

CONNECTING FOR HEALTHSM
MARKLE FOUNDATION *A Public-Private Collaborative*

CONNECTING AMERICANS TO THEIR HEALTHCARE

Final Report

Working Group on Policies for Electronic
Information Sharing Between Doctors and
Patients

July 2004

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WORKING GROUP ON POLICIES FOR ELECTRONIC INFORMATION SHARING BETWEEN DOCTORS AND PATIENTS

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Executive Summary

From January 2004 through June 2004, within the framework of Phase II of Connecting for Health, the **Working Group on Policies for Electronic Information Sharing Between Doctors and Patients** examined the barriers to adoption of interoperable health information systems that provide for significant patient access and control.

The 25 members of the Working Group represented government and private sector electronic medical record creators, consumer and patient advocates, medical groups and health systems, and practicing clinicians. Working Group staff conducted literature reviews, interviewed experts, and visited 10 leading examples of PHR installations nationally to evaluate how rules for electronic information exchange have been developed — and how well they're working. The Working Group also commissioned consumer focus groups and conducted a national telephone survey to measure public perceptions about electronic personal health records. During a series of bi-weekly teleconferences, the Working Group developed a framework for evaluating Personal Health Records and a series of recommendations for critical next steps to advance this field.

Recommendations

The Working Group appreciates the many creative efforts now underway to offer electronic solutions that cross the patient-clinician information chasm. We discovered enthusiastic patients, clinicians and technologists, united in their passion to permit individuals to be more engaged and successful managers of their own health. These pioneers recognize that the long-term goals of safe, affordable and high-quality healthcare are unlikely to be achieved without tools that permit patients and families to be more active and successful.

Our review of these early PHR projects and the emerging challenges they have uncovered leads us to make three principal recommendations for action for 2004 to 2006:

- 1. Increase public understanding of the value of connectivity in healthcare through a coordinated, public-private communications campaign.**
- 2. Seek vendor and provider agreement to a body of specific and comprehensive design principles and policies.**
- 3. Conduct a small number of PHR demonstration projects that incorporate both the "common framework" recommended by the *Connecting for Health Roadmap* and the PHR design principles and policies recommended in this report.**

Findings

1. The time is now to accelerate the development of personal health records.

- The paper-based, fragmented U.S. healthcare system, as thoroughly documented by the Institute of Medicine and others, is broken. Health information technology and electronic connectivity can help transform the system to better meet the needs of patients and their families. The widespread adoption of clinician-controlled **electronic health records (EHRs)** is critical — but not enough.
- A key part of a necessary transformation in healthcare is putting patients' information directly into their own hands, and enabling patients to put often-missing information into the hands of their clinicians (e.g., what medications they are actually taking). **Personal health records (PHRs)** can and should play an important role in helping bridge an information gap that exists too often today between people and the health professionals who serve them.
- Connecting for Health research shows that most people want convenient access to their health information. (**61 percent** of respondents to a national telephone survey "strongly agree" and **22 percent** "somewhat agree" with the statement: "It's my health information. I should have access to it any time, any place.")
- Market, technology, demographic, political and social trends have converged to generate an unprecedented window of opportunity for PHR development.
- Still, several sobering obstacles — technical, cultural, professional, legal and financial — must be addressed in order for PHRs to equitably meet the needs of the American public.

2. PHRs are a means toward a necessary end: increased consumer health awareness, activation, safety and self-efficacy.

- Early installations suggest that PHRs can help a significant subset of people understand their health issues, become more engaged in the decisions they face, and improve their communication with clinicians. However, more study is needed to validate the benefits of PHRs and demonstrate how to improve adoption and utilization rates.
- Early efforts to promote PHR adoption should focus on people with chronic conditions because of greater potential improvements in the coordination, effectiveness, safety and efficiency of clinical care as well as self-care and self-management.
- The Working Group agrees that the electronic PHR will be an essential tool for integrating the delivery of healthcare and putting each person at the center of their care. It can support the shift from episodic and acute care toward continuous healing relationships with physicians and healthcare professionals.

- Over the long term, the PHR will help catalyze a transition from a patient health record that is physician-centered, retrospective and incomplete to one that is patient-centered, prospective, interactive and complete.

3. There is no single correct path to a ubiquitous PHR.

- The ideal PHR is controlled by the individual and provides easy access to all one's health data compiled from all one's healthcare providers and is accessible anywhere, anytime, over a lifetime. This is out of reach for almost all Americans today.
- PHRs are in their infancy, with several different models at various levels of market acceptance.
- Widespread PHR adoption will require commitment by individuals, families, physicians, payers, provider organizations and others. The necessary commitments will occur when each stakeholder understands the specific value PHR brings to it and appropriate incentives are in place to stimulate demand and use. Each early implementation of PHR should systematically evaluate the costs and benefits of the PHR offering and should be undertaken with an explicit understanding of the operating incentives — including financial incentives, opportunities to increase safety and quality, reductions in liability, increases in adherence, increases in efficiency, and reductions in inappropriate health care utilization.
- Some PHR models already enable meaningful electronic information sharing between patients and clinicians and allow people to begin to manage their own health. PHR innovators can take incremental steps that will support national progress in meeting patients' needs for information in this pluralistic and complex environment.
- Ultimately, these diverse strategies toward PHR development all serve the same customers — the person and family. Competing PHR models have a common need to maintain the trust and confidence of the American public.
- To do so, we believe that all PHR models need to evolve in a number of common ways. These include:
 - Common means of correctly identifying each person and ensuring privacy protections.
 - Common data sets, common secure data exchange standards, and common data coding vocabularies.
 - Common sets of values and policies that place each person at the center of controlling his or her own information, support the secure storage of both professionally sourced and patient-sourced data, and promote the portability of the information based on each person's needs and wishes.
- We offer the following common policy recommendations:
 - PHRs are voluntary. That is, the relationship between a PHR supplier and an individual person should be based on the person's discretion to enter into it, and to continue it.
 - Except as previously agreed upon, the patient bears primary responsibility for the information in the PHR, and clinicians and other healthcare entities are not responsible for contributing to or reviewing that information. Nonetheless, we strongly encourage the development of policies and incentives that encourage

- clinicians and other healthcare entities to provide at least certain core data elements into the PHRs of all patients within a 10-year time frame.
- PHR suppliers should make every effort to be transparent about their policies for privacy, security, data exchange, terms and conditions of service. PHR user agreements and other forms of disclosure (including face-to-face encounters) should be clear in setting patient expectations of how the physician will or will not use information in the PHR.
 - The default policy of a PHR is that the consumer controls the access: No one may access the information — either personally identifiable information or de-identified aggregate information — without the consumer’s authorization.
 - The sharing of PHR information between patients and clinicians should generate time-stamped, source-stamped transactions that are traceable in audit trails.
 - All PHRs should take HIPAA requirements as a given whether the PHR is sponsored by a covered entity or not. It is also important to consider state variations in privacy and health information disclosure laws.
 - We support experimentation to reimburse clinicians fairly for online interaction that leads to more continuous healing relationships with their patients. This is particularly desirable for activities that demonstrate a reduction of office visits as a result of safe and effective online interaction.
 - Medical professional societies, patient advocates, policymakers, legislators and medical malpractice insurance underwriters should collaborate to develop formal guidelines on legal risk-reduction as it relates to the PHR. We believe that the existence of such guidelines, particularly if endorsed by all major stakeholders, would serve as a reference for legal practitioners and the judiciary in any eventual PHR-related lawsuit.

4. Data set commonality is a vital starting point to increased PHR utility and interoperability.

- **PHRs must ultimately transmit and accept structured data in order to become commonly accepted for information exchange between individuals and clinicians.** PHRs are unlikely to be embraced by either health professionals or the public if they overload either party with unstructured data. Developing a common structure depends on three steps:

1. Establishing a set of common data fields. (In other words, what will PHRs and EHRs talk **about**?)
2. Establishing a secure protocol for electronic information exchange. (**How** will the PHR and EHR talk?)
3. Establishing common clinical vocabularies. (**What** “language” will the PHR and EHR use?)

The first two steps must go together as long as the information exchange is electronic. The final step is critical, but will take more time than the first two steps because healthcare providers will not adopt common, comprehensive data-coding practices overnight.

- **A common data set** is the basis of PHR communication with other information sources across the healthcare system. An initial goal should be to establish a

common data set to enable PHRs to exchange data with EHRs — and with other PHRs — on a bi-directional and vendor-neutral basis for the core health information repository functions of the PHR, such as the patient's identifying information (e.g., name, address), insurance information (e.g., health plan group ID number), health status (e.g., conditions, medications, allergies) and other clinically relevant information (e.g., care plans).

- **Implications for EHR developers, healthcare providers and other holders of professionally sourced patient data:** By agreeing to build their applications around a common data set to support core functions, the various PHR vendors can lower the barriers for EHR vendors to build basic PHR data import and export functions into their applications. Eventually, other custodians of professionally sourced health data (such as health plans, PBMs, retail pharmacies) will see the advantages of (or be competitively forced into) doing the same. (Their entire data sets may be much bigger than the common data field foundation, but they agree to send and receive extracts for those data fields within the common foundation.)

Implications for PHR developers: The common data set is neither a minimum data set nor the maximum allowable data set for PHRs. However, it should be the default set of fields that any PHR developer should always try first to use to drive any of its functions. This is an important distinction because we do not view PHRs solely as repositories of retrospective health information. Some PHR models are much broader, featuring an array of transactional services (e.g., e-consultations or online prescription refills) or other health management software (e.g., risk assessments, health expense tools). Other PHR models may specialize only in a much narrower issue (e.g., diabetes). Any of these applications may require additional data fields beyond those in the common data set.

- Rather than creating their own common data field standard, PHR vendors should first try working with existing standards emerging for minimum data sets of clinically relevant patient information. Critical criteria for any such common data set should be:
 - Acceptance by the medical community and consumers.
 - An HL7-compliant platform for secure data transfers.
 - There should be a clear upgrade path and incentives that lead to the universal population of common data set fields with standardized controlled clinical vocabularies.
- Nearly one of every two U.S. adults has difficulty understanding basic information necessary to make appropriate health decisions. This underscores the importance of simplicity in language and user interface in the PHR. The U.S. government has made SNOMED-CT clinical vocabulary available free to clinicians in an effort to encourage it as a standard for recording a large portion of clinical information. SNOMED concepts — there are more than 357,000 of them! — are designed for highly trained clinicians and medical librarians, not consumers. To be useful for most people in a PHR, SNOMED and other clinical lexicons need to be translated into consumer-friendly terms.

5. The Working Group has created a list of functions that have been implemented or envisioned across the PHR models.

- The function list is not exhaustive nor is it intended to constitute an industry standard for PHRs. Our Working Group does not propose that any PHR model today should achieve all of the functions on the list. Rather, our aim is to provide a recommended checklist of functions that PHR vendors and implementers will consider and decide upon based on their circumstances.
- This list includes a proposed reference to identify the significant areas of overlap of PHR functions with EHR functions (as defined by HL7 Functional Model) and a significant subset of data field categories in the Continuity of Care Record (CCR).
- Ultimately, standards bodies need to harmonize overlapping functions among PHRs, EHRs and common data sets of information to flow between them.

6. Key findings from early installations of PHRs.

Clinicians:

- Physician promotion is key to achieving high consumer adoption in most places.
- Physician acceptance requires large up-front efforts to gain buy-in.
- If PHR is viewed as beneficial only to patients, it's hard to get physician support.
- PHRs are unlikely to gain widespread clinician acceptance unless they are integrated into the clinical workflow, such as through integration with the office EHR.

Patients:

- Patient-provider secure messaging, online refills, lab results, medication lists, and disease management plans are among the functions that consumers single out as particularly useful.
- Patient-provider messaging wins over an enthusiastic subset of both patients and doctors, and does not overwhelm the inbox of doctors.
- Patients feel more empowered when they have access to their health information, and many early physician adopters find that helpful.
- People with chronic conditions are most likely to need and use PHR-like applications.

7. The American public is largely unaware of, but receptive toward, the potential value of PHRs.

For the past two years, Connecting for Health has conducted successive rounds of focus groups and national surveys to investigate the public's awareness of and willingness to adopt an electronic PHR. Some of our findings:

- **People have a limited understanding of health IT today.** When presented with messages about the potential benefits of PHRs, more than half said they had never thought about such concepts before. Examples:
 - **54 percent** had never thought: "It's my health information. I should have access to it anywhere, anytime." (Yet **61 percent** strongly agreed.)
 - **69 percent** had never thought: "My own online medical record would help me get all my doctors on the same page when they treat me." (**38 percent** strongly agreed.)
- **People want access to and control of their health information.** *Examples from the 2004 survey:*
 - **49 percent** "strongly agreed" and **23 percent** "somewhat agreed" with the statement: "I want to be involved in medical decisions that affect me. Having my own medical record would help me make better decisions."
 - **38 percent** "strongly agreed" and **24 percent** "somewhat agreed" with the statement: "I'd like to have all my health information in place – and get to it with the click of a mouse."

Participants in the 2003 focus groups 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.

- **The preferred medium of a PHR varies by population and age.** In the 2004 telephone survey, the preferred medium was the Internet (33 percent), followed by paper (24 percent), portable electronic devices (22 percent), and a computer's hard drive (18 percent) among those 45 and under. The top two were almost inverted for people over age 45 (34 percent preferred paper vs. 21 percent Internet).
- **When probed, people are receptive to the convenience possible with online PHRs.** In the 2003 survey of online Americans, these services were desired by large majorities of respondents:

○ 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
- **People want to work with their doctors.** In the 2003 online survey, 96 percent of respondents were most comfortable with their primary care doctors having access to their medical record, and less comfortable with the idea of having family members (69 percent) and their health insurance (65 percent) having access. Similarly, 58 percent of respondents stated that they would like to see their doctor's office be the host of the online medical record system.

8. Demonstration projects are a critical next step.

- The Working Group findings and the messaging findings should be integrated into the design of a coordinated set of demonstration projects. Examples:
 - Projects to coordinate care for people with chronic conditions across multiple care settings.
 - A project to implement a “personal medication record” — a consolidated medication list and perhaps management system — as a precursor to a richer PHR.
 - A project helping patients track and manage their out-of-pocket personal health expenses.
- Each demonstration project should have a rigorous evaluation plan to assess and/or quantify:
 - Feasibility of the technical infrastructure.
 - Value – especially economic value – returned to each stakeholder.
 - Patient and provider acceptance, utilization and satisfaction.
 - Recognizable improvements in efficiency and quality of care.
 - Potential risks to patient safety, privacy or quality of care.

Working Group on Policies for Electronic Information Sharing Between Doctors and Patients

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CHAPTER 1 Introduction

Is this scene familiar?

"Please fill this out," says the nurse, handing you a medical history questionnaire.

"We'll call you in a few minutes."

You struggle to concentrate in the noisy distractions of the waiting room. Some of the information is easy: name, address, phone, reason for visit, etc.

But other things are problematic:

- **Family history** ("What type of cancer did my uncle have?")
- **Medications** ("What is the name of the blue pill for my blood pressure? Should I list things like aspirin and vitamins?")
- **Emergency contact information** ("What's my brother's new phone number?")
- **Immunizations** ("Who can remember this stuff?")
- **Reactions to medications** ("What do they mean? Allergies? What about the hives from the last kidney X-ray?")

The nurse calls you, attaches the form to your file, and places it outside the door of the exam room.

The doctor talks with you and scribbles a few notes in your file. You never see it. You wonder what the doctor wrote.

You ask your doctor about your cholesterol because you can't remember your numbers from a year ago when you had a blood test at a different office. The doctor suggests you call the other office, or get another test.

You leave the 12-minute doctor's appointment with a barely legible paper prescription. Your medical file stays behind in a cabinet.

When you go to doctor at a different facility, the process repeats. No one seems to know much about your medical history or what the last doctor did.

And so on, at every healthcare visit, throughout your life ...

The major stakeholders in U.S. healthcare — patients, physicians and other healthcare professionals, payers and policymakers — are asking fundamental questions about this familiar scene:

- Why do people have to fill out paper forms containing variations of the same information again and again?
- Why are doctors and patients still relying on incomplete or absent data to make decisions that impact our health and safety?
- Why can't people easily add important details, like their over-the-counter therapies or a new illness in the family, to health records that they can conveniently share when needed with multiple healthcare practitioners?
- Why don't people with chronic medical conditions have online records and management plans to help each of their doctors know what the others are doing or prescribing?
- Why — in the face of concrete evidence that patients forget much of their doctors' recommendations — aren't we using information technology to supplement the brief and pressured doctor's visit?
- Why do doctors and nurses still spend so much of their time inefficiently playing telephone tag to try to communicate with patients and each other?
- Why don't people have tools to keep their own health records in a conveniently accessible way, so the information is always available for any need, including life-threatening emergencies?
- Why, perhaps most fundamentally, don't we enable people to become more involved in learning about and managing their own care?

By themselves, personal health records will not solve these problems.

However, based on mounting evidence, we conclude that personal health records are an important tool to help people:

- Become more active in their own health and healthcare.
- Bridge the gaps between their unconnected clinicians who often don't communicate with each other.
- Enrich communication and create a more continuous healing relationship with physicians.
- And ultimately, improve the efficiency, patient-centeredness, timeliness, quality and safety of care.

CHAPTER 2 Purpose and scope

Introduction

The **Markle Foundation** launched **Connecting for Health ... A Public-Private Collaborative** in September 2002 to bring greater visibility and coordination to the many government, provider and industry efforts to speed up the adoption of electronically connected health information systems.

In Phase I, ending in June 2003, more than 100 health information leaders collaborated within the Connecting for Health framework to:

1. Support adoption of several essential data standards.¹
2. Compile best practices for health information privacy and security.²
3. Publish the first definitive characterizations of a "personal health record" as a model for a patient-controlled health information infrastructure.³

This report is a component of Phase II of Connecting for Health, building upon the Phase I work related to personal health records. It addresses barriers, emphasizes opportunities, and recommends guidelines for electronic information sharing between patients and clinicians. Specifically, in envisioning a world beyond the paper-based patient "chart," it examines the role of patient-controlled **personal health records (PHRs)** and their interactions with clinician-controlled **electronic health records (EHRs)**.

Phase II was supported by grants from the **Markle Foundation** and the **Robert Wood Johnson Foundation**.

Personal Health Working Group

From January 2004 through June 2004, within the framework of Phase II of Connecting for Health, a group of health information experts and consumer advocates met as the **Working Group on Policies for Electronic Information Sharing Between Doctors and Patients** to develop this report. The Working Group sought to address barriers to adoption of **interoperable** health information systems that provide for significant patient access and control.

The 25 members of the Working Group represented government and private sector electronic medical record creators, consumer and patient advocates, medical groups and health systems, electronic record experts and practicing clinicians. David Lansky, PhD, President of FACCT – Foundation for Accountability, chaired the Working Group. **Appendix A** lists the Working Group membership. To

Definitions

Personal health record (PHR) – an electronic application through which individuals can access, manage and share their health information in a secure and confidential environment. It allows people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it. (See Chapter IV for details.)

Electronic health record (EHR) – an electronic version of the patient medical record kept by doctors and hospitals. The data in the EHR are controlled by and intended for use by medical providers.

The EHR is also known as the Electronic Medical Record, Electronic Patient Record, Electronic Health Record, Computerized Patient Record and Computer-based Patient Record.

Definition

Interoperable – the ability of one system to send, receive and use data from another system.

supplement the effort, FACCT staff visited 10 leading examples of PHR installations nationally to evaluate how rules for electronic information exchange have been developed — and how well they're working. FACCT also conducted consumer focus groups and organized a national telephone survey to measure public perceptions about electronic personal health records.

Why personal health records?

Every one of us is touched by the U.S. health system – from before birth until death. During our lives, we experience both predictable and unpredictable needs for healthcare assistance. Every time we encounter the healthcare system, information about our background, medical history, health status, and insurance is immediately required. And every medical encounter produces its own trail of documentation.

There are, for example, more than 880 million doctor office visits per year in the United States.⁴ A complex patchwork of healthcare practitioners and payers process information for each one of those visits. The records are either on paper or in separate computer systems that typically have limited, if any, ability to exchange data electronically (except for purposes of reimbursement).

In all those files of paper and streams of data, no one has a bigger stake in the information from a particular clinical encounter than the patient who needed it. And, in nearly all circumstances, no one in the system can know more about the person's life than *that* patient.

For example, the doctor might see in your chart that you were prescribed a medication. But without asking you, the doctor doesn't know whether you actually took the medication, how well it worked, what other remedies you're taking, or whether you had side effects.

Those 880 million doctor visits each year are only one aspect of healthcare. Important information is also kept by insurance companies, pharmacy benefit managers, retail pharmacies, hospitals, labs, physical and occupational therapists, alternative medicine facilities, and so on.

Historically, these many actors in our health care have not found it worthwhile to manage information collaboratively or to routinely share it with their patients. As a result, health professionals have no way of accessing all of the important information about our health, and we have no way of compiling and managing the information about ourselves. And even motivated patients have no reasonable and efficient way to share information about themselves with their healthcare providers.

We agree with the Institute of Medicine's finding that the healthcare system is broken and that an investment in information technology is necessary to help fix it.⁵ In our fragmented and pluralistic delivery system, the electronic personal health record is an essential tool for integrating the delivery of healthcare and putting each patient at the

center of their care. It can support the shift from episodic and acute care toward continuous healing relationships with physicians and healthcare professionals. It represents a transition from a patient record that is physician-centered, retrospective and incomplete to one that is patient-centered, prospective, interactive and complete.

PHRs are early in development. A great deal of study is needed to measure the impact, potential benefits and potential risks of PHRs. However, Working Group members — several of whom have implemented versions of PHRs — outline many benefits possible compared to a status quo without PHRs:

Empower patients and their families

PHRs give people a better way to:

- Verify the accuracy of the information in their medical records at care providers' offices.⁶
- Gain a deeper understanding of the health issues and decisions they face.⁷
- Share in the decision-making process and assume a greater responsibility in their care.⁸
- Monitor important data about themselves on a regular basis, such as blood pressure readings, symptoms, medical visits, glucose levels and other periodic information, particularly in the context of managing chronic conditions.⁹
- Provide a convenient way to involve friends and family as needed in the care situation.
- Remember to schedule appropriate preventive services.

Improve the patient-clinician relationship

Patients with PHRs can:

- Improve their communication with clinicians.¹⁰
- Engage in continuous relationships with physicians and healthcare teams.¹¹

Clinicians can:

- Better document their communication with patients, potentially reducing their exposure to medical malpractice liability.¹²
- Increase the ratio of "quality time" with patients, spending less of the visit on administrative and information-hunting functions.¹³

Increase patient safety

Information from patient-controlled PHRs can:

- Alert doctors and patients to avoid potential drug interactions, contraindications, side effects and allergies.¹⁴
- Alert doctors to missed procedures and lapses in adherence to treatment regimens.¹⁵
- Alert doctors to test results that are misfiled or misplaced.

Improve the quality of care

Information from PHRs can help:

- Doctors have a more complete history of the patient to make more accurate diagnoses.

Patient observations

"It's put me in a position of being more aware of the conditions that I have and what I have to do about them."

"It's saved me a number of times from having to go into the ER."

"Appointment reminders are very important to me because I have a problem with short-term memory. It's probably prevented 8 or 9 mix-ups on appointments."

— retired man with several chronic conditions, who uses a PHR and secure physician communication tools at Beth Israel Deaconess Medical Center in Boston. (Interviewed March 16, 2004.)

- Patients improve their continuity of care with consistent, up-to-date information provided to all clinicians — across time, between institutions, among multiple physicians and caregivers.¹⁶
- Patients increase their understanding of and engagement with physician recommendations and disease management plans.¹⁷
- Caregivers keep track of the health information of ailing loved ones.

Improve efficiency and convenience

PHR has the potential to help:

- Patients avoid bureaucracy in tracking down their information.¹⁸
- Doctors reduce duplicative tests that otherwise would be ordered for lack of up-to-date information.¹⁹
- Patients and clinicians take advantage of asynchronous, secure communications tools rather than play inefficient “telephone tag.”²⁰

Improve privacy safeguards

Patients can authorize specific providers to have access to their PHR, allowing for greater selectivity of information sharing. Information gated by proper user authentication can be more secure than paper files.²¹

Save money

Health systems that have implemented early versions of PHRs expect to:

- Reduce the number of unnecessary, duplicative tests.²²
- Increase the efficiency of making and responding to requests for information from various providers.²³
- Improve the outcomes of care for people with chronic conditions, who have the greatest need for PHRs.²⁴
- Reduce the costs of medical malpractice.
- Save professional, administrative and patient time.²⁵

Why now?

By 2013, health spending is projected to reach \$3.4 trillion, accounting for 18.4 percent of the gross domestic product (GDP). As perspective, the United States has the world’s largest economy, and it already spends a higher percentage of its GDP on healthcare (14.9 percent in 2002) than any industrialized country.²⁶

Anywhere from \$30 billion to \$293 billion of current spending is on unnecessary paperwork, by various estimates.²⁷ And still, doctors and patients are routinely frustrated in their inability to get the right information to the right person at the right time. Preventable medical errors are unacceptably common and subject to numerous national and state legislative initiatives, while recent research demonstrates that

almost one-half of all care fails to reflect current medical knowledge and practice standards.²⁸

There is a widening consensus that increased electronic connectivity is a critical part of improving the quality and safety of healthcare. Healthcare providers are increasing their spending on information technology, including a handful of groundbreaking projects that make EHR data available to patients through PHRs. Although these projects are an important step, they are largely confined to particular care settings.

