Personal Health Record (PHR) Keeping

Introduction

There has been a recent trend that patients adopt a proactive stance toward collecting and organizing their own medical information. Emerging software applications allow patients to enter information abstracted from medical records into files stored on personal computers. On the other hand, the Internet also profoundly influences the delivery of health care in the 21st century by changing the loci and ownership of the record, from one that is distributed amongst the various health care providers to one that is accessible from anywhere in the world and under the shared ownership and control of the patient and his/her provider(s). Current implementations of these records fall into one of three arbitrarily defined and named categories: personal health records, electronic medical records, and personal health profiles (Sittig, 2002).

Personal health records (PHR) are created and maintained by an individual patient or healthcare consumer, based upon his/her own understanding of his/her health conditions, medications, laboratory tests, diagnostic studies, problems, allergies, vaccination history, etc. It can be PC-based as well as Internet-based. Useful features of PHR include the ability to enter and record important health events, calculate health risk indices, do simple medication interactions, and perhaps print a copy to take to the physician’s office or on vacation. Such records can help patients concisely explain their health problems when meeting with their doctors. In addition, they can help documenting information that may be useful when filing health insurance claims.

Electronic medical records (EMR), or electronic health records (EHR), or electronic patient records (EPR), are a sub-set of the physician's actual medical record as maintained in an electronic record format, which is created on the Internet by the provider in a secure web site and shared by patient and physician alike. Features of the internet-based record not only include all of those of the PHR, there is also the ability for the patient to communicate with their providers, request prescription refills and appointments, view a sub-set of the true medical record, see who has accessed the EMR (audit report). Patients can also use EMR to serve various electronic commerce requests such as prescription fulfillment at an Internet pharmacy, and perform highly personalized and tailored information retrieval for themselves based on their diagnoses and medications or interests. Other services, such as automated claims submission and coordination, etc, are also available at the fingertips of the patients.

Personal Health Profiles are medical knowledge-based characterization of a user of a medical information service. Such a technology facilitates convenient and personalized access to knowledge produced by medical practice—the primary knowledge construction process. Therefore, a personal health profile enables exchange, debate, and reasoning about personal experiences with disease and the health care system as a secondary knowledge construction process. Users can also be directed to specific chat rooms and message boards where patients
and caregivers debate and exchange information regarding their personal experiences with disease and health care.

Regardless of the individual difference, these three types of records are all ‘electronic’ and ‘shared’ health records. They work together to build a shared care setting, in which electronic healthcare records are functioning and benefiting all of the possible users, ranging from physicians-specialists and general practitioners, nurses, health managers, public health authorities and epidemiologists, researcher, and ultimately the patients. Due to the broad scope and great importance, the EMR is most heavily studied among the three types. In this review, however, we will focus more on the PHR and mainly discuss its development in the United States.

PHR Researches

As mentioned before, most current researches of electronic medical records focus on EMR rather than PHR. As such, it is still difficult to find literatures that directly discuss PHR. However, as the issues discussed in many EMR researches are essentially common to all types of electronic medical records and not exclusively to EMR, the opinions and insights offered by these EMR researches shed light on the developments of PHR as well.

The current researches of electronic medical records focus on three aspects: communication, security, and utility/interface.

Communication

Fig. 1

Fig. 1 (Sittig, D. F., 2002) illustrates several of the key actors and the relationships that are possible in the current shared health setting or the e-health environment. With the power of PHR, the patient becomes the center of the setting. Actors communicate with each other via shared electronic personal health records. As addressed in many studies, how widely electronic health
records can be implemented largely depends on how effectively these records can facilitate smooth communication between the various actors in the shared health setting. Communication functionality becomes a big concern of various electronic health records, especially for clinical EMR.

This concern for communication is twofold. First, the sources of electronic medical information that currently exist (e.g., laboratory data, pharmacy data, and physician dictation) reside on many isolated islands that have been very difficult to bridge, as can be seen in Fig. 2 (McDonald, C. J., 1997). Each island system contains different data, different structures, and differing levels of granularity, and each uses a different code system to identify similar medical concepts.

