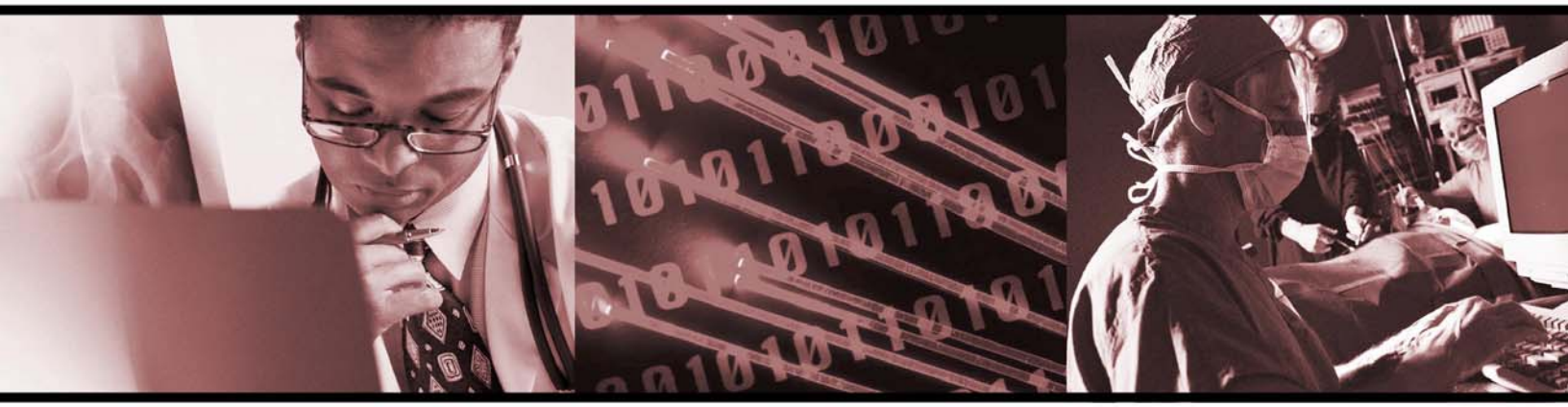
MARKLE FOUNDATION

CONNECTING FOR HEALTH

A Public-Private Collaborative



The Personal Health Working Group

Final Report

July 1, 2003

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I. Executive Summary

The information gap in modern health care

Information is the currency of modern health care. Knowing an individual's family background, history of diagnoses and procedures, test results and medications, and diet and exercise habits is essential to managing health, assessing problems, and preventing medical error. Today medical information is scattered among the many health care providers people see throughout their lives. It is stored in individual memories, on scraps of paper and in spreadsheets on personal computers. Some doctors and hospitals keep computerized medical records, but most personal health information is stored in thick paper files that line office walls. There is no coordinated system, no standardized, private and secure way to integrate an individual's health information in one place. A visit to a new doctor means new forms to complete, new tests to run and new conversations reviewing your personal medical history -- conversations that depend almost entirely on memory alone. People need effective tools to help them manage their health and their care.

What is a Personal Health Record?

The Personal Health Record (PHR) is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHRs offer an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results, and information from their pharmacies and insurance companies. Individuals access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location. Family members, doctors or school nurses can see portions of a PHR when necessary and emergency room staff can retrieve vital information from it in a crisis. People can use their PHR as a communications hub: to send email to doctors, transfer information to specialists, receive test results and access online self-help tools. PHR connects each of us to the incredible potential of modern health care and gives us control over our own information.

From November 2002 through May 2003, a group of health information experts and consumer advocates met as part of *Connecting for Health…A Public-Private Collaborative*. The goal was to examine the potential benefits of personal health records, how consumers perceive PHR, the concerns consumers have, and the issues to be addressed as PHR technology becomes more widely available. This overview and the subsequent full report summarize the findings of the working group.

What is new about the Personal Health Record?

The PHR is a single, *person-centered* system designed to track and support health activities across one's entire life experience; it is not limited to a single organization or a single health care provider. The PHR differs from the electronic medical record (EMR) - a computerized platform for managing detailed medical information collected during a hospital stay or in a doctor's office. EMRs usually contain a health history, doctors' notes and laboratory and radiology results and are generally owned by and limited to the information collected by one doctor or hospital. The EMR rarely contains information provided by the patient. Not all doctors use electronic medical records and many different systems exist, so when people change doctors or move to a new city their personal health information does not move with them. Health professionals are now adopting new data standards that will make transfer of clinical data between doctors more common, but even connecting different doctors' medical record systems will not tie together all the important health information for each patient. An EMR might indicate that a doctor wrote a prescription, but it would not show whether the patient filled the prescription, took the medication or if the treatment worked. EMRs can supply information to PHRs, but the PHR will also capture information from many EMRs and directly from patients.

The PHR has several distinct attributes:

- **Each person controls his or her own PHR**. Individuals decide which parts of their PHR can be accessed, by whom and for how long.
- **PHRs contain information from one's entire lifetime.**
- **PHRs contain information from all health care providers.**
- **PHRs are accessible from any place at any time.**
- **PHRs are private and secure.**
- **PHRs are "transparent."** Individuals can see who entered each piece of data, where it was transferred from and who has viewed it.
- **PHRs permit easy exchange of information** with other health information systems and health professionals.

Who will use the Personal Health Record?

The individual person is the primary user of the PHR. That person may allow access to all or part of the PHR to anyone - a doctor, family member, employer, summer camp, or insurance company. Other potential PHR users are "stakeholders" who - *when the primary user of the PHR gives his or her permission* - can make valuable use of the information being kept in the personal health record. In addition to the individual patient, doctors and hospitals may benefit from having quick, inexpensive access to medical information. Employers and insurers may be better able to evaluate and reward high-quality care by looking at aggregate data. Researchers and advocacy organizations can assess patterns of disease and treatment across the health care system. Public health officials may be able to detect disease outbreaks. The government and society as a whole may see significant gains in efficiency as more medical decisions are based on current and accurate information. All of these benefits can result from individual users' willingness to share selected health information with the stakeholders mentioned above.

How do people feel about using a Personal Health Record?

The PHR is a new idea, but it builds upon several more familiar tools Americans already use. Some people currently e-mail their doctors. Some doctors use EMRs, and a small but growing number permit patients to access their records on the Internet. Some people keep their medication lists online at their local pharmacy. Some track their insurance claims and deductibles online. Some people already keep track of their own health information in an electronic diary or spreadsheet.

As part of the *Connecting for Health* initiative, the Foundation for Accountability (FACCT) conducted a national survey of 1,246 online households to find out which elements of PHR are of greatest interest and what concerns people have.

- ***Over 70 percent of respondents would use one or more features of the PHR***
  - Email my doctor 75 percent
  - Track immunizations 69 percent
  - Note mistakes in my record 69 percent
  - Transfer information to new doctors 65 percent
  - Get and track my test results 63 percent

  The chronically ill, frequent users of health care and people caring for elderly parents report the highest and most urgent interest in PHR. Almost two-thirds (65 percent) of people with chronic illness say they would use at least one of the PHR features today, compared with 58 percent of those without chronic illness.

Thirty five percent of respondents would use seven or more features of a PHR today if it were available.

- ***People recognize many benefits of having a PHR:***
  - Help me understand my doctor's instructions 71 percent
  - Prevent medical mistakes 65 percent
  - Give me more control over my care 64 percent
  - Help me ask better questions 62 percent
  - Change how I take care of myself 60 percent

- ***Almost all respondents (91 percent) are very concerned about their privacy and keeping their health information secure.*** However, most people believe that technology provides appropriate protections and would not be reluctant to use the PHR features that they value. People report less concern with services like tracking immunizations and e-mailing their doctor (16 percent concerned), and more concern with sensitive information such as doctor's notes (32 percent concerned). Only about one-fourth of respondents said they would not use the PHR at all because of privacy issues.

- ***People who suffer from chronic illness and/or are frequent health care users are less concerned about privacy and security.*** When it comes to sensitive personal health information, people who need and use the health system report somewhat less concern than others. For example, 21 percent of healthier people would not use a PHR to manage immunization information due to privacy or security concerns, but only 19 percent of the ill express that concern; 41 percent of the healthy would not want to receive their lab results on-line due to these worries, compared with 36 percent of the ill.

- ***People trust their doctor to host, manage, and access their PHR.*** People do not want their PHR maintained by their insurance company, their employer or the government, and they want to limit family members' and others' access to it without their specific permission.

How will the Personal Health Record become a reality?

Early experiments have shown that a successful PHR will draw from information collected and exchanged during routine medical care from doctors, pharmacists, hospitals, and insurance companies. People will not have to gather and record all this information.

- ***All health care organizations and clinicians need to adopt electronic information systems and use common data standards*** to enable integration.

- ***Health care organizations and clinicians must see themselves as guardians of our health information, rather than "owners" of business information.***

- ***Health care organizations and other participants in PHR must monitor and adopt state-of-the-art practices to assure the privacy and security of personal health information.***

- ***Health care organizations must work with each other to safely and reliably exchange information across a community network.*** A key challenge is development of a reliable, consistent method to match patient data between organizations and clinicians.

- ***Health care organizations, clinicians and community leaders will need to create a transparent mechanism for governing PHR systems***, so that public concerns about ownership, security, and privacy are addressed.

- ***Health care payers will need to create incentives or a "business case" for those who accelerate the adoption of systems, standards, and PHR technology.*** In the current payment environment, there is no business benefit in sharing information with other organizations or creating easy data exchange with the patient and family. To achieve the long-term community and health benefits, financial incentives must be present.

How close to reality is the Personal Health Record today?

Innovative health care systems around the country have introduced EMRs that connect their many hospitals and doctors to each other to improve patient care. Some provide a "gateway" allowing patients to view their medical records and communicate with their doctors online. In Santa Barbara, CA, Winona, MN, and Spokane WA, hospitals, clinics, and other local health care organizations have agreed to permit information exchange with one other and with their patients. Members of the *Connecting for Health* collaborative have agreed upon data standards which are beginning to be widely adopted, studied noteworthy privacy and security practices being used today to protect personal health information, and outlined the elements of a basic data set for a PHR. Selected PHR projects across the US already offer many of the services that consumers want, including e-mail, tracking test results and medications, supporting self-care activities and transferring information between providers.

What's next?

Over the next few years, a number of steps will be taken by leading health care organizations, technology vendors, and community leaders to ensure that more people can take advantage of the revolution in health information. These include:

- Major health care organizations, clinicians and information technology vendors will adopt data standards.
- The public will become more aware of the PHR's benefits.
- Online tools for managing health and health care will be improved.
- Community-wide demonstrations of health information exchange between organizations, clinicians and patients will multiply.
- Health insurers and the federal government will offer economic incentives for electronic record-keeping.
- Early adopters of PHR, including people with chronic illness and those caring for sick parents, will demonstrate the benefits of easy, inexpensive, and secure access to all their health information.

Who are we?

Connecting for Health…A Public-Private Collaborative is a program of the Markle Foundation. The Personal Health Workgroup included twenty innovators and consumer advocates who came together between November 2002 and May 2003 to discuss the state-of-the-art in managing personal health information. Work group members included:

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I. Introduction

When you see a new doctor, do you scratch your head to remember the details of your health history – all the names and dates – as you fill in the registration and medical history forms?

FACT: The U.S. health system spends anywhere from $30 to as much as $293 billion annually on unnecessary paperwork.[1]

Are you confident you will get safe, coordinated, health care in today's environment?

FACT: Forty-two percent of Americans say someone in their family has been a victim of a medical error.[2]

In an accident, do you think emergency room doctors could get vital information about you?

FACT: Twenty-five percent of Americans think so – but almost no emergency rooms can actually retrieve your critical health information.[3]

Do specialists ask you to have blood tests or X-rays repeated, even though your regular doctor recently ordered them?

FACT: Experts say that up to ten percent of the tests that doctors order are unnecessary or duplicative.[4]

Do you think your doctor keeps your medical information on a computer?
FACT: Forty percent of Americans think so – but only five percent of doctors actually do![5]

When you have a change in your health, can you easily let your doctor know about it, check your previous information, and figure out what to do?

