Electronic Personal Health Records

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What is Health Information Technology?

Health information technology (HIT) provides the umbrella framework to describe the comprehensive management of health information and its secure exchange between consumers, providers, government and quality entities, and insurers. HIT is in general increasingly viewed as the most promising tool for improving the overall quality, safety and efficiency of the health delivery system. Broad and consistent utilization of HIT will:

- Improve health care quality
- Prevent medical errors
- Reduce health care costs
- Increase administrative efficiencies
- Decrease paperwork
- Expand access to affordable care
- Increase personal accountability and tracking of information

HIT makes it possible for health care providers to better manage patient care through secure use and sharing of health information. HIT includes the use of electronic health records (EHRs) instead of paper medical records to maintain people's health information. (Terry, Gunter, 2005)

Improving Patient Care

With the help of HIT, health care providers will have:

- Accurate and complete information about a patient's health. That way they can give the best possible care, whether during a routine visit or a medical emergency
- The ability to better coordinate the care they give. This is especially important if a patient has a serious medical condition
- A way to securely share information with patients and their family caregivers over the Internet, for patients who opt for this convenience. This means patients and their families can more fully take part in decisions about their health care
- Information to help doctors diagnose health problems sooner, reduce medical errors, and provide safer care at lower costs

Widespread use of HIT can also:

- Make our health care system more efficient and reduce paperwork for patients and doctors
- Expand access to affordable care
- Build a healthier future for our nation
- Promote development of a nationwide HIT infrastructure that allows for electronic use and exchange of information that:

  - Ensures secure and protected patient health information
  - Improves health care quality
  - Reduces health care costs
  - Informs medical decisions at the time/place of care
  - Includes meaningful public input in infrastructure development
  - Improves coordination of care and information among hospitals, labs, physicians, etc.
  - Improves public health activities and facilitates early identification/rapid response to public health emergencies
  - Facilitates health and clinical research
  - Promotes early detection, prevention, and management of chronic diseases
  - Promotes a more effective marketplace
  - Improves efforts to reduce health disparities
- Provide leadership in the development, recognition, and implementation of standards and the certification of HIT products
- Facilitate strategic planning for HIT adoption and health information exchange

HIT in California

Achieving electronic health information exchange (HIE) through the application of health information technology (HIT) is one of the cornerstones of the overall healthcare reform strategy in California. Effective application of HIT and the implementation of interoperable HIE are key strategies to achieve the goals of better health care outcomes, efficiencies in the delivery of healthcare, and strengthening emergency and disaster response preparedness.

The California Health and Human Services Agency (CHHS) serves as the lead agency on HIE and HIT issues for the State. CHHS works with the State Chief Information Officer (OCIO), the Department of Managed Health Care, the Business, Transportation and Housing Agency and others to oversee the State's HIE and HIT related efforts.

California eHealth Purpose

To dramatically improve safe and secure patient and provider access to personal health information and decision-making processes, benefiting the health and wellbeing, safety, efficiency, and quality of care for all Californians.

California eHealth Objectives

1) To ensure patients have safe, secure access to their personal health information and the ability to share that information with others involved in their care

2) To engage in an open, inclusive, collaborative, public-private process that supports widespread EHR adoption and a robust, sustainable statewide health information exchange

3) To improve health care outcomes and reduce costs

4) To maximize California stakeholders' access to critical ARRA stimulus funds

5) To integrate and synchronize the planning and implementation of HIE, HIT, telehealth and provider incentive program components of the federal stimulus act

6) To ensure accountability in the expenditure of public funds

7) To improve public and population health through stronger public health program integration, bio-surveillance and emergency response capabilities

More information can be found at:
http://www.ehealth.ca.gov/

Background on Personal Health Records

Two groups of health care stakeholders are in favor of personal health records (PHRs): purchasers and policy makers. Purchasers want to reign in costs while preserving or improving quality of care to ensure optimal worker productivity. Employers can match PHRs to health risk assessment results, which serve as a funnel into disease prevention programs, hoping that investments in PHRs will be returned in health care savings and improved worker productivity. Some cite increases in employee health awareness and participation in wellness programs as early measures of success (Wynia and Dunn, 2010).