Connecting for Health and several other public and private organizations are working toward standards designed to create more portable and interoperable systems. Patient advocacy groups and other organizations are working to mobilize grassroots pressure to address the need for personal health records and electronic medical records. The Health Insurance Portability and Accountability Act (HIPAA) and Medicare Modernization Act ensure patient privacy and information rights while at the same time encouraging the use of electronic records. National political leaders of traditionally opposing camps agree on the need to invest in technology to enable increased portability of patient medical information with privacy safeguards.

Two powerful technology responses are emerging — the computerization of medical record systems (EHRs) and the creation of electronic personal health records. Computerized medical records allow clinicians to deliver better, more efficient, and safer care to patients,²⁹ while personal health records empower patients to control and access their own medical information. A third possible trend is interconnectivity across systems.

More powerful trends are demographic and social. The Baby Boom Generation will create unprecedented demands on the system in the next three decades. At the same time, consumers of all ages are becoming more and more technologically savvy. In less than a decade, the Internet has become an essential utility for most households. Millions of consumers pay their bills, do their taxes, book their travel, and buy and sell everything imaginable online. Online management of personal health information, however, is currently much less widespread, despite the fact that patients are becoming more involved in their care and are expected to pay an increasing share of healthcare costs. Technology and research are advancing at such rapid speeds that real-time information sharing is no longer an option. It is a necessity.

Our Working Group underscores the importance of responding to these trends by creating a more connected, efficient, responsive, patient-centric and quality-oriented health information infrastructure.

Why personal records? Why now? Simply put, because today's U.S. healthcare system is broken and it needs to be transformed to better meet the needs of patients. An important part of this transformation is putting patients' information into their own hands.

Patient Observations

"I guess I've gotten to the point where I expect to be able to do these transactions electronically. I just expect to do business this way with the organizations that I deal with ... **Expectations change. In 2004 you expect to be able to do everything online. That's different from 2002.**"

— Boston woman who uses a PHR and secure physician communication tools at Partners HealthCare in Boston. (Interviewed March 15, 2004.)

What is the scope of this report?

There are enormous technical, economic, professional, legal and policy challenges to the goal of a universally accessible, fully functional PHR. This report addresses barriers and summarizes the Working Group's findings by:

- Defining the functions of the personal health record.
- Examining three patient scenarios to identify issues and potential solutions.
- Evaluating the demand for personal health records among patients and physicians.
- Recommending best practices in key areas of PHR implementation.
- Summarizing some lessons learned from existing PHR projects.
- Focusing on opportunities for productive next steps in the PHR movement.

The Phase I report was the first comprehensive public definition of the Personal Health Record. This report is a more practical implementation guide and provides recommendations for integrating the personal health record with existing provider-based electronic health records.

Who should read this report?

This report is primarily intended for anyone involved in purchasing, installing or creating PHR functionality. It is designed to be helpful to anyone with interests in healthcare information technology and patient empowerment trends.

The Working Group also hopes that the new opportunity to give patients more information and more power to manage their own care gains increased visibility among all major stakeholders in U.S. healthcare: clinicians, payers, policymakers, advocacy groups, foundations and — the biggest stakeholder of all — patients.

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CHAPTER 3

What is a personal health record?

Introduction

The idea of a Personal Health Record is rapidly gaining national political support, including the President's expectation that every American have one within 10 years.¹ Large segments of the public appear to want the key conveniences envisioned in PHRs.² It's easy and tempting to articulate how the personal health record works *in theory*.

In practice, however, the PHR is still largely undefined. PHR models are still in their infancy, essentially in test incubators across the country. The word "record" suggests a retrospective tool, i.e., a repository of past health information. However, many PHR models emphasize transactional services, such as e-consultations and online prescription, and/or other integrated health management applications, such as adherence programs, health expense management or health risk assessments. (Some people are now using the term "personal health systems" instead of "personal health records.") It's not yet clear which model or models will survive, and what type of environment they'll need to achieve significant impact in U.S. health and healthcare.

Many factors will shape the success or failure of the PHR: market forces, technology, standards, infrastructure, government policy and shifts in the demands of patients, medical professionals and other stakeholders. Just how these factors will emerge or converge is not a simple thing to predict.

In July 2003 as part of Phase I of Connecting for Health, the Personal Health Working Group defined the ideal PHR as:

... 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.

Further, the Phase I Personal Health Working Group concluded that the PHR should have these seven attributes:

1. Each person controls his or her own PHR. Individuals decide which parts of their PHR can be accessed, by whom and for how long.
2. PHRs contain information from one's entire lifetime.
3. PHRs contain information from all health care providers.
4. PHRs are accessible from any place at any time.
5. PHRs are private and secure.
6. PHRs are "transparent." Individuals can see who entered each piece of data, where it was transferred from and who has viewed it.
7. PHRs permit easy exchange of information with other health information systems and health professionals.³

However, due to several practical limitations, it is unreasonable to expect that any PHR model in existence today can achieve all these attributes. The Working Group recognizes that:

- **Attributes 1, 4, 5 and 6** should be part of any PHR today.
- **Attributes 2 and 3** are particularly elusive due to the fragmented nature by which one's health information is kept from cradle to grave, and the lack of standards or incentives for sharing it electronically (even if some elements are available electronically).
- **Attribute 7** is achievable today only for a small number of patients, and typically only for data associated with one institution or a single service (such as pharmacy information).

Despite these barriers, there are noteworthy public and private sector PHR models that currently enable meaningful electronic information sharing between patients and clinicians and allow patients to manage their own health — which is the fundamental purpose of PHRs. In this chapter, we discuss these models and provide a list of functions that have been implemented or envisioned across this dynamic spectrum. In doing so, our objective is to highlight what has been achieved and point to what is possible in the near term.

To understand this rapidly changing field, we briefly review how the initial implementers are addressing key design issues:

- **The medium** — Where and how do patients 'touch' their PHR?
- **The data** — How does information get into the PHR?
- **The functions** — What is the range of things that people can do with their PHRs?
- **The limitations and opportunities** — Where do we go from here?

The medium – Where and how do people ‘touch’ their PHR?

Paper remains the only available or practical means of storing health information for many people, either because they don't have electronic access or their clinicians maintain only paper records. It may be the preferred means for some people even if they do have access to electronic PHRs. Despite the obvious weakness of paper as a medium for exchanging information securely and rapidly, we believe that it is better for consumers to maintain paper records than no records at all.

Our focus, however, is on health information that can be stored and accessed electronically and conveniently managed and exchanged to improve health. Today's PHR applications enable consumers to store their health data electronically on a variety of platforms:

- **Desktop-based:** Consumers may store PHR data locally on the hard drive of their personal computer. For example, consumers can type in information or scan paper files into a software application or file folder.
- **Web-based:** Applications may store PHR data centrally on a secure Web server. Consumers access their private accounts by connecting to the Internet and logging in with a unique user name and password. Web-based platforms include application service providers (ASP), which require no software downloads. They also may include peer-to-peer information-sharing services such as secure email, document sharing and even video conferencing for home consultations (“telemedicine”).
- **Portable devices:** The capabilities of portable devices are expanding rapidly and may lead to a whole new generation of PHR applications. There are products that enable consumers to store personal health information on smart cards, personal digital assistants (PDAs), mobile phones or Universal Serial Bus compatible memory devices (USB) that can plug in and exchange data on almost any personal computer.

Each of these information storage mechanisms has its own merits. Advances in technology continue to blur the lines between them. We believe that no matter what medium is used to store information in the PHR, the Internet — whether through wired or wireless access — will probably provide the best way to update the PHR with information from professionals and institutions.

The data – How does information get into the PHR?

Fundamentally, the PHR contains two types of information:

1. **Patient sourced:** Information provided directly by the patient or caregiver.

2. **Professionally sourced:** Information provided by entities involved in the delivery of or reimbursement for care (e.g., clinicians, pharmacies and pharmacy benefit managers, insurance companies).

The potential of any PHR application expands significantly when it provides consumers a means to access or exchange data with clinicians and other custodians of professionally sourced health data. Stand-alone applications, which rely solely on patients entering their own health data and have no connections to professional data sources, have not proven to be attractive to large numbers of users or economically viable to vendors.

Bringing data from providers and institutions into a PHR application has proven to be difficult, however. There is no short-term incentive or immediate return on investment to justify the significant cost of developing a PHR that can exchange data with disparate, non-standardized and often reluctant institutional sources. There is no evidence, yet, that a significant market of paying customers exists for such a service.

However, some PHR models are successfully providing consumers with online access to their professionally sourced data:

Institutional gateways: These applications are connected to and dependent entirely upon data from a single institution, such as a specific healthcare facility, an integrated delivery network (IDN), a health insurance company, a pharmacy benefit manager (PBM), or a government payer-provider network, such as the Department of Defense and the Department of Veterans' Affairs.

The business justifications for institutional gateways are typically focused on:

- Increasing efficiency of information sharing within the institution.
- Improving consumer loyalty and retention.
- Improving adherence or self-management of chronic conditions in hopes of preventing or delaying expensive complications.

There are two basic types of institutional gateways:

- **Integrated-service gateways** provide professionally sourced data from multiple medical services within an institution. Examples include gateways provided by integrated health systems, such as staff model health maintenance organizations (HMOs), government health programs such as the VA, or large integrated delivery networks. These PHR installations, some of which are currently moving beyond the pilot stage to system-wide rollouts, can deliver a robust range of professionally sourced data from centrally managed EHRs into institutional PHRs.

- **Single-service gateways:** A single-service gateway provides patients an online view of professionally sourced data from a single institution for a single service. Example: A pharmacy benefit manager provides a service for members to log in and view their prescription history.

In both cases, the available professionally sourced data in the PHR is limited to and determined by the institution.

Aggregator models: These applications are designed to gather information from the consumer and from multiple professional sources. They are not “tethered” to one institution as the source of data. They face the challenge of integrating with legacy healthcare provider systems and/or contracting with other custodians of health data, such as PBMs, health insurance companies or data warehouses.

These information aggregators are targeting a handful of distinct markets to pay for their services, including:

- Risk-bearing entities such as insurance companies or self-insured employers.
- Sponsorship from pharmaceutical companies.
- Hospitals and other healthcare facilities.
- Consumers themselves.
- Governments or foundation grants.

The business model that will substantiate initial investment in PHRs and ongoing financial support for PHR services is not clear. Financial investment and market viability are practical issues that must be addressed if PHRs are to become widely available. Clearly, standardization of data storage and transfer protocols could lower the hurdles for independent models to succeed in gathering information from multiple sources. Beyond standards, though, in most cases there are currently no clear incentives for professionals and institutions to share patient information with third-party aggregator applications.

As with institutional gateways, aggregator models can be **multiple-service** or **single-service**. For example, a single-service aggregator could provide patients a way to consolidate their medication data from several pharmacies or PBMs, but not attempt to provide professionally sourced information from other services, such as doctor’s visits, labs, etc. A multi-service aggregator would pull together professionally sourced data from multiple institutions across multiple types of services.

There are two basic models for community architecture to support third-party aggregator models.

- **Third-party repositories:** A third-party establishes a database through which personal health information is transmitted — with the patient’s permission — from data sources (doctor’s office, pharmacy, lab) to the PHR and vice versa.

- **Record locator service:** A third-party establishes a repository of identifying information about an individual, and this identifying information is the only thing held centrally. The identification repository provides a protocol for authorized persons to query and request data on a particular patient from all the participating professional health data sources. In this model, the linked data is not retained in the system but is generated on demand or at specified intervals — and only with the patient's authorization.

The functions: What can people do with their PHRs?

As a practical matter, there is no one functional definition of a PHR. Nearly everyone agrees that it must be a core repository of personal health information, such as:

- Name and demographic information
- Emergency contacts, next of kin
- Family history
- Insurance information
- Problem list (diseases and conditions)
- Medications (Rx, OTC, vitamins, herbals and other alternative therapies)
- Allergies and reactions
- Immunizations
- Labs and tests
- Hospitalizations / surgeries
- Other therapeutic modalities (counseling, occupational therapy, alternative, etc.)
- Visit summaries
- Advance directive form
- Spiritual affiliation / considerations
- Other concerns – free text field to explain things you want your doctors to know
- Goals, next step or disease management plan

In addition, many PHR models include optional content or transactional services, such as:

- Links to patient education, self-care content and consensus guidelines
- Secure messaging
- Doctor's notes and other narrative information
- Standardized intake questionnaires
- Appointment scheduling and reminders
- Preventive service reminders
- Adherence messaging
- Patient diaries (pain, symptoms, side effects)
- Longitudinal health tracking tools (charts, graphs)
- Drug interactions checking
- Rx refills
- Financial information, such as Explanation of Benefits
- Scanned images, such as CT scans

Appendix B lists the functions that have been implemented or envisioned across the various PHR models. This list is not comprehensive, prescriptive or standardized. Instead, it serves as a checklist of functions that PHR vendors and implementers — and ultimately, consumers and patients — can consider and decide upon based on their circumstances. This list may also provide a starting point for discussion of the elements that should comprise a functional model of the Personal Health Record.

Limitations and opportunities

If we look at the above simplified categorization of PHRs through the lens of the status quo, the fundamental limitations are depicted in the diagram below:

Barriers to realize full value of each PHR model:

Multiple-Service Institutional Gateways	Multiple-Service Aggregators
PHR not updated or portable when patient leaves institution.	Lack of standards and incentives make data-sharing difficult and business model unproven.
Single-Service Institutional Gateways	Single-Service Aggregators
PHR limited to one service, and not updated or portable when patient leaves institution.	PHR limited to one service, and lack of standards and incentives make data-sharing difficult and business model unproven.

In short, each model – the institutional gateway and the independent data aggregator — faces a critical barrier. Privately sponsored institutional gateways are intended to build loyalty and retention among their members, and do not profit by increasing interoperability with other systems. Privately sponsored aggregators have difficulty identifying sufficient paying customers to reward cooperative data-

sharing among competing entities and support a sustainable business model.

These barriers make it implausible to imagine a sudden, quantum leap of the entire U.S. system to a universal, interoperable personal health record. Instead, we recognize incremental steps that innovators in each category can take in order to make national progress toward the desired PHR. Below is a quick summary of simultaneous opportunities that are currently being explored in the marketplace and policy arenas.

Opportunities for single-service institutional gateways: When initiated and sustained through loyal relationships with the patient, these applications can create significant patient convenience and improve access to personal health data. *Examples:* A Web-based ASP system that allows physicians to create PHRs and offer e-consultation services to their patients, or a national pharmacy chain that provides online access to one's prescription history and a convenient way to order refills.

Opportunities for multiple-service institutional gateways: Patients who receive most of their care from one institution, and remain loyal to that organization for a long period of time, can get significant benefits from accessing a well-integrated personal data set. As the EHR market evolves, EHR vendors will compete on the PHR-like functions they integrate into their offerings as well as the interoperability they achieve with other EHRs.

Opportunities for single-service aggregators: Some aggregators are building focused applications that significantly help patients deal with specific, common challenges of health care. Examples include:

- A reliable, consolidated medication list for each patient. A service could focus on aggregating medication data from a variety of professional sources (e.g., pharmacies, PBMs, EHRs) – as well as the patient.
- PHR applications that focus on the management of specific conditions, such as diabetes.
- PHR applications that focus on managing medical expenses, such as premiums, co-pays, deductibles, annual out-of-pocket maximums, drug card accounts, flexible spending accounts, etc.

Opportunities for multiple-service aggregators: More than the other models, this area poses more profound policy choices, including the commitment to addressing accurate patient identification, data coding and data exchange standards. Initiatives that may prove helpful are:

- **National Health Information Infrastructure (NHII) and Local Health Information Infrastructure (LHII)** initiatives to enable data sharing among national or regional healthcare providers may lead to new opportunities to provide patients a more data-rich and interactive PHR. For example, LHIII projects could build in selected PHR functionalities from the

Helpful resources

The National Health Information Infrastructure:

<http://aspe.hhs.gov/sp/nhii/index.html>

beginning that provide the consumer a view into her own data that's shared among participating providers.

- Several medical professional societies are supporting emerging standards for a **Continuity of Care Record (CCR)** — a minimum data set of clinically relevant information about a patient that can be transferred in a variety of formats from clinician to clinician. A possible PHR extension of the CCR would enable minimum data set transfers to go not just from clinician-to-clinician on the patient's behalf, but also from clinician-to-patient or patient-to-clinician. In such cases, the patient's PHR could be a collection of CCRs, stored in a secure Web site or a portable device. A notable number of EHR and PHR vendors have recently announced that they are building CCR compatibility into their applications.
- New programs are likely to emerge from the new **Medicare Modernization Act** to encourage greater use of IT. Some have proposed that the Medicare "first physical" upon enrollment be standardized and used to capture baseline data electronically about the patient, and to use this as a spearhead toward a "Medicare PHR."

Definition

The CCR, or Continuity of Care Record, is a standard specification being developed jointly by ASTM International, Massachusetts Medical Society (MMS), the Health Information Management and Systems Society (HIMSS), and the American Academy of Family Physicians (AAFP) and now supported by other medical professional societies. It is designed to improve continuity of patient care, to reduce medical errors, and to assure at least a minimum standard of health information transportability when a patient is referred to another provider.

http://www.astm.org/COMMIT/E31_ConceptPaper.doc

Conclusion

The Working Group does not yet see a single correct path toward establishing widely available PHRs. Instead, we see multiple ways of meeting patients' needs for information in a pluralistic and complex environment. Yet these diverse strategies all serve the same customer — the patient and family — and will need to evolve in a number of common ways. While each system will provide some benefit to some patients, they will never move the nation toward the desired PHR attributes presented earlier unless they also all conform to some common practices and policies. Using common standards for data coding and exchange, correctly identifying each person, ensuring private and secure information storage and transfer and, most importantly, maintaining the trust and confidence of the American public will be essential and universal requirements of all of these applications. The Working Group recommends some approaches to these issues in the chapters that follow.

¹ "Transforming Health Care: The President's Health Information Technology" Viewed online on May 23, 2004, at http://www.whitehouse.gov/infocus/technology/economic_policy200404/chap3.html.

² Connecting for Health – Personal Health Working Group, Final Report, July 1, 2003. (http://www.connectingforhealth.org/resources/final_phwg_report1.pdf)

³ Ibid.

CHAPTER 4

How Can PHRs Solve Problems? – Three Use Cases

Introduction

To illustrate how patients armed with fully functional PHRs could help solve connectivity problems typical in U.S. healthcare today, the Working Group examined three use case scenarios in detail. The use cases are fictitious, but they encapsulate issues that cause frequent frustrations for patients trying to move their personal health information from Point A to Point B in an unconnected healthcare system.

The Working Group created these scenarios based on the following assumptions:

- The patients possess and are motivated to maintain a fully functional PHR with electronic data interchange capabilities to view both their professionally and personally generated medical information.
- The clinicians and pharmacists support the patients' desire to import and share information electronically through the PHR.

These assumptions are in sharp contrast with the reality most patients and clinicians encounter today. We offer these scenarios to provide a vision for a model of care that is less visit-based, less paper-based, more interoperable, and more patient-centric. In this model, the PHR enriches the relationship between doctor and patient, leading to continuous, higher-quality and safer care.

Three scenarios raise a number of challenging policy issues; these will be addressed in detail in **Chapter 8**.

Samantha

Samantha's problem

Samantha, her husband and young child have just discovered that she's pregnant with a second child. They also realize that her previous obstetrician-gynecologist is not listed in the provider network of the family's new health insurance carrier.

To avoid significant out-of-pocket expenses, she has to find a new obstetrician-gynecologist who is in-network, and then transfer her medical records from her first obstetrician-gynecologist (OB-GYN-1) to the new one (OB-GYN-2).

Samantha also wants to know how information about the post-partum depression she experienced after her first pregnancy will be handled in the records transfer.

Each year in the United States, 17 percent of privately insured people change health plans¹, and 11 percent change doctors.²

Samantha's experience in today's paper-based world

If both providers are unconnected and completely paper-based, and Samantha has kept no record of her own, her experience is likely to be something like this:

She needs to go to OB-GYN-1's office to sign a release authorizing transfer of her medical files to OB-GYN-2. Because of common misunderstandings about what is allowed or prohibited under the Health Insurance Portability and Accountability Act (HIPAA), this process could take anywhere from a few days to a few weeks. It could also cost Samantha significant out-of-pocket expenses in copying fees, not to mention taking her valuable time.

Her records may not arrive at OB-GYN-2's office before her first appointment. She will have to fill out blank paper forms similar to the ones she had to fill out at OB-GYN-1's office just 2 years ago. If Samantha's records do arrive at OB-GYN-2's office prior to her first appointment, the staff may not have opened a new chart for her until that first visit anyway. Typically, the records go into a loose file, where they can be lost. Either way, her first appointment is likely to involve starting over — filling out paper forms and spending much of her brief face-to-face time with OB-GYN-2 trying to rehash her medical history. Samantha leaves without much discussion of what's really on her mind: this pregnancy, not the last one.

More alarmingly, OB-GYN-2 may never learn of Samantha's previous post-partum depression. If she experiences depression after her second child and needs medication again, OB-GYN-2 may prescribe Samantha the same drug that caused troublesome side effects the first time. Chances are Samantha will not remember the names of the medications she took, as it was during a very busy time in her life that now seems long ago.

Samantha's experience with a connected personal health record

Although the two physicians have separate practices and use different EHR systems, they participate in a regional health data-exchange program.

While a patient at OB-GYN-1, Samantha opens her PHR account. The PHR will give her access to professionally sourced data from her treatment by OB-GYN-1. Samantha provides her personal information to authenticate her identity, which is validated with information in her EHR chart, and she requests a temporary password, which is mailed to her home address.

She uses the temporary password to sign on, and is instructed to change the password immediately for security purposes. She agrees to the terms and conditions as well as the data exchange policies of her

new PHR, thereby authorizing health institutions to make her data available to her through her PHR.

Throughout her first pregnancy, Samantha uses a diary section of her PHR to record her symptoms and feelings. A month after delivering the baby, she is diagnosed with post-partum depression. Her diagnosis and the prescription to treat it are entered into the PHR. The medication has significant side effects, which she also notes in the PHR. OB-GYN-1 reviews the side effect information during their next visit and prescribes a different medication, which helps Samantha without any adverse effects. She begins to feel better and tapers off the medication in a couple of months.

More than a year later, Samantha selects her new doctor and needs to transfer her records to OB-GYN-2. She could request that OB-GYN-1 send her records directly to OB-GYN-2. However, she also has the option to generate a report from her own PHR that can be sent to the new doctor's office.

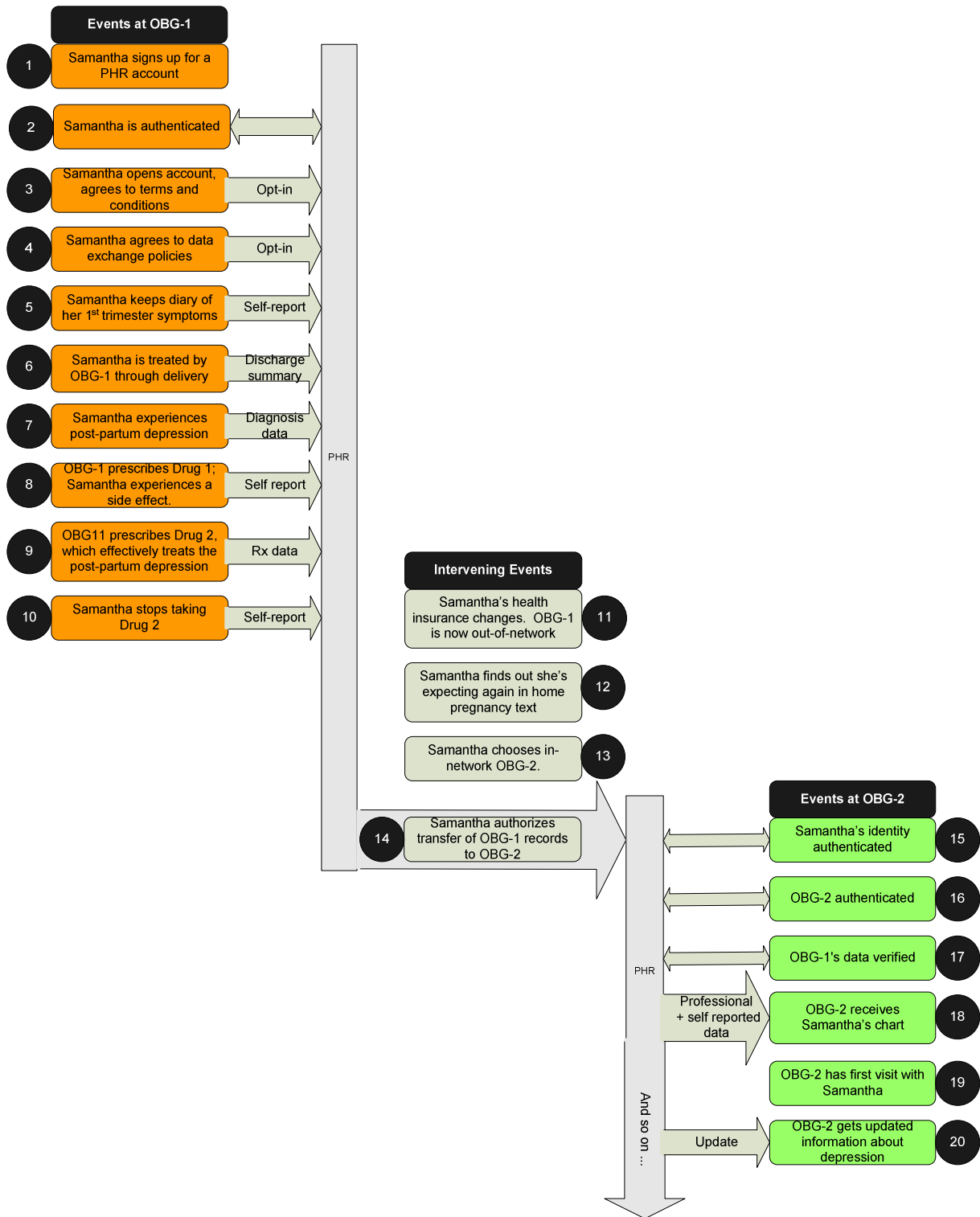
In doing so, she has the option to "withhold" certain data. Uncomfortable with the subject, she withholds the post-partum depression diagnosis and the two related prescriptions before generating the report. The report creates an easy-to-read, bulleted list her of demographic information, medical conditions (except the depressive episode), lab tests, medications (except the two antidepressants), family history of diseases, and other pertinent information in a standard format. On the back end, the data entries are coded using standardized clinical vocabularies.

