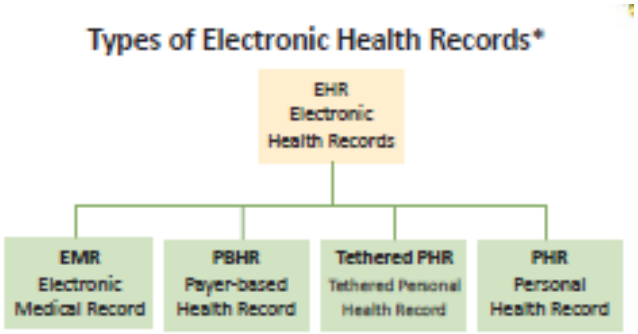
Introduction

What is a Personal Health Record (PHR)?

A Personal Health Record (PHR) compiles your health information electronically. Your PHR belongs to you. You create it, manage it and you control it. As information is added to your PHR, it becomes a "longitudinal" collection of your healthcare and health related data. Longitudinal means a lengthwise view over time. A longitudinal PHR can provide a view of someone's healthcare and health related data from the beginning to the end of their life.

Although both are computer based, a PHR differs from an electronic medical record (EMR) in three important ways:

1. A PHR is controlled by an individual rather than a healthcare organization. EMR's belong to care providers.
2. A PHR is comprehensive. It includes information from all a person's healthcare providers. An EMR only stores information for the medical practice maintaining the system.
3. A PHR is holistic. It contains information about a person's *health* when they're not sick, plus information about their *care* when they're not well. An EMR only collects the type of information a care provider needs to diagnose and treat an illness, and is required so the provider can get paid for delivering that service.



* Miller, Yasnoff and Burde. (2009). *Personal Health Records: The Essential Missing Link in 21st Century Healthcare*. Chicago: HIMSS.

What is the purpose of this Guide?

This guide will help you utilize available electronic information management technology to begin keeping track of your medical and health related information. It will help you safely start your own Personal Health Record.

Who will benefit from this Guide?

This guide is written for general public use; for those of us who do not have a "clinical background". It uses common language to present new terms and concepts that need to be learned. It makes this information much easier to understand and use.

It helps "designated daughters" and "selected sons" collect the information needed to care for an aging parent. It helps husbands or wives gather information that assists their spouse to manage a chronic condition. It helps a parent with an ill child record the data needed to manage and oversee services the healthcare system is providing. This guide helps people of all ages learn to use a PHR to be more pro-active and conscientious about health decisions.

This is a practical and user-friendly Guide for anyone who wants to become more knowledgeable about PHRs right now, even though the technology is still in its infancy. This Guide teaches people how to organize, manage and protect their personal health information, so they can make good choices about what data to share and how to share it efficiently and effectively. It explains how people can get started collecting and protecting information about their health and their care which accumulates over time. It refers to both health care and wellness activities, so all this data will be available today for your benefit. And it will be available as a reference for future generations as well.

What information belongs in a PHR?

Is the purpose of a PHR to help healthcare professionals provide care more effectively and efficiently, or does it serve a more personal wellness purpose? Is the information in a PHR for private use only, or is 100% of the information intended for sharing? Where are the edges and boundaries of the information contained in this new technology? A PHR can be used to document all aspects of your physical health and care. There is no limit to the ways in which you can use this information to improve the healthcare you receive and to maintain your wellness. When you control access to the information, you can share as much or as little as you choose. But what about the personal health information that is stored in systems where you don't control the access?

What should I know about privacy issues?

When it comes to electronic health records, privacy is, and should be, a major concern. Much can be revealed about a person by knowing the information contained in their health record. Who has access to how much of a person's health record is a hotly debated issue today, and will likely remain a hotly debated issue over time. New technology does not change the fact that privacy has been, and will continue to be, an aspect of the human condition that causes us to struggle. How much to share, and with whom, and in what ways, are all questions of vital importance to consider.

There is no avoiding the issue of privacy. Our job is to figure out how to address and balance the need to simultaneously provide and control access to personal information. Having all your health data available in one place will make it easier for you and others to use your information in beneficial ways, but it will also increase the potential for others to gain access to and possibly misuse information about you.

As more and more data about your health and care become captured electronically, it is important for you to be well informed about privacy issues. You should begin to understand what information about your health is being recorded, and where it is being shared. Until privacy controls are more mature, you will need to be very careful about what information you record for the purpose of sharing. Right now, you may not be able to adequately control where your personal information, in whole or in part, is being shared. So for now, it is better to be safe than sorry by documenting only the minimum data required in systems you do not control.

In the future, personal health information technology will offer more functionality aimed at protecting your privacy. However, at this time, functions to control and see who has access to your information, are nearly non-existent. Few standards exist to guide system developers on what is required. Valuable work is underway in this area, but until significant improvement is achieved, individuals must be vigilant about managing and monitoring who has access to their personal health information.