Policy makers are also interested in PHRs. They hope that the PHRs can bring radical improvements in efficiency and quality of care. A 2008 study by the Center for Information Technology Leadership projects that the U.S. could save as much as $21 billion a year if 80 percent of the population were to use PHRs. A report by the National Committee on Vital and Health Statistics credits PHR systems with more than 30 benefits, including the ability to strengthen disease prevention, improve population health, and expand health education opportunities (Wynia and Dunn, 2010).

There are a variety of uses for a PHR. First, it promotes communication, including scheduling appointments, receiving testing or treatment instructions, asking questions, and renewing prescriptions. Improving communication may be of greatest interest to someone with a chronic illness, such as a mental disorder. Second, it promotes data use. The data in PHRs can be useful of tracking diseases across populations, for quality control, and for marketing. Third, the

PHR increases patient responsibility, empowering patients to serve at “stewards” of their own health data and increasing patient engagement in managing their own health care. PHRs can deliver teaching materials, clinical prompts, and other management tools (Wynia and Dunn, 2010).

There are several ethical issues associated with PHRs. The first related to confidentiality. PHRs are not subject to HIPAA protections. Organizations are advised to take several steps to protect patient privacy. These include patient education about privacy protection and their benefits, informed consent, polices, complaint procedures, opt-out provisions, vendor practice audits, and participation in national programs. “Patient Privacy Rights” (found at http://www.patientprivacyrights.org) offers a toolkit that addresses many of these topics, including consumer-providers discussions. Another resource for consumers and providers is the World Privacy Forum, (http://www.worldprivacyforum.org), which recommends regular medical record and payment review to counter medical identity threats and theft (Fetter, 2009)

Another ethical issue relates to access to PHRs. Those without computers or who are less comfortable using them, and those with lower levels of literacy, lower levels of trust in medicine or medical technology, and who do not speak or write English all may be less able to take advantage of PHRs. PHR-based educational materials should be designed to meet the needs of low literacy and non-English speaking populations. Special communication strategies should be used to promote use of these tools among diverse populations.

What is a Personal Health Record?

Personal health information is a valuable resource to clients, families, and healthcare professionals who provide treatment and care. What many people do not realize is that, in most cases, a complete record of all of their personal health information can not be found in any single location or consistent format. The more complete and accurate health information is the better tool it is to help play an active role in the quality of healthcare. In a medical emergency, quick access to health information is vital. A PHR can reduce or eliminate duplicate procedures or processes, and save valuable time and healthcare dollars.

The PHR is a tool that can collect, track and share past and current information about a patient’s health or the health of someone in their care. Sometimes this information can save money and the inconvenience of repeating routine medical tests. Even when routine procedures do need to be repeated, a PHR can give medical care providers more insight into the personal health story of the patient. The patient is ultimately responsible for making decisions about their health. A PHR can help accomplish that.

Important points to know about a Personal Health Record:

- A patient should always have access to their complete health information.
- Information in a PHR should be accurate, reliable, and complete.
- The patient should have control over how the health information is accessed, used, and disclosed.
- A PHR may be separate from and does not normally replace the legal medical record of any provider.

Medical records and PHRs are not the same thing. Medical records contain information about health compiled and maintained by each of the healthcare providers. A PHR is information about health compiled and maintained by the patient. The difference is in how the PHR is used to improve the quality of healthcare.

The specific content of health record depends on the type of healthcare received. Listed below are documents common to most health records and additional documents that accompany hospital stays or surgery.

Reports Common to Most Health Records:

- Identification Sheet – A form originated at the time of registration or admission. This form lists name, address, telephone number, insurance, and policy number.
- Problem List – A list of significant illnesses and operations.
- Medication Record – A list of medicines prescribed or given.
- History and Physical – A document that describes any major illnesses and surgeries, any significant family history of disease, health habits, and current medications. It also states what the physician found.
- Progress Notes – Notes made by the doctors, nurses, therapists, and social workers that reflect response to treatment, their observations and plans for continued treatment.
- Consultation – An opinion about the condition made by a physician other than a primary care physician. Sometimes a consultation is performed because a physician would like the advice and counsel of another physician.
- Physician's Orders – Physician's directions to other members of the healthcare team regarding medications, tests, diets, and treatments.
- Imaging and X-ray Reports – Describe the findings of x-rays, mammograms, ultrasounds, and scans. The actual films are maintained in the radiology or imaging departments or on a computer.
- Lab Reports – Describe the results of tests conducted on body fluids. Common examples include a throat culture, urinalysis, cholesterol level, and complete blood count (CBC). Surprisingly, a health record does not usually contain a blood type. Blood typing is not part of routine lab work.
- Immunization Record – A form documenting immunizations given for disease such as polio, measles, mumps, rubella, and the flu. Parents

should maintain a copy of their children's immunization records with other important papers.
- Consent and Authorization Forms – Copies of consents for admission, treatment, surgery, and release of information.