Samantha has a choice of formats to send the information to OB-GYN-2's office. She can print out a copy and send it by mail, or take printouts with her. She can store it on a CD or USB-compatible memory device and bring it with her to the office.

Or, because Samantha's PHR and OB-GYN-2's EHR are compatible in transferring a minimum data set using the Continuity of Care Record (CCR) standard, she can transmit much of her PHR directly into a secure holding area of the new doctor's EHR, saving everyone involved a great deal of time. This latter option requires that she find OB-GYN-2's name and facility from a menu of care providers who participate in the information-sharing network.

She selects OB-GYN-2 and sends the report. She gets a confirmation: "Your record has been successfully sent." When she comes in for the first visit, the nurse asks her to provide some validation data to further authenticate Samantha's transmission. Upon verification, the nurse releases the information into a new patient record for Samantha in the office EHR.

When Samantha sits down with OB-GYN-2, they discuss the information in her record. Each source of information is clearly identified by source and date. The doctor asks a series of questions to confirm the accuracy of the information.



By the time of her second visit, Samantha's comfort level has increased with her new doctor, and she decides to discuss the depression she experienced after the first baby. She goes back online and generates a new report, this time releasing the data of the depression diagnosis and two prescriptions, including the side effects from the first one. For her second visit at OB-GYN-2, the updated data are already in her EHR

chart, clearly marked as an update that draws the doctor's attention when he pulls up her record during the visit.

Samantha and her new doctor now discuss the importance of preventing a new depressive episode, and, if necessary, how to treat one.

Paul

Paul's problem

Paul has just been diagnosed with Type 2 diabetes. His various healthcare professionals do not work in the same facility and do not share the same EHR. They don't even know each other. Still, Paul needs them each to know what the others are doing. They need to help him monitor his blood glucose levels, especially in the early stages as they develop a treatment plan that includes medication, insulin doses, and changes in diet and exercise routines.

Chronic disease care is an enormous challenge. According to the National Center for Chronic Disease Prevention and Health Promotion, more than 90 million Americans have a chronic illness, accounting for 75 percent of the nation's \$1.4 trillion medical care costs.³ The average health care cost for a person with diabetes is \$13,243, compared with \$2,560 for a person without diabetes. Seventeen million Americans have diabetes.⁴

Paul's experience in today's paper-based world

Paul's diabetes educator, doctor and other care providers ask to see his medical records, and Paul is responsible for requesting (in writing) that his records be copied and sent to each of his care providers. Because of the various information needs of each of his providers, this is a confusing — and expensive — process. There is no method of ensuring that any of his care providers have his complete medical information, including co-morbidities and medication history.

After his diagnosis, Paul needs to get information from his healthcare professionals. But he finds communication to be largely hit and miss. The typical diabetes patient sees his or her doctor five or six times each year, and there is much that needs to happen between these frequent visits. If Paul has questions or concerns, he must engage in a game of phone tag, or wait until the next appointment. But he often leaves appointments with unanswered questions, and he can't always remember what his doctors say during the brief encounters.

During visits, valuable time is lost attending to administrative details, when it could be used to manage his fear and educate him about his condition. It's easy to feel overwhelmed and slip into denial.

Communication among his various providers is rare. Even when the providers talk to each other, Paul is mostly out of the information flow.

The current visit-based system of care makes it very difficult to track disease management recommendations and ensure compliance. It provides for acute care needs, but does little for those who are learning to live with and manage a chronic condition every day.

Paul's experience with a connected personal health record

The diagnosis is a shock to Paul. But the health professionals begin to arm him with information. After completing baseline labs and a routine screening for depression, Paul's primary care doctor refers him to a Certified Diabetes Educator (CDE), who counsels Paul on diet, exercise, and available services. The educator introduces Paul to a shared-access PHR. For the first time in his life, Paul has easy access to his own medical information.

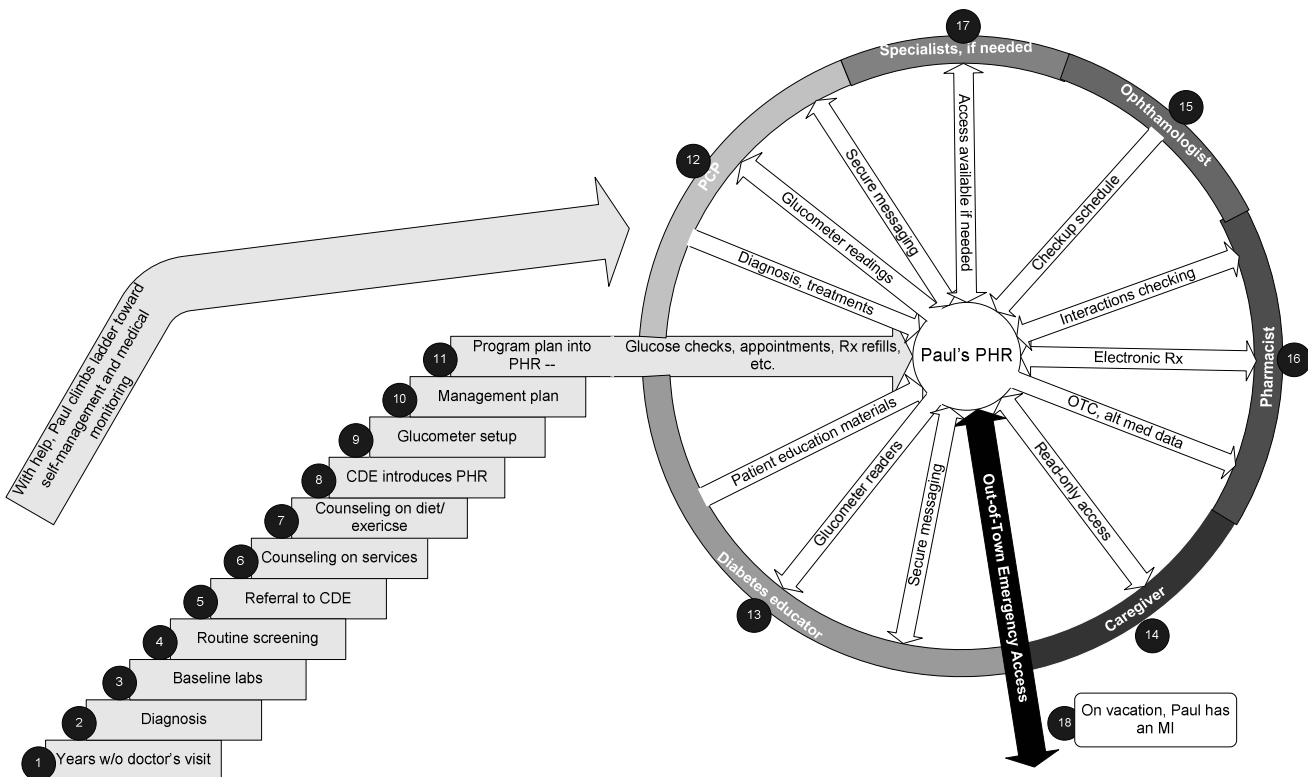
The CDE shows Paul how all the things they discuss in their visit will be accessible from home in his PHR, including links to articles about diet and exercise and information about how to join a support group. She also shows Paul how to upload his glucometer readings into the PHR and understand the graphs that it generates. He can see how his blood sugar levels fluctuate with changes in insulin, diet and exercise. He sends the latest graphs to his primary care doctor before each appointment.

Together, Paul and his doctor create a management and monitoring plan, which is entered into his PHR so that Paul can access it anytime. It includes automated appointment and medication reminders, sent to the secure inbox of his PHR.

Paul can even add his over-the-counter medications and check for interactions with the medications that he's been prescribed. He provides read-only access to his wife, who helps him stay on track.

By helping Paul set up a PHR, the CDE essentially hands over control and management of the illness to him. Paul's PCP, CDE and specialists are able to view the same information. Those who aren't connected to the PHR-compatible electronic information-sharing network can print out copies, including his latest blood-sugar graphs, and store them in Paul's chart in their office. He can handle routine questions using secure email with his primary care doctor and diabetes educator.

Paul has climbed from a feeling of powerlessness to empowerment. He has settled into a routine maintenance cycle for his condition. In the diagram below, Steps 2 through 11 depict actions that medical professionals took to help Paul reach a cycle of self-maintenance with his PHR as a central application. This is not meant to imply that each step is a prerequisite of Paul's constructive use of a PHR. However, it does encapsulate a model that includes significant levels of human interaction to introduce the technology.



Years later, when Paul has a heart attack while vacationing, his wife's ability to call up his information at a rural emergency room helps make the difference between life and death.

His wife provides her username and password to the ER staff, who access Paul's history, medication and insurance information. The ER staff refers Paul to a cardiologist in the hospital. During recovery, Paul tells his wife his own password, which gives her the ability to add all of the procedures, diagnoses and medications that he undergoes out of town.

When he gets home, his care team will know the specifics of what happened. His primary care physician refers him to a new cardiologist, who prescribes new medications and makes modifications to the care plan.

Paul's risk has increased, his care team has expanded, and his care plan has become more complex — all the more reason to keep track of everything in a PHR.

Dr. Bednarek's problem

Dr. Bednarek's patient, Jane, has a serious abnormality consistent with breast cancer detected in a mammogram screening. Jane, a long-time patient of Dr. Bednarek's, is referred to a Cancer Center two hours away for further tests and to decide on a treatment option. Following a lumpectomy with sentinel node biopsy, Jane and her oncology team decide that surgery followed by chemotherapy is the best choice to fight her cancer. Jane gets a checklist of things she needs to consider before starting treatment, including getting a flu/pneumonia vaccine, dental cleaning and dental work to minimize risk of chemotherapy-related infections.

Dr. Bednarek wants to know how Jane is doing as she goes through her regular treatments at the Cancer Center, and to see the results of CBC and other labs as well as side effects and complications. When Jane returns home, Dr. Bednarek wants to make sure that she gets appropriate screenings for endometrial, colorectal, ovarian and cervical cancers — for which she is at higher risk based on her decision to take a SERM class medication. Dr. Bednarek also wants to make sure she receives continued comprehensive care to minimize the risk of recurrence.

Dr. Bednarek would like to stay informed about the treatment, including how the cancer is progressing, how the chemotherapy is being administered and side effects of the treatment.

This year, 1.3 million people will receive a cancer diagnosis.⁵

Dr. Bednarek and Jane's experience in today's paper-based world

Jane is asked to collect her records prior to her first visit to the Cancer Center. That means more than what's contained in Dr. Bednarek's files. There are a lot of important records at her gynecologist's office and at a few different pharmacies. She doesn't even know where some of her records are. She doesn't realize that the oncologist will need originals of some documents. Dr. Bednarek has a report on the mammogram, for instance, but the film is at the hospital. Jane feels like she has to navigate a bureaucratic juggernaut while dealing with the trauma of a cancer diagnosis.

Once Jane goes to the oncologist, Dr. Bednarek is completely out of the loop. If correspondence is received in the mail, it is easily lost in the sea of paper at her office. It may be inserted into Jane's chart, but if Dr. Bednarek has no reason to pull her chart, she will not see the new information.

While undergoing treatment, Jane stays at the Cancer Treatment Center. If her treatment is successful, she will eventually be referred back to her community and Dr. Bednarek. Dr. Bednarek will need to

know about any medications Jane is on, her treatment regimen, what to screen for, how to react to new symptoms and handle potential complications.

At this point, the roles and responsibilities of Jane's various doctors are often left undefined and uncommunicated. Neither the cancer treatment center or Dr. Bednarek have complete medication information. Jane may assume that her providers are talking to each other when in fact they are not.

There is a high likelihood of drug interactions, unnecessary repetition of tests, and healthcare decisions based on incomplete information. If Jane winds up in an emergency room in her hometown, chances are the ER staff would have no way of easily finding out critical details about her recent treatment regimen.

Dr. Bednarek and Jane's experience with a connected personal health record

Prior to her diagnosis, Dr. Bednarek and Jane had set up a PHR, which included a screening program based on Jane's family history of breast cancer. She receives an automatic reminder for her mammogram and makes her appointment online.

Dr. Bednarek discusses the suspicious abnormality with Jane and refers her to a cancer specialist. Dr. Bednarek also counsels that Jane will play an important role in ensuring communication among her doctors, and that she can help by keeping her PHR up to date. The mammogram report and image are scanned into Jane's PHR, along with information already collected from her gynecologist and pharmacists.

Jane sends her PHR information to the Cancer Center, which participates in a regional health information-sharing network able to send and receive a minimum data set from her PHR. She also backs up a copy of everything on a CD Rom that she carries with her.

After a series of appointments at the Center, Jane is flooded with terminology that's foreign to her. She understands that the growth is malignant and needs to be treated as soon as possible. She and her oncologist agree on a treatment plan that includes surgery to remove the malignancy and then chemotherapy.

After the surgery, the surgeon's report goes into the PHR, as well as a pathology report that indicates that Jane is estrogen-receptor positive. There's an embargo period before these results are released, however. It gives the oncologist time to discuss them with Jane. When the results are released into the PHR, the application translates some of the more complex medical terms to more consumer-friendly terms, which also have links to corresponding patient education materials. Jane's understanding increases rapidly through the combination of her doctor's explanations and the information in her PHR.

The oncologist prescribes a combination of chemotherapy agents, and throughout the course of her treatment Jane can access her platelet

Record locator service

What if Jane can't remember where all her records are kept?

Connecting for Health's Working Group on Accurately Linking Information for Health Care Quality and Safety has recommended a "Record Locator Service" to facilitate the collection of a patient's scattered clinical data.

In this system, a third-party establishes a repository of identifying information on patients who opt-in to a regional health data-sharing system. The identification repository provides a protocol for authorized persons to query all participating health data sources for the existence of records on a particular individual. In this model, no patient health information is retained in the Record Locator Service. It only shows authorized individuals which participating institutions hold data on that patient.

In this example, Dr. Bednarek – with Jane's permission – would query the repository to receive a list of institutions in the region that hold her health information. The doctor or Jane would contact those institutions to request copies or, if feasible, electronic transfers of the data.

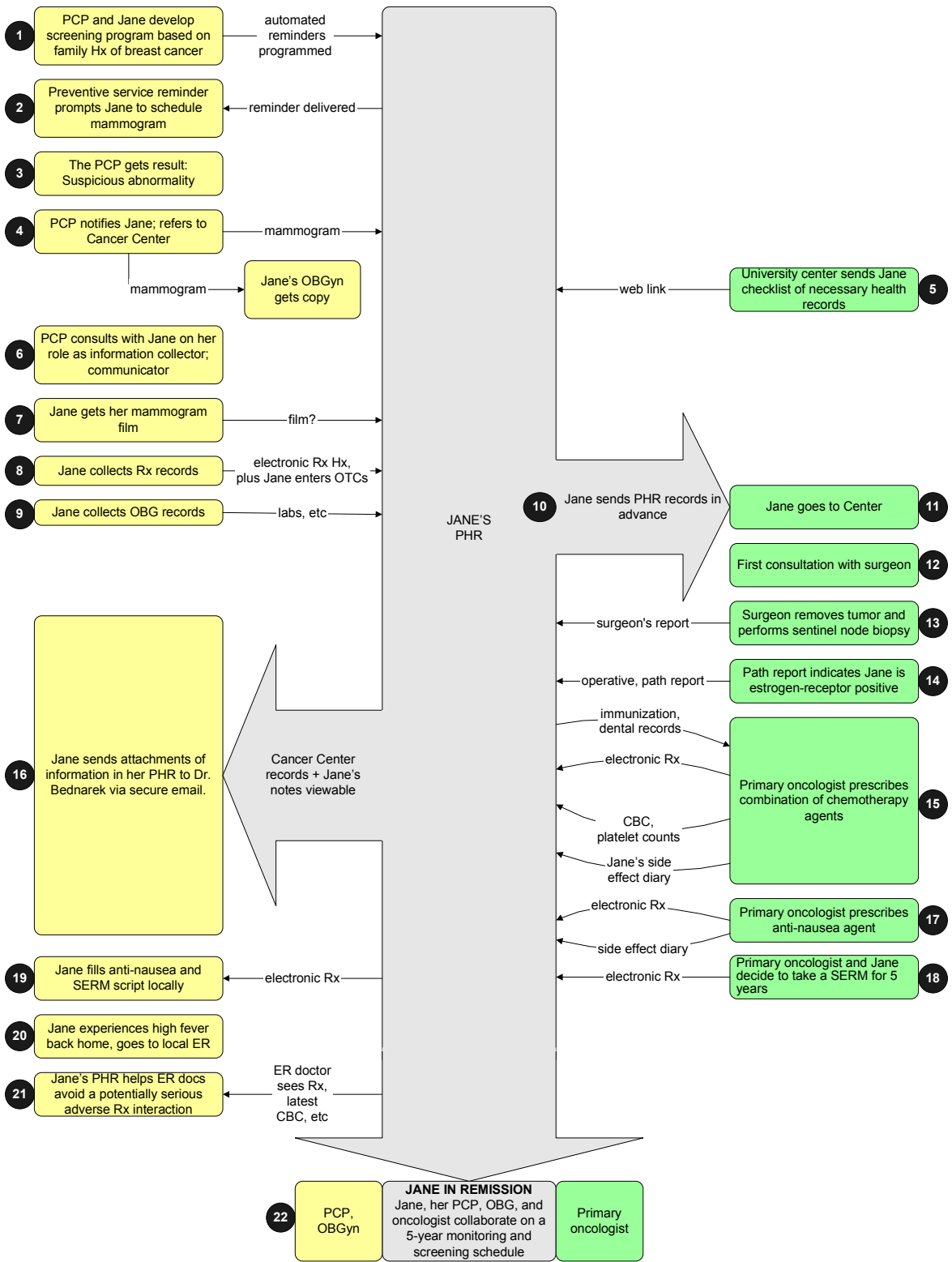
For more on this recommendation, see the **Connecting for Health Preliminary Roadmap**.

http://www.connectingforhealth.org/resources/cfh_aech_roadmap_072004.pdf

counts as well as keep a symptom diary so that she can discuss reactions and trends with her doctors.

She's suffering terribly, but each time she gets to read an update in her record, it helps her recall what her doctors said about the results. Using the secure email associated with her PHR, she sends attachments of Cancer Center reports to Dr. Bednarek's nurse, who stores them in Jane's chart in their local EHR system.

Finally, the chemotherapy sessions are complete and Jane leaves the center, taking her prescriptions for anti-nausea agents and the SERM with her. One night, she experiences a fever so high that she goes to the Emergency Room at her local hospital. Thankfully, she's able to call up her PHR from an Internet-connected computer in the ER. Based on information in her PHR, the ER staff avoids a potentially serious adverse medication interaction.



Once Jane is in remission, the Cancer Center oncologist recommends a long-term monitoring and screening schedule. Jane sets up automated reminders for the appointments in her stepped-up screening schedule.

¹ Cunningham PJ, Kohn L. Health plan switching: Choice or circumstance? *Health Affairs*. 2000;19:158-164.

² Reed MC, Trude S. *Tracking Report: results from the community tracking study*. Center for Studying Health System Change, 2002.

³ "Chronic Disease Overview" Centers for Disease Control, National Center for Chronic Disease Prevention and Health Promotion. Accessed online on May 21, 2004 at <http://www.cdc.gov/nccdphp/overview.htm>.

⁴ "Diabetes: A Serious Public Health Problem" Centers for Disease Control, National Center for Chronic Disease Prevention and Health Promotion. Accessed online on May 21, 2004 at http://www.cdc.gov/nccdphp/bb_diabetes/index.htm.

⁵ "Estimated New Cancer Cases and Death by Sex for all Sites, US, 2004" National Cancer Society. Accessed online on May 21, 2004 at <http://www.cancer.org/downloads/MED/Page4.pdf>.

CHAPTER 5 Are consumers ready for PHRs?

Introduction

In 2003 and 2004, Connecting for Health conducted a progressive series of original research studies to investigate the public's attitudes and readiness to adopt electronic PHRs.

The key findings summarized in this chapter are:

1. The American public is largely unaware of, but receptive toward, the potential value of PHRs. People have a limited and inaccurate understanding of health information technology issues today.
2. Most people want convenient access to and control over their health information, and many express a desire to check the accuracy of the records that clinicians keep on them.
3. When presented with options, most people prefer electronic access to their medical records. However, the preferred medium of a PHR varies by age, with younger people more receptive to electronic tools and older people more inclined toward paper.
4. Most people do want certain healthcare services and information available electronically, particularly when it represents a convenience.
5. People prefer to work with their doctors to access these services.

Connecting for Health Research on PHR

Through focus groups, cognitive interviews and two national surveys, Connecting for Health staff examined public attitudes toward access to online medical records. The data collection included 10 focus groups (six in 2003, four in 2004) with samples of the general population, caregivers and people with chronic illness. A 2003 series of focus groups studied attitudes of early PHR adopters. The 2003 survey was conducted online with 1,246 respondents, and examined interest in various features of personal health records, comfort with use of online tools for the storage of personal health information, concerns about privacy and security, and level of trust in various information sources and hosts.

In 2004, our research progressed to testing messaging and communications

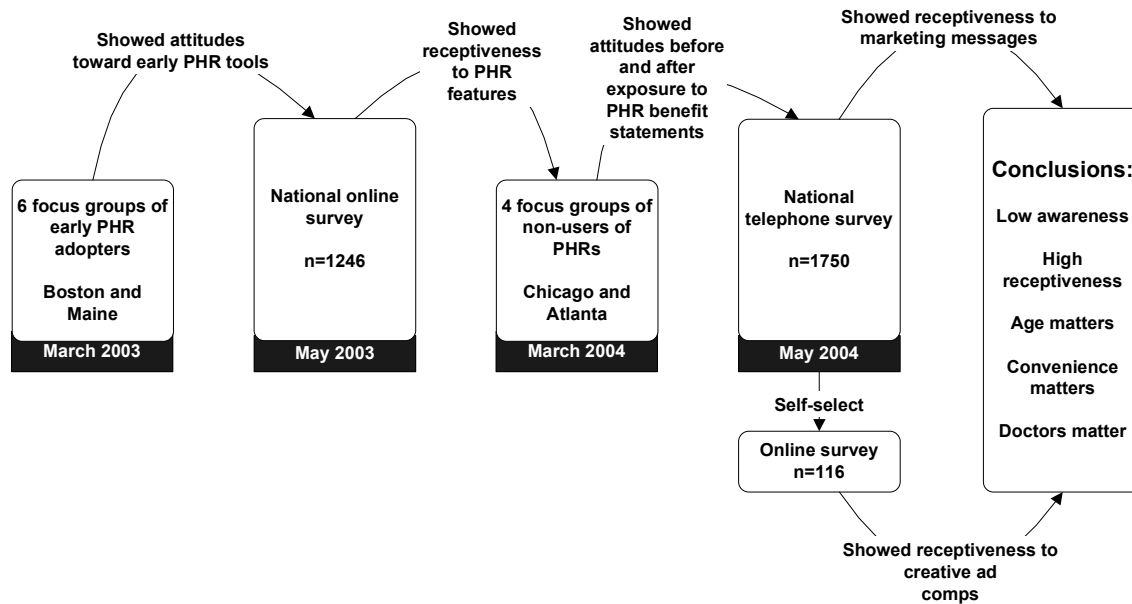
Key differences in survey samples		
	2003	2004
Over 65	22%	33%
Internet access	100%	71%
Chronic illness	61%	69%

strategies. We used a series of focus groups to develop messages of PHR benefits. A 2004 national telephone survey included 1,750 respondents (of whom 1,201 reported chronic illness) and emphasized how well people understood those various communications messages about use of electronic personal health records and related services. A small follow-up online survey also tested mock advertisements to see which images and ideas were most persuasive. The diagram below summarizes the research process. Methodology is described at the end of the chapter.