Understanding how your data may be legally shared and exposed is the first step. The second step is to learn what you can do to limit what consent you give on the sharing of your data. Third, you can manage your data in ways that give you more control over how much data you share, and with whom.

The Janie Appleseed Network provides links to recommended sources of additional information about patient privacy issues and rights at www.janieappleseed.net.

Why do I need a Personal Health Record?

The idea of a "personal health record" is not new. Historically, people have recorded births, deaths, and marriages inside the cover of a family bible. Individuals wear jewelry which alerts others of an allergy or medical condition. From hieroglyphics to folktales, songs to scrapbooks, bracelets to tattoos, over the centuries, people have recorded and communicated information about their health and wellness history.

We know that having access to the dates and complexities of our prior illnesses can make a difference when treating current conditions. The details of our health and care have become very important pieces of data that a person often needs and wants to track. Other personal data and the actions we have taken to prevent illness can also help in the assessment of our ongoing health risks. Personal health information can inform and optimize care plans established to treat current illness and keep us healthier in the future.

Today, the amount and type of health information being recorded has exceeded the capture capabilities of traditional methods of documentation. Old fashioned paper records just don't get the job done properly or efficiently any more. In the information age, where computers are used for a significant portion of the information processing, electronic PHRs have the potential to play a new and important role.

1. **More control:** Having your own record allows you to have all the facts and details of your care at your fingertips. Your PHR makes it easy to have a factual understanding about what's happening with your care, or the care of a loved one, in a way that was never possible before.
2. **More participation:** Nobody cares more about the quality of your care than you and your family. The information in a PHR helps you, and your loved ones, be active decision makers about healthcare choices. PHRs empower people to make a significant difference in the type and quality of treatment they receive. PHRs also have the potential to engage people much more actively in lifestyles that focus on and promote their health.

Consumers are just beginning to see the benefits of PHR technology. Just as with other new technologies, consumers need to gain familiarity so they can become active stakeholders in the ongoing developmental process. Consumer involvement is vital to ensuring this new technology includes the functions and capabilities consumers want and need.

When should I start a Personal Health Record?

It is never too soon to begin collecting your personal health records. This is your data!! You need to have your own copy of ***your*** information. Plus, you have and could be recording other information about your health and the activities you do to stay well. This information belongs to you. The information documented by a care professional is in their hands. At the point of care, when you share information with a provider, you have the right to request a copy of that information. If you record that information, then ***your*** personal health record grows. You never need to worry about trying to collect or recreate your record from other people's records. You'll have your own, and chances are, the records you keep about yourself will be more complete and more accurate because no one has as much incentive as you to be sure this information is correct.

Technology is making it increasingly easier to collect health information and learn about health conditions. Shortly after the birth of the internet, websites emerged to provide consumers with access to medical information that previously would have only been accessible to doctors. Presently, a national initiative to implement electronic

medical records is making it possible for patients to access the information contained in their records kept by care providers. “Smart” devices are being developed that can collect and transmit biometric readings of things like blood pressure and glucose levels directly to their physicians, which allows for real time monitoring and adjustment of treatment plans. Soon it will also be possible for people to author and electronically send information about their physical condition to their care providers using a format that the physician’s medical records system can view and import.

Health information technology standards are helping personal health technology become a reality. Standards are driving how information can be shared, and they will drive new capabilities to control access. Health information technology is revolutionizing the way healthcare is practiced. However, the success of our nation’s investment in health information technology depends on how effectively this new technology facilitates positive health outcomes. These goals can only be achieved if the technology can address and incorporate the needs of individuals and families in practical, relevant and respectful ways. If the goal is to shift our nation’s focus toward maintaining wellness rather than treating illness, then the new technology needs to involve and empower people to take more and more control of their health. That means people need to get on board and start growing their PHRs.

The sooner you get started with your PHR, and the sooner you have your prior information entered, the sooner you will be in a position to simply add new data as it becomes available. The sooner you get started, the sooner you will be begin to see how you can use your PHR to guide your health choices and manage your proactive wellness activities.

What terms and concepts do I need to understand to get started?

Electronic health records have been evolving over the past 30 years or so. The language used to describe this technology includes terms borrowed from computer science as well as the practice of medicine. Initially, there were not established definitions for many of these terms, but as standards have evolved, common understandings have been reached. Awareness of the standard terminology used to communicate about PHRs will make it easier to understand and use the technology.

Standard are important for health information technology. Communicating your information in a standard format increases the chance that it will be understood by care providers. It also increases the chance that this information can be put to meaningful and transparent use in the ongoing effort to achieve health and wellness for you and others in the future.