Too Many Different Separate Systems with Different Data Structures

| Admission discharge/billing* |
| Anesthesia systems          |
| Cytology systems*           |
| Diagnostic image management system |
| EKG carts containing EKG measures* |
| Endoscopist systems         |
| ER systems                  |
| Home care systems           |
| Intensive care monitoring systems |
| Intravenous fluid infusion control |
| Laboratory systems*         |
| Nurse triage                |
| Order entry systems*        |
| Outpatient pharmacy drug dispensers |
| (Baker’s cells)             |
| Pharmacy robot drug dispensers* |
| Pharmacy system*            |
| Pulmonary function system*  |
| Radiology system            |
| Risk management             |
| Scheduling and clinic charge systems |
| Surgery scheduling (surgery logs) |
| Transcription systems       |
| Unit dose dispensing machines* |
| Ventilator management*      |

The solution to the first problem lies in the standards which the informatics community began to develop in the mid 80s: IP, HL7/ ASTM, DICOM, LOINC, SNOMED, and others developed by the medical informatics community. Standards provide the bridges to the many islands of electronic medical data so that the data can inexpensively be combined into an electronic medical record.

Second, we need to capture the free text data in a structured and computer-understandable form. The medical content can be captured in two distinct ways:

1. The most common and easy to implement method is free text data (or natural-language text) entry forms. See WebMDs current version of My-HealthRecord for an example of this type of application at: http://my.webmd.com/my–health–record. Unfortunately, data
captured via free text data entry forms can not be easily used by the computer in any clinical decision support system since the computer can not "understand" or interpret the meaning of the text entered.

2. The healthcare data can also be entered as ‘coded’ or ‘structured’ entries. See WellMed’s WellRecord for an example of this type of interface at: https://www.wellmed.com/wellmed/main/home.asp. In other words, the user enters items by choosing from a list of elements, or first enters a free text string which is compared to a dictionary of ‘allowable’ values and any ambiguous entries can be fed back to the user in a short list for final selection. However, these coded entries are more time consuming and requires the entire universe of data items from which the item will be chosen is relatively small. When there are much ‘unbounded’ free-text medical data is to be entered, this method may fail to function.

McDonald, C. J. (1997) pointed out that full coding of all medical record content will not be possible for the foreseeable future. This means we will have to live with a mixture of coded and free-text information. The challenge then is to find where to draw the line.

As for PHR, strategies to the second problem may vary, depending on the intended uses of future PHR applications. It is assumed that individuals can accurately categorize and prioritize their own medical information. But no documented studies have examined the question of whether this strategy is feasible or efficacious. If PHR is scaled back to provide limited medical history and prescription information, efforts might focus on methods of registering information. At the one extreme, providers might be asked to work with patients to supervise the creation of individual profiles. Other approaches might focus on abstraction of information from billing records or pharmacy databases. If PHR continues to be promoted as entities that mirror the full content of standard institutional records, challenges for refinement will be much greater. At a basic level, patients will need to be guided through the process of sorting through information to determine which elements warrant inclusion. Methods will need to be developed to verify the accuracy of entered information, and logical approaches might focus on optimizing user interfaces to increase accuracy (Kim and Johnson, 2002).

Security

Whenever electronic access to medical/health information is discussed, security issues are among the first ones raised because of concerns about the privacy and sensitivity of medical data. Security approaches designed for electronic commerce, a trade known for security weaknesses for limited financial liability, are not sufficient for personal health data, where the personal damage caused by unintentional disclosure may be far more serious.

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 is a federal legislation that is little known and even less understood outside the health care industry. The legislation’s original provisions focused on protecting the privacy and security of personal health records (PHR) and have been of great concern to CIOs in the health care industry. However, the provisions should also be of concern to non-health care organizations that maintain personal health records of their employees. HIPAA and privacy groups (such as HIEthics) provide a general expectation for protecting privacy.
To facilitate the analysis and design of health information systems, a layered security model has been developed which seems to be now established and well accepted. Fig. 3 describes the technical application security services on a level of higher granularity (Blobel, 2000). Any electronic health record security solution must fulfill the basic principles for open interoperable systems’ design, such as conservatism, minimality, simplicity, generality, relevance, flexibility, and scalability.