Additional Reports Common to Hospital Stays or Surgery:

- Operative Report – A document that describes surgery performed and gives the names of surgeons and assistants.
- Pathology Report – Describes tissue removed during an operation and the diagnosis based on examination of that tissue.
- Discharge Summary – A concise summary of a hospital stay, including the reason for admission, significant findings from tests, procedures performed, therapies provided, response to treatment, condition at discharge, and instructions for medications, activity, diet, and follow-up care.

Records may contain some or all of the forms above. Depending upon the illness or injury, the services of an emergency room, intensive care unit, a physical therapist, or home health nurse may be utilized. Often these specialized services have unique evaluation, measurement, and progress forms that may also be in the health record.

Most literature on PHRs focuses on medical conditions as opposed to mental illnesses. However, PHRs are very applicable to managing a mental illness. Physician visits to psychiatrists and visits to other mental health care providers can be tracked. Psychotropic medication can be recorded as well as laboratory tests. Advanced Directives and Wellness Recovery Action Plans can also be posted to PHRs.

A patient can play a more active role in their healthcare. Research has shown that when consumers actively participate in their own care, the outcomes are better. Using a PHR to assist with decision-making when it comes to potential health conditions, treatment options, costs of treatment, management of chronic conditions, healthy lifestyle choices, preventive actions, and monitoring the accuracy and security of health information are a goal of PHR.

Chances are that patient has a lot of different medical records. They may see many different healthcare providers during their lifetime such as a family practitioner, a psychiatrist, an allergist, a specialist such as a cardiologist, and if necessary, a surgeon. Each of these providers compiles a separate file of information. In fact they each may keep a separate medical record and may not be aware of the other treatment. This can lead to an incomplete and disconnected record of health. This is why a PHR is important.

What kind of information should be kept in a PHR?

A PHR should store the personal and health information patients wish to keep in one place so that it can be looked at it and shared with providers, caregivers, and family members. A PHR should have current personal information, including name, birth date, and address. It should also allow entering special information that is important, such as:

- Names and phone numbers of people who should be contacted in case of emergency
- Names, addresses, and phone numbers of doctors, including specialists and dentists
- Health insurance information, like the name of the insurance company and key phone numbers for service
- Current medications and dosages
- Allergies (to foods, drugs and other substances)
- Important events, dates, and hereditary conditions in the family history
- A list and dates of significant illnesses and surgical procedures
- Results from recent doctor visits
- Important tests results; eye and dental records, immunization records (if the PHR is provided by a doctor or hospital, or it can be entered by the patient)
- Any information that the patient might want to include about their health - such as any exercise regimen, any over-the-counter or herbal medications that are taken and any counseling received.

How to find and choose a PHR?

There are many types of PHRs available. Doctors offer some PHRs, and independent companies who create and maintain these tools on the patient's behalf provide others. The patient might be able to get health information from your doctor or health plan if you give them appropriate permission.

To choose a PHR, here are some questions to ask:

- What kind of information can be stored in the PHR, such as medical conditions (diagnoses), procedures, allergies, medications and other personal information?
- Can the PHR import claims or medical information from health plans and/or doctors?
- What kinds of features does the PHR offer, such as the ability to print a list of medications or conditions?
- Can permission be given to doctors or family members to look at the PHR?
- What kinds of links does the PHR offer for health education information?
- If a doctor offers a PHR can prescriptions be refilled through the tool? Or can appointments be scheduled?

- Is there a monthly or annual fee to use the PHR? Is there a cost for the features chosen?
- What will happen to information if the patient leaves the health plan that offers or if doctors are changed?
- What will happen to information if the company that provides the PHR goes out of business or becomes part of another company?
- What are the PHR's privacy and security policies?

If a doctor or health plan does not offer a PHR today, the availability from other companies can be checked at www.myPHR.com .

How to create a PHR?

Some PHRs are created and updated by the health plan or provider. Other PHRs let the patients enter information. Some PHRs have some data from the plan or provider, and allow adding more information from the patient. If a patient decides not to use a PHR that is sponsored by their health plan or provider, a patient can still select a “stand-alone” PHR tool, and the patient will have to enter all of the information. The process is started by entering the information that already known, like personal information, medications, and doctors' names. It is important to update the information regularly and share it with doctors during appointments.