FACT: Sixty-four percent of doctors use email to communicate with colleagues, but only 23 percent communicate with their patients by email. And fewer than 2 percent of patients say they can reach their doctor by email even though 90 percent say they would like to.[6]

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[1] IBM estimate reported in E-commerce News June 13,2002 (http://www.internetnews.com/ec-news/article.php/1365511); Woolhandler S, Campbell T, Himmelstein DU. Costs of health care administration in the United States and Canada. N Engl J Med. 2003 Aug 21; 349(8): 768-75; U.S. Department of Health and Human Services, "Protecting the privacy of patients' health information; summary of the final regulation," Dec. 20, 2000.

[2] Kaiser Family Foundation, Medical Errors: Practicing Physician and Public Views, 2002

[3] Markle Foundation and FACCT, PHR Consumer Survey, 2003

[4] Bates DW, Boyle DL, Rittenberg E. What proportion of common diagnostic tests appear redundant? Am J Med. 1998 Apr; 104(4): 361-8; . Valenstein P, Schifman. Duplicate laboratory orders: a College of American Pathologists Q-Probes study of thyrotropin requests in 502 institutions Arch Pathol Lab Med. 1996 Oct; 120(10): 917-21; Wang TJ, Mort EA, Nordberg P, et al. A utilization management intervention to reduce unnecessary testing in the coronary care unit. Arch Intern Med. 2002 Sep 9; 162(16): 1885-90.

[5] Source: Markle Foundation and FACCT, PHR Consumer Survey, 2003

[6] Sources: Deloitte Research and Fulcrum Analytics, Taking the Pulse v 2.0: Physicians and Emerging Information Technologies, 2002; Harris Interactive, Cyberchondriacs Update, April 12th, 2001

The information gap in modern health care

> *"My health record is a collective sense of medical records. Here's my history, here's my pediatrician stuff, here's my dental."*
> - ***Focus Group Participant, Bangor, ME***

Information is the currency of modern health care. Knowing one's family background, history of diagnoses and procedures, test results and medications and diet and exercise habits is essential to managing health, assessing problems, and preventing medical error. Today medical information is scattered among the many health care providers people see throughout their lives. It is stored in individual memories, on scraps of paper and in spreadsheets on personal computers. Some doctors and hospitals keep computerized medical records, but most personal health information is stored in thick paper files that line office walls. These paper-based systems are often disorganized, illegible, prone to error, difficult to transfer from provider to patient or specialist and they usually do not include information contributed by patients. In the paper-based world of medical records, there is no coordinated system, no standardized, private and secure way to integrate anyone's health information in one place[7]. A visit to a new doctor means new forms to complete, new tests to run and new conversations reviewing personal medical history -- conversations that depend almost entirely on memory alone. People need effective tools to help them manage their health and health care.

> *"What do I think of my medical record? It's in shambles."*
> - ***Focus Group Participant, Bangor, ME***

The electronic personal health record (PHR) can help solve this problem for patients. PHR is a single, *person-centered* system designed to track health and support health care activities across one's entire life experience. It is not limited to a single organization or a single health care provider.

From November 2002 through May 2003, a group of health information experts and consumer advocates met as the Personal Health Working Group (PHWG) of the Markle Foundation initiative *Connecting for Health…A Public-Private Collaborative*. David Lansky, President of FACCT – Foundation for Accountability, chaired the PHWG. The 21 working group members represented government and private sector electronic medical record

[7] Protti, D., & Peel, V. (1998). Critical success factors for evolving a hospital toward an electronic patient record system: A case study of two different sites. *Journal of Healthcare Information Management, 12*(4), 29-38. Kuilboer, M. M., van der Lei, J., Bohnen, A.M. & van Bemmel, J. H. (1997). The availability of unavailable information. *Proc AMIA Annu Fall Symp*, 749-53 (Annual Volume).

creators, consumer and patient advocates, medical groups and health systems, electronic record experts and practicing clinicians. A complete list of PHWG members and staff is in Appendix 1. The PHWG's goals were to examine the potential benefits of personal health records, the general public's perceptions of PHR, the concerns people have and the issues to be addressed as PHR technology becomes more widely available. This report summarizes the workgroup's findings and outlines the requirements for building a national system to support the implementation of PHR. The report is divided into five sections:

1) WHY – Making the Case for PHR
2) WHAT – Defining and Characterizing PHR
3) WHO – Users and Attitudes toward PHR
4) HOW – Operationalizing the PHR Idea
5) WHERE – PHR Yesterday, Today and Tomorrow.

III. WHY: Making the Case for the Personal Health Record

Imagine going to a new doctor and the office requests information regarding insurance, medical problems, medications, allergies and recent lab work. By accessing a PHR, one could print a copy of the necessary information or even transfer a digital copy of the information into the new doctor's system. After the visit, the doctor could send an update of new medications and the results of any lab or diagnostic tests directly to the individual's PHR and alert him or her that new information was available for review. When that individual goes to see a specialist, that same information could be made available, in printed or digital format, for the specialist to access and review. Upon leaving the specialist, any new problems, medications, lab or diagnostic tests from the specialist would transfer directly to the patient's PHR. If a new school asks for a child's immunization records prior to

JOHN USES HIS VETERAN'S HEALTH ADMINISTRATION (VHA) ELECTRONIC PHR TO MAKE DECISIONS ABOUT CANCER TREATMENT

PROBLEM: Individuals' inability to easily access all of his cancer-related medical information from different providers and centralizing paper versions of his medical records from different doctors' offices. A lack of user-friendly accessible information that allows informed decision making.

SOLUTION: *The Web-based MyHealtheVet (www.myhealthevet.va.gov) allows participating veterans to receive electronic copies of key portions of their health record. From any Internet connected computer, veterans can enter additional medical information, perform selected e-service transactions (RX refills, appointment scheduling, etc), and access a Health Ed Library that contains about 18 million pages of health and wellness information. This approach saves time and money for the veteran and the VHA health care system. It also improves the quality of care and patient satisfaction.*

John, a Gulf War veteran with cancer, logs into his secure, Web-based MyHealth*e*Vet from home and receives updated laboratory results along with personalized electronic information about a new treatment. The information was retrieved from VHA-identified credible sites, based on previously established criteria, including his age, gender, and condition. While in the private Web page within MyHealtheVet, John reviews other medical data stored in his VA computerized electronic patient medical record.

After reviewing the information, John uses the MyHealth*e*Vet Web interface to access benefits and eligibility information and to schedule an appointment for next week at a community-based outpatient clinic close to his home. Although he doesn't use them today, John also has access to electronic prescription refills, cancer specific health information and resources, and record forwarding e-services for second opinions. He can review and upload clinical information through a home monitoring unit or directly, and can authorize access to MyHealth*e*Vet services for family members as well.

During his next physician appointment, John shares treatment information with his doctor and receives guidance and education about its relevance. An oncologist from a renowned specialty cancer center participates in the discussion via videoconference. Based on a mutual decision to pursue the treatment further, John undergoes several tests to decide if he is an appropriate candidate for the treatment.

Once the test results are ready, John is alerted that they have been automatically added to his electronic medical record and are available for viewing in his PHR. Using his Web interface, he reviews the results at home, and authorizes consent to the cancer center oncologist—making the results available to a remote care team so treatment planning can begin.

Story – Douglas E. Goldstein. Adapted from a HealtheVet use case scenario, and used with permission from VA.

admission, a parent could access his or her child's PHR and print a copy to send in. Finally, in the case of an emergency, emergency room personnel could access an individual's PHR to obtain pertinent medical information reducing the chance of a medical error, increasing the speed and accuracy of the diagnosis and reducing the potential for unnecessary or duplicative tests.

> *"I'm frightened to death of being killed by a healthcare provider because they didn't have enough information to save my life."*
> ***- Focus Group Participant, Bangor, ME***

The PHWG describes PHR as: **an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment.** The PHWG's vision is that PHR is an Internet-based set of tools that allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. PHR offers an integrated and comprehensive view of health information, including information people generate themselves such as symptoms and medication use, information from doctors such as diagnoses and test results and information from their pharmacies and insurance companies. Individuals access their PHRs via the Internet, using state-of-the-art security and privacy controls, at any time and from any location. Individual PHR users decide who can see their medical record. Family members, caregivers, doctors or school nurses can see portions of a PHR when necessary and emergency room staff can retrieve vital information from it in a crisis. People can use their PHR as a communications hub: to send e-mail to doctors, transfer information to specialists, receive test results and access online self-help tools. Individuals can manually enter information into their PHR and doctor's offices, hospitals, labs and pharmacies can auto-populate PHRs by way of interfaces such as electronic transcription or secure messaging. PHR connects each of us to the incredible potential of modern health care and gives us control over our own information.

PHR has the potential to save hundreds of hours in time and reduce the cost of health care[8]. By making health information available when it is needed, PHR could help decrease duplicate testing, transfer records more efficiently, reduce adverse drug events and improve preventive care and disease management. PHR is likely to yield considerable cost savings.

[8] McCain, C. (2003). Electronic medical records less costly. Business First of Columbus, July 11. Accessed at http://www.bizjournals.com/industries/health_care/physician_practices/2003/07/14/columbus_focus6.html accessed online on August 8, 2003.

Several studies have already shown that similar technology such as the Electronic Health Record and Ambulatory Computer Physician Order Entry systems contributed to lower costs and improved quality of care by having the necessary medical information available when decisions needed to be made[9].

[9] Bates, D. W., Leape, L. L., Cullen, D. J., Laird, N. et. al. (1998). Effects of computerized order entry as a team intervention on prevention of serious medical errors. JAMA, 280, 1311-6.; Evans, R. S., Pestotnik, S. L., Classen, D. C., et. al. (1997). A computer assisted management program for antibiotics and other anti-infective agents. New England Journal of Medicine, 338(4), 232-8; Graham, Gail, et al. "Information Everywhere: How the EHR Transformed Care at VHA." *Journal of AHIMA* 74, no.3 (2003): 20-24. ihealthbeat (June 3, 2003). North Carolina practice saves with EMRs. California Health Care Foundation, accessed online at http://ihealthbeat.org/members/basecontent.asp?contentid=25164&collectionid=546&program=5 on August 8, 2003.

IV. WHAT – Defining and Characterizing the Personal Health Record

ATTRIBUTES OF THE PHR

> *"I want to control what goes into it. I want to control who looks at it. I'd want to control it 100%."*
> ***- Focus Group Participant, Bangor, ME***

PHR can take many forms and each of these manifestations carries with it different implications for implementation, policy and use. A well-designed PHR enables individuals or their authorized representatives to control personal health information, supports them in managing their health and well being and enhances their interactions with health care professionals. As a key component in a "personal health system," the PHR provides an integrated view encompassing such information as the individual's health status, medical and treatment history and communications with health care providers. The information should include data auto-populated by clinical systems, data received from monitoring devices and information entered by providers and the individual himself or herself. In order to accomplish PHR as described above, it must reflect the following attributes:

1) Each person controls his or her own PHR.
2) PHRs contain information from one's entire lifetime including information from all health care providers.
3) PHRs are accessible from any place at any time.
4) PHRs are private and secure.
5) PHRs are transparent. Individuals can see who entered each piece of data, where it was transferred from and who has viewed it.
6) PHRs permit easy exchange of information across the health care system.

Each of these attributes is described more fully below:

1. Each person controls his or her own PHR.

> *"I would give the hospital unlimited access and my physician unlimited access. I might just give temporary access to somebody else. I might have a time limited access for somebody else. Or a data limited access."*
> ***- Focus Group Participant, Bangor, ME***

Simply put, individual PHR users decide which parts of their PHR can be accessed, by whom and for how long. The person (patient or consumer) owns his or her PHR and can designate others (family, caregivers, clinicians) to manage it for them. Individual users can enter their own information and they may authorize others to add specific types of data into their PHRs. Users or their designee(s) can expect that their PHR remains private, and they can expect that systems that help them

manage their PHR will use accepted security measures to prevent any unauthorized access to their data.