Standards for authorization / permission will become increasingly important. Systems that maintain patient-viewable data should comply with baseline permissions standards (e.g. patients should be able to withhold data that they consider sensitive, or enable read-only access). ‘Sensitive’ data is different for every patient, so enabling patients to establish item-by-item permission is important. Audit trail information standards applied to all systems that maintain patient viewable data would support privacy, by answering ‘who accessed or edited what data, and when?’ As illustrated by the Patient-Centered Access to Secure Systems Online (PCASSO), a research development and evaluation project funded by the US National Library of Medicine (NLM) through its Health Applications for the National Information Infrastructure (NII) Initiative (Baker and Masys, 1999), there are several features that characterize PHR security and privacy protection:

- Multi-level security
  - Low, which is information that is not associated with a particular patient’s identity
  - Standard, which is general patient information associated with a specific patient
  - Deniable, which are categories of patient identifiable data that require special protection by law or by institutional policy. Deniable data include HIV:AIDS,
abortion, adoption, mental health, substance abuse, sexually transmitted diseases and celebrity

- **Guardian-deniable**, which includes patient-identifiable information that is specific to a minor and that can be denied to the parent or guardian. Abortion information is guardian-deniable
- **Patient-deniable**, which is information that the primary care provider considers potentially damaging to the patient if it were it to be disclosed to that patient

- Role-based access control
  - **Researcher role**
  - **Patient role**
  - **Secondary Care Provider (SCP)**
  - **Primary Care Provider (PCP)**
  - **Emergency Provider**

- Strong device and user authentication

- Session-specific encryption

- Audit trails

**Utility/Interface**

Compared to the aspects of communication and security, the utility issue attracts much less attention. To date, there have been only few studies evaluating the accuracy or utility of PHR records generated using patient-entered information (Waegermann, 2001). One pilot study focused on evaluating the performance of a Web based application designed to collect verifiable patient-entered information detailing family health histories (Cohn, 2001). A few studies have evaluated the utility of patient-held summaries of institutional records, documenting significant improvements in levels of compliance with monitoring protocols and immunization schedules (Hertz, et al, 1976; Hetzel, et al, 1979; Miller, 1990; Dickey and Petitti, 1992). A number of recent initiatives have focused on the development of resources targeted to provide patients with direct online access to their own institutional records (Cimino, et al, 2000; Jones, et al, 1999; Masys and Baker, 1997). One recent study reviewed a selection of PHR with a specific focus on features that might affect their utility as resources for critical care, noting significant problems with provisions for emergency access and storage of digitized images (Schneider JG, 2001).

Though not well studied, the issues of acceptability and usability pertaining to human related factors have become a hurdle to the development of electronic health records. Even in the places with the latest technology and the best network access, users complain about non-friendliness: the non-intuitive data input (structured data entry is still unacceptable by most users), security procedures (login taking too much time), the inability of (mobile) interaction with the system. The above problems give rise to a series of challenges from the human–computer interaction (HCI) perspective, related to capturing and input of health data as well as the presentation of the recorded data in a variety of forms, media and output systems, etc. (Tange, et al, 1997). In
particular, specific technological areas that need to be addressed concern input and output devices (e.g. penbased input, speech input), 2D and 3D interaction techniques, intuitive interface metaphors, mobile systems, multimodal interfaces, tailorable and adaptable interfaces, more natural access procedures (e.g. speech interfaces), computer-supported co-operative work intelligent interfaces, user identification procedures, and user interfaces for mobile services (Aisaka, et al, 1995; Williams and Morgan, 1995; Iakovidis, 1997).

The general desired functionalities of PHR include (Kim and Johnson, 2002):

- Providing access to personal medical information
  - Secure password-protected patient access
  - Capacity to provide authorized provider access
  - Capacity to provide directed emergency access

- Providing an organized summary of personal medical information for presentation to health care providers
  - Accurate entry of past and current medical conditions, including medical information about diagnosis and treatment
  - Accurate entry of past and current medications, including information about indication, dose, frequency, and duration
  - Verification of laboratory test results
  - Verification of diagnostic study results
  - Verification of immunizations, including information about dates and sequences

- Serving as a portal to patient-specific consumer-level health care information
  - Accurate entry of medical conditions
  - Accurate entry of medications
  - Capacity to provide links to consumer health care information

- Providing interpretive information about laboratory test and diagnostic study results
  - Accurate entry of medical conditions
  - Accurate entry of medications
  - Verification of laboratory test results
  - Verification of diagnostic study results
  - Capacity to interpret laboratory test and diagnostic study results

