



Assisting Patients in Developing and Maintaining Personal Health Records

A personal health record (PHR), otherwise known as a health profile or a health journal,¹ is the synthesis of a patient's medical, surgical, diagnostic, and therapeutic events combined with a record of his or her unique personal history. Ideally, the PHR is generated, revised, and annotated² by patients with the assistance of family members, caregivers, and providers (physicians, physician assistants, nurse practitioners, and pharmacists).

For decades, providers have utilized "problem lists," emanating from Weed's problem-oriented medical record system.³ The Joint Commission (formerly the Joint Commission on Accreditation of Healthcare Organizations) requires that institutions maintain problem lists for ambulatory patients. Although a patient's PHR and a provider's problem list are similar, they are not interchangeable, as certain differences do exist. For instance, for a problem list, providers tend to document considerable detail and organize past medical events according to their level of importance, risk, and severity. A problem list consists of the symptoms and questions the patient has, which comprise the agenda for the requested visit. A PHR, on the other hand, more closely resembles a travelogue of events. It includes the chronological listing of diseases, illnesses, and procedural encounters—outlining the medical history of a patient over time.

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In a national survey, almost two-thirds of respondents expressed interest in having online access to their personal health information,⁴ while past studies have found that patients can collaborate effectively with their primary care providers in modifying their problem lists.^{5,6} The purpose of this article is to provide a model framework for institutions, nurses, providers, and educators so that they may better assist patients in learning and applying skills for generating and maintaining their own PHR.

BENEFITS AND BARRIERS

Generating a PHR provides an opportunity for patients to take partial responsibility for their own care. The PHR can improve communication between patients and providers, especially when patients are in emergency situations, seeking care in new environments, or traveling. The PHR facilitates a mutual exchange and validation of information, fosters collaborative decision-making, lessens unnecessary test duplication, and has the potential to decrease patient risk. The PHR serves as a resource for providers, institutions, caregivers, and surrogate decision-makers.^{7,8}

Despite the many advantages of generating and maintaining PHRs, many patients become frustrated with the process (especially when entering and revising their information)⁷ since no reliable, user-friendly tutorials for this process are available. Selecting the best tool for establishing a PHR can be a daunting task, owing to the myriad of available hard copy and online products. Additional barriers that prevent patients from creating PHRs

include patients' privacy concerns, the lack of universal software, and variability of provider communication and networking styles. However, these barriers are not insurmountable.

PRINCIPLES OF AN IDEAL PHR

Content, terminology, and brevity

There are several types of information that should be included in a patient's PHR. Although it is important to include information on personal medical history, it is also beneficial to have other relevant subjects detailed in the PHR, such as past employment or education experiences (Table 1). It is important for patients to be familiar with definitions and terms that are germane to the PHR, such as adverse drug event, diagnosis, and power of attorney (see Table 2 on page E1 at the end of this article). Reference sources for definitions can be found in many standard medical textbooks and dictionaries.

Patients and providers often differ in choosing labels for diagnoses, problems, systems, and areas. Providers are more likely to use medical terms (such as cardiovascular, respiratory, dyspnea, and syncope), whereas patients more frequently employ a more common language (using terms such as heart, lung, shortness of breath, and blackouts). The language used in each patient's PHR is a matter of personal preference. A PHR is truly an outline of key points, and it also should be easy to follow visually. Adhering to an outline format requires the omission of verbs, prepositions, articles, conjunctions, and acronyms.

Continued on next page

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Table 1. Components of a personal health record, in order of appropriate sequence

- Contact information
- Adverse drug events
- Medications
- Activities (habits, hobbies, physical, volunteer)
- Blood type
- Childhood diseases
- Diagnoses/problems (medical/surgical)
- Educational history
- Employment history
- Family history
- Immunizations
- Military service
- Procedures (medical, surgical, screening)
- Social history

Availability

Caregivers, emergency responders, specialists, and health care providers must have ready access to patients' PHRs. Ideally, all PHRs would be stored online or on external electronic devices. If a patient prefers a paper format for his or her PHR, a copy should be carried with personal effects and kept in a visible location in his or her home.