2. PHRs contain information from one's entire lifetime and all health care providers.

PHR should be a portable record that aggregates and integrates information from multiple health care professionals and systems and from the patient directly. Unlike many electronic medical records that often only contain episodic and illness-related information, PHR contains an ongoing, longitudinal and life-long record of information that bridges both wellness and illness.

3. PHRs are accessible from any place at any time.

Individual users, their providers and other caregivers can access up-to-date health information using the PHR at the point of care or any time they need it – with appropriate permission. Economic or electronic barriers (such as Internet access in emergency rooms) should not preclude the availability of PHR information.

4. PHRs are private and secure.

New federal regulations under the Health Information Portability and Accountability Act (HIPAA) affirm the right of individuals to control access to their personal health information. One can envision a highly restrictive model in which every access must be authorized in advance, but only a small minority of consumers would find this beneficial. In some cases, people may wish to grant full, unfettered access for providers with whom they have an ongoing relationship. In addition, there should be a "break glass in case of fire" override available for providers who care for patients in emergency situations (EMT, ER, etc.) The confidentiality of these two more permissive modes can be enhanced by allowing consumers to access an "audit trail" that lists who has accessed their record, when and from where. This provides an added deterrent against inappropriate usage by individuals who have access privileges.

5. PHRs are transparent

Individuals should be able to see who entered each piece of data, where it was transferred from and who has

Minimum PHR Data Set *(Illustration)*
Name
*Telephone
*Address
*City
*State
*Postal code
*Country
*Language
*Emergency contact
*Emergency contact telephone
*Emergency contact relationship
Next of kin
Next of kin telephone
Next of kin relationship
Health Care Proxy
Health Care Proxy Telephone
Health Care Proxy Address
Health Care Proxy Relationship
Date Proxy filed
Location Proxy filed
DNR Status
DNR Status Date
Organ Donor
*Witness to Organ Donation preference
*Witness telephone
*Witness relationship
Organ Donation Restrictions
*Health problem, condition or diagnosis
*Status of health problem, condition or diagnosis
*Date of Diagnosis
*Date of Onset
*Clinical Code for problem, condition or diagnosis
*Coding vocabulary
*Coding vocabulary version
*Medication
*Medication Dose
*Medication Form
*Medication Frequency
*Medication sig
*Medication Route
*Do Not Substitute status
*Medication Status
*Date of Prescription
*Prescribing provider
*Clinical Code for medication
*Coding vocabulary
*Coding vocabulary version
*Allergy
*Allergic reaction
*Immunization
*Immunization Date
*Surgical or Diagnostic Procedure
*Procedure date
*Procedure provider
*Clinical Code for procedure
*Coding vocabulary
*Coding vocabulary version
*Laboratory Procedure
*Procedure date
*Ordering Provider
*Facility/location performed
*Normal Range
*Results status
*Clinical Code for lab test
*Coding vocabulary
*Coding vocabulary version
*Health insurance company
*Health insurance plan
*Health insurance plan ID
*Health insurance group ID
PBM
PBM ID
*Care Provider
*Care Provider telephone
*Care Provider City
*Care Provider State
*Care Provider postal code
*Care Provider country
*Care Provider address
*Care Provider fax
*Care Provider Specialty
*Hospital

viewed it. Each piece of information that is added to the PHR should be attributable to its source, with all reasonable measures used to verify both the data and its supplier. This feature supports the premises that the individual has total control over his or her PHR and that the PHR is private and secure.

6. PHRs permit easy exchange of information

Survey Results
31% of respondents would like to lookup their PHR during a doctor visit.

In order for PHR to be comprehensive, exchange of information with other health information systems and health professionals is essential. The user should be able to transfer information between their PHR and other online records based within health plans, pharmacies, doctor's offices and hospital systems. Standards play an essential role in facilitating the secure interaction between PHRs and other systems. A minimum data set could establish the types of information that, where available within other electronic systems, could be accessed by the PHR electronically. The minimum data set might include personal and emergency contact information, physician and insurance information, health conditions, medications, allergies, immunization history, certain test results, surgical history, health risks, lifestyle information and advance directives.

MINIMUM PHR DATA SET

As stated above, PHR should allow consumers to integrate their personal health information from multiple sources, including different providers and health care systems, and to leverage that information to better manage their own health and obtain improved quality and consistency of care. In order to facilitate this process, data sources such as pharmacies, doctors' offices and hospitals, need to capture and store essential information about each patient in a standard format, and be able to exchange that information easily with appropriate permissions.

Survey Results
80% of respondents think it is "very important" for emergency room personnel to have access to their medical records.

The PHWG recognized the importance of a uniform national definition of a minimum PHR data set. A preliminary listing of such a data set is included here for illustrative purposes, though more detailed specifications will certainly need to be developed in future *Connecting for Health* work. Members of the PHWG felt that a more definitive minimum data set was beyond the scope of their work. The preliminary data set includes only the data necessary to communicate an accurate health history to new or emergency care providers, as well as the data necessary to help the individual user identify

appropriate disease management or other resources. The Data Standards Working Group report offers a more in depth exploration of the minimum data set[10].

When the elements within the minimum data set are transferred from an existing record to the PHR, deletions and/or edits should be reflected in an audit trail accompanying the data. Similarly, each data element should be associated with a date and time of entry and the identity of the person who entered it. In order to maintain authenticity, only the information source should be able to directly edit the information that becomes part of the data set. Additional mechanisms of user authentication and authorization must be in place for these data to be shared.

PHR

Electronic medical records (EMR)[11] are being used in a small but increasing minority of physician practices. EMRs usually contain a health history, doctors' notes and laboratory and radiology results and are generally owned by and limited to the information collected by one doctor or hospital. They are essentially electronic versions of the familiar binders of paper notes and test results that are kept by doctors and hospitals, and often include integrated clinical decision support and workflow enhancements. Through the use of information technology, the EMR has made storing, retrieving, displaying and analyzing patient information easier than in paper-based systems. The data in the EMR is primarily intended for medical providers and it rarely contains information provided by patients. Patients have the right to review the information in their medical records, and several institutions have made data from the EMR available to patients through a "patient gateway," however the EMR is "owned" by the doctor or the institution that creates and maintains it.

Not all doctors use EMRs and those who do are not necessarily using systems that can exchange data with other EMRs or information systems, so when people change doctors their personal health information rarely moves with them in an electronic form. Health professionals and organizations are now adopting data standards that will make electronic transfer of clinical data between doctors more common, but even connecting different doctors' EMRs will not tie together all the important health information for each patient. An

[10] Data Standards Working Group Report and Recommendations, *Connecting for Health* 2003. p. 46-47
[11] Electronic Medical Record, Electronic Patient Record, Electronic Health Record, Computerized Patient Record and Computer-based Patient Record are all synonymous for the purpose of this discussion.

EMR might indicate that a doctor wrote a prescription, but it would not show whether the patient filled the prescription, took the medication or if the treatment worked.

By contrast, the PHR facilitates easy access to and portability of one's medical information. It incorporates lists of allergies, medical problems, medications, doctors and key studies that many patients already compile for themselves. It includes information from many institutions and doctors, covers the patient's entire lifespan, and is "owned" by the patient. At the individual's request, data such as immunization history or current medications can be imported from and transmitted to interested parties (doctor, pharmacy) to assist in self-management and coordination of care. The PHR depends on EMR. EMRs supply information to PHRs; the PHR captures information from many EMRs and directly from patients.

Roles of the EMR and the PHR are summarized in the following table:

	EMR	**PHR**
Control of information stored in the record	Provider or institution decides what is in the EMR.	Person controls the data within the PHR and decides who can access which parts of it.
Access	Any authorized clinical or support staff in the doctor's office or institution as part of routine medical practice may access the EMR.	PHR can only be accessed with patient's consent (with possible exceptions for emergencies).
Origin of information in the record	Primarily from one practice or institution	Cross-institutional
Person's entries into the record	Rare	Common
Users	Professionals in the office or institution	Used by the individual person for self-care and record keeping. May be shared with medical professionals for continuity of care.
Integration with decision support tools	Provider-centered medical management	Person-centered self-care
Source of information for other systems	Important source of person's data for the PHR	Important source of person's data for the EMR

RISKS AND CONCERNS ABOUT PHR

Although PHR has many potential benefits, the PHWG recognizes that there are also a number of impediments that have hindered its widespread adoption.

> *"It seems like there should be portions of it that would be accessible. I'm not sure that if I'd had a psychiatric stay, I would want my whole online record to be available to somebody who could put in a password."*
> - ***Focus Group Participant, Bangor, ME***

First, worldwide electronic access to one's personal health information raises both privacy and security concerns. Users may fear embarrassment or discrimination if an unauthorized person sees their health information. The need for robust security will have to be balanced with the need for PHR to be easily accessible; perfect security is incompatible with perfect utility. For security, systems will be needed to authenticate users. Such systems may include technology such as smart cards, hardware tokens or independent agencies that provide digital signatures or certificates to confirm the identity of PHR users. To maintain privacy, people need mechanisms that will allow them to specify what parts of their PHR will be shared with specific providers and institutions.

Sally Manages Her Diabetes Using Online Monitoring Tools and Electronic Communication with Her Doctor

PROBLEM: Adverse events that results from manual systems used to track and support patients with diabetes. Achieving high quality, cost effective, patient centered monitoring of diabetes between doctor visits, while educating and supporting patients in their daily activities.

SOLUTION: An electronic Personal Health Record (PHR) with specific service features that allow self-management of personal and family conditions, immunizations, medications, test results and other personal health information. Additional services allow patients to print or fax information from the PHR to new physicians, or share the information electronically with their existing physician. This saves the patient and the health care system time and money.

Sally is a diabetic who makes every effort to manage her condition. Each day, she uploads her blood glucose monitoring data to her PHR. An automated alert tells her when her blood sugar level is too low. The system automatically sends Sally patient education materials that are related to her condition. It also sends reminder messages for her to verify that her medication list is complete and accurate. When Sally adds to her record that she has begun taking aspirin, an automated alert notifies her that this may contribute to low blood sugar.

After receiving this alert, Sally uses the PHR to communicate electronically with her doctor. She sends a copy of her blood glucose graph in a secure electronic message and asks whether she should stop taking aspirin. The doctor electronically replies that Sally should continue taking aspirin, but cut her dosage of Glyburide in half. He also recommends that she have her Hemoglobin A1c re-checked, and attaches patient education materials for her to read.

As Sally continues to monitor her cholesterol and blood sugar, she notices that her glucose level is trending higher, and asks her doctor what to do. He reviews her combined visit history by accessing the parts of the PHR that Sally has made available, and sees that Sally recently had a steroid injection. The docto88r e-mails to say that the injection could be causing the elevated blood sugars, and recommends that Sally continue to monitor herself closely and send her latest blood sugar readings in three days.

Sally's PHR also allows her to receive lab results electronically via the Web. After receiving results that her cholesterol is high, Sally uses information contained in the PHR to educate herself about cholesterol management, even before she sees her doctor.

Story – Douglas E. Goldstein. Adapted from PHWG presentation, June 5, 2003.

At the same time, emergency room personnel need to be able to access a patient's PHR when necessary. PHR systems need to allow them to "break the glass" to view the information stored in the PHR when the patient is too incapacitated to provide explicit permission. Such access needs to be audited and reported to the patient or caregiver to make sure it is appropriate.

Caregivers can be more effective in helping a loved one manage their care if they have access to a PHR. This is especially important for children, the elderly and others who might be unable to use computer technology or make health care decisions for themselves. PHR systems should permit a patient to grant another person full access to their own PHR in these situations.

The person-centered nature of PHR poses some issues for data integrity. The sources of data in the PHR must be identified and the system must include mechanisms for correcting errors or inconsistencies. Patients may inadvertently introduce inaccurate data directly, or create inaccuracies by editing data that comes from elsewhere. Since the PHR may not be complete, it should not be the only tool for transferring data from one doctor to another, although it will certainly help streamline the process of data transfer. PHR data exchange standards will need to include ways to identify incomplete or censored data so that recipients will be aware of data limitations.

Survey Results

59% of respondents would like to use a PHR to look up their parents' medical information either now or in the future.