What the industry has established as a standard way to organize a care summary may require some explanation for non-clinicians to understand. Once these terms and what they refer to become familiar, a non-clinician can categorize their own or another person’s information much more easily. The sections of health information documented to promote continuity of care include:

Advance Directives	Advanced Directives are your pre-established care preferences and your decisions about what level of care you want to receive under various circumstances.
Alerts	Alerts are issues you want all healthcare providers to be knowledgeable about prior to providing any care.
Allergies and Intolerances	Allergies and Intolerances include any medication allergies, adverse reactions, idiosyncratic reactions, reactions to food items, and metabolic variations or adverse

	reactions to other substances such as latex, iodine, or tape adhesives, etc.
Care Plan	Your Care Plan is the set of actions you should be doing to meet your care needs, optimize your functional status, and achieve your wellness goals. Your Care Plan includes your individual plans of care, the single reconciled view, and your health goals. The Care Plan also includes your routine preventative care and proactive health screenings. Your Care Plan is the future oriented portion of your health record that documents the action you intend to take, going forward, to meet your health goals..
Demographics	Demographics represent all the pieces of information used to identify and characterize you. This includes your name, address, telecommunication addresses, birth date, place of birth, and numbers external authorities have associated with you. It also includes characteristics like gender, race, ethnicity, religion, marital status and language preference, which are commonly used to aggregate your data if it is used for an analysis.
Encounters	An Encounter is an interaction with a health care provider. There are many different types of Encounters, including appointments with a doctor, visits to the emergency department or walk-in clinic, a hospital stay, etc.
Family History	Family History covers the medical background of your biological family members. It also includes some additional details about your own physical circumstances.
Functional Status	Functional Status describes your physical function in ways that enable the information to be compared to what might be considered normal. This includes, for example, your eye sight, hearing, sense of touch and taste. It also includes your mental status and other behavior patterns involving sleep, appetite and sexual function. It covers your body parts which may or may not be present and how they are working. For example, it covers how much weight you can comfortably lift, the number of stairs you can climb, your range of motion, or your ability to concentrate or perform certain tasks, etc.
Health Concerns	A Health Concern is any aspect of physical condition (diagnosis, symptom, functional limitation, etc.) that requires treatment or observation. Each Health Concern will have an associated list of one or more problems being experienced which gave rise to this concern.
Immunizations	Immunizations are vaccinations received proactively to reduce the risk of contracting various diseases.
Medical Equipment	Medical Equipment covers any devices you routinely use to support normal, everyday functioning. This might include a prosthetic device, wheel chair, oxygen tank, eye glasses, hearing aid, pacemaker, cane, etc.
Medications	A Medication is a substance you use that has been prescribed by a doctor. It also includes substances you use for health purposes which are legally available without a prescription.

Payers	Payers cover any insurance providers you may have and the person who is the subscriber for those insurance plans. This is the list of organizations and/or person(s) to whom the bills will be sent for any health care services rendered.
Preferences	Preferences enable a patient to express additional personal wishes regarding their care. Preferences should be taken into consideration during the development of your Care Plan. They reflect personal opinions, values, experience and predetermined choices that will supplement what you have set up thru your Advanced Directives. They refer to an individual's personal evaluation of available healthcare treatment approaches and outcomes.
Procedures	Procedures cover all medical actions that have been performed on you. This would include any screening, diagnostic or treatment procedures performed by a care provider.
Results	Results are the information produced as a result of a screening, diagnostic test, or treatment procedure, etc.
Social History	Social History covers other types of contextual information that are relevant to your health, but are not necessarily considered part of a typical "medical history" or "family history". It includes information about social issues that have links to health such as smoking, sexual practices, occupation and industry, non-prescribed drug use and alcohol consumption, etc. Additional aspects of your relationships and experiences which can relate to your health may also be noted in this section.
Support	Support is a broad category that includes all the people who comprise your care team; your physicians, dentist, chiropractor, pharmacy, NOK (next of kin), emergency contact, religious leader, Home Care Agency staff person, Assisted Living staff contact, etc.
Vital Signs	Vital Signs are physical observations that are directly linked to a person's functional status, such as your blood pressure, pulse, weight, height, oxygen saturation rate, etc.

How do I gather my health information?

This section of this document previously described how to use an excel workbook to store and maintain your personal health data. It was a complex process. It was labor intensive. It also got harder over time because managing the longitudinal changes in data over time had to be done manually. Technology is making your life easier! This whole section of the Guide has been replaced with one simple instruction: Use a PHR.

How do I gather and record prior information?

One of the biggest challenges faced when developing a PHR, is dealing with the overwhelming amounts of prior information only available as paper documents. There is no magic solution to alleviate this problem at this time.

Being able to scan a paper document is one step toward improvement. It eliminates the burden of storing and finding the paper when it is needed. However, it is time consuming and it shifts the paper problem into an identical electronic problem. Even if every discharge summary, progress note, prescription and explanation of benefit came in an electronic form, you would still need to ask yourself where to put them. How do I file this information so I

can quickly access it in the future? Simply moving from paper to digital does not eliminate this age old problem of how to store and access information. Eventually the information coming in digital form will be encoded with metadata that will allow computers to file and index these documents for us. But for now, you can facilitate this shift to electronic records by storing the essential information in the same way a computer would.