Resources

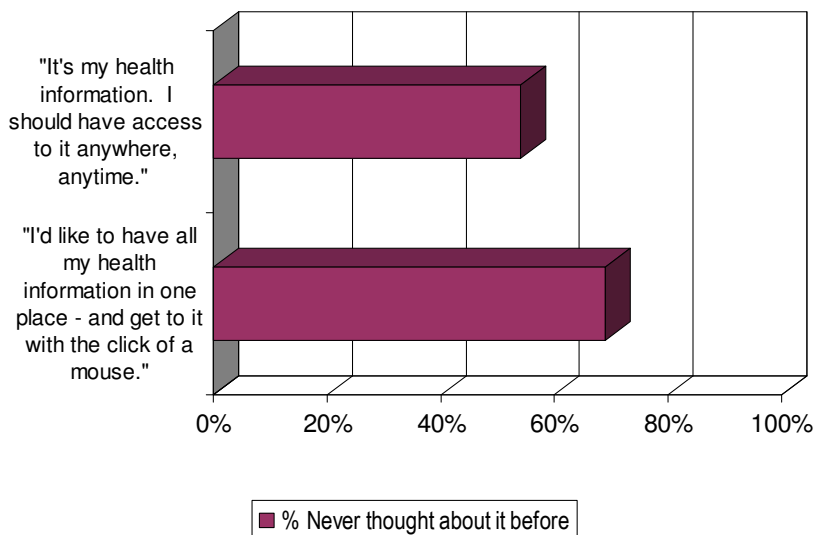
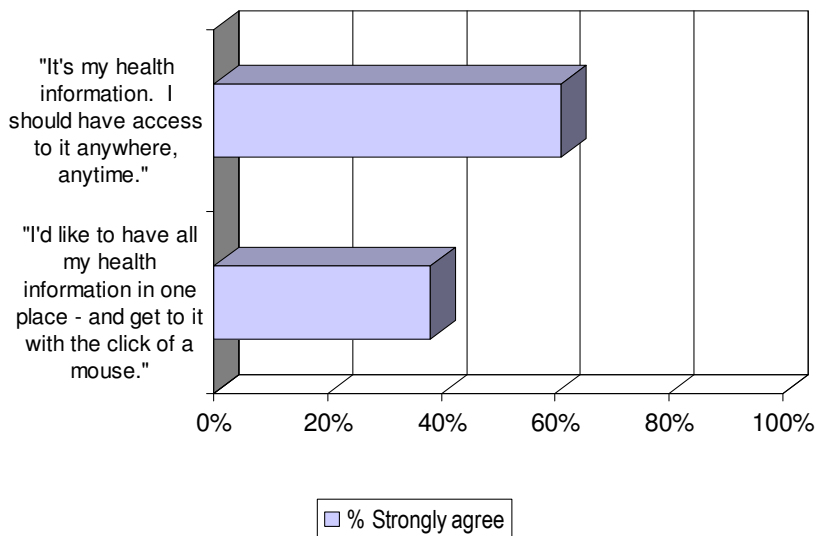
For a more complete review of extant literature on consumer attitudes towards PHR, see Phase 1 report.

http://www.connectingforhealth.org/resources/final_phwg_report1.pdf



No. 1: The American public is largely unaware of, but receptive toward, the potential value of PHRs.

Most people simply have not thought about the potential benefits of having their own medical records online or offline. Respondents in the 2004 telephone survey were presented with a series of messages with variations on the theme of getting convenient access to their medical records. The charts below juxtapose two such messages:



Note that 61 percent of the respondents “strongly agreed” with a general message emphasizing ownership of and access to one’s health data: *“It’s my health information. I should have access to it anywhere, anytime.”* Another 23 percent “somewhat agreed.” Yet more than half of all respondents said they never had thought about it before, and roughly one-third of those under 65 who strongly agreed had never thought about it before.

The second message, *“I’d like to have all my health information in one place – and get to it with the click of a mouse,”* adds the concept of managing one’s health information on a computer. Agreement was lower (38 percent agreed “strongly” and 21 percent agreed “somewhat”) than with the statement that didn’t refer to computers. Still, this is a high level of agreement given that two-thirds of all respondents had never thought about this concept before. Roughly half

of those under 65 who strongly agreed with this concept had never thought about it before.

We noted that statements directly promoting online storage of one's health records were the least likely to have been thought about before. This supports our overall finding that people often do not consider electronic solutions to their personal health information management needs. Still, a large portion of Americans under 65 are receptive to the idea, as indicated by 1) the very high levels of "strong agreement" with statements emphasizing ownership and access to one's health information, and 2), a relatively high level of strong agreement with messages emphasizing "online" solutions even though very few people had thought about the idea before.

See **Appendix C** for detailed demographic results for the 12 messages.

Perceptions of electronic connectivity in healthcare

Americans perceive that doctors are more "wired" than they actually are. In the 2004 telephone survey, 60 percent of respondents believed that their doctor kept their medical records on a computer and an additional 24 percent stated that they were not sure. Best estimates on the proportion of doctors currently implementing EHRs range from 22 percent to 30 percent.¹ In our research, younger respondents (under 45) were less likely to believe this statement and older respondents were more likely to respond that they did not know.

The 2003 online survey showed similar results. In this younger and more technologically sophisticated population, a significant minority (43 percent) believed that their doctor kept computerized records, and another 41 percent did not know. The 2003 respondents were also asked whether they believed that hospital emergency rooms had access to their medical information and how important it was for them to have that access; 29 percent of respondents believed that emergency rooms have access to their medical information now. The vast majority (81 percent) think it is "very important" for them to have this information readily available. To date, however, fewer than 10 percent of U.S. hospitals have adopted an EMR.²

No. 2: People want convenient access to and control of their health information

The majority (61 percent) of the 2004 telephone survey respondents said they were interested in viewing their medical records: 34 percent were "very interested" and 27 percent "somewhat interested." Females were more likely to report being "very interested" in reviewing their own medical records than males (38 percent vs. 28 percent). In addition, 67 percent of those with dependent children said they were interested in viewing their child's records and 62 percent of people in caregiving relationships were interested in viewing the medical record of a family member or friend to whom they give care.

Other resources

A similar survey of over 3,600 adults who had a recent clinic visit found that 36 percent were "very interested" in reading their medical record. The top three reasons given were:

- to see what their physician said about them (74 percent)
- to be more involved in their health care (74 percent)
- to understand their health better (72 percent).

Source: Fowles, et al. (2004), Patients' interest in reading their medical record. *Archives of Internal Medicine*, 164, 793-800.

Focus group quotes

"Wouldn't you like to know what the doctor is saying?"

"I think one of the problems with the healthcare system is that doctor's have typically always kept that information close to their vest. You don't ever get to see the inside of that folder."

— Atlanta focus group participants

Respondents responded positively to messages emphasizing the desire to check accuracy of one's medical records. Fifty-four percent "strongly agreed" and 26 percent "somewhat" agreed with the statement: *"Anybody can make a mistake. I'd like to double check what's in my medical records."*

On the issue of control, early adaptors in the 2003 focus groups reported a strong desire for total control of their PHR, as did the 2003 online survey respondents. Specifically, focus group participants expressed a desire to decide who could and could not access their record and an expectation that they should provide explicit consent to any access. They emphasized that even though they were likely to grant such permission to healthcare providers, they believed that their PHR should have the capability to track and display who accessed their record and when.

Despite the high level of interest in accessing and controlling one's medical record, the vast majority of respondents to the 2003 online survey did not use online medical records. Only 1.5 percent of respondents managed their health records on a computer, and an additional 0.5 percent maintained their records online. Although 40 percent keep some paper medical records at home, 60 percent said they that "should do a better job" of keeping medical records.

To summarize the first two findings: People generally understand the importance of keeping medical records. However, the public has currently does not have a high expectation that electronic applications could or should be available to help with the task. Many simply haven't thought about it.

No. 3: When presented with options, most people prefer electronic access to their medical records

In the 2004 telephone survey, we asked how participants would like to store and access their medical records. Responses varied by population and age. In the 2004 telephone survey, the preferred medium among people age 45 and younger was the Internet (33 percent), followed by paper (24 percent), portable electronic devices (22 percent), and a computer's hard drive (18 percent). The top two options were almost inverted for people older than age 45 (34 percent preferred paper vs. 21 percent Internet). This finding is not surprising, given that Internet use is less common among older people today; currently, only 22 percent of adults over 65 are "wired".³

We found a stronger tendency to prefer paper among people who have a chronic condition. Paper was the top choice for 44 percent of those over 45 who have a chronic condition. However, it should also be noted that those with a chronic condition are more likely to choose paper records than those without a chronic illness, regardless of age.

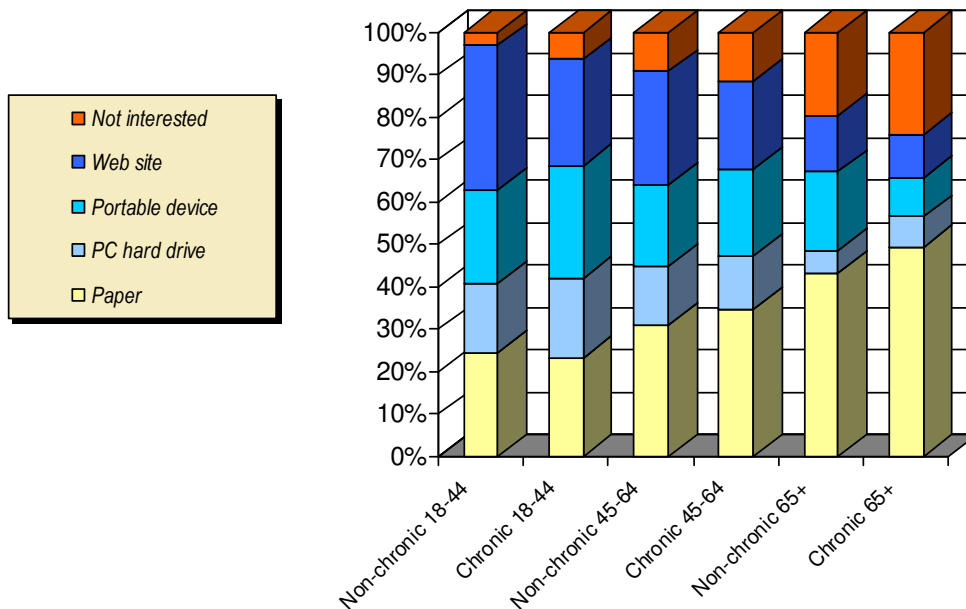
Overall, when all of the electronic PHR information storage media (Internet, portable devices and computer hard drive) are combined and

Focus group comments

"It is inevitable that computers are going to provide a service to guys like me or families that want to check on their parents and find out what is going on."

– Atlanta caregiver

compared to paper, electronic means are overwhelmingly preferred. Among those 45 and under in the general population sample, computer-based solutions are preferred by a margin of almost 3-to-1 (73 percent vs. 24 percent). Although this trend is less pronounced in the other populations, it holds with only one exception: People over 45 with a chronic condition showed a slight preference for paper records.



In the 2004 focus groups, some participants were highly enthusiastic about Internet-based storage and access:

"I like the idea of being able to have my health information available to me if I needed it."

"If it's all electronic, you're eventually going to end up with a huge cost savings. One of the huge expenses in our health care system is all these pieces of paper. You have this piece of paper and three people touch it and enter the exact same information at three different places. Or you end up with incorrect or inconsistent information in three different places."

"If you need to get your medical records today, what you would have to do would be get a form, fill it out, mail it to them, have them make sure, verify, everything. Then they would have to take your records and send them. Even then you might run into problems with things getting lost. I think computers would make it a lot easier to deal with that."

"When you're traveling, you might lose your medicine and you need a refill ... It would make things a lot easier if you could do things by computer where you wouldn't have to wait ... What if you are in a different time zone and your doctor's office isn't open? What are you going to do? You could die."

Other studies

Other research has shown openness to the idea of storing medical records on a computer. A survey of 200 users of the CapMed Personal Health Record found that 84 percent of respondents believe it is important to have health information available at all times and 63 percent believe using a PHR will decrease the chance of errors in treatment.¹ Another study assessing the usage of a PHR found high user satisfaction, especially with the lab results function.² In a study of 1,000 adults reached via random digit dialing, 87 percent of those with computerized access to their medical records were satisfied with the service; however, only 6 percent of respondents stated they had such access. An additional 41 percent of people did state that they would be likely to use such a service were it made available to them, and 39 percent believe that computerized access to their medical records would improve the quality of their health care.³

Sources:

1. Agarwal, R., & Angst, C. (2003). Summary of findings from personal health record (PHR) research, Fall 2002. Robert H. Smith School of Business, University of Maryland.
2. Cimino, J. J., et al. (2000). An evaluation of patient access to their electronic medical records via the World Wide Web. Proceeds of the AMIA Symposium.
3. First Health (2002). Consumer Health Benefits Survey. Power Point presentation created by Harris Interactive.

As reflected in the quotes above, people came up with several advantages to having their medical information available to them through the Internet. Better access to information, cost savings, the ability to transfer records more easily, and solutions to emergency situations were all named as benefits of an Internet-based PHR.

Other focus group participants, however, expressed concern over putting their health information on a computer:

"A lot of times there are things regarding your health that you might not want someone to know ... And with identity theft, you don't want anybody knowing your medical history."

"What happens if your medical records are married with someone else's and someone were to go and pull up your information and think you have a condition when you don't?"

"I wouldn't do it online. I just wouldn't trust it."

In citing benefits of health information technology, participants responded positively to the concept of exchanging e-mail with their doctor, some stating that it was more private than a phone call. They also appreciated the possibility that once personal health information had been entered, it would become part of their permanent record and would not need to be remembered thereafter. Participants also believed that storing personal health information would give their children access to a more complete family health history.

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.

Online survey respondents in 2003 expected that online medical records could help improve their health care experiences. 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).

See **Appendix D** for more details and quotes from the 2004 focus groups.

Focus Group Quote

"I have one son with many allergies to medication, and every time we go to the doctor, or I've been in the emergency room with him, they want to know what those medications are, and how severe his allergies are. It would be easier if it were someplace, so that it was just always there, so that it always existed for him.

– *Chicago general population*

No 4: Most people want certain healthcare services and information available electronically, particularly when it represents a convenience

Our 2003 online survey found that people are interested in using the various features that comprise an electronic PHR. In fact, the majority of respondents would use one or more features of the PHR. Services people wanted the most were:

- | | |
|---------------------------------------|------------|
| • 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 |

There were few demographic differences in the services people wanted. No differences were found based on age, income, education or gender. Nearly two-thirds (65 percent) of people with chronic illness said they would use at least one of the PHR features today, compared with 58 percent of those without chronic illness. Overall, the chronically ill, frequent users of health care and people caring for elderly parents reported the highest and most urgent interest in PHR.

In the 2004 telephone survey, which encompassed an older and less tech-savvy population, we asked respondents to name which two of the following four electronic capabilities would most likely inspire them to try a new online PHR service:

- 41 percent chose an online communication tool to communicate with their doctor.
- 34 percent chose an online tool to keep track of medications and order refills.
- 29 percent chose an online tool to help them keep track of medical expenses.
- 28 percent chose an tool that allowed them to send health information to the doctor's office ahead of time.

It's notable that 27 percent responded "none of the above" or "I don't know."

No 5: People want to work with their doctors

As noted earlier, respondents in the 2003 online survey expressed a desire to control their medical record and who has access to it. The majority of respondents stated that they were comfortable with other entities accessing their PHR *after they had given explicit permission*.

Anecdotal findings from the field

FACCT researchers also conducted face-to-face interviews with small numbers of people who use institutional gateway PHRs in 2004. Patient-doctor secure messaging, online refills, lab results, medication lists and disease management plans were among the functions that consumers singled out as particularly useful.

Focus group participants in both 2003 and 2004 emphasized the benefits of keeping track of medications, allergies and immunizations.

When asked to whom they were most comfortable giving such permission, the respondents overwhelmingly favored medical professionals:

- Primary doctor 96 percent
- Specialist 95 percent
- Emergency room 93 percent
- Hospital 91 percent
- Family member 69 percent
- Insurance company 65 percent

Similarly, 58 percent preferred a PHR system to be hosted by their doctor's office, compared to a distant second of 15 percent who favored their health insurance plan and 12 percent who favored the government.

Peoples' desire to work with their physicians was also borne out in the 2004 telephone survey evaluating promotional messages. Two statements scored lower than the rest:

- *"I've often felt the health care system has all the power. Having my own online medical record seems to even it out a little bit."* (Only 21 percent strongly agreed with this statement.)
- *"I'm tired of playing telephone tag with my doctors and filling out the same forms. Why can't I do some of this stuff online?"* (Only 26 percent strongly agreed.)

These statements have two things in common: (1) they both put a negative spin on the health care system and (2) they both directly mention the Internet as a solution. Previous FACCT research has demonstrated that people want to work with their doctors to improve their health care, not see their doctors as "part of the problem."⁴

Finding the 'right' message

The survey and focus group data indicate that the various features of personal health records — getting lab results, refilling medications, managing one's own health — are very attractive to many Americans. Yet most people are unaware that these services are possible and are not yet asking for them from their providers or from independent information companies. How can we communicate with the public to create interest in the PHR concept?

The 2004 telephone survey tested 12 diverse statements about promoting convenient access to health records. Overall, people tended to agree with the statements addressing the importance of access to medical records. In ranking the statements from 1 to 5, with 1 being "strongly agree" and 5 being "strongly disagree," the range of level of mean agreement was 1.5 to 2.9 for the 12 statements (with a mean of 2.3).

Two statements rated highly among all participants:

- 71 percent of participants strongly agreed with: *"In an emergency, getting my medical records quickly could mean the difference between life and death."*
- 61 percent of participants strongly agreed with: *"It's my health information. I should have access to it anywhere, anytime."*

These results imply that it is possible to reach a broad audience about the benefits of PHR through these two general statements.

People younger than 65 were significantly more likely to strongly agree with all PHR statements than people 65 and over — by a margin of almost 2-to-1. Close to two-thirds of those under 65 strongly agreed with most of the statements; only about one-third of those 65 and over did.

Other experiences influenced peoples' level of agreement with PHR statements. Past experiences with transferring medical records proved to be a significant predictor of message agreement. Those participants who had transferred their medical records in the past three years had higher agreement with a majority of the statements. Of those who had reported their experience transferring records as "difficult," the level of agreement was likely to be higher.

Familiarity with online technology also influenced level of agreement with several statements, especially those statements that specifically mentioned access to one's medical records "online." Those people who have conducted at least one online business activity (shopped, managed financial accounts, made travel arrangements or ordered prescriptions) agreed more strongly with those statements that claimed that online access to medical records was convenient and easy. In contrast, those people who did not conduct business activities online were more likely to strongly disagree with those statements. This finding held true for nine of the 12 statements.

Some variables related to health issues also revealed differences among participants. People who reported having a chronic illness were more likely to strongly agree with 9 out of the 12 PHR statements. For example, people under 65 (i.e., those people more likely to use the Internet) who also reported having a chronic illness, were more likely to agree that *"My own medical record would help me get all my doctors on the same page when they treat me."*

Those people in poor health (i.e., stated that their health was "fair" or "poor") were more likely to agree with these statements than people who reported their health status as being "excellent," "very good" or "good." Similarly, those who reported worrying about their health also reported higher levels of agreement with statements about medical records. Interestingly, level of worry about one's health was significantly, but only marginally, correlated with chronic illness status.

Thus, it appears that one's perceptions and concerns over one's health is a predictor of interest in online medical records and should be considered outside of actual health status and condition. Those people who are both living with a chronic illness and worried about their health were more likely to "strongly agree" with all of the PHR statements than those people who do not have a chronic illness or are not worried about their health.

Age and the presence of a chronic condition both significantly predicted level of agreement with the PHR statements. People under 65 with a chronic condition were more likely to strongly agree with the PHR statements than those under 65 without a chronic condition. This difference did not hold for participants 65 and over, perhaps because they are less comfortable using online services. PHR interest may be highest not simply among those people with a chronic condition, but among those people under 65 with a chronic condition.

Given all of these factors, we sought to determine those characteristics that were most predictive of agreement with the PHR statements. In a multivariate analysis, both level of worry about one's health and involvement in online activities were significant predictors of level of agreement in PHR benefit statements. That is, people who are worried about their health and people who conduct business and financial activities online are more likely to agree with PHR statements after taking their age, health status and chronic illness status into consideration.

Testing creative advertising messages

Connecting for Health commissioned nine magazine-style advertising mock-ups to further test messages to promote PHRs. At the end of the telephone survey, participants with online access were asked to go to a Web site and rank the nine visual ads on a 4-point scale, with 1 being "very persuasive" and 4 being "not at all persuasive." Nearly all of the 116 respondents reported having a chronic illness.

The average ratings ranged from a best score of 1.8 to a worst score of 2.4 (mean was 2.1). Out of the nine visual ads, one was ranked as significantly more persuasive than the other eight. This ad carried the message of needing access to one's medical records in an emergency – a result that replicates the findings of the telephone survey. A significant minority (41 percent) found this ad to be "very persuasive."

There were no demographic differences to differentiate ad appeal among various target audiences. Similarly, no significant differences were found among rates of health care utilization, health status, and level of concern about health issues and level of persuasiveness of the ads.

See **Appendix E** to view the nine advertising concepts and results.



Above is the best-scoring visual ad.

For full results, see Appendix D.

Conclusions

Overall, people find messages about the importance of personal access to medical records to be agreeable and persuasive. Messages that resonated most strongly with our sample of primarily chronically ill participants were those that stated PHR could help get easy, convenient access to one's own health information. In contrast, those messages that resonated least were those that found fault with and/or challenged the current health care system. Messages that assumed an online component of PHR (e.g., suggested an Internet solution to the problem being posed) did not fare as well, compared to messages that did not include an online reference. It is interesting to note that respondents were significantly less likely to have ever previously thought about an Internet solution for personal health information management problems.

However, there were some differences among various target audiences that could help us narrow the field to those most likely to respond to a PHR message. The strongest predictors of interest in PHR appear to be level of worry about one's health and previous experience with online activities such as shopping and managing finances.

Lesser, but also notable predictors of agreement with the benefits of PHR include age (those under 65 being more likely to agree with PHR statements), health status (those in poorer health being more likely to agree with PHR statements) and presence of a chronic illness (those with a chronic illness being more likely to agree with PHR statements and, according to the 2003 survey, state that they would use specific PHR services today). In addition, people who have had experience transferring medical records may be more open to the idea of having access to their medical records online.

How can proponents of PHR communicate effectively with the public?

Unsuccessful PHR launches by commercial vendors have led to the conclusion there is no viable market for PHRs. We hear that there simply is not enough public demand for these services. Our data suggests the contrary. Although we have noted low levels of use of PHR, we find high interest in it. And although we find little active demand for it, our research suggests that the kinds of things that are possible with PHR would be attractive to many people, that people are open to the concept of storing medical records using computer-based technologies, and that, when presented with the possible benefits of managing their medical records, they agree with these statements. However, the fact remains that most people have never before thought of getting these services conveniently, electronically. They can't imagine what they've never seen.

This scenario suggests a two-part communications strategy: first, show the public what's possible - the things we know they'd like to do. In this

manner, PHR promotion should educate people on how PHR can allow individuals easy and convenient access to their own health information and related electronic services.

Secondly, we need to show people that it is important to create this capability. One of the most seminal findings of this research is the notion that a significant number of people were receptive to the ideas and benefits of PHR despite the fact that they were novel concepts. As shown above, people are relatively ignorant about the role of information technology in the healthcare system and are often cautious about the idea of having their medical records online. Nevertheless, when presented with statements about how PHR could help them interact with the health care system and improve their lives, people are able to see PHR's positive value despite its novelty. This phenomenon of almost instant persuasion in a desired direction has been cited in present day attitude, persuasion and communication theories, including Petty & Cacioppo's Elaboration Likelihood Method (ELM). ELM suggests that the most significant and long-lasting type of persuasion is that which occurs as a result of a person's careful and thoughtful consideration of the true merits of new and interesting information presented in support of an innovation (e.g., PHR). The presentation of new, issue-relevant information leads to 1) cognitive elaboration (extended time spent thinking about the information) and 2) evaluation of a message that combines with individual and situational factors. The result can be attitude changes which show significant temporal persistence, prediction of behavior, and resistance to counter-persuasion.

Combining our findings with ELM, we believe that the time is right for consumers to listen to and be ready to adopt the notion that PHR can help them improve their health as well as their interactions with the healthcare system. And we know the most fundamental and important aspect of this interaction is the doctor-patient relationship.

Are consumers ready for PHRs? We conclude that they are, but they don't know that they are.

To transform a latent, unexplored interest into an active demand for PHRs, consumers need to receive and contemplate messages that:

- Promote access to their health information (and when feasible emphasize their ability to check its accuracy).
- Stress both privacy safeguards and convenience of electronic services.
- Target people with the most relevant need, such as those with chronic conditions.
- Are provocative enough to get their attention but not confrontational toward clinicians or the healthcare system.

Research Methodology

2003 Focus Groups: Sample and Methodology

In March 2003, FACCT staff conducted six focus groups with 35 people in Bangor, Maine, 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.

2003 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 (see chart). 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.

Demographic comparison with 2000 U.S. Census data

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

*Numbers may not add up to 100 percent due to rounding

2004

Given our understanding that people are interested in various aspects of a personal health record and, the more they are experienced with one the more they like them, our next step was to determine how to market the concept of a PHR to both the general public and those people who have a chronic illness (i.e., those people in the first series of studies who reported being more interested in using a PHR now as well as those people to whom current PHRs are currently designed for). To that end, we conducted a series of focus groups and two surveys – one via the telephone and one online – to test the appeal of different messages which attempted to relay the importance and usefulness of owning a PHR.