44% of current caregivers would like to do this now; another 26% would like do it sometime in the future.

There is no clear business model to encourage development of PHR. Although many people like the concept of a PHR, they have not yet expressed a willingness to pay for PHR services. Since the PHR is cross-institutional, there is no clear market advantage for a single organization to house a PHR repository. Likewise, there is no obvious source of funding for the inter-institutional linkages that would allow data to flow into and out of the PHR at the patient's request. Until a critical mass of patient and institutional PHR users provides a sufficient network effect, there will be no incentive for individuals and institutions to devote the resources to collaborate.

The PHWG is concerned that the PHR may initially be available to more affluent patients and those affiliated with advanced integrated health systems. Patients with lower incomes and

lower levels of literacy, especially people of color, bear a disproportionate burden of disease[12], but are less likely to have experience with or access to the Internet[13]. In addition, people of color and those with lower income and literacy levels are less likely to have access to health care, a regular physician, and overall receive lower quality health care when they do have health insurance[14]. Finally, people of color and those less educated are less likely use the Internet to search for health information online as compared to affluent whites[15]. Taken as a whole, this research implies that it is possible that those people who could most benefit from a PHR – i.e., those in the poorest health and with the lowest access to a regular source of health care – may be the least likely to have access to a PHR. Devoting resources to supporting the PHR could potentially divert resources from the underserved only to produce marginal benefits for those who already enjoy good care. Over time, however, experience with the Internet is becoming increasingly common in all strata of society, and inequities in access to and the value of the PHR should become less problematic.

Finally, the PHWG discussed some unresolved issues regarding the effects of integrating the PHR into medical practice. Some working group members perceived that the PHR would create new demands on providers even though there is no evidence that indicates this is the case. They also speculated that more informed people might expect their doctors to assist in interpreting and acting on information that became available from sources other than that physician. Second, the flow of information and the authority to view it raises unresolved questions related to the policies and procedures for PHR use. Transfer of worrisome test results (such as HIV status or pathology reports) directly to the patient may need to be put on hold until the doctor can review them and help the patient interpret them. Psychiatric records may need to be embargoed, as they can be burdensome and counter-therapeutic for the patient to read. Doctors may have acquired and charted sensitive information – for example, provided in confidence by family members – that should not be accessible to the person's PHR.

[12] Collins, K. S., Hughes, D. L., Doty, M. M., Ives, B. L., Edwards, J. N., & Tenny, K. (2002). Diverse communities, common concerns: Assessing health care quality for minority Americans. Commonwealth Report #523
[13] Spooner, T., & Rainie, L. (2001). Hispanics and the Internet. Pew Internet and American Life Project.
[14] Collins, K. S., et. al, Commonwealth Report #523.; Health Resources and Services Administration (2002). Fact Sheet: Expanding access to health care. U.S. Department of Health and Human Services. Accessed online August 7, 2003 at http://newsroom.hrsa.gov/factsheets/access2002.htm.
[15] Fox, S.,& Fallows, D. (2003). Internet health resources: Health searches and email have become more commonplace, but there is room for improvement in searches and overall Internet access. Pew Internet and American Life.

V. WHO – Users and their Attitudes toward Personal Health Records

The individual person is the primary user of the PHR. That person may allow access to all or part of the PHR to anyone - a doctor, family member, employer, summer camp or insurance company - indefinitely or for a set period of time. Other potential PHR users are "stakeholders" who, when the primary user of the PHR gives permission, can make valuable use of the information kept in the PHR. In addition to the individual user, doctors and hospitals may benefit from having quick, inexpensive access to medical information. Employers and insurers may be better able to evaluate and reward high-quality care by looking at aggregate de-identified data. Researchers and advocacy organizations can use it to assess patterns of disease and treatment across the health care system. Public health officials may be able to detect disease outbreaks. The government and society as a whole may see significant gains in efficiency as more medical decisions are based on current and accurate information. All of these benefits can result from individual users' willingness to share selected de-identified health information with the stakeholders mentioned above. Potential stakeholders include:

Care Providers

- Primary care providers
- Medical specialists
- Emergency department staff
- Hospital and clinic staffs
- Alternative care providers
- Employers
- Schools
- Home health care providers
- Nursing homes
- Pharmacists
- Medical equipment providers
- Disease management companies/care management programs
- EMT/paramedics
- Public health care providers

Administrators

- Payers
- Health Plan administrators
- Hospital administrators
- Employers

Researchers and advocates

- Patient advocates
- Health services researchers
- Quality improvement/outcomes researchers
- Biomedical researchers

Public health professionals
- Community health agencies
- State, county and federal health agencies

Vendors & application developers

Employers and employer coalitions

Government Agencies

PREVIOUS RESEARCH: CONSUMER ATTITUDES TOWARD PERSONAL HEALTH RECORDS

A significant percentage of Americans look for health information on the Internet, with estimates ranging from 40 to 80 percent.[16] This number is likely to grow as younger people use the Internet more and grow up with it as a viable source of information.

The PHWG conducted a literature review of recent research regarding consumer experience with or opinion of electronic health records. Some studies focus specifically on Americans' concerns about privacy and security on the Internet when looking for health information. Although *66 percent of online health seekers are "concerned" or "very concerned" about privacy* on the Internet, this usually does not prevent people from accessing health information[17]. Of those who report never having looked for health information online, only 17 percent of them state that this is because of privacy and security concerns. Overall, *older* Internet users tend to be *less trusting*, and Asian-Americans show the highest level of privacy concerns (74 percent), followed by African Americans, Hispanics and then Whites.[18]

Research focusing more directly on consumer attitudes towards keeping medical records online is scant, but slowly growing. Currently, only six percent of the population has access to their medical records online.[19] Generally, consumers seem to be wary about the general concept of PHR; *63 percent of health seekers* and 60 percent of all Internet users think that

[16] Wong, N. Consumers demand combination of "high tech" and "high touch" personalized services to manage healthcare needs. Harris Interactive, 2001 & 2002. Safran, C. Electronic medical records: A decade of experience [perspective]. msJAMA 2001; 285(13): 1766. Fox, S, Rainie, L. (2000). The online health care revolution: How the Web helps Americans take better care of themselves. The Pew Internet & American Life Project.
[17] Cyber Dialogue (2000). Ethics survey of consumer attitudes about health Web Sites. California Health Care Foundation.
[18] Fox, S. Rainie, L., Horrigan, J., Lenhart, A., Spooner, T., Carter, C. (August 2000). Trust and privacy online: Why Americans want to rewrite the rules. The Pew Internet and American Life Project, Washington, D.C.
[19] FirstHealth, Harris Interactive (2002). Consumer Health Benefits Survey: Executive Summary. FirstHealth.

"*putting medical records online" is a "bad idea,"* even if the records are on a secure password protected site.[20] A significant minority of people (38 percent of Internet users) state that they would access their medical records online; 40 percent would not because of privacy and security concerns. Among those who do not currently keep their medical records online, 21 percent are very likely, 23 percent are somewhat likely, 17 percent are not too likely and 37 percent are not at all likely to do so in the future. Two percent of respondents said that they did not know if they would access their medical records online.[21]

Privacy and security concerns seem to be the major factors behind consumers' hesitancy towards adopting a PHR; a majority of consumers in the Harris/FirstHealth study (58 percent) believed that "computerized access to medical records will threaten the privacy of people's health information" while only 36 percent agreed that "computerized access to medical records will give people greater access and control over their own health information".

Two studies found demographic differences regarding keeping medical records online. About *70 percent of people aged 25-34 want online access to their medical records while only 35 percent of those over 65 do*.[22] Somewhat paradoxically, those people in "poor health" are less likely to be concerned about keeping their medical information online than those in better health.[23]

Despite general concerns about keeping medical records online, studies show that consumers still recognize the benefits that such a PHR could offer. When asked about specific aspects of a PHR, consumers react very favorably to the idea of having online access to their medical information:

- 83 percent of healthcare consumers want lab tests available online (Harris)
- 69 percent want online charts for managing chronic conditions (Harris)
- 80 percent want to receive personalized medical information online from their doctor after an office visit (Harris)

Ross[24] surveyed patients with congestive heart failure who expressed an interest in using a patient-accessible electronic medical record to assess their beliefs about the benefits and concerns regarding patient-accessible electronic medical records:

[20] Cyber Dialogue (2000). Ethics survey of consumer attitudes about health Web Sites. California Health Care Foundation.
[21] FirstHealth, Harris Interactive. (2002).
[22] Institute for the Future. (1998). Executive Summary: Twenty-first century health care consumers. 1998 Health Care Horizon program report. Institute for the Future.
[23] Cyber Dialogue (2000). Ethics survey of consumer attitudes about health Web Sites. California Health Care Foundation.
[24] Ross, S.E., Lin, C.T., Earnest, M.A., Wittevrongel, Loretta. Providing patients access to online medical records: a comparison of physician and patient expectations. University of Colorado Health Sciences Center, Denver, CO.

Benefits

- 89 percent of patients believe an online medical record would help them prepare for appointments
- 68 percent believe a PHR would increase trust in their physician
- 89 percent believe a PHR would increase patient understanding
- 85 percent believe a PHR would clarify physician instruction
- 89 percent believe a PHR would reassure patients
- 76 percent believe a PHR would improve compliance

Concerns

- 16 percent of patients believe lab data in a PHR would confuse them
- 5 percent believe a PHR would make patients worried
- 3 percent believe patients would take offense after viewing a PHR

Control of one's PHR is another critical issue. The vast majority (78 percent) of Internet users say it is important that a PHR site allow them to see who has access to their profile; another 78 percent want the user to be able to make choices about how their personal health information is used[25].

Carol Uses a PHR to Manage Health Data for Her Children

PROBLEMS: No easy way to efficiently transfer medical information from one physician to another after an out-of-state move. Photocopying medical history data is not efficient and doesn't support quality health care. There is no clinically effective way to manage the medical histories, lab results and physician encounter data for an entire family.

SOLUTION: A PHR with convenient, secure, interactive, features that includes a medical history repository, automatic data transfer/update system and multi-media medical resource center.

Carol, her husband and their daughter Kristin have just moved to a new city. Prior to the move, Carol transferred the family's medical information into an online PHR. Once the family has settled in to their new home, Carol uses the PHR's physician-finder tool to search for a new pediatrician in the area.

After being presented with three physicians that match her preferences, Carol reviews an audio-video profile of each and selects Dr. Mary Winkle. Still online, Carol connects directly to Dr. Winkle's Doctor-Patient Web service, completes registration online and schedules an appointment through an automated Web interface. This information is then electronically transmitted into Carol's electronic Web-based PHR, and integrated with the Outlook Calendar in her computer.

To prepare for Kristin's appointment, Carol populates Dr. Winkle's health risk assessment and new patient history form by electronically transferring data from the family electronic PHR. Based on the pre-existing conditions entered, the Doctor-Patient Web Service automatically e-mails links to educational videos about managing Kristin's ADHD, as well as about fostering healthy eating habits for kids 5-10.

On the day of the appointment, check-in is simple. An electronic eligibility check by the office staff indicates that Kristin's office visits and in-office lab tests will be covered. Staff also informs Carol that they have successfully tested the e-connection between the office and her PHR which means that relevant portions of the medical record at Dr. Winkle's office will be automatically transmitted.

After examining Kristin, Dr. Winkle provides suggestions about managing her ADHD through dietary changes. She also e-mails Carol a series of resources, including online and offline support groups for moms with kids who have ADHD, and relevant regional Web sites.

When it's time for Carol to check out, her co-pay is deducted from her Cyber wallet and Dr. Winkle's staff sends a claim to her insurance company. Key information and lab results from the visit are electronically transmitted to Carol's PHR by the end of the day, at which point she updates the family's medical data repository.

Story - Douglas E. Goldstein

Note: This case study scenario is based on features used in demonstration projects of electronic PHRs from organizations such as: MyHealth eVet PHR and Secure eVAult – from the Veterans Health Administration; Web-based Personal Health Record project in Eastern Maine by Cerner Corporation; Computer Based Personal Health Record from CapMed Corporation and eCleveland Clinic – Personal Health Record and other applications.