- Serving as a database of information for patient-specific self-monitoring and disease management
  - Accurate entry of medical conditions
  - Accurate entry of medications
  - Verification of monitoring study results
  - Capacity to interpret monitoring study results
  - Capacity to provide evaluation and treatment recommendations
  - Capacity to provide wellness checkups (For example, the system may have a mental health checkup that "screens" a patient for depression or stress and then offers some advice on how to deal with any problems uncovered.)
o Capacity to provide secure communication between patients and providers

- Providing patient-centered portability and shareability
  o Capacity to provide emergency record summaries
  o Capacity to provide paper, fax, electronic, phone, smart card integration
  o Capacity to provide interoperability with electronic data with other medical systems

Sun (2001) developed a model for comparison of Personal Health Record sites and identified a series of elements to evaluate the PHR utility. These elements taken together serve as an indication of the PHR interface quality, which include:

- Ease of navigation
- Time to complete tasks
- Ability to find desired information
- Site presentation and layout
- User’s satisfaction level
- Percentage of tasks completed correctly
- The number of problems encountered
- The amount of assistance required

In the view of the author, this list is not complete as to be a sufficient utility indication for PHR applications. Besides the above points, several other bullets should be added in. Shneiderman’s (1998) ‘eight golden rules’ provides general guidelines for PHR interface design as well. In particular, the following two issues can make a big difference in the ease of PHR use:

- to offer error prevention and simple error handling
- to enable shortcuts for frequent use and emergent use

As Marshall (2001) pointed out, PHR terminologies have great influence on PHR usability and thus become another important consideration for evaluating PHR interface. Marshall took WellMed’s consumer health terminology (CHT) and IMO’S personal health terminology (PHT) as examples to demonstrate the features of true ‘interface’ terminologies.

- to provide good consumer health terminologies
  o provide the ability to interface patients to complex terms and concepts at a specified reading level
  o provide the ability to translate colloquialisms and common phrases into medically-valid concepts
PHR Products

Recently, a number of companies have involved in the PHR business. Table 1 shows the companies currently attempting to deliver PHR service, mainly derived from a PHR website list (Sittig, 2002) and supplemented by Google search conducted by the author. Allowing patients to post their own medical records on the Internet is becoming big business. Configured along the lines of standard provider entered records, these PHR services allow patients to directly enter information about their own diagnoses, medications, laboratory tests, diagnostic studies, and immunizations. Host sites use this information to generate records that can be displayed for review or transmitted to authorized receivers. Although a few have been set up by nonprofit organizations, most have been developed as commercial ventures. While initial revenue models were based on sales of advertising, current business strategies aim to use PHR to provide laboratory, prescription, and billing information to designated providers. One prominent commercial site recently reported enrollment of 10,000 active users based in the United States.

CapMed, HealthAToZ, WellMD, and PersonalMD are famous in the PHR business in the United States. In particular, CapMed’s PHR is the industry leader with more than 375,000 copies already in distribution—by far the largest number by any company in the personal health records market. CapMed’s PHR received TEPR award for "Best of Breed Health Technology Solutions.” in 2001, for CapMed’s PHR can be private-labeled and customized to meet the needs of distribution partners. For further information visit their web site. In 2002, CapMed collaborated with Robert H. Smith School of Business, the University of Maryland on a study of the usage and acceptance of technology for personal health management. For this study, a total of 875 CapMed Personal Health Record (PHR) users were asked to complete a survey examining personal health technology acceptance and usage relative to health care needs, perceptions of the system and its value, and demographic variables. Nearly 200 usable responses were received. Findings indicate that characteristics of the CapMed PHR system are associated with the user's characteristics and healthcare task needs. The detailed statistics of this study can be accessed at http://www.capmed.com/pdfs/UMD.PDF.