Here is a strategy that can save time and reduce the risk that information is stored somewhere, but can't be found:

1. Rate any paper healthcare information you get in terms of "potential for future access". Ask yourself, "What is the chance I will want to access this information again in the future?"
2. If the potential for future access is low, file the document in a paper filing system that is organized by year and month. This will make it easier to find the information in the future if ever needed.
3. If the potential for future access is medium, file the document in a paper filing system that is organized by year and month, and record the date of the encounter and who it was with, or the final result of a test that was performed on a certain date.
4. If the potential for future access is high, then scan the document and upload it into your PHR. This will make it much easier to find the information in the future.

Reference Appendix

Advance Directives

What does Advance Directives cover?

Advanced Directives are your pre-established care preferences and your decisions about what level of care you want to receive under various circumstances.

Why are they useful in a PHR?

Having your Advance Directives documented in your personal health record increases the chance that your wishes will be followed. When this information is not available at the point of care, health care providers can follow other protocols rather than adhering to your wishes. Family members may not know your desires for your care in certain circumstances, and having your wishes clearly documented will help them make decisions on your behalf, if that is needed. Deciding certain choices ahead of time ensures that the right choices will be made during situations that can be highly emotional times.

Where do I get the information?

If you have a Living Will, some of the common advance directives may be stated there. You can also get a copy of an Advance Directives form at your local hospital or nursing home. Your driver's license may record certain choices you have made about organ donation. Once you understand the decisions you can make for yourself and your care, you can document them in your PHR so they will be readily available to your family members and care providers and well understood by everyone on your care team.

Key Question

If you were to die tomorrow, in a way that permitted your organs to be re-used by someone who needed them, would you want your family to donate your organs for that purpose? Have you ever discussed this topic with members of your family to see how they feel about your choices and to learn what choices they would make for themselves?

Alerts

What does Alerts cover?

Alerts are issues you want all healthcare providers to be knowledgeable about prior to providing any care.

Why are they useful in a PHR?

Sharing information about certain problems or issues you have experienced in the past can avoid problems in the future. Alerting care providers about severe allergies will minimize the risk that you will be exposed to a substance which causes you a bad reaction. Being able to alert care providers to any communicable conditions is another example of how information placed in this section can be helpful. If you know you should always get an IV in your left arm because your lymph nodes under your right arm have been removed, care providers should know that head of time. Documenting your Alerts in your PHR makes sure the right information gets to the right people at the right time. It prevents you from forgetting to mention something that may be important. It also ensures that care providers get this information right away in an emergency, especially if you are not able to speak for yourself.

Where do I get the information?

To formulate an initial set of Alerts, you will need to review your personal scenario and think back over past situations to look for any issues that should be documented. These could be things like religious beliefs that may contradict common medical practices or common problems that you tend to talk to every doctor's administrator about, like an unusual name which makes it hard to find your prior records. For example, someone named Harold Michael Smith may go by the name Mike and more formally writes his name as H. Michael Smith. If a search is done for the records of Harold M. Smith, the full extent of available information may not be located.

Key Question

If you arrived at the Emergency Room and were unconscious, what special information would you want them to know before they started administering your care? What is your blood type? Do you have any metal or electrical implants in your body, like a pacemaker, which they would need to know about before doing an MRI, etc?

Allergies and Intolerances

What does Allergies and Intolerances cover?

Allergies and Intolerances include any medication allergies, adverse reactions, idiosyncratic reactions, reactions to food items, and metabolic variations or adverse reactions to other substances such as latex, iodine, or tape adhesives, etc. Allergies are an immune response, while Intolerances are usually associated with a chemical reaction. The symptoms of food intolerance can be similar to a food allergy. The symptoms can also be associated with conditions including asthma, chronic fatigue syndrome and irritable bowel syndrome (IBS). Allergies and intolerances can vary in severity. Anaphylaxis or anaphylactic shock is an extreme allergic reaction and can be life threatening.

Why are they useful in a PHR?

Doctors need to take any known allergies and intolerances into consideration as they diagnose your current problems, prescribe medications, or order treatments.

Where do I get the information?

To document your allergies and intolerances, you may summarize prior symptoms or reactions to certain substances. You also can document information provided from Allergists and other care providers who may have documented previously experienced allergies and intolerances.

Key Question

If you arrived at the Emergency Room and you were unconscious, what special information would you want them to know before they started administering your care? Have you ever had a reaction to anything that resulted in a decreased ability to breathe normally? Have you noticed that "the usual" dose of a particular medication seems to be more than what your body size or system sensitivity is able to tolerate? Symptoms requiring emergency treatment can multiply if medical staff is not adequately informed about existing allergies or intolerances.

Care Plan

What does Care Plan cover?