2004 focus group methodology

In March 2004, FACCT staff conducted four focus groups with 41 people: two groups took place in Chicago while the other two took place in Atlanta. Participants were drawn from a commercial focus group company in each area, and were diverse in age, ethnicity, and level of income. Two focus groups represented the general population, one consisted of informal caregivers, and the other consisted of people who had a chronic health condition.

A semi-structured protocol asked participants about their opinions of, and experiences with getting access to their medical records. Focus groups were 90 minutes in length and participants received \$20 for their participation.

Participants were asked to complete an exercise in which they were asked to individually rank nine reasons people may want to keep their medical records online, where “1” represented “most important” and 9 “least important.”

Focus group sessions were transcribed and analyzed for emergent themes and ranking results.

The results of the ranking exercise were remarkably similar across all four groups. The same three statements were rated as the top reasons for wanting to keep medical records online. Those statements were:

1. I have access to all my health information
2. I know whether my health information is complete and accurate
3. I can better remember information about my health

All these statements reflect individual desire to be able to control their health information and be at the center of their care. “The best care would be knowing and having all of my health information,” said one participant in Atlanta.

2004 survey methodology

The first portion of the survey was fielded from May 12-18, 2004, to assess America’s response to messages about the ways that patients can access their own medical records in the U.S. health care system. .

Again, we defined 'medical records,' as "the personal health information such as your 'medical chart' from the doctor's office, results from any diagnostic tests, X-rays, prescriptions and the like."

The results are based on telephone survey sample of 1750 respondents solicited via random-digit dialing. Participants were recruited and invited to participate in two different waves, such that the first sample of 750 respondents represented the general population, while the second sample of 1000 respondents stated that they had a chronic illness; this latter sample was partially recruited from a list of people potentially interested in responding to telephone surveys gathered previously by the survey vendor. Response rates for the samples were 4.5 percent for the general population, and 7.5 percent for the chronic illness sample. Data was analyzed using SPSS. Below we compare our samples to the US population based on the latest Census data.

	<u>U.S. Current Population</u>	<u>PHR General</u>	<u>PHR Chronic</u>
AGE			
18-24	13 percent	12 percent	1 percent
25-44	41 percent	35 percent	12 percent
45-64	30 percent	33 percent	43 percent
65 or older	16 percent	19 percent	44 percent
EDUCATION			
H.S. or less	50 percent	35 percent	40 percent
Some college	27 percent	27 percent	34 percent
College +	23 percent	39 percent	26 percent
GENDER			
Male	48 percent	47 percent	24 percent
Female	52 percent	53 percent	76 percent
RACE/ETHNICITY⁺			
Caucasian	73 percent	82 percent	92 percent
African-American	12 percent	8 percent	4 percent
Asian	4 percent	2 percent	.5 percent
Hispanic	11 percent	5 percent	1 percent

*Numbers may not add up to 100 percent due to rounding
 +Participants could select other responses such as "mixed race"
 "Native American" and "other" in the PHR survey

After the telephone survey, those participants who stated they had access to the Internet and a regular email address were invited to participate in an online component of the survey in which nine visual ads were rated for their level of persuasiveness. Of the 1750 telephone participants, 116 went online to complete this portion of the survey. Although this number represents only 6.6 percent of the sample, not all telephone participants "qualified" for the online portion since 29 percent stated they did not have access to the Internet and 41 percent stated that they did not have an active email account. After removing these

respondents from the pool of possible online participants, the response rate for the sample was a more respectable 11 percent.

¹ Cain, M., & Mittman, R. (2002). Diffusion of Innovation in Health Care.

Prepared by the Institute for the Future for the California Health Care Foundation; Von Knoop, C., Lovich, D., Silverstein, M. B., & Tutty, M. (2003). Vital Signs: E-health in the United States. Boston Consulting Group.

¹ Goldsmith, J., Blumenthal, D., & Rishel, W. (2003). Federal health information policy: A case of arrested development. *Health Affairs*, 22, 44-55.

² Goldsmith, J., Blumenthal, D., & Rishel, W. (2003). Federal health information policy: A case of arrested development. *Health Affairs*, 22, 44-55.

³ Fox, S. (2004). Older Americans and the Internet. Pew Internet and American Life Project.

⁴ Lansky, D., et al. (2003). Report and key findings from FACCT's Quality Counts Initiative, Phase III. Funded by the Robert Wood Johnson Foundation.

CHAPTER 6

Are clinicians ready for PHRs?

Introduction

Personal health records are only now coming into use, and very few physicians have patients who manage their health information using a PHR. Much of the published research into patient-provider communication and consumer attitudes toward quality of care, however, emphasizes how much patients continue to rely on their physician to identify and endorse the information and tools they use. For PHRs to flourish, the early experience suggests that it will be important for doctors to increase their systematic use of EHRs in the clinic and hospital, and for them to encourage their patients to become more active in reviewing and sharing their personal health information. The doctor is a key enabler of increased patient use of personal health records. In order to gauge the interest or concerns doctors may have in supporting greater patient use of PHRs, we can begin by examining their experiences with EHR and with patient-provider communication tools (email and secure messaging).

Current use of electronic health records

Doctors are using information technology, but not primarily for reasons directly related to patient care. About 46 percent of doctors have a PDA and 17 percent use tablet PCs.¹ About one-fourth of all medical practices have someone who uses a handheld computer,² but most of those people use them for maintaining their calendars (78 percent) and contact information (71 percent) as opposed to checking medications (26 percent) or lab results (9 percent). About 40 percent of doctors use at least one of the following three tools: electronic prescribing (16 percent), EHR (30 percent), and remote disease monitoring (7 percent).³

It is unclear how many doctors currently use electronic services, given the different terms and questions asked in different polls. One study states that 96 percent of doctors use "Web-based technologies."⁴ Similarly, it is reported that 90 percent of doctors "access the Internet for professional purposes."⁵ The most popular Internet uses were researching clinical information (90 percent) and reading articles from online medical journals (74 percent).⁶ However, another survey found that less than half of doctors (49 percent) use "online content and services."⁷ Doctors also report using technology to help them reduce administrative burdens such as claims reporting (78 percent) and receiving payments (55 percent).⁸

Substantially fewer doctors use the Internet as a communication tool; those who do tend to be younger and newer to medical practice. About 60 percent of doctors report using the Internet to communicate with colleagues;⁹ only 16 percent to 19 percent of doctors use the Web "to connect with patients."^{10,11} About one-third use the Internet to look up

"patient information."¹² This demonstrates that doctors are entering the electronic world, but most are not using technology on a widespread basis to service patients directly.

Perceived benefits

A few studies and surveys have focused on what doctors see as benefits of both electronic and personal health records. This research has focused on health IT in general, as well as specific tools such as online disease management tools that involve both the doctor and patient and e-prescribing.

Efficiency

Doctors often report being unable to access the people, information, and other resources they need to do their job. One of the main sources of inefficiency is time wasted on the telephone.¹³ Doctors rank efficiency as one of the primary reasons for adopting online patient care tools.¹⁴

Improved patient-doctor relationship

Even though most doctors do not use the Internet to communicate with patients directly, the electronic world does seem to influence the patient-doctor relationship. According to the Boston Consulting Group, 76 percent of doctors believe that information they have obtained from the Internet has had an impact on the way they interact with their patients. BCG also reports that from 2001-2002, more physicians report using interactive electronic tools to improve patient care. For example, of those physicians who have adopted remote disease monitoring technology, 84 percent did so in 2001 in order to deliver better care, whereas in 2002, that figure rose to 93 percent.¹⁵

Enhanced quality of care

In the case of e-prescribing, doctors believe the new technology improves their compliance with drug formularies and the quality of care they deliver. The majority of doctors believe that e-prescribing service would result in fewer medical errors (79 percent), save time (72 percent), lead to fewer pharmacy callbacks (71 percent), and increase accuracy and legibility (71 percent).^{16,17}

Streamlined administration¹⁸

Doctors report being overwhelmed by administrative overhead and feel that the burden of paperwork has reduced the quality of their interaction with patients.¹⁹ As one doctor states, "There are so many ways to lose information the way we manage health (records) today. I'm amazed we do as good a job as we do with paper."²⁰ Doctors report that electronic medical records can help streamline their administration processes and cut down on paperwork.

Share information more readily²¹

With computerized medical records, information can be accessed and managed more easily. A pediatrician who uses a diabetes management tool said: "It's ideal because we know who did what and said what to

Physician Comments

"One of the goals of PHR is to make us [doctors] all more efficient, more accountable, better providers."
— Michael Wood, MD, pediatrician at Spectrum Health. (Interviewed on March 29, 2004)

"It's good to put the information into the patients' hands. Make it theirs."
— Richard Handler, MD, neurosurgeon at Denver Children's Hospital. (Interviewed on March 8, 2004)

"This serves as a safety net. Patients can see whether or not something was done. It can serve as a safety net to make sure that patients are getting the right care."
— Rich Parker, MD, Beth Israel Deaconess Medical Center (Interviewed on March 16, 2004)

whom and when it all took place.” A neurosurgeon whose hydrocephalus patients have online tools to store their baseline CT scans says: “Without the patient record, it would take me hours to find the information I need to make my diagnosis. This system is easy to use. I get the information instantaneously, and the information is all there.”²²

Perceived barriers

A literature review and interviews of physicians and EHR vendors reveal a number of barriers to adopting EHRs or generally increasing the use of computers in their workflow.

Cost

Almost half of non-users (44 percent) stated that the cost of implementing an EHR was a major barrier for them.²³

Lack of reimbursement or other incentives

The cost and time spent to adapt daily routines to take advantage of new electronic tools are typically not reimbursable, nor are incentives offered to encourage the use of new technology. Offering tax breaks or rewarding doctors on a “pay for performance” basis may motivate doctors to use an EHR/PHR without actually being reimbursed directly for the work associated with the new system.

Time and work flow adjustments

Many doctors fear that implementation of a PHR will add another “hassle” to an already demanding work day. One neurosurgeon familiar with PHR believes that this is a major barrier to doctor acceptance: “Deviating from their (physicians’) patterns is what it’s really about.”²⁴

Patient-doctor relationship

Some physicians believe the presence and use of a computer in the examining room has a detrimental effect on the doctor-patient relationship. They worry that the doctor spends more time looking at a computer screen than interacting with patients, especially during the learning process.²⁵ Physicians cite loss of eye contact, less conversation, and a less personable encounter when a computer is used as a mediator between the physician and the patient. Loss of physical touch has been cited as a concern elsewhere.²⁶

Technology problems

The primary reason for not adopting e-prescribing tools was technological incompatibility, according to one study.²⁷ At a handful of sites that have installed PHRs for patients, doctors and nurses told FACCT interviewers that they wished PHRs and EHRs were more seamlessly integrated. For example, a nurse who helps patients keep their medication list in online PHRs reported finding it awkward to transition from her EHR to the patient’s PHR in order to make sure information is consistent and up-to-date.

Case study

A doctor who uses an online diabetes management tool with his Type 1 diabetes patients says it makes his job a lot easier. To prepare for an office visit, his patients send him their glucose levels in advance. The mail system is too slow, faxes are not HIPAA compliant, and phone messages listing several numbers are awkward. The ideal solution, he says, is for patients to send their glucose levels via the diabetes management system. The data come to him in a secure, easy-to-read format. Additional features allow patients to adjust their own insulin doses, see glucose level trends over time, and keep track of the relationship between their eating habits and diabetes management. “The only way people can learn to manage their diabetes is by trying it and getting a critique,” said the doctor. “You don’t learn to cook from a textbook. You learn from doing it.”

He believes that the tool has made his contact with patients better and caused patients to be more invested in their care. He has also witnessed better disease management skills in those patients who use the online system.

However, this doctor has been challenged implementing this program. Because this system is separate from his email account and requires him to log onto a different Web site, he says, “the toughest part is teaching yourself to look at it every day. I need to get into a groove where I check those messages every day.”

Lack of awareness

Another barrier to physician adoption of disease monitoring appears to be lack of awareness of such tools.²⁸ One report states that 10 percent of doctors do not believe that online disease management programs are a good use of time, and a full 40 percent are not sure.²⁹

Trust of patient-initiated information

Some doctors question the accuracy of information in PHRs. Although much of the clinical information comes directly from patients who fill out intake questionnaires or answer oral questions, it is a new paradigm for a patient to come into a doctor's office with his or her own PHR. Several physicians have suggested that it puts them in a position of having to make judgments on the validity of the information in the PHR.

Liability concerns

Some physicians are concerned that online medical records could be hacked, raising the possibility of a breach in confidentiality. In addition, if patients have access to their complete medical record, some doctors are concerned that "data-mining" attorneys will gain more convenient means to dig for information to support medical malpractice litigation.

Training

Doctors are concerned about the amount of time it will take them to learn not only a new technology, but also a new way to communicate. If the PHR is to include doctor notes, for example, doctors will have to learn to write them more clearly and concisely so that a layperson can understand them.

Reliability of the technology platform

Physicians also ask questions such as: What happens when the technology goes down? What sort of backup system is in place? What happens if a computer crashes and records are lost? To overcome this barrier, doctors need to be assured that electronic medical records are reliable.

Doctor reactions to examples of electronic healthcare

Because the overall experience with PHRs is too limited to be conclusive, it's useful to examine physician reactions to two related technologies: EHRs and patient-provider communication through e-mail or secure messaging tools.

Positive reactions to EHRs

Most of the doctors using EHR report that they result in increased efficiency (58 percent), better care (87 percent), and enhanced patient satisfaction (78 percent). The majority (74 percent) also believe that EHRs save their practice money.³⁰

For example, Cooper Pediatrics in Duluth, GA, is a small practice that adopted an electronic information system in 1995. "We never lose a chart ... It makes everyone incredibly more efficient," said Jeffrey

Cooper, MD.³¹ The system allows his practice to see more patients and has decreased drug refill turnaround time.

Although only a small number of doctors (7 percent) use remote monitoring tools to track patients with chronic conditions between visits, those who do are favorable regarding the impact on their practice. The overwhelming majority (96 percent) state that it improves patient satisfaction and delivers better care (93 percent). They also believe that it improves their overall efficiency (83 percent) and to some extent saves the practice money (50 percent).³²

Negative reactions to EHRs

In one study, after using an EHR in the exam room, a majority of doctors believed that the computer created a physical barrier between them and their patients, causing the visit to seem more distant. However, patients did not sense this loss of rapport.³³

In another study looking at a particular system, 90 percent of doctors felt that working with the EHR took more time than using paper charts, 95 percent thought the system was difficult to use, 63 percent thought the quality of patient care declined.³⁴ This study highlights the need to choose electronic medical record systems carefully, as not all systems are equal in terms of usability, comprehensiveness and functionality.

Patient-clinician communications

Only 23 percent of doctors e-mailed their patients in 2001. They actually e-mailed their patients less about clinical matters (e.g., lab results, consultations) than they did in 2000. More administrative tasks are being conducted over e-mail, however.³⁵ The trend of e-mailing patients does not seem to be growing, unlike other online health tool usage; however, demand from patients for e-mail communication is cited by half of those who currently do so.³⁶

Most doctors (61 percent) believe that online patient-physician communication will be mainstream in less than five years, and only 3 percent believe it never will be.³⁷

Doctors who e-mail their patients report many benefits. The vast majority (86 percent) say it improves patient satisfaction and 73 percent say it helps them deliver better care. A minority claim it saves them money (38 percent), but 67 percent state that it improves their overall efficiency.³⁸

Perceived benefits and barriers

More than a quarter (28 percent) of doctors said they started e-mailing patients to improve their overall efficiency. A strong majority of doctors (83 percent) are "looking forward to using the Internet as an educational tool" for their patients.³⁹

However, among doctors not currently e-mailing patients, more are concerned they will get overloaded with e-mails than be liberated.⁴⁰

Physician comments

"I was surprised at how much patients really like it. I was surprised how much I appreciate e-mail communications with patients as an alternative to the telephone."

— Rich Parker, MD, Beth Israel Deaconess Medical Center
(Interviewed on March 16, 2004)

Reimbursement is clearly a big issue. Although only one-fifth of online physicians currently e-mail their patients, another one-third would be interested in doing so if certain conditions such as security assurance and reimbursement policies are in place.⁴¹ One study reported that 15 percent of doctors who do not e-mail their patients would do so if there were reimbursements in place; others cite this issue as a barrier to greater adoption of patient-physician electronic communication.⁴²

More than one in five doctors (22 percent) who don't communicate with patients online cite privacy and security concerns as reasons, and other studies also find this to be a barrier for e-communication adoption.⁴³

In 1997, the American Medical Association endorsed a set of guidelines for the clinical use of email with patients.⁴⁴ These guidelines emphasize effective communication and interaction and observance of privacy and security. The guidelines address creating a secure environment and responsible interaction between patient and doctor. Also addressed are issues of consent and the concept of a contractual relationship. It is important that patients actively consent to the idea of doctors e-mailing them and it is clear that doctors and patients understand when an e-mail dialogue needs to "escalate" to a more personal interaction.

Many health professional groups, like the AMA, maintain their own electronic communication guidelines. (For a list of guidelines, see: <http://www.e-pcc.org/>).

Lack of tangible evidence of ROI

A return on investment is relatively easy to assess on the administrative side of an office, but not on the clinical side.⁴⁵ What outcomes can physicians hope to affect with increased use of electronic health records? Better health? More satisfied customers? Lower inappropriate medical utilization? Few evaluations of desired clinical and health outcomes have been conducted.

Conclusion

Although more physicians are adopting healthcare IT, it is unlikely that the general population of physicians will be the primary advocates for PHRs. Nonetheless, those physicians currently using some form of PHR report many benefits to both their practice and their interactions with patients. They find that PHRs and secure messaging tools are not as threatening as they are perceived by many of their peers. However, many barriers to broad PHR implementation exist from the physician perspective. Without directly addressing these concerns, particularly reimbursement and accountability issues, physician support of PHR will be limited.

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CHAPTER 7

Snapshots from the field

Introduction

During the spring of 2004, FACCT staff conducted on-site interviews of patients, clinicians and others using PHR applications at 10 leading installations across the country. The visits represented a range of PHR models, including:

- **Large integrated health systems** that provide patients with views of their own data from the system EHR as well as integrated transactional functions, such as online appointment scheduling, online prescription refills and e-consultations.
- **A physician in solo practice** who uses a third-party, Web-based platform to offer e-consultations and other services.
- **Specialized PHRs** for specific patient populations, including a PHR for migrant farm workers with data entry by clinic nurses, a PHR for parental caregivers of children with hydrocephalus to maintain baseline CT scans, and a shared care plan for diabetes patients with heavy involvement by nurse educators.

All quotations are from cognitive interviews during the on-site visits between February and April 2004.

Key Findings

We detected the following patterns at most sites:

- Promotion by clinicians is key to getting high consumer adoption.
- Clinician acceptance requires large up-front efforts to gain buy-in.
- If PHR is viewed as beneficial only to patients, it's hard to get clinician support.
- PHRs are unlikely to gain widespread clinician acceptance unless they are integrated into the clinical workflow, such as through integration with the office EHR.
- Patient-clinician secure messaging, online refills, lab results, medication lists, and disease management plans are among the functions that consumers single out as particularly useful.

- Patient-clinician messaging wins over an enthusiastic subset of both patients and doctors, and does not overwhelm the inbox of doctors.
- Patients feel more empowered when they have access to their health information, and many early physician adopters find that helpful.
- People with chronic conditions or their caregivers are most likely to need and use PHR-type applications.

Clinicians

Patient participation rates in early stage PHRs at integrated delivery networks appear to hover at around 15 percent. The sites we visited generally reported that they had to promote the PHR heavily to both clinicians and patients to reach this level. Most interviewees indicated that the most effective means of encouraging patient participation was a direct communication about the PHR by the patient's doctor(s).

However, obtaining physician enthusiasm for the PHR has proven to be a significant hurdle. Some places tried to offer a PHR without first getting buy-in from physicians, and the results fell well below expectations. Physicians and their staffs are typically very busy and reluctant to try something new that will require time to learn and implement. As one PHR implementer told us, "Never underestimate the depth to which you have to reach out to the practicing physicians."

One practice that had success in getting patients to sign up for a PHR credits the commitment of everyone in the office, "from the person who answers the phone to the physicians."

"In order for it to be successful, you need to talk about it as a group," an administrator said. "You needed to get support for the idea that we should bring in technology to make us more efficient. You need to set expectations at the beginning that there will be bumps in the road. It won't do everything that we want it to, but we are going to get it better together."

In general, PHR systems that are not integrated easily with the EHR have bigger hurdles in gaining patient and clinician acceptance. "It's more time added to a day that doesn't have much time," according to a PHR implementer at a large IDN whose PHR and EHR require clinicians to log in to each system separately. "If this were all in one system, within one application, you'd see a lot more acceptance to using it."

We conclude that PHRs are unlikely to gain widespread clinician acceptance unless they are integrated into the clinical workflow. Clearly, more study is needed to assess how PHRs can be efficiently integrated into clinical workflows, and whether doing so can save time, save money or improve the quality of care.

Quotes – Physician acceptance of PHR

"You should try it before you become negative."

— Physician at the VA, to colleagues

"There's a range of reactions, from love to hate, with indifference in between."

— Boston internist, about colleagues' response to PHR

"It takes a lot of convincing for doctors to use this. Some doctors will use it, but a lot of them are too busy to do something that requires them to log in and use something new ..."

"We have three customers — the patients, the doctors and the practices. And we need to have reasons for each of them to use the system. If this is looked at something for just the patients, and if that's the perception, then you aren't going to get other people to use it."

— Another Boston physician involved in a PHR implementation

"It's very good idea to have your medical staff on board before you start a venture like this ."

— Administrator at VA

Patients

"We spent an enormous amount of time, and still use an enormous amount of time, encouraging our patients to use it," a practice administrator at a large IDN in Boston said of the PHR. "We looked at our patient population and felt that they were computer-savvy. We politely remind them that this (the PHR) is a better way for them to access us."

As mentioned previously, several PHR implementers have concluded that the best marketing of a PHR comes from the physician's direct appeal to patients. One IDN plans to encourage staffers to wear buttons instructing patients to ask about its PHR application. Group Health Cooperative, a Seattle-based IDN, has produced a CD Rom with a tour of the PHR service for clinicians to give to patients.

Some PHR systems we examined have started by targeting a specific population: children with diabetes or asthma and their parents, people with heart disease or Type 2 diabetes, children with a rare disease such as hydrocephalus and their parents. A narrow scope makes it easier to market, outline goals and show benefits. Some implementers believe that targeting people who frequently use medical services can be most effective in reducing telephone calls in favor of more efficient online appointment scheduling, refill requests and e-communications.

"The evidence is anecdotal right now," says a physician who has led an implementation at a large IDN in Boston. "I think it takes half the time to handle a (PHR) request than a phone request. Patients who have 10 medications on their medication list are consuming more practice time than patients with one medication on their list. If you can get 5 percent of the patients to use it, but it's the right 5 percent, you might be able to cut out a large portion of the (telephone) messages."

E-communications between patients and clinicians is a clear winner in terms of popularity among early PHR installations. Some physicians clearly fear that adopting electronic correspondence with their patients will substantially increase their workload or flood them with inappropriate requests. Yet our interviews with physicians who do communicate electronically with patients found this fear to be largely unfounded. Interviewees reported that patients have used e-communication responsibly. In fact, several patients we interviewed volunteered that they felt that the asynchronous communication allowed them to make their requests more concise and precise.

Case study 1: Baseline images for a rare condition

A Colorado Springs woman uses a PHR to keep a baseline CT scan of her 9-year-old son who has hydrocephalus. When the boy suffers from headaches, she is able to go to the local hospital to get a CT scan and compare it to the baseline scan in the PHR to see whether she needs to

Quotes

"There was a lot of fear of portal misuse and inappropriate messages, we found that messages that are inappropriate are exceedingly few."

— Boston physician

"It's definitely nice to think that if you have a question in the middle of the night, you can do something about it, and not sit there and think whether I'm going to remember to call my doctor in the morning."

— Patient who communicates with her physician and refills prescriptions online

"When the doctor answers, I'm not expecting some long email. It has to be very simple. If it's complicated, then it should be handled in the office."

— Patient

make a trip to specialists at Denver Children's Hospital, more than an hour away.

"If I'm out of state, it's just awesome," she says. Having the scan online provides her with the data in a much more convenient format than the large, fragile documents that are sensitive to sun and water exposure. It is difficult to travel with the physical CT scans or even carry them around in the car (with her four kids and dog). "It has made me more confident and knowing," she says. "I feel more secure. (her son's) health is no longer a guessing game ... I definitely feel safer. Now we can go places."

She has, however, experienced resistance in getting local doctors to reference the baseline scan in the PHR. In order for Taylor to be operated on in locally to relieve painful swelling, the doctors would have to do several scans (about one a day) before detecting sufficient changes to warrant the procedure. But with her own access to the baseline document, Tracy compares the images herself and decides whether to travel to Denver for surgery to relieve her son's pain.

Case study 2: Underserved populations

Some have raised legitimate concerns that the PHR will deepen the so-called "digital divide," encouraging a system of personal health information haves and have-nots. Although this is certainly a troublesome possibility, one project with migrant farm workers demonstrates that it need not be the case.