What other PHR resources are available?

- MyHealthVet - This is a personal health record specifically designed for, and used by, Veterans. It is a comprehensive and interactive tool for diagnoses, procedures and medications, including refill requests.
- myPHR - This website is provided as a free public service by the American Health Information Management Association (AHIMA). It provides comprehensive information about personal health records.
- American Heart Association - In addition to comprehensive information about heart health, in 2007, the American Heart Association launched the Blood Pressure Management Center, an online health management tool that was built on HealthVault - the Microsoft Corporations consumer health platform. Blood Pressure Management Center will allow consumers to track their health information online to help better manage their risk for heart disease and stroke, with an initial emphasis on managing high blood pressure.
- MyMedicare.gov - MyMedicare.gov is an internet portal allowing registered beneficiaries the ability to view claims, enrollment, deductibles, and address of record information. You can also choose a Part D Prescription drug plan from MyMedicare.gov. You can also download your data to your own computer, using the new Blue Button feature.
- Centers for Control Disease and Prevention - The CDC provides comprehensive information about many health issues, and is a good tool for researching certain conditions.

- National Health Council - The Council works with organizations across the country to find ways to improve health and health care for all people, particularly those with chronic diseases and/or disabilities.

Companies Providing PHRs

FollowMe

The right information at the right time…
Testimony from the founder of 'FollowMe'.
'*If you've ever had a family member or loved one suffer a serious or catastrophic illness, you know the overwhelming sense of helplessness, that tight knot in your gut each time there is a crisis. For millions of Americans who suffer from a chronic condition, having instant access to their medical information when they need it is critical – it can even be a matter of life and death.*

When my son Alex was 7, he was diagnosed with a brain lesion that resulted in hydrocephalus. Over the years, Alex has had nearly 20 brain surgeries and hospitalizations. Today, just by looking at Alex, you would not know that he has two shunts implanted in his brain that drain off cerebral spinal fluid. If these shunts should block or break Alex could go into a coma, suffer brain damage or even die. He also has allergic reactions to several antibiotics.

For years I was the keeper of Alex's medical information, storing his records and scans in boxes and keeping them ready in the trunk of my car. I soon learned it was my task to coordinate his care, making sure that each of his doctors had all the information from the several other doctors treating him. At one point, Alex was under the care of five different specialists in different locations. Since then, some of his doctors have retired, while others have moved to other locations, leaving his records behind.

For years, I constantly lived with the fear that Alex might have a medical emergency and I wouldn't be there to help him. That fear hit home in 1999 when Alex landed in an emergency room in a small rural hospital out of state.

When I got that late night call, I spent a long time trying to explain Alex's complex condition, his allergies, his shunts and recent medical treatment. I was terrified that they would do something that would cause harm to Alex or make things worse. Lucky for us, the situation turned out ok.

The FollowMe PHR was born out of desperation to keep my son safe. We developed a personal health record that could be accessed anytime by Alex, his family, his doctors or emergency teams. It only made sense.' (Solomon, 2000)

Everyone should have access to their important health information 24/7. We are told everyday that medical errors may kill or maim us or our loved ones. And, that

access to accurate and timely information is the key to eliminating many of those errors.

2010 marks the 10th anniversary of FollowMe. Today, the idea of allowing consumers to have access to their medical information and to transmit and receive information electronically from their PHR to their physicians and hospitals is becoming an “expectation” of consumers. FollowMe is working at the technical and policy level to keep the “consumer” as the focus in accessing and exchanging health information. Several of their products now link providers and patients with a shared network while others have very rigorous permission and consent tools.

The vision as we move to a new decade is – consumers accessing their own health information from multiple sources, including doctors’ offices, hospitals and health systems and easily managing that information at their fingertips, with the ability for them to share that information electronically with high-level security assured by appropriate consumer-controlled permissions and consents.

MiVIA™

MiVIA™ was launched in 2003 as a personal health record for migrant and seasonal workers in Sonoma Valley, California. Today MiVIA™ provides an electronic record for several thousand people and their families across the country. The program has expanded opening the door for other populations with special or unique needs. It is especially useful for people who have no insurance, who have chronic medical conditions and/or who access care from many different providers or locations.