Organization

It is easier to enter and revise data (and track changes) on a PHR when using an alphabetical framework of systems and areas and a chronological order. Selected detailed descriptions of systems and areas^{9,10} and standard textbooks of medicine are excellent reference points for identifying those systems and areas that are appropriate for use, including cardiovascular, gastrointestinal, and immune

systems and areas such as genetics, infection, abdomen, and extremities (see Table 3 on page E2 at the end of this article).

Organizing a PHR is comparable to organizing a hand of cards. Card players often arrange their cards both numerically and by suit (clubs, diamonds, hearts, and spades). In a PHR, the system or area is the equivalent of the suit, while the chronological order is the equivalent of the numerical order. Chronological sequencing frequently yields patterns of cause

RESOURCES

A number of commercial,^{11,12} practice-based,² and public^{1,13,14} Web sites are available for the entry and storage of health-related information. Nearly all permit "cued" entry or "prompt" entry, while several permit "free text" entry. Many of the sites provide modules for the methodic collection and organization of pertinent personal health record information,^{7,11,15-17} including the family history¹⁸ as well as hard copy templates.¹⁹⁻²² However, in a review of public PHR Web sites,²³

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and effect. Hypertension typically precedes angina and myocardial infarction typically precedes congestive heart failure. Organizing a PHR according to a chronological order serves as a reminder that every disease has a beginning, middle, and current status (Table 4).

The category "miscellaneous" is neither a system nor an area, but it does have a place in the PHR, as some problems are nonspecific and cannot be placed under either umbrella term. For example, if a patient is experiencing shortness of breath, its cause may be undetermined at first. Is it cardiac? Is it pulmonary? Is it severe anemia? Over time, and with more clinical data, it might become apparent what (diagnosis, disorder, illness) is causing the difficulty breathing. To that end, the problem would move from being in the miscellaneous category (early) to being listed in a more appropriate area or system (later).

most were deemed inadequate for patients presenting with acute situations, and many sites merely represented electronic versions of PHRs in paper-based formats.

Security and legal liability issues also are concerns for PHR Web sites.^{24,25} Vendors and public agencies must guard confidentiality, as the public is rightfully unforgiving when violations do occur. However, both security and confidentiality were effectively addressed in almost 95% of the products in the above-mentioned review.²³

The challenge is to find an ideal model for gathering and collating information that is compatible with paper, word-processing, and online formats, as well as one that is user friendly in terms of level of understanding and data entry.²⁶ Paper format is grossly inefficient because of the inherent need to regularly revise PHRs. Current online formats are not substantially better since

many are code based according to the International Code of Diagnosis (ICD) and, therefore, are not problem or patient focused. While many products permit online, free entry, it is cumbersome to move data from one field to another. Software developers for PHR sites have not yet adopted the “click-and-drag” feature for moving entries that is found elsewhere online (such as on weather and sports Web sites). To increase usability, a model Web site should recognize both brand and chemical names of medications—even when misspelled—and it should list the medications alphabetically by both brand and chemical names.

MyHealthVet²⁷ is one site that has considerable potential as a model for generating and maintaining PHRs. This is not a surprise since, for decades, the VA has expected providers and informatics technology professionals to collaborate in developing its computerized patient record system (CPRS). Other prime examples are the publicly offered Google Health Web site,¹⁷ and the site known as KatrinaHealth, which was established to provide medication and dosage information for individuals affected by Hurricane Katrina.²⁸ The KatrinaHealth site is secure, and it allows providers, including pharmacists, to have nationwide access to the health and medication data of evacuees.²⁹

RECOMMENDATIONS FOR PATIENTS

Obtain medical records

Patients can begin creating their PHRs simply by trying to recollect their personal medical history. Collaborating with a family member also can be productive. Although the provider, practice, clinic, hospital, surgical center, or nursing care facility are legally the rightful owners of the information in medical records, patients have an

Table 4. Examples of chronological listing in personal health record for 1 body area and 1 system

Area—breast	
Right breast biopsy—cyst	1980
Left breast mastitis—nursing	1984
Right breast biopsy—fibrocystic adenoma, benign	1996
Yearly mammogram—last study, negative	2009
System—cardiovascular	
Father died (age 32 years)—heart attack	1955
Intermittent high blood pressure	1982
High blood pressure—treatment started	1990
Mild heart attack	1996
Heart catheterization—blockage 2 arteries	1996
Heart by-pass (CABG)	2000
Congestive heart failure	2004
CABG = coronary artery bypass graft.	

ethical and legal right to the information.³⁰ In general, discharge summaries, operative reports, procedures, and pathology reports possess a higher degree of specificity than records from routine visits. Although health care providers may have some reservations, patients should be provided a copy of the problem list from their medical record. Ideally, the content of the problem list and PHR should be very similar, despite the use of different terminology.