VIA (Visitantes Información Acceso), based in Sonoma, Calif., and financed through grants from Rural Community Assistance Corp. and The California Endowment, provides a Web-based medical record "home" for the migrant farm workers who pass through the region. The workers are often uninsured and tend to seek care from multiple providers such as community clinics, mobile health clinics and hospital ERs as they move from place to place. Data entry is often aided by clinic nurses, and volunteers have helped train necessary computer skills for the migrant workers themselves. Participants access their accounts directly in the clinics or through Internet services at libraries and resource centers, according to program organizers.

There are over 1,000 accounts currently on the VIA system (one account represents an entire family). People who use VIA have said that it helps them communicate better and overcome language barriers with clinicians.

Case study 3: A large integrated delivery network

Editor's note: The following was authored by Personal Health Link¹, Kaiser Permanente Northwest (KPNW).

Personal Health Link (PHL) is a Web site provided by KPNW. KPNW members registering for PHL are given access to personal, password-protected Web site that contains their health information. They may use the site to send secure messages to their Primary Care Provider (PCP), an advice nurse, a pharmacist, the medical records department, and the appointment department. By April 30, 2004, more than 4,300 members and 77 clinicians were using PHL; about 50 percent of the registered users had sent at least one message to their PCP.

Eighteen internal medicine and family practice clinicians at two facilities tested the service during an evaluation managed by Kaiser Permanente Clinical Systems Planning and Consulting. Below we describe some the evaluation findings:

Early in the evaluation, eight physicians invited all of their panel members to participate. Over 16 percent of these panel members registered for PHL. The remaining 10 clinicians invited only a portion of their panel members to participate in PHL. However, by the end of the evaluation, 14 of the 18 participating clinicians wanted to offer PHL to their whole panels.

During the evaluation, 1,955 members registered to use PHL; 42 percent of them were registered for less than 3 months. Women age 55-64 years and men older than 45 years were more likely to sign up. Also more likely to register were members with a higher than average number of primary care visits in the preceding year or members with chronic conditions.

Many clinicians were initially concerned about how their workload would be impacted as more patients used PHL. However, the PHL clinicians typically received two to four member-initiated messages per day, depending in general on how actively the PCP used PHL in his or her practice. The average number of words per message from members was 90.

In the opinion of both members and clinicians who used PHL, PHL messages between clinicians and patients largely substituted for phone calls, but about 15 percent were estimated to substitute for office visits.

Female members in the 45-64 age range and male members older than 45 years, as well as members with diabetes or a high number of primary care visits during the previous year, had significantly above-average PCP message-use rates.

Non-messaging pages were visited in about one-third of the sessions. Among all non-messaging pages on the PHL Web site, the most commonly visited were Current Health Issues, Current Medications, Recent Visits, After Visit Summary,

¹ Please contact Sharon.m.fox@kp.org for additional information about PHL and Yvonne.y.zhou@kp.org for additional evaluation findings.

and Future Appointments (Lab results were not available during the evaluation period).

An overwhelming majority of Kaiser Permanente members who used PHL was happy with the service, especially with being able to message PCPs directly. In a follow-up survey of members who were registered to use PHL (with a 49 percent response rate), 86 percent of members indicated that PHL enables a more personal relationship with their PCP. Eighty-seven percent reported that PHL helps them to better follow PCP instructions. Furthermore, 70 percent indicated that PHL helps them to communicate their needs more fully to their PCP; and 31 percent reported that PHL enables them to manage their health and health care more fully.

CHAPTER 8

Personal health record policy areas

Introduction

Challenging policy issues arise in the largely uncharted area of PHR implementations. As noted in **Chapter 3**, there are essentially two types of sources for personal health data in the PHR: **patient-sourced** and **professionally sourced**. From the perspective of a person who receives care from multiple unconnected providers, the table below summarizes key obstacles in assembling both types of data into a PHR.

Type of data	Key Obstacles
<p>Patient-sourced: Information entered directly by the person who owns the PHR or that person's caregiver or proxy.</p>	<ul style="list-style-type: none"> • How to earn the patient's trust in a third-party PHR system? • How to motivate the patient to enter information accurately and consistently? • How to transfer patient-sourced information to clinicians who are not connected to the PHR system? • How to get clinicians to accept unstructured patient-sourced information due to concerns over its time burden, liability, accuracy, etc.?
<p>Professionally sourced: Information that comes from professional healthcare entities such as:</p> <ul style="list-style-type: none"> • Individual clinicians and small practices • Larger group practices • Integrated delivery networks (IDNs) • Hospitals • Insurers • PBMs or drug clearinghouses • Retail pharmacies • Labs and lab clearinghouses • Health data warehouses 	<ul style="list-style-type: none"> • How to authenticate the patient's identity and track the patient's authorizations across multiple data custodians? • How to create custom interfaces to exchange data with multiple custodians? • How to integrate information into a PHR when multiple data sources store and codify it differently? • How to forge data-sharing agreements with multiple custodians? • Who will pay to sustain all these transactions?

Left unaddressed, any one of these obstacles is sufficient to derail significant scalability of connecting patients electronically to their clinicians and to the other custodians of their health data. Taken as a whole, the obstacles are probably insurmountable in the status quo. For this reason, the Working Group finds it necessary to identify incremental (yet still ambitious) steps toward progress.

In seeking insights and feedback for this policy section, Connecting for Health convened the following:

- The collective experience of the **Working Group on Policies for Electronic Information Sharing Between Doctors and Patients**, whose membership included several leaders and investigators at a range of PHR projects.
- On-site interviews of patients, clinicians and others using PHR applications at 10 leading installations across the country.
- A symposium in collaboration with the American Medical Association Institute for Ethics on the ethical and professional implications that PHR applications raise for physicians.¹
- Two conferences in collaboration with the Agency for Healthcare Research and Quality to gather reactions from medical professional societies and federal government agencies, respectively.

The policy discussion in this chapter represents a synthesis of these efforts. The purpose is to explain how some of the early implementers have developed policies and — when the Working Group achieved consensus — make specific policy recommendations for common practices and policies of PHR applications.

The recommendations are not standards; they carry no binding authority. They are offered on the basis of collective wisdom and in the spirit of collaboration.

Section A: Content

“Content” is so broad a term that it could constitute everything in a PHR: branding, navigation and user interface, functions and features, icons and images, text and links, and much more. Solid execution of each of these is important in any software or Web site. In this section, however, we focus on the information in a PHR.

The reason for this narrow scope is simple: The value of the PHR is ultimately proportionate to the value of the information that it holds.

¹ This report reflects the views and opinions of the authors and should not be construed as representing AMA policy.

The first stakeholder in determining the value of the information in a person's PHR is, of course, *that person*. Ultimately, however, other players in the healthcare system will need to place a value on information in the PHR in order to sustain its long-run viability.

This purpose of this first section is to recommend policies that will accelerate the ability to collect valuable information in the PHR. In later sections we discuss the implications and policies around the sharing of this information.

[In **Appendix B**, our Working Group identified a set of functions and services that have been incorporated or envisioned across the dynamic range of PHR models. For more information about a broader range of potential content areas of a PHR, please refer to Appendix B.]

The case for data field commonality

We agree that the PHR must ultimately transmit and accept structured data in order to become a commonly accepted vehicle for information exchange between individuals and clinicians. PHRs are unlikely to be embraced by either health professionals or the public if they transmit and display an overload of unstructured data.

We recommend the establishment of a **common data set** as the basis of PHR communication with other information sources across the healthcare system. An initial goal should be to establish a common data set to enable PHRs to exchange data with EHRs — and with other PHRs — on a bi-directional and vendor-neutral basis for the core health information repository functions of the PHR, such as the patient's identifying information (e.g., name, address, race/ethnicity, preferred primary language, religious affiliation), insurance information (e.g., health plan group ID number), health status (e.g., conditions, medications, allergies) and other clinically relevant information (e.g., care plans). (See Functions 1-20 in **Appendix B**.)

Developing a common structure of information depends on three steps:

1. Establishing a set of common data fields. (In other words, what will PHRs and EHRs talk **about**?)
2. Establishing a secure protocol for electronic information exchange. (**How** will the PHR and EHR talk?)
3. Establishing common clinical vocabularies. (**What** "language" will the PHR and EHR use?)

The first two steps must go together as long as the information exchange is electronic. The final step is critical, but will take more time than the first two steps because healthcare providers will not adopt common, comprehensive data-coding practices overnight.

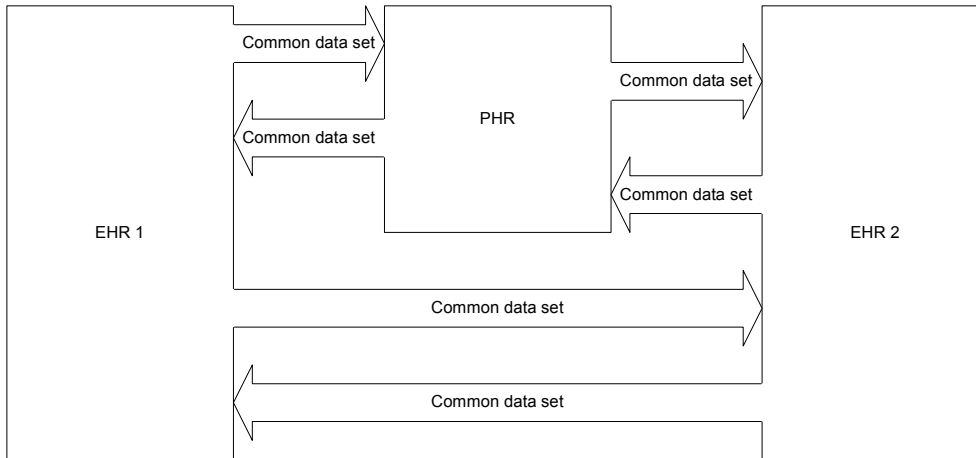
Implications for EHR developers, healthcare providers and other holders of professionally sourced patient data: By agreeing to build their applications around a common data set to drive core functions, the various PHR vendors can lower the barriers for EHR vendors to build basic PHR data import and export functions into their applications. Eventually, other custodians of professionally sourced health data (such as health plans, PBMs, retail pharmacies) will see the advantages of (or be competitively forced into) doing the same. (Their entire data sets may be much bigger than the common data field foundation, but they agree to send and receive extracts for those data fields within the common foundation.)

Implications for PHR developers: The common data set is neither a minimum data set nor the maximum allowable data set for PHRs. However, it should be the default set of fields that any PHR developer tries to use first to drive any of its functions. This is an important distinction because we do not view PHRs solely as repositories of retrospective health information. Some PHR models are much broader, featuring an array of transactional services (e.g., e-consultations or online prescription refills) or other health management software (e.g., risk assessments, health expense tools). Other PHR models may specialize in a narrower issue (e.g., diabetes). Any of these applications may require additional data fields beyond those in the common data set. Conversely, they also may never need some of the fields in the common data set. The common data set doesn't limit these models; it is simply the starting point for identifying data storage and exchange fields.

Further, we recommend that rather than creating their own common data field standard, PHR developers should first try working with existing standards emerging for minimum data sets of clinically relevant patient information. Critical criteria for any such common data set should be:

- Acceptance by the medical community and consumers.
- An HL7-compliant platform for secure data transfers. (No. 2 above)
- A clear upgrade path and incentives that lead to the universal population of common data fields with standardized controlled clinical vocabularies. (No. 3 above)

The diagram below illustrates this vision:



Each of the arrows marked "Common data set" could represent an independent transaction, providing multiple means by which the patient's basic information can be exchanged with proper authorization. Through standardization, the minimum available fields are always the same, which lowers costs for vendors and IT departments to support interoperability. Each transaction is time-stamped and source-stamped. Vendors can compete on such things as the intelligence they can apply or presentation features they bring to the data, but all accommodate a basic level of information exchange.

For example, we recognize and appreciate the momentum of the **Continuity of Care Record (CCR)** as a minimum data set on an XML platform designed to improve the quality and consistency of clinician-sourced information transfers when a patient is referred from one clinician to another. The CCR is specifically designed for such clinician-to-clinician information transfers of patient information. However, it's worth exploring that the CCR could become a common structure not only for clinician-to-clinician, but also for clinician-to-patient (EHR-to-PHR) and patient-to-clinician (PHR-to-EHR) information sharing.

If the CCR is to become a data set to be used commonly by PHR and EHR applications, we recommend that:

- PHR vendors and patient advocates collaborate further within appropriate standards bodies **to modify the CCR data fields** to include relevant patient-sourced information that can be shared with clinicians through PHRs.
- PHR vendors, EHR vendors and patient advocates collaborate within appropriate standards bodies **to identify a minimum set of data fields** to enable standardized, vendor-neutral electronic transfers of basic patient information from EHR-to-PHR, from PHR-to-EHR, and from PHR to PHR. (For parties still reliant on paper as a means of transferring information, there should be a clear upgrade path and incentives to shift to an electronic transfer standard.)
- All such electronic transfers of CCR data should comply with security requirements of HL7 v2.x. (or latest version) and NCPDP.
- There be a clear upgrade path that leads to the universal population of CCR data fields with standardized controlled clinical vocabularies.

This final step toward standardized vocabularies is vital to achieve many of the long-term efficiency and likely safety gains from automating the exchange of consistently codified patient data across the healthcare system.

For example, in the above diagram, if all of the information exchanged were codified by common clinical vocabularies, the EHR and PHR applications could conceivably apply intelligence to bundle the information in useful ways, such as bundling related data fields to track progress in specific areas over time.

By contrast, if all of the information were free text, then the end users of the applications — either the patient or the clinician — would likely have to apply their own time and intelligence to make sense of information, possibly by manually going through each data transaction chronologically.

However, because of the widely varying technological sophistication and investment resources among healthcare providers, this final step is likely to evolve at a slower pace. Without some combination of incentives, standards or competitive pressures, it may not evolve meaningfully at all.

Although we strongly support the movement toward standardization of clinical languages, we don't want the first steps (i.e., common data fields and common secure data transfer protocols) to be held up by the lagging final step (i.e., standardization of code sets and vocabularies).

Simplicity in text and user interface

It is estimated that nearly one of every two U.S. adults has difficulty understanding basic information necessary to make appropriate health decisions.

This alarming statistic is not based on the struggles of lay people to understand complex clinical terminologies. It is based on a "health literacy" survey assessing U.S. adults' understanding of basic, consumer-targeted healthcare communications, such as such as prescription instructions, test results and insurance forms.¹

There is an even wider gap between clinical terminology used by healthcare practitioners and lay language understood by most patients.

The implication for PHRs — and any consumer-targeted health communications — is the importance of simplicity in language and user interface.

The U.S. Department of Health and Human Services has made the deeply granular and technical SNOMED-CT clinical vocabulary, developed by the American College of Pathologists, available free to clinicians in an effort to encourage it as a standard for recording a large portion of clinical information. SNOMED concepts — there are more

Other resources

Organizations that provide guidance in usability issues include:

Web Accessibility Initiative:
<http://www.w3.org/WAI/>

TRUMP - a EU-funded project:
<http://www.usability.serco.com/trump/resources/index.htm>

and

<http://www.usability.serco.com/research/guidelines.htm>

than 357,000 of them! — are designed for highly trained clinicians and medical librarians, not consumers. To be useful for most people in a PHR, SNOMED and other clinical lexicons need to be translated into consumer-friendly terminologies. This is an enormous task that requires ongoing support, and one that may best be achieved through cooperative efforts.

In summary, sharing information is not enough. The end user — the patient, caregiver, consumer, health professional, etc. — must understand and accept the information being shared.

Sample issue: Physicians' progress notes

The notes that a clinician writes in the chart are often a mystery to patients. Focus group participants said they'd like to see what those notes say. By singling out this issue, we do not mean to imply that progress notes are essential content to a PHR. In fact, as the brief discussion below indicates, they are controversial.

Some argue that including physicians' notes in the PHR will:

- Improve communication and retention of information by the patient.
- Encourage physicians to document the visit more carefully.
- Help patients correct inaccurate information.
- Improve the doctor-patient relationship by providing a "report" on their meeting.

Arguments against this practice are that it might lead to:

- A deluge of calls from patients who don't understand or agree with what the doctor noted.
- An increased burden on already overloaded clinicians.
- A counter-therapeutic result in some cases, particularly behavioral health.
- A "dumbing down" and/or "cleaning up" of physician notes, to avoid complex ideas, medical/scientific terminology, or any mention of potentially worrisome diagnoses.
- The creation of "shadow files" that contain physicians' additional thoughts/ideas regarding diagnostic possibilities that may be unlikely, but especially fearsome.

Under HIPAA, a patient can request to see the entire record, including the progress notes. However, making those notes available in the PHR as a matter of routine would change the dynamic considerably. Clearly, the area needs more study.

Possible directions:

The system could enable the routine release of doctor's progress notes into the PHR on an optional basis, subject to an explicit request from the patient to the doctor.

Voices at the VA

"It's very nice to see what the doctor wrote rather than just try to remember what they say."

— Patient at VA hospital in Albany, where a pilot program includes the posting of progress notes into patient PHRs.

"I think open access is a good thing for practitioners because it will force them to document more effectively and appropriately."

— Elina Fishman, MD, chief of staff, Stratton VA Medical Center, Albany, NY

Physician voices

"I would understand if a patient said, 'I want every single one of those automatically downloaded into my PHR as soon as you're done with it.' I would understand why they would do that, but if someone asked me to do that, it would change the way I use the record. I would probably have to code things more than I do. I would certainly dumb down what I said in the record so they would be able to understand it — I would have to. I would be now dictating a note to the patient rather than a note to myself if I know that they have access to the record right now."

"I think it would be — at best an inconvenience for me that I would no longer feel comfortable putting down: 'There's a distant possibility of a brain tumor. If the headaches are still going on two weeks from now, let's get a CT scan.'"

— Infectious disease specialist, Chicago.

Section B: Authorization

The term “authorization” in this section covers policies that determine **who** gets to do **what** in the PHR. Specifically, who has permission to view, contribute to, or alter which pieces of data, and when?

Authorization issues are straightforward when the PHR is maintained by one person and never seen by anyone else. If, however, the PHR is used for information-sharing, particularly between patients and their healthcare professionals, then policies for authorization become more complex. Because of the variance of PHR models, there are no “one-size-fits-all” answers.

Authorization begins with consent

A key characteristic of the PHR is that the patient or consumer controls the data within it. Although PHR models may offer varying degrees of consumer control over data-sharing functions, we believe that all PHRs should begin with a fundamental principle of control: PHRs are voluntary. That is, the relationship between a PHR supplier and an individual consumer should be based on the consumer’s discretion to enter into it, and to continue it.

Compared to other online relationships between consumers and entities, the stakes are much higher in the relationship between the PHR supplier and the consumer. In the financial industry, for example, mistakes can be corrected in form of a reappropriation of money. In the enterprise of managing a person’s health data, however, there may be no acceptable way to compensate for the mishandling or unauthorized use of the information.

It is therefore critical that this voluntary relationship be shaped by the value of transparency. Our core recommendation is that PHR suppliers adopt policies of transparency and full disclosure for privacy, security, data exchange, terms and conditions of service. Further, the business model and data-mining and data-portability policies must be clearly disclosed hand-in-hand with marketing materials describing services.

The ASTM International specification E 2211-02 covers important points of transparency and disclosure in the relationship between the consumer and a PHR supplier.

Beyond executing a legal agreement, the process by which the consumer agrees to terms and conditions and data policies is a critical step to set appropriate expectations in a relationship of trust. Although necessary, the legal text to which the consumer agrees is only one means of setting appropriate expectations — and generally not the most accessible or effective means of doing so. It’s well-established that

Helpful Resources

ASTM International has a standard specification that emphasizes transparency in the relationship between a consumer and a PHR supplier.

Although the specification, called E 2211-02, doesn’t specifically cover PHRs offered by a health insurance plans or healthcare providers, it is an important resource for any PHR developer.

For more information, see the ASTM Web site (no spaces in the following address):

http://www.astm.org/cgi-bin/SoftCart.exe/DATABASE.CART/REDLINE_PAGES/E2211.htm?E+mystore

people don't read legal agreements, even if they know they should. PHR suppliers can help by:

- Putting their agreements and policies in as plain a language as possible.
- Supplementing the agreements with bulleted summary statements. For example:

“This service **WILL** ...”
“This service will **NOT** ...”
“You **WILL** be able to ...”
“You will **NOT** be able to ...”
“You **AGREE** to ...”
“We **AGREE** to ...”
“We do **NOT AGREE** to ... ,” etc.

- Testing their marketing and disclosure materials with the target audience in realistic settings to make sure the materials communicate accurately and effectively.
- When feasible, training nurses and other medical professionals to explain the basic policies to patients. (This recommendation is applicable to institutional gateway model PHRs and may not apply to current aggregator models.)

The voluntary nature of the PHR applies to all personally identifiable information that goes into it. For example, in one of the use cases described in **Chapter 4**, “Samantha” agreed to open her PHR account by affirming a user agreement and consenting to terms of conditions of service, including a transparent privacy policy. She also actively opted-in (physically ‘clicked’ in a checkbox) to represent her agreement with policies to make professionally sourced data from OB-GYN-1 and other providers available in her PHR. The PHR must explicitly describe which data sources are available to participate in the data exchange. If feasible, Samantha should be able to authorize each data source individually. (Of course, she controls her own self-entries of data.)

Levels of authorization

The above section describes Samantha’s control of **what** goes into the PHR. Now we switch to the individual’s controls on **who** has access to his information. In the second use case, for example, “Paul” needed to share information with multiple clinicians to manage his diabetes.

The default policy of a PHR is that the consumer controls the access: No one may access the information — either personally identifiable information or de-identified aggregate information — without the consumer’s authorization.

There are three basic levels of permission possible in a PHR (although PHR models may not support all three):

How aggressively to market?

Modest incentives may be a defensible marketing tactic to promote adoption and utilization of a PHR program. The same cannot be said for any punitive policies toward people who do not opt to create or use a PHR for themselves. For example, making benefits conditional upon opening a PHR account may be construed as punitive. Providing a discount or reward for people to enroll in PHR-aided disease management or smoking-cessation programs is more defensible. Still, any such inducements must be carefully scrutinized for fairness and respect for the individual’s privacy.

- **Read-only:** Authorized person may not add or alter any information.
- **Read-write:** Authorized person may view existing information and add new information.
- **Read-write-edit:** Authorized person may view and edit existing information, and add new information.

If his PHR supports multiple levels of permissions, then Paul should be able to specify the level for anyone to whom he authorizes access, and the amount of time that the access is granted. The simplest way to do this is for Paul to provide his own user name and password to his caregiver. However, this method has limitations. If multiple people use the same username and password, then audit trails will not be able to distinguish between their separate actions. It's also a security risk (for example, if the caregiver writes down the password on a slip of paper and leaves it on a shared desk space). It would be better if Paul can authorize a caregiver by setting up a guest username and password for time-defined access tied to specific permission levels.

Providing a guest user name and password may be appropriate for granting access to caregivers or perhaps case managers. But it is likely not the most practical means when Paul wants to share information routinely with his medical professionals. Medical professionals have an obligation to keep their own records. They generally don't have time to go hunting around in each patient's PHR, and many are disinclined to do so out of concern for medical malpractice lawsuit exposure. We recommend that PHRs evolve toward capabilities to generate time- and date-stamped "reports," rather than open access through guest passwords, for the sharing of information between patients and clinicians. This will enable both parties to have an auditable record of the information transactions between them. Clinicians can take each PHR-generated report and add it to the patient chart. Ideally, this is a person-to-person electronic transaction of structured information through a secure socket layer. If, however, the clinician keeps a paper chart, then each PHR report can be printed and placed in the patient file.

Sample issue: Patient's ability to modify, withhold or correct professionally sourced data

This issue may apply when a patient accepts professionally sourced data into a PHR and then shares it with a different medical professional. What ability should the patient have to alter, append notes to, and withhold professionally sourced data before it's transferred to a new medical professional? For example, in the first use case, Samantha initially choose to withhold information about her post-partum depression from OB-GYN-2.

Our Working Group recognizes the complexity of this issue. On one hand, the exchange of information such as a past depressive episode

poses privacy concerns for Samantha. On the other hand, getting that information into the hands of the new doctor could lead to better — and conceivably life-saving — treatment by putting vital emotional health issues front and center. Another dichotomy: A significant subset of patients might not trust an application that doesn't give them complete control over the information, but clinicians might not trust an application that enables patients to change professionally sourced information.

It is widely recognized that some patients do withhold information about their past, usually by simply not mentioning facts to their current medical professionals. In some cases, such withheld information may be irrelevant to their current care (e.g., why does a podiatrist need to know about a long-past abortion?) In other cases, it's vitally relevant (e.g., Samantha's post-partum depression, or past adverse reactions to medications). Patients aren't always in a good position to know which portions of their medical history are relevant to their current care. Overall, however, the patient's wish to withhold information from certain clinicians is largely a social issue that cannot be resolved by building a perfect PHR.