MiVIA™ is increasingly being adopted by clinics, mobile medical units, rural hospitals and practices as a simple easy-to-use and cost effective electronic medical record (EMR) connecting providers serving MiVIA™ members and each other.

Program History

Using Technology to Improve Health for Agricultural Workers

MiVIA™ (My Way) was designed as a collaborative effort of Vineyard Worker Services, St. Joseph Health System- Sonoma County and Community Health Resource & Development Center in 2002. Since then, these community based organizations have worked closely to help improve the quality of life and health conditions of farm workers living and working in the Sonoma Valley and beyond.

Migrant and seasonal farm workers and mobile population groups suffer disproportionately from undiagnosed and/or unattended chronic medical

conditions due to a lack of continuity of care resulting from a transient lifestyle. This fragmentation of care contributes to poor health outcomes and increased costs. MiVIA™ offers a solution. MiVIA™ is an electronic and therefore transportable, Personal Health Record (PHR). The ability to store and download critical health information such as diagnosis, medications, allergies, chronic conditions, treatment plans and test results will support continuity of care, enhance health outcomes and decrease duplication of services.

Each member's PHR is password protected, using 128 encryption and is HIPAA compliant providing audit trails, secure messaging and provider entry portals. MiVIA™ allows patients, or any advocate whom they authorize, to download their information at any time or to have the information downloaded by a health care provider.

MiVIA™ was initially funded by the Rural Community Assistance Corporation (2002-2004) and the California Endowment (2005-2006).

Purpose Statement

The MiVIA™ personal health record (PHR) was created for mobile people for the purpose of storing and downloading health information and for the purpose of being able to share that information with multiple doctors and clinics. This is especially important for people who go to many health clinics, move frequently or have serious medical conditions and see many health care providers. Every year thousands of people get sick or even die because of medical mistakes. Many times these mistakes happen because the doctor or the hospital does not have enough information or the right information about a person's medical history. The ability to store health information such as diagnosis, medications, allergies, immunizations, chronic conditions, implanted devices, and test results can help improve the healthcare you receive and can also help avoid getting duplicate tests which can save you, as a MiVIA™ member, time and money.

How to Use MiVIA™

MiVIA™ is very simple to use. Once enrolled as a member the patient will receive a login and password. They can enter information about their health at any time. MiVIA™ also has family accounts so that a patient can register either as an individual or as a family and manage up to 8 family member's records.

MiVIA™ members also receive an Emergency Identification Card that list emergency contacts, medical conditions and any medications or allergies. These cards can be printed at any time when such information is updated or changed and can be given to schools, teachers, carried in wallets, stored in the car glove box, or given to other family members.

A patient can share information with their doctor or clinic in three ways. (1) They can print out a summary report of their MiVIA™ record and present it to the doctor, (2) they can give them the login and a special password and they can view the information and add to it, (3) your doctor or clinic can also sign up as a MiVIA™ Network Provider and view and enter information into the record, with permission by the patient, securely.

My HealthVet

My HealthVet (http://www.myhealthvet.va.gov) is an integrated PHR that includes health information entered by Veterans, data from the Veterans Administration unified EHR, health education information, health management tools, and links to other resources. There are three levels of MHV access with a progressive increase in functionality. First, portions of MHV can be accessed by anyone with an Internet connection. Second, veterans can create an account by performing an online registration, which provides them with functions not available to the general public. Third, veterans who choose to complete a onetime in-person authentication (IPA) can also view a growing array of additional information extracted from the VA EHR. Functions of the MHV include:

- Personal health history
- Family health history
- Medical events
- Health calendar
- Tests
- Medications
- Prescription refills
- Allergies
- Immunizations

MHV has been visited over 28 million times, more than 810,000 people have registered (16.3% of veterans currently receiving VA healthcare services) and over 130,000 veterans have completed the IPA process (Nazi et al., 2009)

For more information, please visit any of these sites:

- http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__home/1204
- http://www.allhealth.org/issues.asp?wi=4
- http://www.va.gov/bluebutton/
- http://www.myphr.com/
- http://www.cms.gov/EHRIncentivePrograms/30_Meaningful_Use.asp

- http://www.nlm.nih.gov/medlineplus/personalhealthrecords.html
- http://www.followme.com/
- http://www.myphr.com/your_record/what_include.as[
- http://www.markle.org/archives/library/
- http://www.cchit.org/phr/

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