Your Care Plan is the set of actions you should be doing to meet your care needs, optimize your functional status, and achieve your health goals. A Care Plan often comprises several plans of care. A plan of care may address only certain health concerns. A plan of care may be developed by a clinician who focuses on a specialty area of care. For example, your diet and exercise may be one plan of care, while your cardiology plan of care may include the specific instructions and activities associated with the health of your heart. You consolidate the plans of care provided by several care providers into a single view called your reconciled plan of care. Your Care Plan includes your individual plans of care, the single reconciled view, and your health goals. The Care Plan also includes your routine preventative care and proactive health screenings. Your Care Plan is the future oriented portion of your health record that documents the action you intend to take, going forward, to meet your health goals.

Why is it useful in a PHR?

Documenting your Care Plan in a PHR offers many benefits. It gives you the ability to integrate the instructions from many different care providers into a single integrated plan. When this information is presented visually as a single plan, it is easier to follow. The information you track in a PHR allows you to see how well you are following the plan and measure the outcomes you are experiencing as a result. Your reconciled plan of care also helps to identify any treatment contradictions that sometimes inadvertently occur.

Where do I get the information?

To compile your Care Plan, you need to consider all the medications, treatments, screenings, activities, etc. you have been advised to do or are planning to do going forward in time. You Care Plan may simply consist of eating right and getting a flu shot and an annual examination from your PCP. You may take vitamins or prescribed medications. You may have specific goals, for your weight or for control of your blood sugar. You may have exercise goals or a plan for stress management. If you see specialists in addition to a PCP, you may have a separate care plan with different types of instructions from each different doctor. You need to collect the recommended future actions from your doctors, dentist, physical therapist, nutritionist, etc. To reconcile the different plans of care into a single view, you may need some assistance from a nurse or pharmacist who is knowledgeable about drug interactions and how to resolve conflicting instructions. You may need to reflect on your own goals and priorities to establish a set of wellness goals.

Key Question

Do you have health goals? What do you do today to identify and track your progress toward attaining your health goals?

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Demographics

What do Demographics cover?

Demographics represent all the pieces of information used to identify and characterize you. This includes your name, address, telecommunication addresses, birth date, place of birth, and numbers external authorities have associated with you. It also includes characteristics like gender, race, ethnicity, religion, marital status and language preference, which are commonly used to aggregate your data if it is used for an analysis.

Why are they useful in a PHR?

1. To make sure the person is correctly associated with the right identity. This will help to avoid safety problems resulting from having the wrong person's information. It will also avoid having no information associated, when information exists that would be helpful to the problem diagnosis and care decision making process.

2. To facilitate secondary use of the health and wellness information. Demographic data allows health information to be characterized in ways that facilitate analysis. Privacy concerns are valid and important to consider here. If your health information does not include standard demographic classification information, it may be less useful for certain purposes. If you are concerned about providing your demographic information, you will need to find ways to request that it be masked, but few systems have this capability today.

Once adequate and trustworthy de-identification methods exist to safely separate your identify from your health data, re-use of this information stands to be very valuable for improving health outcomes for our population as a whole. If your data can provide statistical evidence that helps our health system be more accurately informed, without sacrificing your privacy, then this would be very valuable. Someday we will have systems that make it possible to safely share our health information in ways that lead to future improvements in healthcare, without taking on the potential and unforeseeable risks associated with exposing our identities.

3. Time and cost savings coupled with quality of care improvements. PHRs minimize the time it takes to provide safer, better care. They can help us minimize the cost of care while improving it. PHRs allow people to find mistakes in documentation that can negatively impact current and future care. We aren't going to get safer, better care for free, but we can minimize what it costs to attain these goals by enabling people to contribute to achieving these aims. No one is as motivated to achieve safer, high quality care, than the people who need these care services to live healthy, productive lives.

Where do I get the information?

Most Demographic information you need to populate a PHR is information you already know about yourself. Most people know their birth date, race, ethnicity, marital status, etc. If you didn't know your place of birth, you could find it on your birth certificate. If you weren't sure about your marital status, you could check the status you use when filing your tax returns. It is possible to record more than one ethnicity, so you may want to review your family tree to determine your full ethnic make-up. Gender in the demographics sense of the word is considered an administrative characterization, and does not reflect sexual orientation or physical anatomy. If the options of male or female don't provide the correct administrative characterization, there is a third possibility called "other".

Key Question

The US government assigns you a unique number called your social security number for the purpose of paying taxes. What other organizations have assigned you a unique number by which they can determine your identity? What are the names of those organizations and what number did they assign?

Encounters

What does Encounters cover?

An Encounter is an interaction with a health care provider. There are many different types of Encounters, including appointments with a doctor, visits to an emergency department or walk-in clinic, a hospital stay, etc.

Why are they useful in a PHR?

Having an accurate view of the care you have received over time paints a valuable picture for a care provider who is attempting to diagnose a new problem or treat an ongoing situation. The list of medical encounters you have had and the reason for each visit creates a more complete picture of your health. Sharing a timeline of prior encounters can quickly communicate much important information to your care provider. It provides helpful clues about your health in the past that can contribute to treatment of a current issue, and promote better health in the future.

Where do I get the information?