In an effort to find some practical middle ground, we propose the following:

- **Editing professionally sourced information:** When technically feasible, it's reasonable and appropriate for a PHR system to prevent patients from altering professionally sourced information. (E.g., Samantha would not be able to change the depression diagnosis as entered by OB-GYN-1 to something else, such as "stress.") Our reasoning is there needs to be a baseline of acceptance among medical professionals in the PHR concept. If the patient can change a professionally sourced data entry, it undermines the fundamental trustworthiness of the applications.
- **Withholding professionally sourced information:** It's reasonable to allow the patient an ability to withhold specific data fields when generating a report for healthcare providers. (E.g., Samantha clicks on a checkbox next to the data entry of her depression diagnosis to exclude it from a report she generates for OB-GYN-2.) Our reasoning is the PHR cannot change the fact that some patients will want to withhold information, nor will it change the fact that clinicians should assume that they are not getting the complete medical record from any source, including the patient. This is no different from the current system, in which physicians ask patients for information directly and through questionnaires and rely on the patient's discretion in disclosing information about themselves. The PHR should not replace the patient-clinician interaction in which the clinician tries to fill in the blanks of missing information. We believe it's better to encourage patients to maintain the most complete record possible by providing them control over the release of their data in as granular a way as practical. We realize that in some cases, it may be very

difficult to provide such granular control that a patient could easily withhold the full trail of a complicated medical situation.

- **Appending notes to professionally sourced information:** It's desirable, when feasible, to enable patients to append their own comments to entries of professionally sourced data. (E.g., Samantha could not alter the data from a professional source, but could be able to append her own comments to it.) The PHR should be transparent to the patient as to whether it offers any notification capability to the physician of any patient-appended comments. In the absence of any such notification mechanism, the PHR should make clear that any such appended comments will not be seen by any physicians through the PHR, and that patients should not rely on their own appended notes to correct erroneous data at its source, which is where it needs to be corrected. If there is such a notification system, then the patient should be forced to designate which clinicians should see the comment, and actively send the comment to those specific clinicians. All transactions should be tracked in an audit trail, including a "status" as to whether the designated physicians have viewed the comment, and included in the patient's record in the clinician-controlled EHR.
- **Correcting professionally sourced data:** PHRs that should provide instructions on how the patient can correct or dispute professionally sourced information. This policy does not suggest that the PHR must necessarily be the vehicle for such disputes. However, it is important that patients have an idea of how to contact the source of information they believe to be inaccurate.

Sample issue: Release of lab results

It is commonly the case today to receive a telephone message from a clinician that lab tests are in, and then spend hours trying to reach that physician to hear the results. In some models, particularly institutional gateway model PHRs, lab results are delivered online. In a system that can release lab results directly into a patient's PHR, should physicians be allowed to control the timing or manner of patient access to abnormal, complex, or worrisome findings?

Some argue that the physician should have the chance to look at lab results in advance, prior to talking with and (presumably) helping the patient to interpret the results. Another point of view is that timely release of lab information to patients provides better service and even safety, for example, if a patient needs to take results to another doctor before the initial ordering physician calls with the results. In the status quo, delays in lab findings are a frustration to many patients.

Some large integrated delivery networks with PHRs have determined that it's most efficient to release in real time lab results that are within normal ranges as established by the lab (with exceptions such as CT

scans and all pathology reports, which are embargoed to give clinicians time to contact the patient.) For lab and other test results that are out of normal ranges as set by the lab, systemwide embargoes may be an appropriate way to deal with the issue. The embargo is designed to give the ordering physician time to review the results and then contact the patient. State and local laws and restrictions need to be examined, particularly with regard to HIV, STD's and mental health conditions.

We believe that best-practices in the online release of lab results include the setting of a default policy for timely release of findings within normal ranges whenever practical. At the same time, we believe it is desirable to enable clinicians the ability to configure the release rules on a case-by-case basis, should they choose to do so. Some systems today allow the physician to set lab result release rules on a patient-by-patient basis. This may be the ideal, although it may not be practical in many cases, and in the event of such physician configurability, there needs to be a clear default policy. It is very important to set the patient's expectations in accordance with the policy. If the physician overrides the default policy, then it's appropriate to communicate this with the patient.

Section C: Privacy laws and regulations

This section briefly outlines principal laws and regulations that affect electronic data-sharing with patients. The **Health Insurance Portability and Accountability Act (HIPAA)**, which went into effect in 2003, establishes minimum federal standards and permissions required for the use and disclosure of individually identifiable health information.

We focus here on a relatively narrow set of policy questions raised by electronic personal health records that include data-sharing between patients and entities covered by HIPAA regulations. Our purpose is not to provide legal advice, and nothing in this paper should be construed as such. The "Helpful Resources" box provides information about more comprehensive HIPAA guides.

HIPAA basics

Organizations that must comply with HIPAA regulations are referred to as "covered entities." Covered entities are health plans, healthcare clearing houses, healthcare providers, and any "agents" performing functions involving personally identifiable health information on their behalf.

Oftentimes, a PHR is offered to consumers through a covered entity, such as a health plan or healthcare provider. In these cases, the PHR is required to abide by HIPAA standards. There are other PHR models offered through commercial vendors not associated with any covered entity. In these models, the PHR may not be legally bound to comply with HIPAA standards. For example, a PHR software vendor that hosts personal health information on behalf of a covered entity is covered under HIPAA. The same software vendor could offer its services directly to consumers without being covered by HIPAA because individual consumers are not covered entities. Yet the vast majority of people are unconcerned about such fine distinctions; they just want to know their information is protected. Indeed, strong consensus on this point has been articulated by ethicists and other healthcare leaders: in short, every person or entity with access to personally identifiable health information is ethically obliged to act as a trustee of this sensitive information.

Therefore, we recommend that all PHRs take HIPAA requirements as a given whether they are offered by covered entities or not.

Helpful resources

There are several guides to privacy and HIPAA available on the Web. Among them:

The Privacy / Data Protection Project of the University of Miami Ethics Programs.

Home:
<http://privacy.med.miami.edu/index.htm>

Glossary:
<http://privacy.med.miami.edu/glossary/index.htm>

Frequently asked questions:
<http://privacy.med.miami.edu/faq/index.htm>

U.S. Department of Health and Human Services:

HIPAA home:
<http://www.hhs.gov/ocr/hipaa/>

Fact sheet:
<http://www.hhs.gov/news/facts/privacy.html>

The privacy rule:
<http://www.hhs.gov/ocr/hipaa/finalreg.html>

The security rule:
<http://www.cms.hhs.gov/hipaa/hipaa2/regulations/security/default.asp>

Health Privacy Project
www.healthprivacy.org

The Ethical Force Program Consensus Report on Privacy and Confidentiality
<http://www.ama-assn.org/ama/pub/category/7726.html>

Authentication

For covered entities, the PHR can be positioned as a complication or a solution to HIPAA compliance, and perhaps some of both. Policy makers must be careful in creating a system that permits remote patient access to their medical records, which is necessary if a person is to be truly able to control his or her PHR. Encryption and secure Internet connections provide acceptable assurances against direct hacking into a central source of data. Identity management is a perhaps bigger challenge. One of the essential ingredients of a remote access system is letting each person into the data he or she is authorized to while keeping unauthorized people out. In a remote computer networked environment, there are three methods to verify your identity:

1. You provide something that you **know** (e.g., a username and password or personal identification number, or PIN).
2. You provide something that you **have** (e.g., a smart card, a credit card, or some other object).
3. You provide something that you **are** (e.g., a fingerprint, retina scan, typing behavior).

By themselves, usernames and passwords are least expensive to implement but are a weak means of authentication. People often use a password that is easy to remember, and thus can be more easily guessed by an intruder. Requiring "strong" passwords (at least eight characters with letters and digits) is intended to make it harder for an intruder to guess, but it also may be harder for the authorized person to remember. This may encourage the authorized person to write down the strong password, again opening an opportunity for unauthorized snooping.

Therefore, it's more secure to require some other form of authentication in combination with username and passwords. Currently, No. 2 above is more practical than the biometrics required for No. 3. Some PHR systems today have decided to physically deliver a unique PIN to an authorized person via U.S. Mail. For example, one such system FACCT researchers visited handled it this way:

- An individual is invited to request access at a Web site, providing several personal identification fields.
- If the fields all match the individual's records in the EHR, then the system sends a temporary PIN via U.S. Mail to the physical address of the individual.
- The individual can then go back to the Web site to log in with the temporary PIN, then must change the username and password. (The PIN expires after a given period of time to lower the risk of it being usable in the wrong hands.)

Determining appropriate authentication methods is a difficult balance. Generally speaking, the more stringent the authentication requirements, the greater the barriers to consumers to use the system. Conversely, the less stringent the requirements, the higher the risk of unauthorized access to protected health data. For example, a PHR system must decide whether the initial establishment of an individual's identify must be in person (in which case a driver's license or other form of material identification may be viewed), or whether it can occur remotely (without any physical identification). Again, there's a tradeoff: An in-person process is likely to require more personnel and training but provide better identification, whereas a remote process can be more automated but provide weaker identification assurance. Two additional important factors are the expense of the authentication requirements (including the handling of forgotten-password requests) and the sensitivity of the information in the PHR. Clearly, there is no one-size-fits all answer.

Authentication challenges aside, there are areas in which a PHR system can facilitate HIPAA compliance for covered entities. An April 2004 survey by the American Health Information Management Association of found that various healthcare institutions have had difficulty complying with information-sharing rules of HIPAA, particularly:

1. Accounting for the release of protected health information (mentioned by 39 percent of respondents).
2. Obtaining protected health information from other providers (mentioned by 33 percent of respondents).
3. Accessing and releasing of information to relatives or significant others (mentioned by 32 percent of respondents).²

A patient-controlled PHR with standardized data exchange and caregiver access protocols, as recommended in this report, could play a role in alleviating these challenges. After all, patients — who are not covered under HIPAA — can provide their personal health information to whomever they wish. Providing patients with a convenient capability to share clinically relevant, up-to-date information directly to their providers potentially removes many of the inefficiencies of the unconnected status quo as well as a perceived burden of HIPAA mandates.

State Laws

Although HIPAA is the federal standard that PHR implementers must begin with, it is critical to consider state variations in privacy and health information disclosure laws. HIPAA is described as a "floor," not a "ceiling," because it sets the minimum requirements but does not pre-empt stronger state laws. A good starting point to understand state laws is the Health Privacy Project (www.healthprivacy.org), sponsored by the Institute for Health Care and Research Policy at Georgetown University.

Patient rights under HIPAA

There are portions of HIPAA that relate directly to an individual's control over his or her medical records that are hosted by covered entities. Under HIPAA, a person has the right to:

- Request and receive a paper copy of one's most recent medical records.
- Ask a health care provider to make changes to one's health information. If the request is denied, a person may write a statement expressing disagreement. All documentation of this event should be stored in the medical record.
- Ask for and receive a list of disclosures of one's health information.
- Ask a health care provider to limit what health information they tell other providers, unless this information is necessary for proper medical treatment, or in cases of emergency or law.

Based on information gathered by the Health Privacy Project, we examined the laws of five states – California, Florida, Massachusetts, Montana, and Texas. Below are a few examples of state variations:

- States vary as to how long a healthcare provider may take until it releases personal health information to a particular individual. Whereas Texas gives a specific time frame (within 15 days), Florida’s language is more vague: “in a timely manner.”
- Florida places extra restrictions on an individual’s rights to view his or her medical information pertaining to mental health and substance abuse while the patient is considered in treatment for those conditions.
- Many states have additional laws based on the content of the health information, most notably mental health status, HIV status, and the results of genetic testing. States such as Florida, California, and Massachusetts restrict mental health and HIV status records from being transmitted among providers without the written consent of the patient.
- Some states also require that sensitive records be destroyed or returned to its source after a certain amount of time. California requires the requesting entity to submit in writing the intended use of the information and specifying the length of time the information will be kept before being destroyed. Massachusetts allows some records (nature of the service, dates of service, and financial data) to be released for peer review or financial collection purposes.
- California appears to require that physicians review lab test results before allowing them to be posted to the patient online. (Health & Safety Code §123148)

Conclusion

In health IT projects, the legal, ethical and policy issues can be more challenging than the technical issues. This very brief discussion of privacy concerns and regulations is meant merely to underscore the importance of a careful review of the ethical issues raised in each particular organization as well as a compliance review with regard to all state and federal laws and regulations. HIPAA is a means to an end — in this case privacy and confidentiality protection — and not an end in itself. All healthcare stakeholders must engender cultures of privacy protection because it is necessary for high-quality healthcare, because it is what patients want, and because it is the right thing to do.

Section D: Managing expectations and liability

The use case scenarios in **Chapter 4** articulate a vision of patients and clinicians working together with the aid of connected PHRs and EHRs. In this vision, the PHR helps speed the shift in communication modes away from telephone and fax machines to computer-aided information sharing — improving speed, sharing timely and relevant information and assembling written communication in one place where the patient can access it. It envisions that these changes increasingly provide opportunities for clinicians to educate and empower patients to take control of their own health, ultimately resulting in healthier patients.

We recognize that fulfilling this vision will require more than the successful navigation through technical barriers, such as common data fields and code sets, authentication and privacy standards, data authorization and exchange protocols. And it will require more than a lowering of financial barriers to support necessary investment, maintenance and incentives.

Clearly, to reap the benefits of electronic connectivity, there must be shifts in attitudes and expectations that both patients and clinicians traditionally bring to their relationship. There are of course many factors that shape attitudes and expectations across the massively complex healthcare system. In this chapter, we focus on only a few. Our purpose is to identify a manageable number of policy approaches that we believe can help frame the PHR discussion constructively.

Policies to set appropriate expectations

The PHR does not change the fundamental roles of the patient or clinician. It may, however, catalyze changes in their relationship. For example, PHRs that include electronic communications between patients and clinicians could expand clinician responsibilities between visits but might also lessen the burden of telephone tag, speed communication, and avoid errors related to missed communication (e.g., non-notification of important test results). If patients can input data from home, then the patient-doctor relationship could become less visit-based as the doctor is able to access and provide guidance on important self-monitoring information (e.g., glucometer readings) between visits. Additionally, some clinicians express concern that if a PHR enables patients' and clinicians' timely, shared, electronic access to lab results and other information, it's possible it will encourage a class of electronically super-empowered patients who become more demanding in making sure the information in their record is "complete" to their satisfaction and that they are getting the best care (or at least what they believe to be the best care).

Each example raises questions about the expectations on both ends of the PHR-enabled information sharing. Will patients' electronic access cause disruption to the clinical workflow? If a patient sends a message,

how soon is the clinician expected to reply? If a patient's home-monitoring data in a PHR shows a dangerous trend, is the doctor liable for failing to act on it?

The ideal electronic information exchange has clear, accessible policies to answer such questions and set appropriate expectations for both patients and clinicians. Policies must be established locally. Among the factors to consider: the capabilities of the software being used, the needs and capacity of the people who use it, and, of course, the resources and objectives of the institution that pays for it.

Policy references

One starting reference is the "eRisk Guidelines" developed in 2002 by the eRisk Working Group for Healthcare, a consortium of professional liability carriers, medical societies and state board representatives. The group was convened by online health tool developer Medem, Inc., a private company partially owned by medical professional societies. Although the guidelines are specific to patient-clinician electronic messaging and online consultations, they offer practical advice on setting appropriate expectations and limiting liability in any type of electronic information sharing between patients and clinicians.

Summary of eRisk Guidelines*	
Clinicians possibly <u>decrease</u> their liability if they:	Clinicians possibly <u>increase</u> their liability if they:
Obtain up-front patient consent to policies for appropriate uses and limitations of the technology, such as avoiding electronic means of communication for emergencies, setting appropriate expectations for response times, using extra consideration for highly sensitive medical topics. (Informed consent to the policies should be obtained from the patient for any remunerated services.)	Interact with patients online without ever establishing a previous doctor-patient relationship. (Clinicians should not accept money for online-only services in the absence of a prior, face-to-face encounter.)
Publish the policies and make them part of the legal documentation and medical record when appropriate.	Communicate online with a patient who is outside a state in which the clinician holds a license.
Keep a record of online communication and other information exchanges as part of the patient's chart (either electronic or paper).	Make a diagnosis or treat a new condition based solely on information obtained online.
Understand that online consultations or services, particularly those that are fee-based, carry the same legal rules, ethical guidelines and professional etiquette and obligations for patient care and follow-up as face-to-face, written and telephone consultations.	Fail to identify exactly who conducted the communication with the patient (e.g., doctor does not review advice that a subordinate sends to a patient in the doctor's name).
Inform patients upfront about any fees and the fact that they might not be covered by insurance.	
Inform patients that online consultations are based only upon information made available by the patient during or before the online consultation, including referral to the patient's chart when appropriate, and therefore may not be an adequate substitute for an office visit.	
Consider developing selection criteria for electronic correspondence to eliminate patients unlikely or unwilling to adhere to the terms of use.	
Take reasonable steps to properly authenticate and protect the privacy of patients.	
<p>* Used with the permission of Medem, Inc. and the eRisk Working Group for Healthcare" The full guidelines are available at: http://www.medem.com/phy/phy_eriskguidelines.cfm (accessed online on July 7, 2004)</p> <p>Please note that these guidelines are not meant as legal advice and providers are encouraged to bring any specific questions or issues related to online communication to their legal counsel.</p>	

In the above chart, behaviors that potentially increase liability are largely things that clinicians would be ill-advised to do in the presence or absence of a PHR.

The PHR raises policy questions that go beyond patient-clinician electronic messaging and online consultations. Our Working Group agreed on the following:

- Except as previously agreed upon, the patient bears primary responsibility for the information in the PHR, and clinicians and other healthcare entities are not responsible for contributing to or reviewing that information. Nonetheless, we strongly encourage the development of policies and incentives that encourage clinicians and other healthcare entities to provide at minimum certain core data elements into the PHRs of all patients within a 10-year time frame.
- Another element of expectations involves money. Simply put, clinicians rightfully expect to be paid for their time and services. We support experimentation to reimburse clinicians fairly for online interaction that leads to more continuous healing relationships with their patients. This is particularly desirable for activities that demonstrate a reduction of office visits as a result of safe and effective online interaction.
- When medical professionals or other healthcare entities agree to **contribute** professionally sourced information into the PHR, they should develop policies that make clear to the patient:
 - The sources of the information.
 - The timing and procedures for releasing new data.
 - The expected response time for patient electronic inquiries.
 - The means by which the patient can contact the source to contest the accuracy of the data.
- When medical professionals or other healthcare entities agree to **review** information in the PHR or **accept information transfers** of information from the PHR, they should have policies to make clear to the patient:
 - The procedure by which the patient actively makes the PHR-based information available to clinicians.
 - The expected intervals and procedures for any such review.
 - The procedures for confirming when a review has taken place and by whom, and/or when an information transaction has been received and by whom.

In either form of information sharing, medical professionals or other healthcare entities have obligation to disclose the applicable privacy policies. And of course, the PHR medium is not different from telephone messages or face-to-face encounters as it relates to the

Helpful resources

The following are additional resources on e-communications between patients and medical professionals:

American Medical Association:

<http://www.ama-assn.org/ama/pub/category/2386.html>

For a list of guidelines, see:

<http://www.e-pcc.org/>

clinician's obligation for appropriate clinical follow-up based the information exchanged.

In addition, status-indicators are helpful in an asynchronous communication mode. *Example:*

“Your message has been successfully received. The status of your message is ‘pending.’ Our normal response time is within one business day. If your matter is urgent, please do NOT rely on this electronic communication – use the telephone or go to an Emergency Room.”

For all the reasons discussed in the Authorization section of this chapter, we recommend that PHR-related information exchanges between patients and clinicians be time-stamped, source-stamped events that are traceable in audit trails. Ideally, all transactions are stored in real time in both the PHR and the EHR, and are archived and easily searchable for both the clinician and the patient.

There is a significant advantage to building PHR-based information sharing on a “transactional” model (i.e., a specific message at a specific time from a specific person to a specific person) rather than an “open access” model (i.e., the clinician logs into the PHR directly.) Clinicians are justifiably concerned about having a new patient data resource that they do not control. Are they responsible for checking it routinely? Are they supposed to go on “hunting expeditions” to find information that may be buried deep within a PHR with which they are unfamiliar? Can they be sued for missing important information that was just “one click away?”

Transactional sharing of electronic information, in which both the patient and the clinician get “copies” of exactly what occurred, creates a transparency of information that often doesn't exist today and may help render some of the above questions moot. A self-documenting EHR and PHR can help demonstrate when the physician acted responsibly, followed evidence-based guidelines, and communicated the patient's responsibility in the treatment regimen. When the clinician departs from evidence-based guidelines, it's plausible that mitigating factors will have been documented in the shared electronic record.

However, it's important to note that concern about medical malpractice lawsuits is a major barrier to PHR acceptance among clinicians. Some fear that patient electronic records may provide medical malpractice attorneys a more convenient means to look into a patient's (or a large group of patients') lifelong medical records, scanning for evidence of neglect, e.g., if a physician failed to take into account historical information buried deep within the patient's record.

To address these concerns, we recommend that:

1. PHR user agreements and other forms of disclosure (including face-to-face encounters) be clear in setting patient expectations of how the physician will or will not use information in the PHR.

2. Medical professional societies, patient advocates, policymakers, legislators and medical malpractice insurance underwriters should collaborate to develop formal guidelines on legal risk-reduction as it relates to the PHR. We believe that the existence of such guidelines, particularly if endorsed by all major stakeholders, would serve as a reference for legal practitioners and the judiciary in any eventual PHR-related litigation.

Sample issues: Patient diaries and monitoring device data

Patient diaries are often a useful means to record symptoms or other clinically relevant information, particularly compared with trying to recall past details during a doctor's office visit. At a pilot PHR project at a Veterans' Administration hospital in upstate New York, for example, a patient tracks intermittent chronic pain online and sends the information to a pain management specialist. Checking the information asynchronously, the specialist is able to recommend changes in the medication regimen to provide better relief. To enjoy the advantages of managing a serious condition with the aid of asynchronous electronic technology, both patient and specialist must establish a deep trust, perhaps more so than in the typical patient-doctor relationship. The specialist relies on the patient to accurately report symptoms (particularly important if narcotics are involved). The patient relies on the physician to respond to messages within an expected time frame.

In the above example, it is not practical to expect that the busy specialist be accountable for checking the patient's diary routinely to assess whether symptoms are getting worse. The default expectation should be that any communication about developments in symptoms or other problems be initiated by the patient, just as it would be in the absence of the PHR and messaging technology.

The scenario is the similar in the **Chapter 4** use case in which "Paul" shares his glucose readings via his PHR. It's not appropriate or practical to require or assume that providers will be monitoring the data of every patient at any given time or interval. In signing up for the system to import monitoring-device data, the patient should "opt-in" to a statement that makes it clear that providers are not responsible for monitoring the data at their own initiative.

Paul's primary care physician, who may see hundreds of patients, should not be considered responsible for logging in to Paul's PHR and checking his latest blood sugar charts (unless he wants to and both he and Paul agree that he do so.) It is more appropriate for Paul and his PCP to agree on a regular interval for Paul to send his latest glucose level graphs into the PCP's office, and that the transaction be incorporated into Paul's EHR or paper chart at the doctor's office. Some sophisticated systems include the ability for the physician to establish patient-specific thresholds that will trigger an automated notification to the physician or case manager that the patient's blood sugar readings

Patient quotes

"It's a diary of what level my pain is at any particular time of day ... It saves time. She has what I sent back to her right in front of her when I go in."

— Chronic pain patient in VA pilot project

are too high or too low. Such technology holds promise for improved clinical follow-up. However, it should be undertaken based on a clear understanding between the patient and the physician of the physician's responsibility, if any, when a notification occurs indicating that the patient's numbers exceed the thresholds.

Conclusion

This chapter is the result of our Working Group's best assessment of new and complex policy territory. Our overriding purpose is to provide a reference for healthcare stakeholders in this area. Many of our recommendations call on organizations that create standards and other collaborative efforts for further development. In addition, we would like to see the recommendations set forth in this paper to be put into practice in demonstration projects that will inevitably expand the collective understanding of these issues.

¹ Lynn Nielsen-Bohlman, Allison M. Panzer, David A. Kindig, *Editors. Health Literacy: A Prescription to End Confusion* Committee on Health Literacy, Institute of Medicine, 2004. Viewed online 4 June 2004 at <http://www.iom.edu/report.asp?id=19723>

² "The State of HIPAA Privacy and Security Compliance," A report by the American Health Information Management Association, April 2004.

CHAPTER 9 Conclusion

Involving the American public as partners

Each one of us — whether healthy consumer, needy patient, or caregiver — plays a vital role in healthcare. Each of us needs to receive useful information to help manage our own health and to be assured that professionals who provide services to us can get the information they need in a timely, accurate and usable way.

The Working Group appreciates the many creative efforts now underway to offer electronic solutions to the patient-clinician information chasm. We discovered enthusiastic patients, clinicians and technologists, united in their passion to permit individuals to be more engaged and successful managers of their own health. These pioneers recognize that the long-term goals of safe, affordable and high-quality healthcare are unlikely to be achieved without tools that permit patients and families to be more active and successful.

Our review of these early PHR projects and the emerging challenges they have uncovered leads us to make three principal recommendations for action for 2004 to 2006:

- 1. Increase public understanding of the value of connectivity in healthcare through a coordinated, public-private communications campaign.**
- 2. Seek vendor and provider agreement to a body of specific and comprehensive design principles and policies.**
- 3. Conduct a small number of PHR demonstration projects that incorporate both the “common framework” recommended by the *Connecting for Health Roadmap* and the PHR design principles and policies recommended in this report.**

1. Increasing public understanding of health information technology

The American public expresses high levels of interest in many of the potential functions of successful electronic health records (EHRs) and personal health records (PHRs). Unfortunately, more than half of consumers believe that their own doctor, and the health system as a whole, is far more “wired” than they actually are. Indeed they believe

that the expected benefits are already in place. As a result, we find that the public first needs to be made aware of the possible advantages of a more connected health system and then needs to be told that it is not a reality today but could be tomorrow, with their support. We believe that a public that sees personal advantage in increased connectivity will support initiatives such as the financial, community and policy initiatives that are addressed by the Connecting for Health Roadmap, the National Health Information Infrastructure, and many regional initiatives.