[25] Cyber Dialogue, 2000.

Some current PHR projects have emerged from use of a paper-based personal health record, and their early findings provide some guidance for development of electronic systems. Tang (1998) evaluated a paper-based PHR provided to the patient following a doctor visit. The value of a paper-based PHR was rated as uniformly positive by patients because:

- it gave patients a *permanent record* of their health
- it provided them with *customer satisfaction*
- it helped them *adhere to therapy*

Overall, he found that patients with acute chronic conditions:

- want information accessible after a doctor visit
- want as much information as possible about their own health
- were open to the idea of having their medical information on the computer and focused more on the benefits for care than threats to privacy.

MedicaLogic (2000) piloted an online PHR system and reported that patients see *great value* in having access to their medical records because:

- they *don't have to remember* what was said during a visit
- they can *better prepare* for visits
- they can print out *relevant information* and give it to other doctors

After the completion of the study, 74 percent of participants said they would "definitely" use a PHR. They believed they could be more active in their care using the PHR tool and thought it would help increase their quality of care. Similarly, Masys (2002) piloted a PHR system and reported that all participants stated that having their medical records online was "valuable" or "very valuable."

The PHWG's review confirms that the public has significant concerns about Internet privacy and that Internet users want to be able to control their online medical records as much as possible. The public is unfamiliar with and uncertain about electronic health records, and older people are more hesitant than younger to use such a system. Findings also show that people in poor health may be more open to the idea of having their medical records online. None of the literature reviewed addressed a correlation between socio-economic status and interest in using an electronic health record. When asked about specific aspects of a PHR (e.g., accessing test results, personalized medical information, charts for managing their

health), consumers respond more favorably to the concept of keeping their medical records online.

CURRENT CONSUMER ATTITUDES TOWARDS PERSONAL HEALTH RECORDS

The PHWG literature review helped to identify perceived benefits and risks of online medical records, but did not provide enough information to identify possible early adopters, the relative value of various features and services or the likely size of the user population. Similarly, past research pointed to several public concerns, but did not help the PHWG to understand which population segments felt these concerns most strongly and to what degree they might affect adoption of PHR.

In order to address these remaining questions, the PHWG conducted focus groups with people who had experience with online medical records and administered a public opinion survey to capture the attitudes of the online public towards PHR.

Focus Groups: Sample and Methodology

> *"I have one concern in regards to, say, your insurance company … having access to your records and being able to deny you for what they perceive as a pre-existing condition."*
> ***- Focus Group Participant, Bangor, ME***

In March 2003, PHWG staff conducted six focus groups with 35 people in Bangor, ME and in the Boston metropolitan area. Participants had access to and varying levels of experience with one of three PHR-like tools that were offered to them through their medical groups. A semi-structured protocol asked participants about their experiences using these tools and their overall attitudes and opinions towards online medical recordkeeping. Focus groups were 90 minutes in length and participants received a gift certificate to a local business.

More women than men participated in the focus groups (11 men and 24 women), reflecting the general trend that women are more interested in health care issues and more active in health care decision making. Participants reflected a broad age range (late twenties to mid-seventies), though the average age of participants was in the late forties. At least four of the participants were retirees, the rest being full-time employees; seven were caregivers of parents (one father/daughter caregiving team came together) and seven participants talked openly about their own chronic illness. Approximately half of the participants had dependent children. The focus groups were not racially diverse.

Results

Participants liked the idea of keeping their medical records online but were disappointed in the functionality of the tools provided to them. On the positive side, participants liked the fact that they could e-mail their doctor, some stating that it was more private than a phone call. They also liked that once personal health information had been entered, it became part of their permanent record and therefore they did not have to remember it later. Participants also believed that storing personal health information would give their children access to a more complete family health history.

> *"I think that if they can hack into the public defense computers periodically, then some medical records system is going to be child's play. So I guess I'm a little callous about that."*
> ***- Focus Group Participant, Bangor, ME***

Participants mentioned other benefits including the notion that online records are more credible to other professionals than "my personal notes", and could be used for referrals and when changing doctors. The PHR-like tools helped participants keep track of their medication history, which was especially important for those with a chronic illness. Finally, they liked being able to store their children's personal health information (e.g., immunizations).

Participants criticized several aspects of the tools they had used, particularly their design and navigation. Participants stated that the tools were not user friendly; entering information was not easy, medication management was difficult and it took too much time to register their account (too many security questions). Their overarching critique was the impossibility of consolidating all of their medical records from different providers to document their entire health care experience; participants wanted their whole health care team involved and this was not the case with any of the tools available.

> *"I put my information in, but I had a hard time with it. The hospital doesn't use it. My doctor doesn't use it. So it's got some promise, but it's all promise at this point."*
> - ***Focus Group Participant, Bangor, ME***

Focus group participants did not express widespread concern about privacy and security but did voice frustration with the time and hassle it took to register and log into the system. No one stated that they were hesitant to use the system because of privacy and security concerns.

Participants reported a strong desire to have total control of their personal health information, wanting the power to decide who could and could not access their record and an expectation that they should provide explicit consent to any access. While participants, for the most part, indicated that access to their records should be granted to all doctors who care for them, family members designated by them, the hospital and the pharmacy for purposes of filling prescriptions, they did not want insurance companies, employers, wellness nurses at work, the Federal government, pharmaceutical and medical equipment companies or other marketing entities or legal professionals (for fear of online ambulance chasing) to have access to their records.

> *"I've heard other people's sensitivity about confidentiality. I share their concerns, but what was prominent for me is for them to know my information so they treat me well."*
> ***- Focus Group Participant, Bangor, ME***

Demographic Comparison with 2000 U.S. Census Data

	U.S. CPS	PHR Survey
AGE		
18-24	13%	12%
25-44	41%	42%
45-64	30%	24%
65 or older	16%	22%
EDUCATION		
Less than H.S.	17%	4%
HS/GED completed	33%	25%
Some college	27%	43%
College or more	23%	28%
GENDER		
Male	48%	23%
Female	52%	77%
INCOME		
Less than $15,000	11%	13%
$15,000 to $24,999	12%	14%
$25,000 to $34,999	12%	19%
$35,000 to $49,999	17%	20%
$50,000 to $74,999	21%	14%
$75,000 or more	28%	23%
RACE/ETHNICITY		
Caucasian	73%	77%
African-American	12%	7%
Asian	4%	4%
Hispanic	11%	14%

*Numbers may not add up to 100% due to

Participants believed that emergency room personnel should be able to access *part* of their record, but only what is necessary to treat them in an emergency. No matter who was allowed to view their personal health information, participants believed that their PHR-like tool should note who accessed their record and when.

Public Opinion Survey: Sample and Methodology

The goal of the survey was to capture a broad profile of consumer attitudes toward PHR. An online sample of 1,246 respondents was solicited via e-mail from a previously established panel of over 350,000 randomly selected and pre-qualified potential respondents; the survey was fielded online from April 29 through May 7, 2003. For the purpose of this study, "online medical records" were defined as "personal health information such as your 'medical chart' from the doctor's office, results from any diagnostic tests or routine medical screenings, and X-rays."

Respondents answered questions about their current use of online medical records, perceived benefits of keeping medical records online and issues of privacy and security regarding online medical record systems. To gauge their interest in online medical records, the survey asked about 15 different features of an online medical record and if respondents were: (1) interested in using that feature now; (2) interested in using it sometime in the future; (3) not interested in using it because of privacy and security reasons or (4) not interested in using it for some other reason.

Respondents were recruited and invited to participate such that the sample's age, race and ethnic representation approximated 2000 U.S. Census figures. The final sample was disproportionately female, and not representative of education and income levels. To adjust for these demographic discrepancies, the data were weighted to match census figures. The results of the survey did not change significantly (no data point changed by more than 3 percent, and these changes did not effect significance test results), so the unweighted sample results are reported here.

Results

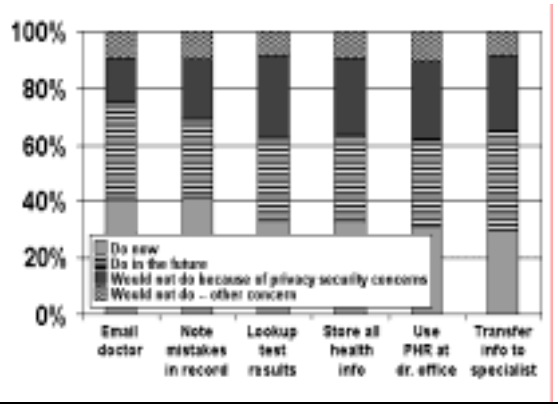
> *"Whoever medically treats you, you want them to have all the information. They would better understand your medical condition."*
> - ***Focus Group Participant, Welleslev. MA***

Currently, respondents do not use online medical records, although 40 percent keep some paper medical records at home, and the majority feels that it should "do a better job" of keeping medical records.

Only 1.5 percent of respondents manage their health records on a computer, and an additional .5 percent maintains their records online.

Despite few respondents actually keeping their medical records online, many expressed interest in doing so. Over 60 percent of respondents are interested in using at least one feature of an online medical record now or sometime in the future (Figure 1). Additionally, 35 percent of respondents say they would use a complete online medical record (i.e., using seven or more of the suggested 15 tools) if it was available to them today.

Figure 1 - Sample PHR services people would use

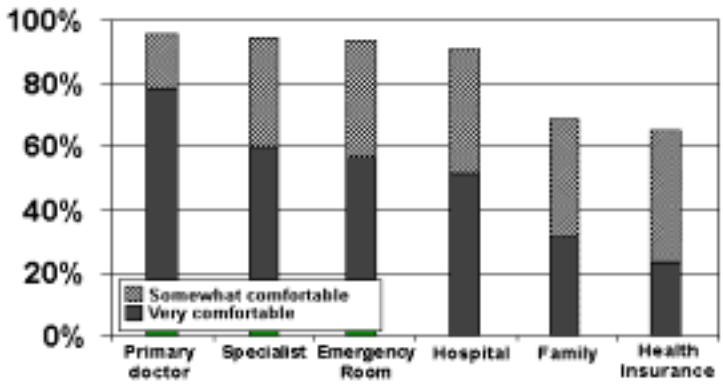


Respondents did indicate some concerns about the privacy and security of online medical records, though this concern was somewhat qualified. Almost all (91 percent) respondents said that privacy and security of their online medical record would be *very* important to them. However, only 7 percent of respondents said that they would not use *any* of the fifteen features of an online medical record because of privacy and security concerns. Only about 25 percent of respondents said that they would not use a complete online medical record tool because of privacy and security concerns.

> *"I would be more proactive in my own interpretation of things. I wouldn't just lay back and be an ostrich, so to speak."*
> ***- Focus Group Participant, Newton, MA***

Survey respondents wish to control their medical record and the access to it. Although the majority of respondents stated that they were comfortable with other parties accessing their medical record *after they had given explicit permission*, they expressed more concern with some than others (Figure 2).

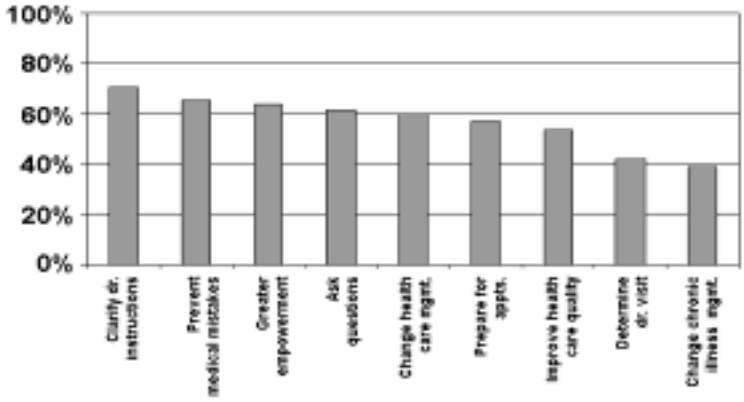
Figure 2 - Allow use of PHR by:



Respondents were most comfortable with allowing care providers to access their medical record (primary doctor - 96 percent; specialist - 95 percent; emergency room – 93 percent; hospital – 91 percent), and less comfortable with the idea of family members (69 percent) and health insurance companies (65 percent) having access. Similarly, respondents overwhelmingly stated that they would prefer to have their doctor's office host the online medical record tool (58 percent stated that this was the most desirable host); their health insurance plan came in a distant second (15 percent) as the next most desired provider and the government was third (12 percent).