Collecting Encounter information is best done as the encounters happen. Once you have a PHR, your list of Encounters accumulates naturally as the encounter information is recorded. To collect information on prior encounters, you may be able to go back through your personal calendar or collect copies of records about your care which are kept by physicians and hospitals where you have received care in the past. In some cases, a simple summary that you create yourself will suffice to cover your prior Encounter history.

Key Question

How many times have you ever had to go to an emergency room or hospital for care? Can you recall which hospital and the approximate dates? What was the purpose of those visits? Can you think of all the doctors you have seen in the past year and list their names and phone numbers? What is the process you must follow to request a copy of your records?

Family History

What does Family History cover?

Family History covers the medical background of your biological family members. It also includes some additional details about your own physical circumstances.

Why is it useful in a PHR?

Many medical issues are linked to genetics and pass from parents to their children. Knowing the medical history of your mother and father, grandparents and siblings provides important clues that can help provide the right care for you. A PHR provides a tool for compiling an accurate picture of the health issues of previous generations and others within your own generation including age of onset and outcome. If patterns exist, they can be easier to notice. Certain information about your children can also be useful in your own PHR.

Where do I get the information?

Collecting a Family History may take some time. You may need to consult relatives or research public records to put together a complete picture. The good news is that once you have a PHR, future generations will never have to worry about collecting prior family histories. This information will be readily available.

Key Question

What medical conditions did your parents have? When did those problems first begin in their lives? What about your grandparents, did they have any medical problems? What was their cause of death and at what age did they die?

Functional Status (and Review of Systems)

What does Functional Status cover?

Review of Systems is a major component of Functional Status. Functional Status describes your physical functioning in ways that enables the information to be compared to what might be considered normal. This includes, for example, your eye sight, hearing, sense of touch and taste. It also includes your mental status and other behavior patterns involving sleep, appetite and sexual function. It covers your body parts which may or may not be present and how they are working. For example, it covers how much weight you can comfortably lift, the number of stairs you can climb, your range of motion, or your ability to concentrate or perform certain tasks, etc.

Why is it useful in a PHR?

Documenting your functional status in a PHR provides a clear picture of what is normal for your health and what is not. Keeping track of your functional status gives you a view of how your health is progressing so you can tell if treatments or changes are contributing to positive health outcomes or not.

Where do I get the information?

Think about things you currently cannot do which you have been previously able to do. Identify any ways in which your body functions differently from other people's bodies. Do a mental inventory from your head to your toes. Document anything about your physical capabilities that you are trying to do more of or less of.

Key Question

What is normal for your body? Do you experience pain or any limitation which you would want to track in order to tell if it is getter better or worse over time?

Health Concerns

What does Health Concerns cover?

A Health Concern is any aspect of physical condition (diagnosis, symptom, condition, functional limitation, etc.) that requires treatment or observation. Each Health Concern will have an associated list of one or more problems being experienced which gave rise to this concern.

Why are they useful in a PHR?

Having an accurate list of Health Concerns in your PHR makes it possible for you to begin managing them more effectively. For example, you can relate the medications you take to the Health Concerns that have been identified. You can see how activities on your Care Plan address these Health Concerns.

Where do I get the information?

The health records kept by your physicians may include prior diagnoses or conditions. You can also reverse engineer a list of Health Concerns by considering each of the medications you currently take and asking what problem that medication addresses. Some functional limitations may also belong on your Health Concerns list.

Key Question

How do the items on my list of Health Concerns relate to the other sections of my PHR? Are there procedures or items in the Care Plan that address each of the areas of Health Concern that are being noted?

Immunizations

What does Immunizations cover?

Immunizations are vaccinations received proactively to reduce the risk of contracting various diseases.

Why are they useful in a PHR?

Keeping track of your immunizations prevents you from having to be unnecessarily vaccinated. If your tetanus vaccine is up to date, and you know it, you won't be given another one unnecessarily. A good immunization record also helps care providers rule out certain conditions which become less likely for someone who has been vaccinated against them.

Where do I get the information?

Your primary care physician may have some records of your immunizations. You may need to gather information from other places too. If you get your flu shot at a local drug store, your primary care physician may not have a record of that immunization. If you have received other vaccinations for tetanus or hepatitis at an Emergency Department, you may need to collect that information separately.

Key Question

Do you have a current record of your child's immunization records? What immunizations should each member of your family be getting in the coming year or coming 5 years?

Medical Equipment

What does Medical Equipment cover?

Medical Equipment covers any devices you routinely use to support normal, everyday functioning. This might include a prosthetic device, wheel chair, oxygen tank, eye glasses, hearing aid, pacemaker or cane, etc.

Why is it useful in a PHR?

Anyone caring for you should be aware of the medical Equipment you use or require. In the event that the equipment needs to be replaced, having exact specifications of the make and model or size can be very helpful. In the case of a pacemaker, this information can be critical to care providers who need to reprogram or adjust the

functioning of the device. Medical equipment, even implanted devices, can be subject to recalls. For convenience and for safety reasons, it is important to have all your medical devices documented in your PHR.