Review medical records

Medical records contain useful information for patients, not only for generating PHRs but also for learning more about their health problems (even if they are unclear about the meaning behind some of the included terminology). Patients should dedicate several time-limited sessions to list as many problems, diagnoses, or health events and interventions as possible.

Choosing to use only chemical names or only brand names of medications can provide consistency,

although it is not essential. Arranging medications in alphabetical order is strongly recommended as it simplifies the process for patients and providers when they attempt to reconcile their respective lists (see Table 5 on page E3 at the end of this article).

Revise and update frequently

A PHR is outdated the moment a patient leaves the provider's office. Patients frequently present with symptoms for which the cause may not be readily apparent. Over time, and with additional diagnostic testing, a more specific disease, disorder, or pathologic finding may explain a symptom. What was labeled as back pain on first presentation could be labeled as degenerative arthritis after x-ray or lumbar stenosis after computed tomography scan of the lumbar spine.

There also may be times when it may not be readily apparent where a certain health problem or event should be included. It is personal preference, and it is perfectly acceptable to list a problem under more than 1 category (Table 6). To keep

Table 6. Example listing of diagnoses/problems in more than 1 location

Diagnosis/problem	System	Area	Procedure
Colonic diverticular abscess	Gastrointestinal	Infection	Surgical
Tendon repair knee	Musculoskeletal	–	Surgical
Urinary tract infection	Urology	Infection	–
Cardiac angiogram	Cardiovascular	–	Medical
Premature death (father heart attack)	Cardiovascular	Family history	–

them current, patients should present their PHR to their provider at each visit. The PHR represents a nonverbal cue that should be acknowledged and acted upon by the provider. For example, data support the fact that providers do respond to cues relating to diabetic foot care^{31,32} and treatment of heart failure.³³

LOOKING AHEAD

PHRs empower patients and allow them to become more proactive in their health care. They have many advantages, as when PHRs are imple-

mented they engage providers, foster collaboration, improve communication, decrease risk and duplication of care, and potentially ensure better outcomes. An overview of the value, content, and principles of PHRs, as well as mechanisms to obtain pertinent information, can be addressed in orientation booklets and seminars as patients make initial contact with their respective health care plans. VA providers can incorporate their own problem lists into the after-visit summary of instructions, medication changes, and upcoming appointments. Sharing such information is consistent with project “Open-Notes,” the multicenter initiative in which primary care providers invite their patients to read online notes.³⁴

There are several priorities for the future. Performing a comprehensive assessment of available products with established criteria should identify those resources that are user friendly

as examples of “meaningful uses” of electronic records would allow health care institutions to acquire funding as part of the federal economic stimulus program. Finally, providing patients with positive incentives for implementing PHRs will encourage and reward their efforts (such as redirecting a portion of a patient’s monthly premium dollars into a health savings account or discounts for medications and fitness activities). The implementation of PHRs into the health care system, although not yet perfected, is an important work in progress. ●

Capitalizing on PHR patient initiatives as examples of “meaningful uses” of electronic records would allow health care institutions to acquire funding as part of the federal economic stimulus program.

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for patients to access and employ. Establishing standards for definitions, categories, systems, and areas would promote a universal language more easily understood by all parties. Conducting research regarding methodologies for engaging patients would identify the best strategies to assist in developing and maintaining PHRs. Capitalizing on PHR patient initiatives

combinations—including indications, contraindications, warnings, and adverse effects—before administering pharmacologic therapy to patients.