Survey respondents reported that online medical records could help improve their health care experiences (Figure 3). A strong majority (71 percent) believed that having access to their online medical records would help clarify their doctors' instructions after an office visit; 65 percent believed that having their medical records online would give them a greater sense of empowerment regarding their health. Respondents also believed that an online medical record tool would improve health care quality (54 percent) and help prevent medical mistakes (65 percent).

Figure 3: PHR effects



Surprisingly, there were few demographic differences in attitudes toward personal health records. No differences were found based on age, income, education, or gender. Regarding race and ethnicity, Hispanics were generally more in favor of having medical records kept online than other ethnic groups. Respondents who indicated that they would be interested in using a PHR today (i.e., stated that they would use at least 7 of the 15 PHR features now if they were made available) were more likely to be chronically ill, frequent users of the health care system, caregivers for a sick relative and/or current e-health users.

Those people who were more likely to report being interested in PHR system now or in the future were caregivers and e-health users (Figures 4a & 4b).

Figure 4a: Who would use a PHR *today*

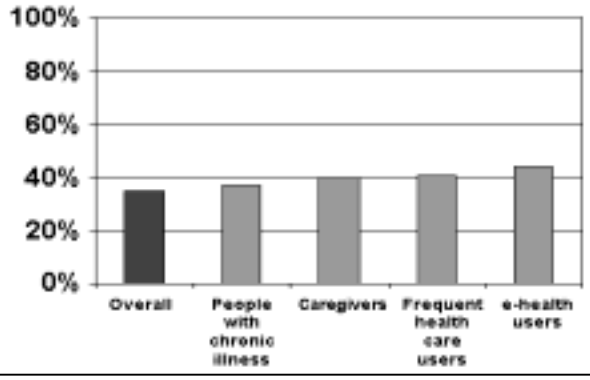
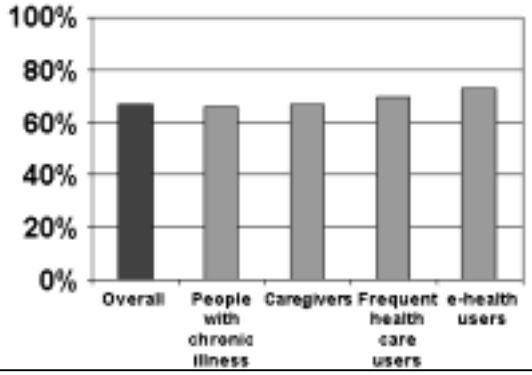


Figure 4b: Who would use PHR *now or in the future*



VI. HOW – Operationalizing the Personal Health Record Idea

COMMUNITY ARCHITECTURE - ESSENTIAL TO PHR IMPLEMENTATION

Fulfillment of the vision of PHR hinges on establishing a community-level architecture that provides an electronic blueprint for how data will flow to and from people and institutions enabling coordination at the local, regional or national level. The purpose of community architecture is to support user access to and interaction with his or her record.

The blueprint should incorporate rules relating to security and privacy, and reflect the agreement to share and use personal health information only with permission from individual PHR users. In addition, there are important design considerations relating to aggregation, analysis and storage of PHR data.

Principles of Community Architecture

The PHR community architecture should support the key PHR attributes. First and foremost, the individual owns and controls access to the PHR. Key elements include ready access to and control of PHR content, ability to store data over time, assurance of privacy and security and interoperability with other clinical and administrative systems. In addition, the architecture should be flexible enough to enable the PHR to work in any geographic location, and to send and receive data from multiple sites of care regardless of source of coverage. The architecture must permit the electronic transmission of data necessary to support the PHR, but it should also allow for alternatives that facilitate use of PHR information in locations that lack Internet access.

Survey Results

87% of respondents said it was *"very important"* to be able to control who saw their medical record.

62% of respondents said it was *"very important"* to be able to grant a person access to only parts of their medical record.

Features of the PHR Community Architecture

Certain core features need to be addressed in any PHR model, regardless of its sponsorship or configuration.

- Connectivity is required to permit scheduled and on-demand updates using data from disparate locations. The ideal vision of PHR relies on periodic updating and refreshing of

"If you go to a specialist, would the PHR input the information into your records? Then your own primary care physician would see the record right away and know what the other guy did for you."
- Focus Group Participant, Wellesley, MA

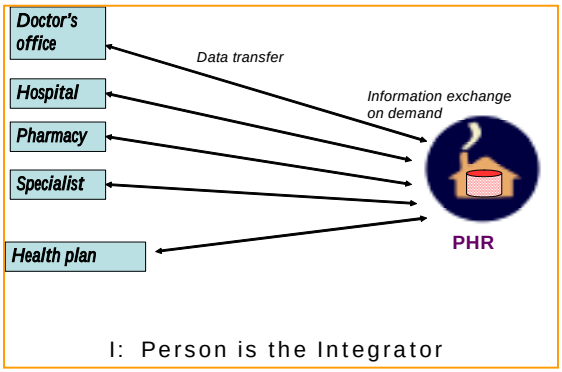
personal health information, as well as flexible access to the PHR from a variety of locations.

- Policies and processes are required to ensure security and to facilitate and authorize provider receipt and transmission of PHR data. Authentication is required to validate users, and the system needs to know who is accessing a given PHR and that person's authorization level. Procedures for ensuring security need to be embedded in the community-wide technology supporting the PHR architecture.
- Data integrity processes are necessary to ensure that the information transmitted to and stored in the PHR is accurate.
- Data models and transaction services are required to support aggregation and analysis of information within a PHR. Raw data alone will not be meaningful to PHR users. PHRs need to incorporate services that can translate and format disparate data from various sources into information that people can use to manage their health and health care.

Community Architecture Models

Taking these principles and features into account, there are several community architecture models in existence today that could support implementation of the PHR (see Appendix 2). There are important differences in resource requirements and capabilities across these models. In choosing the ideal model, a key consideration is whether individual users create and maintain the PHR themselves, or whether an intermediary organization facilitates people's access to their PHRs.

Model 1: Person is the Integrator - One community architecture model assumes that individuals make direct requests for data from health care providers and other sources, captures that electronic information in standardized form across the Web into a home computer application and remains responsible for establishing and maintaining the PHR themselves. Ideally, the PHR is automatically updated with new data supplied by various provider organizations on a scheduled basis or on demand.



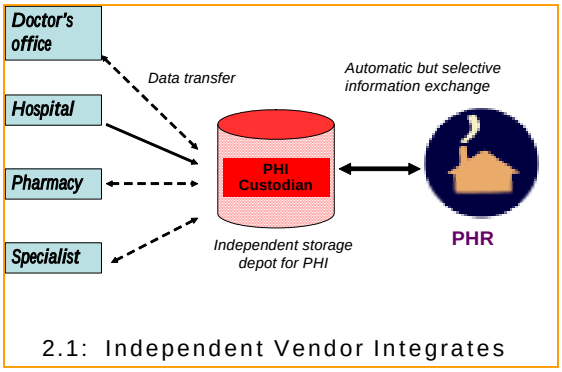
I: Person is the Integrator

This model might utilize a pre-formatted table structure that could readily store data by category (e.g., physician visits; amounts paid or reimbursed) and generate reports at the consumer's convenience.

Model 1 reflects the purest form of a consumer controlled PHR system, but it poses significant challenges given the diversity of provider and payer systems that would need to contribute and receive data. The reports would be valuable for a limited set of personal health management functions, the data would only be available for the individual's use and would be difficult to share with health care providers. Comparative analyses would require additional resources that could be linked to but reside separately from the individual PHR. Some form of authentication would be needed to ensure confidentiality, and security features would need to be built into the consumer and provider systems that transmit and receive PHR data.

Model 2 – A second community architecture model assumes that an intermediary helps collect and organize the personal health information in the PHR. Unlike Model 1, this type of architecture allows exchange into and out of the PHR. There are two major variations of this model:

Model 2.1: Independent Vendor Integrates – In this model, a sponsor establishes a central database through which PHR data is transmitted from data sources (doctor's office, pharmacy, lab) to the PHR and vice versa. PHR reports could be generated on demand or automatically at specified intervals from the central database for use by the individual user and, with permission, for use by providers and other trusted entities (e.g., child's school, pharmacy, specialist).

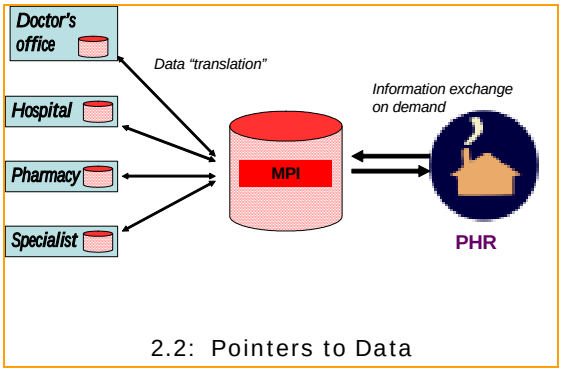


2.1: Independent Vendor Integrates

Model 2.1 makes it easy to collect data from a variety of sources on behalf of an individual. This model might be easier for people to use since they would not have to establish and maintain the PHR on their own; however, concerns could exist about the physical security of personal health information and the mechanics of enabling user control of all information releases. Additional research would be needed regarding people's trust and acceptance of a third party sponsored system. Providers would need to have the capacity to interface with

the system using community wide data standards or by means of "translation" protocols operated by the vendor.

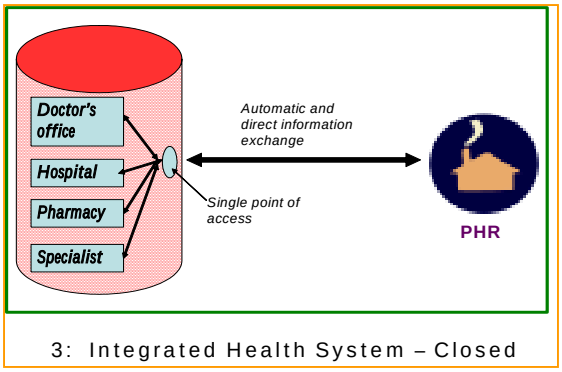
Model 2.2: Data Pointers - An alternative to the central sponsor model is to establish a repository of identifying information about an individual, rather than a centralized personal health information database, and a system to map the identifiers to all of the associated data sources in the community. In this model, reports are generated on demand, or at specified intervals, but the linked data is not retained in the system.



2.2: Pointers to Data

Model 2.2 has similar advantages to Model 2.1 in terms of consumer ease of access and use. Provider systems requirements are minimized since data is retrieved in whatever forms it currently exists. The application of clinical decision support tools and real-time analytical protocols across this distributed data environment could be cumbersome, and the compilation of longitudinal data would require each data supplier to follow common archiving protocols.

Model 3: Integrated Health System – In Model 3, the PHR is a direct by-product of an integrated information system established for a "closed" health care delivery system. Examples include staff model health maintenance organizations and the Veterans Health Administration's MyHealth*e*-Vet system. In this case, there are already or soon will be information systems designed to support all facets of health care delivery and payment within the system. The PHR in this model is generated as a subset of the data collected through the "closed" system.



3: Integrated Health System – Closed

Model 3 might represent the least burden to the user, by reducing the need to identify and interact with multiple information suppliers. It provides a formal structure that facilitates clinical integration and care coordination for individual users and the enrolled community. On the other hand, these closed systems of care are not universally available or desired. Members of such systems often utilize services and providers that are not part of the system, necessitating additional steps in the process to ensure that both clinical and personal health

information is complete. Model 3 could support a longitudinal record, but it would only be valid and complete as long as the individual maintained their membership or affiliation in that system. Finally, the closed system would need to invest significant resources to build and maintain the clinical information infrastructure that would feed the PHR.