Where do I get the information?

Once you make a list of the medical devices you use, you can determine how to document the information. You may need to consult prior records kept by your physician. You may have paper receipts or id cards for implanted devices that were given to you after they were implanted. You may need to contact your optometrist to get the exact details about the prescription for your glasses.

Key Question

Have you ever broken your glasses while you were on vacation? If you needed to replace your elderly father's hearing aids because an orderly accidently changed the bed linens without noticing that the hearing aids were in the bed, what would you have to go through to determine the right aids to re-order?

Medications (and Supplements)

What does Medications cover?

A Medication is a substance you use that has been prescribed. It also includes substances you use for health purposes that are legally available without a prescription.

Why are they useful in a PHR?

Tracking use of medication use is one of the most valuable purposes of a PHR. Having a current, complete, and legible list of all your medications and over the counter products you take saves time and improves safety. Without a clear and complete list of everything you are taking, it is impossible to identify potential incompatibilities.

Where do I get the information?

Your physician will have a list of the medications you have been prescribed. Your pharmacist will have a list of the medications you have had filled. But, only you know what you are actually taking. You may need to get information from a few different sources. You may also need to get information about the vitamins or other over the counter medications you take. You can compile this information from the labels on the bottles of your medications. Besides documenting what you take, you need to record how much and how often you take each medication. If the medication is a tablet you take orally, the instructions for use may be different from an eye drop or a topical cream. You can also record who prescribes the medication, where you get it refilled and what problem it addresses. Recording medication information is one of the most complicated aspects of your personal health record, but it is one of the most beneficial places to keep detailed and accurate records. It is equally important to have a record of any Supplements you take.

Key Question

What over the counter products need to also be on your medication list? How does your list of medications compare to the list of medications your doctor currently has on file for you? If they are not identical, what caused the two lists to be different?

Payers (and Insurers)

What does Payers cover?

Payers cover any person who is the party responsible for your bills, any insurance provider(s) you may have and the person who is the subscriber for these insurance plan(s). This is the list of organizations and/or people to whom the bills will be sent for any health care services rendered.

Why are they useful in a PHR?

Payer information is needed any time you receive care. You may need to contact a payer to authorize care prior to receiving a service. You may need to contact a payer to understand what your coverage will be for a certain procedure.

Where do I get the information?

If you have medical insurance, your insurance identification card contains the details you need to document in your PHR. If you have multiple insurance policies, you may need to record multiple payers. Dental and eye care insurance may be provided by a different carrier than the one providing your medical coverage.

Key Question

Do you have a clear picture of what your insurance plan covers and what it does not? How do you stay abreast of what you are spending on healthcare and how much your insurance is covering? Do you have a way to review healthcare cost information that helps you arrive at decisions about care?

Preferences

What does Preferences cover?

Preferences enable a patient to express additional personal wishes regarding their care. Preferences should be taken into consideration during the development of a Care Plan. They reflect personal opinions, values, experience and predetermined choices. They refer to an individual's personal evaluation of available healthcare treatment approaches and outcomes. A Preference could be associated with name brand medications versus generics or a decision to minimize medical interventions when you have reached an advanced age. Issues which do not seem significant enough to belong in the Alerts, the Allergies and Intolerances or the Advance Directives sections can be expressed as a Preference.

Why are they useful in a PHR?

When communicated and documented, patient preferences can influence decision-making about your care.

Where do I get the information?

If you have strong feelings about the care and treatments you do and do not want to receive, you need to document your preferences. Communicating your choices ahead of time can help clinicians select treatments that match your values.

Key Question

Have prior experiences left you with a clear sense of how you would want things to happen? Have some treatments works better or been more comfortable than others? If you were given a choice, what would you select? The answers to these questions are what you should document as your preferences.

Procedures (Surgical and Other)

What does Procedures cover?

Procedures cover surgical and other procedures performed to treat an illness or condition. This would cover operations and services which are performed to address or resolve a diagnosed problem. A procedure is performed to bring about a positive change in your physical state or condition. It does not include screenings or diagnostic tests. Tests and screenings are performed to generate additional information and are recorded in the Results section along with the associated results obtained.

Why are they useful in a PHR?

When dealing with a current illness, it can be very helpful to know what type of care you have received in the past. Knowing what treatments were successful or not, and the extent to which a prior treatment was successful, can help determine which activities may lead to positive health outcomes for a current problem.

Where do I get the information?

Medical records kept by physicians and hospitals will include listings of procedures that were performed on you. Insurance companies also keep records of the procedures performed on you that were billed by various providers. This is another section where it may be sufficient for you to simply summarize your historical information. Or your Procedures section may include a combination of information you recall, supplemented with certain more detailed pieces of information from other sources.

Key Question

For each procedure performed on me, what was the outcome? Was a problem removed from my list of Health Concerns as a result of the outcome of the treatment? Or, was the status of a problem changed?