<table>
<thead>
<tr>
<th>COMPANY</th>
<th>PRODUCT</th>
<th>URL</th>
<th>SITE ACTIVE?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agency for Health Care Research and Quality</td>
<td>Personal Health History</td>
<td><a href="http://www.ahcpr.gov/ppip/ppinfrec.htm">www.ahcpr.gov/ppip/ppinfrec.htm</a></td>
<td>No</td>
</tr>
<tr>
<td>Bank of Health</td>
<td>Health ATM</td>
<td><a href="http://www.bankofhealth.com">www.bankofhealth.com</a></td>
<td>No</td>
</tr>
<tr>
<td>CapMed Corporation</td>
<td>Personal Health Record (PHR)</td>
<td><a href="http://www.capmed.com/">http://www.capmed.com/</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Care Group Health Care System</td>
<td>Patient Site</td>
<td><a href="https://patientsite.caregroup.org/">https://patientsite.caregroup.org/</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Catholic Healthcare West</td>
<td>My Health</td>
<td><a href="http://www.chw.healththinkonline.com/index.asp?ID=14">www.chw.healththinkonline.com/index.asp?ID=14</a></td>
<td>No</td>
</tr>
<tr>
<td>CBS Health Watch</td>
<td>About My Health</td>
<td><a href="http://www.aboutmyhealth.com/">www.aboutmyhealth.com/</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Cerner</td>
<td>Personal Health Record</td>
<td><a href="http://www.iqhealth.com/index.html">http://www.iqhealth.com/index.html</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Data Critical</td>
<td>Your Health Chart</td>
<td><a href="http://www.elixis.com/yhc.html">www.elixis.com/yhc.html</a></td>
<td>Yes</td>
</tr>
<tr>
<td>4HealthyLife.com</td>
<td>Medical History Storage</td>
<td><a href="http://4healthylife.com">http://4healthylife.com</a></td>
<td>No</td>
</tr>
<tr>
<td>Global Medic</td>
<td>Global Medic Health Record (GHR)</td>
<td><a href="http://www.globalmedic.com/L2/index.jsp">http://www.globalmedic.com/L2/index.jsp</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Hamilton Scientific</td>
<td>My Patient Charts</td>
<td><a href="http://www.mypatientcharts.com">www.mypatientcharts.com</a></td>
<td>Yes</td>
</tr>
<tr>
<td>HealthCPR.com</td>
<td>Personal Health Account (PHA)</td>
<td><a href="http://www.bankofhealth.com/">http://www.bankofhealth.com/</a></td>
<td>No</td>
</tr>
<tr>
<td>Service Provider</td>
<td>Service Type</td>
<td>Website/Link</td>
<td>Provided?</td>
</tr>
<tr>
<td>------------------------------------------------------</td>
<td>---------------------------------------</td>
<td>------------------------------------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Healthprofiler.com</td>
<td>Health Profile</td>
<td><a href="http://www.healthprofiler.com/healthpage/profiler.com">www.healthprofiler.com/healthpage/profiler.com</a></td>
<td>No</td>
</tr>
<tr>
<td>i-Beacon.com Inc.</td>
<td>i-Return Consumer Health Record</td>
<td><a href="http://www.i-beacon.com/home.htm">http://www.i-beacon.com/home.htm</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Lifeline Medcom</td>
<td>Lifeline</td>
<td><a href="http://www.lifelinemed.com/">www.lifelinemed.com/</a></td>
<td>No</td>
</tr>
<tr>
<td>Medical Edge</td>
<td>Medical Registry</td>
<td><a href="http://www.medicaledge.com/medreq.htm">http://www.medicaledge.com/medreq.htm</a></td>
<td>Yes</td>
</tr>
<tr>
<td>MedicalLogic/Medscape Inc.</td>
<td>Personal Health Record (PHR)</td>
<td><a href="https://www.aboutmyhealth.com/">https://www.aboutmyhealth.com/</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Medical Network Inc.</td>
<td>E Mate 2.0</td>
<td><a href="http://www.healthatoz.com/atoz/login/emat">http://www.healthatoz.com/atoz/login/emat</a></td>
<td>Yes</td>
</tr>
<tr>
<td>MedRecs Express.com Inc.</td>
<td>The Medical Record</td>
<td><a href="http://12.250.216.98.90/momr">http://12.250.216.98.90/momr</a></td>
<td>No</td>
</tr>
<tr>
<td>MyOnlineMedicalRecord.com</td>
<td></td>
<td><a href="http://www.themedicalrecord.com/signup">http://www.themedicalrecord.com/signup</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Oxygen Media</td>
<td>Your Health Portrait</td>
<td><a href="http://thriveonline.oxygen.com/cqi-bin/hmi">http://thriveonline.oxygen.com/cqi-bin/hmi</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Personal MD</td>
<td>Health Manager</td>
<td><a href="http://www.personalmd.com/">http://www.personalmd.com/</a></td>
<td>Yes</td>
</tr>
<tr>
<td>Profile MD</td>
<td>Personal Medical Profile</td>
<td><a href="http://www.e-medtools.com">http://www.e-medtools.com</a></td>
<td>Yes</td>
</tr>
<tr>
<td>QuickViewHX</td>
<td></td>
<td><a href="http://glacier.ucdmc.ucdavis.edu/servlet/P">http://glacier.ucdmc.ucdavis.edu/servlet/P</a></td>
<td>Yes</td>
</tr>
<tr>
<td>UrgentLink</td>
<td>Online Safety Deposit Box</td>
<td><a href="http://www.urgentlink.com">www.urgentlink.com</a></td>
<td>No</td>
</tr>
<tr>
<td>Web MD Corporation (Healtheon)</td>
<td>My Health Record</td>
<td><a href="http://my.webmd.com/my_health_record">http://my.webmd.com/my_health_record</a></td>
<td>Yes</td>
</tr>
<tr>
<td>WellMed</td>
<td>Personal Health Manager</td>
<td><a href="http://www.wellmed.com/wellmed/">www.wellmed.com/wellmed/</a></td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Table 1**