DEVELOPING AND MAINTAINING THE PHR COMMUNITY ARCHITECTURE

Personal health record technology cannot exist without cooperation and data exchange among many providers across a community and even the nation. While several early models of the kind described here are already in operation, several additional issues need to be addressed in order to advance large scale PHR implementation. The following reflect the PHWG's discussion and should be considered a starting point for further public deliberation.

- Some structure of governance or administration is implicit to most of the community architecture models described above. Diverse organizations will need to agree on protocols for patient identification and data transfer, data standards, rules for authentication, access, and data maintenance, and so on. The PHWG did not specify a particular governance model for the PHR "system" but this will need to be addressed as models are developed and implemented. Regardless of the model, PHR users should be included in the design and decision-making process.
- The PHWG recognizes that people place a high value on controlling their personal health information, and that access to this information should be limited to authorized uses and users. The security of systems that collect and transmit personal health information is also a great concern. Information technology provides many features and tools that can enhance the security of PHR, but there may be additional costs associated with these measures.
- Health care providers currently use electronic records for a variety of different reasons, many of them compatible with the community architecture models described above. The models recognize that health care may be delivered in a decentralized fashion, but it is evident that an efficient and effective community architecture model requires greater standardization of data models and definitions.
- Additional work is necessary to clarify the benefits, costs and risks associated with community architecture models. As outlined above, community architecture models require resources to develop and maintain. Further analysis on these issues will advance the development and adoption of PHR by individuals, health care providers and potential PHR intermediary organizations.

POLICIES NEEDED TO FACILITATE PHR ADOPTION

Federal health policy has historically focused on coverage for selected populations, regulation of some therapies and, more recently, on patients' rights and privacy concerns. Although the PHWG did not evaluate specific legislation or policy proposals, it recognized that widespread adoption of PHR depends on federal policies that support the PHR attributes and architecture models defined in this paper. In turn, broad adoption of PHR could help improve the effectiveness of other health policies.

- Privacy: HIPAA – the Health Information Portability and Accountability Act, which took effect earlier this year, includes the first federal privacy standard to protect patients' medical records and other health information. It guarantees people access to their medical records and provides more control over how their personal health information is used and shared. Since HIPAA includes provisions encouraging electronic transactions and requires new safeguards to protect the security and confidentiality of health information, it certainly supports the PHWG's vision of PHR.

> Survey Results
> 62% of respondents would release their unidentified medical information to improve health care quality.

- National infrastructure: In January 2002, the National Committee on Vital and Health Statistics, which advises the US Department of Health and Human Services (HHS) on health information policy and HIPAA, published a consensus vision of the national health information infrastructure (NHII) along with recommendations for its development.[26] The NHII is envisioned as the technologies, values, practices, relationships, laws, standards, systems and applications that support the delivery of health and health care related information to people when and where they need it, so they can use it to make informed decisions. The personal health dimension of the NHII is as important as the clinical and public health dimensions, and facilitation of information across these three dimensions is imperative. The NHII includes a personal health record that is maintained and controlled by the individual or family. The NHII is intended to help improve access to health information, facilitate the tracking of lifetime health history, remind people about appointments, improve patient-provider communication, offer decision-support and increase personal involvement in health and health care management.

> *"Information is life. Information makes everything possible and I think the more places that the information can go, to establish a database, the quicker they're gonna spot different kinds of health problems around the state, different areas."*
> ***- Focus Group Participant, Bangor, ME***

[26] http://ncvhs.hhs.gov/nhiilayo.pdf

Public-private collaborative efforts to promote the NHII were launched in 2002, including the e-Health Initiative (http://ehealthinitiative.org) and the Markle Foundation's *Connecting for Health* initiative. In 2003, HHS began to take steps that lay the groundwork for the NHII.[27]

- Data standards: A key policy consideration supported by the PHWG and included as one of the PHR attributes is the development, promulgation and adoption of data standards to facilitate information exchange. Data standards are the protocols designed to support common ways of defining, storing and exchanging health information among the myriad EMRs and PHRs currently in use and in development today. The concept of interoperability was defined by the Data Standards Working Group of Connecting for Health as ensuring the "rapid flow of secure, private and completely digitized information about all facets of patient care, ranging from common administrative tasks to rarefied clinical minutiae." [28] In March 2003 the Departments of Health and Human Services, Defense and Veterans Affairs announced the first set of uniform standards for the electronic exchange of clinical health information to be adopted across the federal government. The three departments are coordinating with other federal agencies to implement standards across all federal health information systems as part of the Consolidated Health Informatics (CHI) initiative. These same standards were agreed upon by the Steering Group of *Connecting for Health* in September 2002 indicating broad support by many constituencies in the health care community.
- Payment to providers for EMR adoption: The Centers for Medicare and Medicaid Services (CMS) and other agencies are exploring various models for moving beyond fee-for-service payment, which has historically failed to support adoption of innovative clinical and administrative practices. CMS is interested in ways of compensating "non-visit care", in creating incentives for adoption of EMR and CPOE, and in bundling appropriate services together that support coordinated care for complex and chronically ill patients. Current legislation proposes requiring or encouraging e-prescribing as part of Medicare reform, and could provide a platform for a "thin" personal health record that enables people to manage their medications online. Any of these developments can help accelerate movement towards Personal Health Records, and PHR innovators should participate in these payment designs to ensure

[27] http://hhs.gov/news/press/2003pres/20030701.html
[28] http://www.hhs.gov/news/press/2003pres/20030321a.html.

that they create an environment which rewards movement towards patient-centered care and information sharing.

- Federal agency leadership: The Veteran's Health Administration and Department of Defense have been early adopters of system-wide EMR, and are moving rapidly to allow patients to access their records on-line. They will continue to be leaders in designing, deploying and evaluating the features of PHR discussed here. These agencies may also be able to accelerate PHR adoption by developing de facto data and communications standards, software applications or patient-side tools and making them available in the public domain for others to use at low cost. Many veterans receive significant health care services from non-VA providers, so as the VA creates community interfaces between its internal systems and others', it may also provide leadership to the design of common identifiers, data integration algorithms and applications that run against such consolidated data sets. Finally, these public agencies can serve as national research laboratories, documenting both the costs and benefits of PHR implementation, and exploring the larger ramifications of widespread PHR use, such as development of error or public health surveillance systems and disease and outcomes registries. The government should have an active program of communications and outreach based on findings from these important programs, including site visits, publication of best practices, and distribution of methods, tools, and algorithms on the web.
- Possible policy impact of PHR adoption: In a world where PHR were fully developed and widely adopted – equivalent to the use of bank ATMs today – a number of health policy issues could be affected.
    - Today, both the Medicare and Medicaid programs – and the dual eligible programs – are seeking ways to support chronic care management without requiring an HMO financing model. Interoperable EMR and connected PHR would establish a mechanism for virtual coordination of care as well as non-obtrusive, patient-centered audits to monitor outcomes and avert fraud.
    - Today, Congress is evaluating mechanisms to reduce medication error and transaction costs, particularly in the context of a Medicare prescription drug benefit. PHR would enable patients –and intelligent rule-based software – to monitor medications and be alerted for possible problems.
    - Today, FDA is increasing its attention to monitoring device and drug problems, but continues to rely on voluntary provider reporting. PHR would enable patients to detect and report medication and device problems.

- Today, CDC is building the NEDSS system to facilitate national public health surveillance and is giving new attention to infectious disease surveillance. PHR would provide an inexpensive and comprehensive way to capture patient reports of such problems.
- Today, the federal government is seeking ways to address substantial disparities in care provided to urban and rural populations, low-income groups, and state-by-state variations. A PHR platform would provide a way for patients to access and consider best practice recommendations from professional societies and institutes and provide a check on supplier-induced utilization.

VII. WHERE – Personal Health Records: Yesterday, Today and Tomorrow

PHR YESTERDAY - A BRIEF HISTORY OF INTERNET-BASED PERSONAL HEALTH RECORDS

Online medical records first emerged in the mid to late nineties as patient maintained, stand-alone, Internet-based, tools [Sittig, 2001] designed to provide an online "shoebox" or "vault" for people interested in maintaining an electronic copy of their personal health information. Most of these tools disappeared as the majority of dot coms, their parent companies, went bankrupt. A key reason for their demise was that individual users, as well as other stakeholders, would not enter data into a computer system without significant short-term, readily apparent benefits. One purported benefit of these tools was the ability to treat patients in emergency departments far from their home. Upon searching a person's pockets, emergency staff would find a card that contained a URL, or in some cases a telephone number to an automatic fax back system, that would allow them to quickly access online personal health information and thus prevent the administration of a drug to which the person was deathly allergic. However, it proved easier and less expensive for people to carry a card with their medication lists and diagnoses in their pockets.

In addition to these stand-alone "shoebox" applications there were several different versions of single condition (e.g., MyAsthma or MyDiabetes) disease management applications that encouraged patients to enter very detailed information pertaining to a single chronic condition. While such applications appeared to provide some immediate benefit to users, simply offering people a means of recording information on a daily basis does not make them better managers of their health and health care. Without a clinician on the other end of the application continually providing advice, making modifications to prescriptions or otherwise providing them with some ideas to help them better manage their condition; these systems were doomed to fail. Several of these types of sites did provide users with access to health care providers either by e-mail or online support groups, but the vast majority of users never had any clinician contact.

Of the 27 PHR-like tools identified in a November 2000 study [Sittig, 2001], only seven (26 percent) were still accessible in May 2003. The main reason for this high rate of failure was the lack of a sound business model for these systems. Specifically, people were not willing to pay to use these systems. While some early PHR developers were able to convince large,

self-insured employers to pay them a small "per user" fee to allow their employees to take advantage of these tools, people were afraid that their employers would "find out" about their health condition(s). While such fears are not unfounded, self-funded employers already have nearly total access to their employees' medical information by the simple fact that they are the payors for their medical care.

Another business model that was tried involved the sale of de-identified, aggregated, clinical data collected from the tools to large pharmaceutical companies. Perhaps the single most important reason these efforts failed was that large clinical information system vendors realized that they had similar access to much "higher quality" clinician-entered data from the clinical systems they had installed across the country. Once this "verified" data became available, the pharmaceutical manufacturers quickly lost interest in the person-entered health information.[29]

A key outcome of the failure of these stand-alone "PHR-like" tools was the subsequent rise of secure, Internet-accessible, on-site, database controlled electronic messaging. Unfortunately, these vendors quickly learned that to be successful they had to enroll individual providers or entire health care systems to insure that they would agree to receive and respond to messages from their patients. Currently, several large health insurers have agreed to pay providers to participate in these online exchanges under the assumption that by enabling patients to send messages they will reduce telephone calls, or even more importantly, office visits. While there is some evidence to suggest that this may be true[30], there is as yet no definitive proof that such savings will accrue.

Another key outcome was the realization that one's personal health information could be used to support the search for relevant patient education materials. Several clinical information system vendors have subsequently begun working on systems to automatically provide customized information for patients[31].

Many of the first generation personal health record products, lacking a viable business model, met a rapid demise. On the other hand, these systems have imparted valuable lessons including:

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[29] SunClinical Data Institute - www.sunclinical.com
[30] Final Results: WebVisit study finds RelayHealth reduces cost of care while satisfying doctors and patients www.relayhealth.com/rh/general/news/newsrecent/news39.aspx
[31] Information Therapy -- www.informationtherapy.org

- By adopting EMRs providers and health care delivery system can facilitate the development and implementation of PHR tools.
- PHRs should offer clear benefits to users and critical stakeholders.