Results (Tests and Screenings)

What does Results cover?

Results cover screening and testing done to diagnose a problem or monitor a condition. Results are the information produced by the test or screening. Results can be a measurement or a score, or they could be an interpretation like normal or abnormal. Results include information about the test or screening along with the results produced.

Why are they useful in a PHR?

Results provide important quantitative and qualitative information which can be tracked over time. The results from screenings and diagnostic tests help to diagnose problems or identify potential problems. Test results and screening information support the clinical thinking process and can reduce the time it takes to diagnose a problem. When previously collected information can be rapidly accessed and meaningfully presented, it supports proactive decision making as well as timely and efficient diagnosis.

Where do I get the information?

For each test you have undergone, results will have been generated. They may be documented in lab reports which have been incorporated into the medical records kept by your physicians. They may exist as notes

documenting the result of reading an imaging study or EKG report. Recording results at the point in time when a test takes place is much easier than trying to gather them in retrospect. Each time you have a test performed, make a mental note that results will need to be recorded. It may take a day or a week to get the results back, but fairly close to the time the test is performed, the results will become available. Documenting them at that point in time is the best practice.

Key Question

How have the results from your blood work changed or remained the same over the past 10 years? Are there certain results your doctor reviews with you each year? What are those measures? What does each measure mean about your health? What things can you do to affect the results? Was an interpretation rendered: normal or abnormal? Was a test result captured: a score, a count, or a percentage measure? If the procedure was a treatment, did it make a difference: positive or negative outcome?

Social History (and Other History)

What does Social History cover?

Social History covers other types of contextual information that are relevant to your health, but which are not necessarily considered part of a typical "medical history" or "family history". It includes information about social issues that have links to health such as smoking, sexual practices, occupation and industry, non-prescribed drug use and alcohol consumption, etc. Additional aspects of your relationships and experiences which c an relate to your health may also be noted in this section.

Why is it useful in a PHR?

Information captured in the Social History section of a PHR is often relevant to your overall health. It covers behavior choices which people have control over which can affect what risk factors are present or not. This information can also provide insight into possible connections between physical and psychological or social situations and your overall sense of wellness.

Where do I get the information?

If you are documenting Social History information for yourself, you have all the information you need. The challenge may be honest representation of what you know to be true. If you are helping someone else create a PHR, or making one for an elderly parent, you may need to be prepared for some challenging conversations about drug or alcohol usage or about relationship patterns that may impact health.

Key Question

How accurate is the information you document about yourself? Are there ways to confirm your accuracy? If you collect all the beer bottles and wine bottles from the alcohol you drank, and counted them at the end of a week, would it match the alcohol consumption numbers you reported in your PHR? Would the empty cigarette packs match the smoking quantity you recorded? Could there be a connection between when you have headaches, and when there has been a relationship problem or an issue at work?

Janie Appleseed

Support (and Care Team)

What does Support cover?

Support is a broad category that includes all the people who comprise your care team; your physicians, dentist, chiropractor, pharmacy, NOK (next of kin), emergency contact, religious leader, Home Care Agency staff person, Assisted Living staff contact, etc.

Why is it useful in a PHR?

Documenting the contact information for all the members of your care team in your PHR ensures that you always have easy access to needed care. As PHR technology evolves it will become easier to manage your information consents to control access to your information. Sharing information across the team will be easier and will be able to occur simultaneously.

Where do I get the information?

Begin by making a list of all your doctors, then add other people you consider part of your care team. The list might include a religious leader or a life-coach or counselor. The list should include your emergency contacts and a next of kin. For an elderly individual this list might include a home care companion or a visiting nurse.

Key Question

How many contacts are on your support team, helping you stay healthy from day to day and year to year? How many of them keep information about you, because of their interactions with you, which you would consider to be helpful to have in your own PHR?

Vital Signs

What do Vital Signs cover?

Vital Signs are physical observations that are directly linked to a person's functional status, such as blood pressure, pulse, weight, height, oxygen saturation rate, etc.

Why are they useful in a PHR?

Like results, vital signs provide a very valuable health indicator, especially when they are tracked over time. They can serve as a measure and a predictor of health, and can be used to spot important health trends. For example, a person working to manage a condition like diabetes may find that monitoring their weight helps keep their blood sugar results under control. Someone who adds a yoga practice to their Care Plan may find that when they attend yoga 3 times a week, their BP remains in their goal range, but when they don't do yoga their BP consistently remains above desirable levels.

Where do I get the information?

Vital signs are commonly documented in the medical records kept by doctors. The information is often shared verbally as it is collected. You can document the information in your PHR manually after collecting or hearing it. There are beginning to be devices available which collect information such as BP and weight and communicate it electronically to your computer system. As telecommunication health standards evolve, entering Vital Signs into your PHR will become more automated.

Key Question

If you drew a line-plot showing your weight over the course of your life, what would it look like?