Based on a general review, the following features are found to be covered by the above personal health record providers.

- **Basic features covered by most PHRs**
  - Personal information
  - Family medical history
  - Immunization history and planner
  - Allergies to food and drugs
  - History of personal illnesses or past procedures
  - Medications and or supplements
  - Contact information for other health care practitioners/clinics/etc.

- **Advanced features covered by some PHRs**
  - Vital signs recording
  - Graphing and trending of health data
  - Visit Information
  - Lab and Radiology results
  - Medical Record Security Audit
  - Mental Illness History
Overall, the patient-entered PHR websites demonstrated limited functionality. At a basic level, each site does manage to provide Web based access to personal medical information. A minority of these sites extends this capacity to provide access to information in emergency situations. This finding is surprising in light of the emphasis placed on this mode of access in the promotion of these applications. Several specific interface problems have been identified from these PHR websites as follows (Kim and Johnson, 2002):

- **Lack of a walk-through instruction**
  Many of the functions I looked at are compromised by limitations related to the process of data entry and validation. Each site required patients to select entries from lists or to type information into text fields without much in the way of guidance or explanation. There are no mechanisms to direct patients through the process of selecting appropriate diagnoses. None of the sites provided any directions to help guide patients through the process of abstracting relevant information from prescription labels or test reports.

- **Lack of effective error prevention and error handling**
  Even simple functions that might ensure greater accuracy, such as spell-checking typed entries or identifying normal dose and reference ranges, are notably lacking. With a few exceptions, there are not any systems to verify information abstracted from test and study reports. Limited ranges of descriptive information further compromised entries that might be called into question.

- **Small coverage of health data elements**
  Given the range of information that can be entered, it is surprising that most of these records fail to include the basic data elements needed to manage one of the simpler problems encountered in outpatient medicine.

- **Low capability of integrating and summarizing health information**
Those PHR that include listings of information keep different elements segregated in discrete sections without problem-based integration. Actual use of information in clinical practice would require abstraction and rearrangement of elements to provide context for analysis.

In conclusion, the current state-of-the-art for PHR is at best characterized as ‘beta releases’ (Sittig, 2002). As such, they have not had the benefit of thousands of users and uses and the iterative cycle of software refinement on either the back-end databases or the user interface that are required for the development of more polished systems. Nevertheless, they offer key insights into the process of trying to figure out how such record systems should work, what information should be contained in them, who will use them and for what purpose and the legal and data confidentiality issues surrounding them. As the field matures and develops more experience, these PHR applications will improve significantly in ease of use and functionality. There remains much work to do and there are still many questions to answer.

Future Direction

As revealed by *Healthcare Informatics* (2002), “Medical Care Goes Home” becomes a clear healthcare trend in future. It indicates provision of health services to homes with new innovative services such as personal health monitoring and support systems and user-friendly information systems for supporting health education and awareness. The trend is towards more involvement of patient in receiving information, in decision-making and in responsibility for own health. The prime feature of this trend is to shift from healthcare-institution-centered care to the patient-centered care and from prevention to rehabilitation. PHR that enables patients to record and maintain their own health records plays a significant role in this trend. PHR will continue to flourish as the related technologies evolve.