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Continue reading for Tables 2, 3, and 5, available exclusively online



Table 2. Component/category and definitions relevant to patients' understanding of their personal health record

Component/category	Definition
Advance directive	Instructions from a patient to a designated authorized third party and his or her health care providers specifying health care actions to be taken if the patient is no longer able to make his or her own decisions
Adverse drug event	Any expected occurrence from a drug that is exaggerated, dramatic, or profound (for example, excessive hypotension from antihypertensive medication)
Allergy	Any (or several) of the following: rash, hives, itching, welts, local swelling, tongue swelling, shortness of breath, airway blockage, wheezing, low blood pressure, blackouts
Area	Anatomical region of body; unique medical topic
Category	Component part of public health record
Chronological order	Using dates (past to present) to list diagnoses, disorders, problems within an area or system
Contact information	Names, addresses, phone numbers, and e-mail addresses of family members, health care providers, and insurers
Diagnosis	Specific label that explains a symptom, sign, or laboratory finding
Disorder	Physiologic disturbance of a system or organ
Medications	Brand name or chemical/generic name; prescription and nonprescription; nonprescription (over-the-counter and herbals)
Living will	Document directing one's health care providers to administer or restrict certain types of care if the patient's condition is incurable, irreversible, or terminal
Power of attorney	Legal authorization to act on someone else's behalf in matters of health care and/or finances
Problem	Symptom or sign not yet labeled with specific diagnosis, due to insufficient information; nonspecific, meaning more than one diagnosis might be considered causative
Procedure (medical/surgical)	Any diagnostic test or therapeutic maneuver with removal of tissue or without removal of tissue
Procedure (screening)	Any diagnostic test offered/recommended for a specific population for a generally common disease that is deemed preventable and treatable
Sign	Physical finding or laboratory finding with some degree of diagnostic significance
Symptom	A subjective concern or symptom report of a patient
Syndrome	Distinct set of findings, which, taken together, explain a certain clinical entity or organ system dysfunction
System	Organ and component parts of an organ with designated function

Table 3. Systems and areas**Systems**

- Cardiovascular (heart, aorta, arteries, veins)
- Gastrointestinal (mouth, esophagus, stomach, intestines, rectum, anus)
- Hematological (blood forming red cells, white cells, platelets)
- Hepatobiliary (liver, gallbladder, pancreas)
- Immune (lymphatics, lymph nodes, spleen)
- Metabolic, endocrine, and hormonal (pituitary, thyroid, ovaries, testes, adrenals, pancreas, diabetes mellitus, lipid disorders)
- Musculoskeletal (bones, bursa, ligaments, muscles, tendons)
- Neurological (brain, spinal cord, nerves)
- Pulmonary/respiratory (mouth, nose, sinuses, trachea, bronchi, lungs)
- Renal/urologic (kidney, ureter, bladder, urethra)
- Reproductive (men) (testes)
- Reproductive (women) (ovaries, fallopian tubes, uterus, cervix, vagina)

Areas

- Abdomen (intestines, liver, gallbladder, groin, pancreas, kidney, bladder, ovaries, umbilicus, uterus)
- Breast
- Chest (heart, esophagus, lungs, ribs)
- Dental (teeth, gums, mouth)
- Environmental (drugs, poisons, toxins, venoms)
- Extremities (arms, legs)
- Genetics (genes, chromosomes)
- Genitals (testes, penis, labia, clitoris)
- Head (ears, eyes, nose, throat)
- Infection (any organ)
- Mental Health (any disorder or entity)
- Neck (thyroid, lymph nodes, carotid arteries, cervical spine)
- Neoplasm (any organ)
- Skin

Table 5. Example personal health record listing of brand names organized alphabetically

Brand name	Chemical name	Instructions	Reason
Aspirin	Acetylsalicylic acid	81-mg tablet daily	Thin blood
Gingko biloba	Gingko biloba	40-mg tablet, 3 times per day	Memory
Minipres	Prazosin	1-mg tablet in evening	Prostate
Multivitamins	Multivitamins	1 tablet daily	Supplement
Paxil	Paroxetine	20-mg tablet, 2 times per day	Depressed mood
Synthroid	Levothyroxine	0.1-mg tablet daily	Low thyroid
Tenormin	Atenolol	100-mg tablet daily	Blood pressure
Zantac	Ranitidine	2 150-mg tablets, 2 times per day	Heartburn
Zocor	Simvastatin	40-mg tablet in evening	Cholesterol