PHR TODAY

The current generation of Internet-accessible PHR-like tools is almost exclusively owned, controlled and maintained by large integrated health care delivery networks (IDNs) for the exclusive use of the patients they serve in an effort to reduce their overall costs. As such, these IDNs are responsible for deciding what information goes into these tools, when it goes in, how long it will be available and who can access it. While such systems are certainly a step forward in providing people access to their medical information as is now required by law [HIPAA, 2003], they do not represent the "ideal" PHR systems as defined in this report. Current approaches are focusing on:

- Providing people with secure electronic messaging with health care providers[32]
- Facilitating the process of obtaining recent laboratory test results[33]
- Allowing people to request prescription refills to be mailed directly to their homes[34]
- Enabling people to schedule and cancel appointments[35]
- Developing online behavioral modification tools (e.g., depression[36], smoking cessation[37] or weight loss[38])
- Providing people with access to trusted medical information[39]
- Encouraging people to participate in moderated online support groups[40]

Currently the key challenges in developing PHR tools include:

- Accurately identifying users of the system and providing them with usernames and passwords in a secure manner that does not add additional work for providers.
- Deciding what information from the provider's electronic medical record should be included in the PHR. For example, should all laboratory results or only the normal values be made available?
- Determining whether people should be allowed to "annotate" the information in their PHR.
- Providing access to authorized caregivers (e.g., parents of minors and children of older parents).

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[32] HealthyEmail -- www.healthyemail.org
[33] LabDat -- www.labdat.com
[34] Prescription refills online -- www.kaiserpermanente.org/members/rxrefill.html
[35] Schedule appointments -- https://ssl-060.vianetworks.net/methodisthealth/online/appoint.htm
[36] Clarke G, Reid E, Eubanks D, O'Connor E, DeBar LL, Kelleher C, Lynch F, Nunley S. Overcoming depression on the Internet (ODIN): a randomized controlled trial of an Internet depression skills intervention program. J Med Internet Res. 2002 Dec; 4(3):E14.
[37] Lenert L, Munoz RF, Stoddard J, Delucchi K, Bansod A, Skoczen S, Perez-Stable EJ. Design and pilot evaluation of an internet smoking cessation program. J Am Med Inform Assoc. 2003 Jan-Feb; 10(1):16-20.
[38] Tate DF, Jackvony EH, Wing RR. Effects of Internet behavioral counseling on weight loss in adults at risk for type 2 diabetes: a randomized trial. JAMA. 2003 Apr 9; 289(14):1833-6.
[39] MedLinePlus -- www.nlm.nih.gov/medlineplus/
[40] Online Support Groups -- www.noah-health.org/english/support.html

PHR-like tools available today offer people views into their EMRs, online templates for entering personal health information, varied services including secure messaging with doctors and other health care providers, appointment scheduling, prescription refills and disease management programs. Today PHR-like tools are provided by a variety of entities including for-profit independent medical record vendors, health plans, medical groups; electronic record data collection systems and e-health Web sites (see Appendix 2). Probably no more than 250,000 Americans have access to such personal health record systems today. To understand the current state of PHR development, the PHWG staff interviewed individuals representing 11 PHR-like vendors. The results of the interviews summarize the vendors' perceptions of the goals of PHR, what providers and their patients want from a PHR, and the necessary contents and features of PHR including vendor recommendations and barriers to use.

Survey Results
Only 6% of survey respondents currently e-mail their doctors.

The PHR vendors interviewed agreed that PHR could serve five distinct goals:

1) To improve the provider/patient relationship.
2) To activate people to become better managers of their health and health care.
3) To create a better record keeping system for both providers and patients.
4) To close the information gap by providing complete personal health information to providers and patients.
5) To meet state regulations for improving continuity of care, where applicable.

Survey Results
42% of people in ill health would keep their medication list online now, as opposed to 30% of people who are in better health.

In designing their tools, the vendors took into account perceived consumer needs and desires as well as the current contents of paper based medical records. In general, the vendors interviewed believe that PHR should be sponsored and overseen by an entity that people trust such as a doctor's office, medical group or independent organization or company even though the applications might be built and maintained by commercial technology companies. The vendors also agreed that people are ready for an electronic record as opposed to the paper files their various providers have kept in the past. Above all, vendors realize that people will insist on privacy and security.

Vendors want to offer people access to all of their personal health information including medical history, lab results, medication and immunization lists, reminders of regular tests and screenings and clinical notes from their doctors. They hope to offer additional features and

services, including secure messaging or email between providers and patients, a "health at a glance" page, links to customized health information, and online tutorials or "help" sections on using the tool.

In planning for the next wave of PHR tools, vendors are considering where patient data should reside, who should supply the service (medical group, employer, independent nonprofit), who will pay for the service, who ultimately controls the medical record, and which information from the EMR should be transferred to the PHR.

PHR FUTURE

Standardization Efforts

Vendors, researchers, and PHWG members agreed that the future PHR must be able to be integrated with a standardized, interoperable network of EMR systems. Successful PHR efforts will have to build upon standards and protocols that are adopted and fully implemented by community providers, insurers and other key data suppliers.

Developers of data standards for PHR face several unique challenges. Standards developed primarily for EMRs do not recognize or anticipate all of PHR's potential benefits and objectives. For example, PHR users are likely to enter important health information that will gain value when interpreted alongside EMR data – such as self-administration of medications, monitoring of blood pressure or glucose levels, dietary or exercise information, or functional and symptom measures. Most of these concepts have not been standardized and algorithms for integrating, displaying or taking action on these data as they interact with EMR data are not available. Similarly, a standard way for people to note and communicate possible errors or conflicts in their record across the network will need to be developed. To ensure widespread adoption and use of PHR, PHR-specific standards should be identified.

PHR advocates face the difficult task of ensuring that standardization efforts include the health data and functionalities specific to the needs of diverse individual users. As such, new guidelines will need to be established for transmitting and maintaining information created by PHR users. Standards for sharing information will need to be developed for care settings inside and outside of traditional health care systems. This will require that PHR data taxonomy, syntax, architecture and communications protocols result in relatively easy and secure transfer of information between people and their various health care providers.

Early tests or pilots of PHR are needed to provide important guidance for initial efforts to define the essential data sets, standards and protocols required to support PHR. Compilation of results from such demonstration projects can also help assess the feasibility of achieving PHR's primary objectives and address potential implementation issues. Experience and knowledge gained from these pilot projects will also provide guidance for broadening PHR data sets and help expedite early adoption. Some form of clearinghouse would be valuable to capture and disseminate early findings and help implementers adopt common best practices.

Identifying the Content of the PHR

The data captured and managed by the PHR will include a subset of EMR information and will also contain data not available from any health care organization. As the concept of PHR is elaborated, developers will have to address several new questions:

- What data elements are essential to PHR?
    - What historical information must be acquired and stored?
    - What personal data is needed to support accurate patient identification?
    - What information is needed to accurately identify providers and health care organizations?
    - What standards must be developed to document and exchange self-reported data, such as diet or medication use data?
    - How should data provided by caregivers be recorded?
- How can clinical data be most easily acquired from the large number of small medical practices that lack substantial IT infrastructure or technical staff?
- How should data be captured and integrated from non-medical sources, including mental health, dental, and alternative providers?
- How should anticipated future PHR requirements influence current standards activities, such as HL7 or Consolidated Health Informatics initiative (CHI)?

Challenges for PHR's Future

Collaboration among health information providers

The development of the personal health record can be facilitated if health care organizations, physicians, and vendors adopt standards and work together on patient-oriented, community-wide initiatives. Historically, this kind of commitment has been rare and often short-lived. In the current environment, collaborative work on information systems appears as a new demand on resources with little short-term financial or clinical benefit. Advocates of PHR will have to address several challenges:

- Lack of widespread awareness of PHR benefits, challenges, or requirements
- Lack of proven financing strategy or demonstrated return-on-investment for implementation of PHR
- No published standard for data elements required to adequately reflect user interests, concerns and objectives
- Few communities have governance mechanism in place to coordinate regional data sharing
- Heightened concern about security and privacy issues under HIPAA
- Poor understanding of or experience addressing patient and consumer information needs.

Business requirements and considerations

The development of a viable business model is certainly one of the most significant obstacles to implementing PHR. Despite a growing awareness of PHR's potential benefits, a great deal of uncertainty exists about who will pay for its development and, once developed, who will pay for its use. An increasing number of health care stakeholders including providers, insurers, employers, health plans and non-profits are convinced that PHR should be part of the future health care landscape, but most believe that one or more of the other groups should finance the costs of PHR implementation.

This lack of general consensus about a PHR business model discourages allocation of funding to support its current development, conformance testing and implementation. Due to the significant time, resources and collaboration needed, no single stakeholder will be willing or able to cover the complete costs for development and implementation efforts. A viable business model for PHR might include several different payment options based on the different components of PHR's costs:

- Developing PHR client technology
- Convening community participants and developing working agreements, both technical and political

- Promoting public awareness and adoption of PHR
- Populating PHR with data
- Hosting and maintaining PHR
- Implementing added-value services into the PHR platform
- Monitoring and evaluating impact of PHR.

These business issues, in turn, will rest upon a set of stakeholder agreements regarding the purpose and value of PHR adoption. Community stakeholders will need to have a common understanding regarding:

- Who benefits from PHR? How do they benefit? How much value do they derive?
- Who is responsible for educating consumers about:
    - Implications of current record fragmentation
    - legal rights to privacy and access
    - tools and services available to help them manage their clinical records and other health information
- Who is most capable of developing and maintaining PHR systems and services?
- If there are multiple PHR systems and services to choose from, how will potential users know which PHR to trust? (Who will certify and monitor vendors?)
- How will PHR achieve acceptable balance across multiple objectives of adequate levels of privacy, security and convenience?
- How can PHR be made available to the groups that need it most?

Before the path for future PHR systems can be charted, answers to the many unknowns need to be based on demonstrated results. Demonstrating and quantifying the benefits of PHR will require collaboration from diverse stakeholders drawn from both the public and private sectors.

VIII. Conclusion

The Personal Health Working Group has offered a skeletal framework for the further development of personal health records in US health care. The PHWG agreed that:

- the individual person controls the PHR and access to it
- the PHR captures a lifelong health record from all sources
- the PHR is private and secure
- the PHR is accessible from any place
- the PHR enables information to be exchanged among providers
- the PHR is transparent and contains an audit trail.

Our review of public opinion and early patient experience provides strong evidence for the public's interest in gaining the benefits of PHR technology. Large majorities of patients and consumers indicate that they would use key PHR services as they are needed – when filling a prescription, sharing information with new doctors, understanding how to care for their own illness or helping a frail parent. If these valuable services become available, and if the PHR technology is managed by a trusted and responsible entity, few people regard privacy and security concerns as barriers to using the PHR.

The PHWG recognized that a successful PHR will only flourish as an information and communication tool in an environment where collaborating health care professionals and organizations manage health information electronically and use common data and communications standards. While there are a few regional initiatives that meet these criteria, the business and policy environment today does not reward organizations that commit time or money to the PHR model.

We complete our review of PHR with great optimism about the ability of PHR technology to improve health care and help people improve their own health – yet sober about the challenges that lie ahead. We can see the outlines of personal health records in today's innovative practices – the patient gateway services offered by some health systems, the local attempts at interoperability among EMRs, the integration of medication information by pharmacy benefits managers and industry consortia, the personal health tracking systems offered by Internet and IT vendors – but the policy and business climate does not reward collaboration or development of infrastructure. People want to be able to manage their personal health information, but the US health care system today has no way to provide a comprehensive and useful response. In the years ahead, a few critical actions will need to be taken:

- National agreement and adoption of data and communications standards
- Generally recognized protocols for correctly and consistently identifying patients, professionals, and institutions
- Financial incentives for adoption of EMR
- Widespread adoption of EMR by professionals and health care organizations
- Public and professional education about the value of personal health information
- Community collaborations that demonstrate interoperability
- Development of client (patient or consumer) applications to integrate and interpret personal health information
- Demonstration projects that document the value of PHR functionality for people in their daily lives
- Financial or policy incentives for participation in collaborative information infrastructure.

This is a daunting agenda. The participants in the Personal Health Working Group remain passionate about the opportunity to improve health outcomes and the health care system by enabling patients to control and use their health information. Health systems, technology companies, health professionals – and of course all Americans – will be essential partners in creating a twenty-first century health care system that takes advantage of the talents of informed and engaged people fully participating in their own health and health care.

IX. APPENDIX 1

Connecting for Health
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X. APPENDIX 2

PHR Tool Vendors Reviewed by the *Connecting for Health*
Personal Health Working Group

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