Standardization will play a more and more important role in PHR development. The main challenges from the technological point of view refer to the storage, maintenance, communication and retrieval of multimedia information in different technological platforms and heterogeneous database systems that may be geographically distributed. Integration and interface of multi-vendor platforms and the development of health sector specific middleware and applications have recently received lot of effort by research and development projects. This integration effort is critical since the number of systems of different purposes (administrative, insurance, clinical, nursing, etc) is rising. The standardization issues among all types of electronic health records, including PHR, EMR, etc. become more and more important. The standardization issues can be grouped into the following categories (Iakovidis, 1998).

- **Standards for record architecture**
  It is an agreed structure that can accommodate all types of data and support different views and at the same time preserve the meaning and the context. This standardized architecture should be a general model of the record so it can enable the development of many different systems with a particular instance of this architecture.

- **Standards for terminology**
It is necessary to preserve the meaning, for proper coding of diseases and classification of medical procedures, for any possibility of multilingualism and possibilities to link and update other knowledge sources. The work on terminology is long lasting and difficult and requires the concerted effort of many disciplines and countries.

- **Standards for communication**
  Communication of the records among the different users is one critical feature of the PHR and any other types of electronic health records. This means technical interoperability independent of provider, format, medical specialty, geographic location, country systems, and legislation, etc. Currently, six different approaches are competing for being a platform for interoperability. They are OSI, CORBA, GEHR, HL7 CDA, OpenEHR, and the generic XML/Ontology approach.

- **Standards for security**
  Security features such as digital signature, digital keys, and other authentication systems need to be standardized. Most of the security applications and technologies are not health sector specific and the development is mainly pushed by the large financial or military institutions. The issues of security are closely related to the requirements of the confidentiality that are inherent in the definition of the electronic health record and will also be legally required by the national legislation.

Usability becomes the key to success in the heated competition in the PHR market. As mentioned above, there are only few patient-oriented research projects targeted to evaluate the performance and usability of PHR application. As shown in the preliminary analysis above, there is still much space for interface and usability improvement for the current PHR applications. As the field matures, increasing effort will be focused on the interface and utility issues. High requirement on the accuracy and completeness of patient-entered health information pose particular challenges for PHR interface design: how can the RHR interface effectively guides health data entry, validation, and information display with minimal user efforts? The large variety of health data types and health data terminologies add more complications to this challenge. In addition, the future PHR applications would serve as a significant component of the ‘shared health setting’, linking hospitals, laboratories, pharmacies, primary care and social centers. The PHR interface should be competent in adapting to different types of users and situations in such a broad healthcare scenario.

**Reference**


Marshall, P. Personal Health Records: Their Benefits and the Role of Standards. Accessed in April 2004 from


**Personal Health Records on the Internet**
- Kaiser Permanente Northwest's Personal Health Link
- Healtheon/WebMD
- Elixis Corporation's YourHealthChart (Click to take a tour)
- Cyberspace Telemedical Office
- Personal MD
- AMA Personal Health History
- Your Health Portrait (questionnaire only)
- WellMed -- WellRecord
- Medscape's Daily Diary
- Personal Health Manager
- 4Healthylife ($24.95)
- Catholic Healthcare West - click on "my page"
- HealthCompass
- CapMed's Personal Health Record (demo only)
- Lifeconnect.com - online record for members of participating health plans
- Accordant's Personal Health Manager
- 98Point6
- AllHealth.com's Personal Health Record - another implementaton of WellMed's WellRecord!
- GlobalMedic's eHealth Record
- LifeLineMed's Record - costs $45 to join
- eMD.com
- Medifile - Available to members of participating organizations only.
- TheMedicalRecord - cost $35 to join
- MyHealthNotes - Personal Health Manager
- HealthAtoZ
- HealthCPR.com - currently only a demo
- QuickViewHX - UserID: pcaware, Password: pcaware.
- My Patients Charts.com
- I-Beacon.com (demo only)
- Your HealthChart.com - (Coming Soon)
- Demonstration of CareGroup's Personal Health Web Site
- Cerner's IQ Health (Demo)
- IDX's Channel Health (Demo)
- UrgentLink's Online Safety Deposit Box (Demo)
PHDtogo - discusses a record, but I can't find it.
The Health Network (No longer available)
MyOnlineMedicalRecord.com (no longer available)
My HealthePage (no longer available)
Health Tracker (No longer available)
StatChart (no longer available)

Personal, Disease-specific health profiles on the Internet
MyAsthma
MyAllergy
MyDiabetes

Internet-based Medical Records
Medical Logic
PCASSO

Systems promised in the near future
MedicAlert
Dr. Koop
UrgentLink