These research findings presented in **Chapter 5** can be used to develop a “communications toolkit” that can be adapted by various vendors, health systems, consumer groups, and government programs so that the public begins to develop a common understanding of our vision, the expected benefits of progress, and the vocabulary of modern healthcare. These messages can empower patients and families to be more effective managers of their own health, better partners in care, and informed advocates of moving the health system toward greater connectivity.



2. Seek vendor and provider agreement to a body of specific and comprehensive PHR design principles and policies

Significant efforts are already underway to develop personal health records. Many of the best early projects provide specific and concrete benefit to well-defined patient populations – people receiving care from the Veterans’ Health Administration, parents of children with hydrocephalus, people managing multiple medications, members of Group Health Cooperative of Puget Sound. Yet few of these systems, even those built on common software platforms, are able to exchange information with each other or directly with the patient and family, and few have been designed with a priority on direct benefits to patients. The Working Group supports the continued efforts to meet patients’ needs through the development of PHR products, and has no desire or ability to recommend any particular approach. Instead, we encourage the PHR and EHR communities to anticipate the increasing need for interoperability and the importance of sharing data directly with individuals by adopting a set of common standards and policies now.

These include:

- Common means for correctly identifying each person and ensuring privacy protections.
- A set of common data fields.
- A secure protocol for electronic information exchange.
- Common clinical vocabularies.
- Common values and policies that place each person at the center of controlling his or her own information.

3. Conduct a small number of PHR demonstration projects that incorporate both the "common framework" recommended by the Connecting for Health Roadmap and the PHR design principles and policies recommended in this report

The Working Group recognizes that diverse approaches to PHR will proliferate across the United States for years to come. Each of these will offer value to specific populations in specific settings. We certainly encourage evaluation and dissemination of the results of these initiatives to facilitate shared learning and progress. At the same time, the ultimate power of PHR depends upon the individual's ability to integrate health information from many sources across space, specialty and time. The process of building and testing these integration strategies across disparate platforms will also require dedicated attention — and we realize that the business case that supports any one vendor or provider's commitment to a PHR product may not support the effort to make that product interoperable with all others. This process is a matter, today, of public interest rather than obvious business necessity.

Rather than suggesting one specific demonstration project, the Working Group proposes A) overarching criteria, B) sample project scoping questions and C) several problem areas that may lend themselves to a future demonstration project.

A. Overarching criteria – All candidate PHR demonstration projects must meet the following criteria:

- i. **Problem:** Address a significant, widespread friction or deficit in providing safe, high-quality care to patients due to flawed information availability.
- ii. **PHR-based solution:** Propose an intervention that includes secure, online patient or caregiver access to personal health records in which users can view, contribute to and share their health information among their health care professionals.
- iii. **Interoperability:** Test patient-authorized sharing of PHR-enhanced information among providers affiliated with multiple organizations, i.e., not only within a closed, integrated system.
- iv. **Assessment:** Develop an evaluation plan to measure:
 - a. Technical infrastructure feasibility
 - b. Economic scalability
 - c. Patient and provider acceptance, utilization and satisfaction
 - d. Recognizable improvements in efficiency and quality of care
 - e. Potential risks to patient safety, privacy or quality of care
- v. **Timing:** Provide a plan to be in the field in the next 18 months

B. Project scoping – Based on a given problem area and available resources, each demonstration project will address scope in at least the following categories:

- i. **Location:** What regions and institutions are best equipped to launch the project?
- ii. **Technology infrastructure:** What PHR technology or application will be used (e.g., Web-based ASP, desktop application, portable memory device)? How much electronic data interchange will be necessary and what organizations will need to participate?
- iii. **Population:** What are the target groups of patients, consumers and care providers who need to be involved?
- iv. **Content:** What specific types of information will be exchanged (e.g., care plans, medications, etc.)?
- v. **Adoption drivers:** How will the project be promoted or incented to the targeted populations? How will the promotion be measured for effectiveness?
- vi. **Stakeholder business metrics:** Which stakeholder groups stand to benefit if the demonstration project proves successful (e.g., patients, payers, small practice doctors, hospitals, etc.)? What key metrics for success do those stakeholders have?

C. Sample problem areas to be considered for demonstration projects

- i. **Medication management:**
 - *Problem:* Patients receive prescriptions from many providers and stay with the same dispensing pharmacy or PBM for limited times. Only patients know what they actually take, and only patients can report their use of over-the-counter products and supplements. Medication errors and poor adherence remain enormous problems. New providers and emergency departments have no way to access a complete and accurate record of medications.
 - *Potential demonstration:* Develop a consolidated medication record through the PHR, reflecting prescribed, dispensed, and consumed medications and allowing the patient to record OTC and alternative product use as well as allergies, side effects, and other pertinent information. Create a regional network that allows hospitals, physicians, school nurses, and others to access the list with appropriate authorization.

- ii. **Coordinated chronic illness care:**

- *Problem:* Patients with complex and long-term illness receive episodic care from dispersed, often uncoordinated providers: primary care physicians, specialists, nutritionists, therapists, etc. Patients often lack a written care plan and lack tools to monitor progress or remind them of essential activities.
- *Potential demonstration:* Develop a PHR-based disease management model that captures information from the patient, family caregiver, home monitoring equipment, physicians, labs, case managers, nurse educators, and other care providers, while tracking progress against the personalized care plan.

iii. Financial management:

- *Problem:* Few consumers have become fully engaged with their health information. Much of it is technical and hard to understand, most of it is inaccessible, and it rarely suggests immediate actions to be taken – so few people are inclined to go to much trouble to assemble their health record. In recent years, more and more people are facing higher premium contributions, co-pays, and coverage limitations.
- *Potential demonstration:* Develop a skeleton PHR tool which consolidates healthcare expense information (from EOB statements, credit card statements, FSA statements, checking accounts, etc.) and provides both expense management tools and a personal overview of clinical care. Create interfaces to allow an EHR, CCR, or patient to supplement the skeletal information with richer clinical content and applications.

Conclusion

The problems facing U.S. healthcare are well-known — and serious. This Working Group, comprised of pragmatic healthcare, consumer, and government leaders, has not viewed electronic health records or personal health records as a panacea. By itself, the improved ability to access, control and interpret one's health information may not greatly improve health, change consumer behavior, or change medical practice. But those urgent social gains are almost unimaginable without a vastly more comprehensive, interconnected, and person-centered health information system.

The business rules of U.S. healthcare make it unlikely that individual enterprises will fully address these challenges, and constraints on the resources and public acceptance of government's role make it unlikely that wide-ranging government actions will occur.

Instead, we foresee several years of continued innovation within the many components of healthcare, and continued efforts to provide more information service directly to patients and families. Given the enormous size and diversity of the U.S. population, this process is more likely to provide value to people in need than a uniform, one-size-fits-all approach to personal health records.

Yet while each of us may get value from a specific application in a specific context at a specific time, over our lifetimes these needs change and we will need to retrieve and consolidate all of our personal health information. For the comprehensive PHR to be achieved, each participant in our national health information network needs to agree to a few policies, standards and practices. Collectively, this agreement will not only bring greater technical interoperability, but it will give the public confidence that the data shared across the network is reliable and trustworthy.

The Working Group sees that a foundational layer is needed — contributed to and shared by all — and that the greatest personal value will come from incremental applications that "sit on top of" that foundation and serve specific groups of people. We encourage everyone interested in increasing Americans' information power and facilitating health system redesign — patients, caregivers, consumers, doctors, managers, policymakers — to collaborate in this work. Together, by sharing approaches, using standards, testing data exchange methods, and disseminating our findings, we can permit millions of Americans to become more engaged in their healthcare and more successful in their pursuit of good health.

Appendix A: Working Group on Policies for Electronic Information Sharing Between Doctors and Patients

Connecting for Health, Phase II

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Appendix B: PHR Function List

This appendix reviews the functions that have been implemented or envisioned across the various PHR models. This list is not exhaustive nor is it intended to constitute an industry standard for PHRs. Rather, our aim is to provide a recommended checklist of functions that PHR vendors and implementers will consider and decide upon based on their circumstances.

EHR functions

Our Working Group recognizes that many PHR functions are related to EHR functions in that they can be driven by the same data. The chart below provides a preliminary mapping of PHR functions to the EHR Functional Model approved in May 2004 by the standards group HL-7. When appropriate in our PHR functional list, we've made an effort to use language consistent with the HL7 EHR functional model. For more information, go to <http://www.hl7.org/ehr/>

Minimum data set

Further, our Working Group recognizes the momentum behind the Continuity of Care Record (CCR) in developing a minimum data set for clinician-to-clinician transfers of patient health data. We envision the patient being able to accept CCR data transfers into a patient-controlled PHR. The final column of the chart below indicates where the CCR data set categories map to PHR functions. Each CCR category includes a number of specific data fields. The data fields identified in the CCR would satisfy a significant proportion of the data requirements of a robust PHR.

Core health information repository functions

Identification Functions				
ID	Function	Description	Related functions in HL7 EHR	Related data category in CCR
1	Manage demographic information	Capture and maintain demographic information that is reportable and, where appropriate, trackable over time. Includes but not limited to date of birth, gender, ethnicity.	S.1.4.1 DC.1.1.2	Patient Identifying Information
2	Manage contact information	Capture contact information including addresses, phone numbers, email address of the unique user. Capture contact information including addresses, phone numbers, email address of the unique user's emergency contact(s). Capture contact information including addresses, phone numbers, email address of the unique user's next of kin.	DC.1.1.2	Patient Identifying Information
3	Medical insurance	Provide the group number and other relevant information to confirm eligibility of medical care coverage, as well as the carrier's contact number, preauthorization requirements.	S.3.3.2 S.3.3.3	Patient Insurance /Financial Information
4	Pharmacy insurance	Provide the group number and other relevant information to confirm eligibility of pharmacy coverage, as well as the carrier's contact number, preauthorization requirements.	S.3.3.2 S.3.3.3	Patient Insurance /Financial Information
5	Medical care provider(s)	Store contact information for the PHR user's health care providers.	S.1.3	
Medical History Functions				
6	Health summary	Provide a one-screen, printable, bulleted summary list of all of the information essential function areas that is sortable both chronologically and by category. A key feature of an personal health record is its ability to present, summarize, filter, and facilitate searching through the large amounts of data. Much of this data is date or date-range specific and should be presented chronologically. The summary is designed to make it easier for a patients and care providers to get a snapshot of clinically relevant information about the person.	DC.1.1.5	

7	Family history	Capture the presence and/or absence of a history of major diseases among the PHR user's close blood relatives.	S.3.5.1	Patient Health Status: Family History
8	Manage problem list (diseases and conditions, symptoms)	Store a problem list that includes chronic conditions, diagnoses, or symptoms and functional status, both past and present. Provide ability to manage problem lists over time, allowing documentation of history information and tracking the changing character of the problem and its priority. Provide fields to store all pertinent dates, including date of onset, diagnosis, changes and resolution.	DC.1.1.3.1	Patient Health Status: Diagnosis/ Problems/ Conditions
9	Manage medication list	Store medication lists (including prescription and over-the-counter medications, vitamins and supplements and alternative therapies). Store all pertinent dates, including medication start, modification, and end dates as well as the dose, form, frequency, do-not-substitute status and prescribing provider. Medication lists are not limited to medication orders recorded by providers, but may include patient-reported therapies (preferably from a menu of medications that are codified according to standardized vocabularies).	DC.1.1.3.2	Patient Health Status: Current Medications
10	Manage allergy and reactions lists	Store known allergens and substances that have produced adverse reactions in a list that is managed over time. All pertinent dates, including patient-reported events, are stored and the description of the allergy and reaction is modifiable over time. The entire allergy history, including reaction, for any allergen is viewable.	DC.1.1.3.3	Patient Health Status: Adverse Reactions/Alerts
11	Manage lab and test results	Store results of the most common clinical screening, diagnostic and home-monitoring tests in a way that can be easily viewed over time. Flow sheets, graphs, or other tools allow patients and care providers to view or uncover trends in test data over time.	DC.1.4.5	Patient Health Status: Laboratory Results
12	Manage immunizations list	Store data on immunizations in a way that can be easily viewed over time.	DC.1.14	Patient Health Status: Immunizations

13	Manage clinical encounter list	Store data on clinical visits and outpatient and inpatient procedures, including date, facility, attending physician, diagnoses and procedures. When feasible, store physician notes and hospital discharge summaries.	S.3.1	Care Documentation: Encounters
Other Relevant Information Functions				
14	Manage list of other therapeutic modalities (counseling, occupational therapy, alternative, etc)	Enable the user to add information in free text about other modalities of treatment used, both past and present.	DC.1.1.7.2	
15	Patient diaries	Enable the patient to self-report symptoms or concerns (e.g., pain, anxiety, sleeplessness, seizures) in a chronologically sortable diary.	DC.1.1.7.2	
16	Spiritual affiliation / considerations	Enable the user to add information in free text about religious/spiritual beliefs that he or she wants care providers to know.	DC.2.1.4	
17	Case management	Store information about case management programs in which the patient is enrolled.	DC.1.2.2	
18	Other concerns	Enable the user to add information in free text about any other information he or she wants clinicians or allied health professionals to know.	DC.1.1.7.2	
Planning Functions				
19	Manage advance directive form	Capture the user's advanced directive as well as the date and circumstances under which the directives are provided, and the location of any paper records of advanced directives as appropriate.	DC.1.5.2	Advance Directives
20	Goals, next steps or disease management plan	Enable the user or anyone the user has authorized to add in free text information about personal health goals, next steps or a specific disease management plan.	DC.1.1.7.2	Care Plan Recommendation

System Functions

ID	Function	Description	Related functions in HL7 EHR	
21	Manage patient-sourced health data	Enable patients and consumers to self-report health data. Display health data — both patient sourced and professionally sourced — in the user interface with consumer-friendly terminology.	DC.1.1.7.2	
22	Map patient data to standardized codes	The data entered by patients should map to controlled, standardized code sets or nomenclature.	DC.1.1	
23	Use consumer-friendly terminology	Display health data — both patient sourced and professionally sourced — in the user interface with consumer-friendly terminology.		
24	Display professionally sourced health data	Enable the consumer a view of professionally sourced data (e.g., information from health care providers, pharmacies and pharmacy benefit managers, medical or home monitoring devices and insurance companies).	DC1.1.7	
25	Utilize standardized code sets and nomenclature	<p>Store health information according to consistent terminologies, data correctness and interoperability by complying with standards for health care transactions, vocabularies and code sets. Examples that PHR applications need to support are a consistent set of terminologies such as: LOINC, SNOMED, ICD-10, RxNorm, and messaging standards such as HL7 and NCPDP.</p> <p>Enable version control to ensure maintenance of utilized standards. Version control allows for multiple sets/versions of the same terminology to exist and be distinctly recognized over time. Terminology versioning supports retrospective analysis and research, as well as interoperability with systems that comply with different releases of the standard.</p>	DC.1.1 I.4.1	

26	Data interchange standards	<p>Support the ability to send data from PHR to external institutionally owned electronic medical record systems, in standard HL-7 data interchange formats, and operate seamlessly with complementary systems (EHRs and entities authorized to interact with EHRs and PHRs) by adherence to key interoperability standards. Interoperable PHR applications require infrastructure components that adhere to standards for connectivity, information structures, and semantics ("interoperability standards").</p> <p>Ensure common-field compatibility with emerging standards for minimum datasets for clinical information transfer (e.g., Continuity of Care Record).</p>	I.5.1	
27	Secure data exchange	<p>Exchange of PHR information requires appropriate security and privacy considerations, including data obfuscation and both destination and source authentication when necessary. For example, it might be necessary to encrypt data sent to remote destinations. This function requires that there is an overall coordination regarding what information is exchanged and how the exchange will occur, between PHR and entities with which it engages in electronic data interchange. The policies applied at different locations must be consistent or compatible with each other in order to ensure that the information is protected when it crosses entity boundaries within the PHR or external to the PHR. Route electronically-exchanged PHR data only to/from known, registered, and authenticated destinations/sources (according to applicable healthcare-specific rules and relevant standards).</p>	I.1.5 I.1.6	
28	Audit trail	<p>Ensure that all data entries in the PHR are transparently time-, date- and source-stamped. Provide audit trail capabilities for resource access and usage indicating the author, the modification (where pertinent), and the date/time at which a record was created, modified, viewed, extracted, or deleted. Audit trails extend to information exchange. Audit functionality includes the ability to generate audit reports and to interactively view change history of PHR data.</p>	I.2.2 I.1.4	

29	Append notes	<p>Enable users of the PHR to append comments to data entries. For example, the PHR user would not be able to alter the data from a professional source, but should be able to append his or her own comments to it. The PHR should be transparent to the patient as to whether or not the PHR offers any notification capability to the physician of any patient-appended comments.</p> <p>In the absence of any such notification mechanism, the PHR should make clear that any such appended comments will not be seen by any physicians through the PHR.</p> <p>If there is such a notification system, then the patient must designate which clinician should see the comment. All transactions must be tracked in an audit trail, including a "status" as to whether the designated physician has viewed the comment, and included in the patient's record in the clinician-controlled EHR.</p>		
30	Unique identification and authentication of users	Store key identifying information and link it to a unique user record. The user identity is authenticated in each session of the PHR. Both users and application are subject to authentication. The PHR must provide mechanisms for users and applications to be authenticated. Users will have to be authenticated when they attempt to use the application, the applications must authenticate themselves before accessing or contributing information to PHR.	DC.1.1.1 I.1.1	
31	Terms and conditions, opt-in authorizations	Capture user opt-in agreement to the terms and conditions of the PHR service and explicit authorizations to other people or entities to view and/or contribute data to the PHR.	DC.1.5.1 I.1.2	
32	Secure access	To enforce security, adhere to the rules established to control access and protect the privacy of PHR information. Security measures assist in preventing unauthorized use of data and protect against loss, tampering and destruction. Verify and enforce access control to PHR information and functions for end-users, applications, sites, etc., to prevent unauthorized use of a resource, including the prevention or use of a resource in an unauthorized manner.	I.1.3	

33	Privacy policy and enforcement	Capture user opt-in consent to a fully transparent privacy policy. Privacy rule enforcement decreases unauthorized access and promotes the level of EHR confidentiality. Although not all PHR providers are believed to be covered entities under HIPAA, all PHRs products should be built to conform with HIPAA. Capture user consent to any use of data, including aggregate data.	I .1.8	
34	Caregiver proxy access	Provide the ability for a user to set up a separate login for with "read" and/or "write" access authorization.		
35	Reliability	Ensure that the system is available 24/7 with 99.9 percent reliability and response time adequate to integrate into clinical workflows.		
36	Durability of data	Retain and ensure availability all health record information according to organizational standards, legal requirements and in accordance with the terms and conditions.	I.2.1	
37	Printer-friendly format	Each page of the PHR will have a printer-friendly format.		

Optional Services

ID	Function	Description	Related functions in HL7 EHR	Related data category in CCR
38	Patient education, self-care content and consensus guidelines	Provide reliable patient education information to answer a health question, follow up from a clinical visit, identify treatment options, or other health information needs. The information may be linked directly from entries in the health record, or may be accessed through other means such as an index or key word searching. Receive, validate and routinely integrate updates of patient education material from trusted sources to ensure timeliness and accuracy.	DC.2.2.1.6 DC.2.7.2 S.3.7.2	
39	Clinician-directed links to patient educations, self-care content and consensus guidelines	Enable those authorized by the PHR user to identify and create electronic links to any educational or support resources for patients, families, and caregivers that are most pertinent for a given health concern, condition, or diagnosis and which are appropriate for the patient. The provider or patient is presented with a library of educational materials and where appropriate, given the opportunity to document patient/caregiver comprehension. The materials can be printed or electronically communicated to the patient.	DC.3.2.4 S.3.7.2	
40	Secure patient-provider messaging	Enable encrypted, password-protected electronic communication between patients and clinicians. The message exchanges should be archived in the PHR and easily integrated into the patient's EHR by the clinician.	DC.3.2.3	
41	Doctor's notes and other narrative information from clinicians	Clinical documents and notes may be created in a narrative form and made available through the patient's PHR. The documents may also be structured documents that result in the capture of coded data.	DC.1.1.6	

42	Standardized primary care visit intake questionnaires	Provide a standardized primary care office visit intake questionnaire that patients fill out through their PHR accounts and send electronically into the doctor's office before their primary care visit. Another example would be to allow patients to view and add notes, symptoms, reasons for visit, etc., to a Continuity of Care Record as part of a transfer process from one clinician to another.		
43	Standardized specialists visit intake questionnaires	Provide a standardized intake questionnaire for high-volume specialties that require a predictable set of information from all patients. (Examples could be glucose readings for people with diabetes or blood pressure readings for people with hypertension. Request that patients fill out the questionnaire through their PHR accounts and send electronically into the doctor's office before a specialist visit.		
44	Appointment scheduling and reminders	Enable the patient to request an appointment with current health care providers from a menu of possible times and dates. Create a secure mechanism to electronically notify the patient about the status of the request.	S.1.6	
45	Guidelines-based reminders	Identify appropriate screening tests/exams, and other preventive services in support of routine preventive and wellness patient care standards. Upon each session, the patient is presented with due or overdue activities based on protocols for preventive care and wellness. Examples include but are not limited to, routine immunizations (adult and well baby care), age and sex appropriate screening exams (such as PAP smears). External means of delivering notification are optimal, such as sending an email to patients notifying them that they have a secure message waiting in the PHR, which they can access by logging in. Receive and validate formatted inbound communications to facilitate updating of patient reminder guidelines from external sources such as Immunization Registries.	DC.2.5.1 DC.2.5.2 S.3.7.3	

46	Individually programmable reminders	Provide the ability for the patient's clinician to individually configure and generate automated notifications and reminders to patients regarding activities that are due or overdue, and capture these communications in a PHR archive as well as the clinician's EHR. Examples include but are not limited to time sensitive patient and provider notification of: follow-up appointments, laboratory tests, immunizations or examinations. The notifications can be customized in terms of timing, repetitions and administration reports. E.g. a Pap test reminder might be sent to the patient a 2 months prior to the test being due, repeated at 3 month intervals, and then reported to the administrator or clinician when 9 months overdue. Note: This function is not mutually exclusive with #45. The guidelines-based reminders could be set as defaults, with individually programmability an option that lets clinicians override the default settings.	DC.2.5.2	
47	Adherence messaging for specific medications	Enable the patient's physician, with patient's consent, to enroll in an automated, secure messaging program based on evidence-based guidelines for specific medication adherence.	DC.2.2.1.6	
48	Adherence messaging for specific conditions	Enable the patient's physician, with patient's consent, to enroll in an automated, secure messaging program based on evidence-based guidelines for managing a specific chronic condition, such as diabetes.	DC.2.2.1.6	
49	Structured care plans	Provide for structured care plans, guidelines, and protocols that may be site-specific or based on industry-wide standards. They may need to be managed across one or more providers. Tracking of implementation or approval dates, modifications and relevancy to specific domains or context is provided. Guidelines or protocols may contain goals or targets for the patient, specific guidance to the providers, suggested orders, and nursing interventions, among other items	DC.1.2.1-2	
50	Patient-specific instructions	When a patient is scheduled for a test, procedure, or discharge, specific instructions about diet, clothing, transportation assistance, convalescence, follow-up with physician, etc. may be generated and recorded, including the timing relative to the scheduled event.	DC.1.2.3	

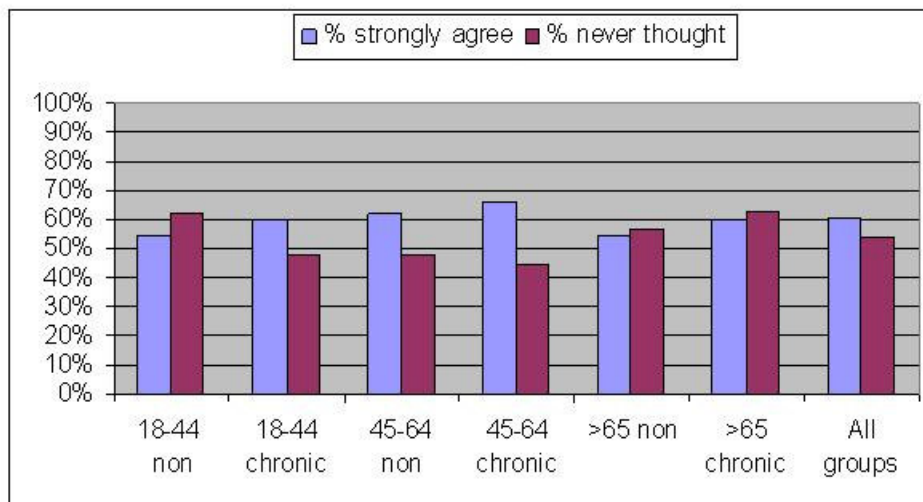
51	Longitudinal tracking / graphing tools	Enable the patient to store baseline comparison sets and subsequent results in a way that can be tracked or graphed over time. Example: Enable a patient to enter data that graphs multiple data points over time, such as weight, exercise and meals.	DC.1.1.5	
52	Monitoring device data	Provide mechanisms to allow consumers to connect various computer-based physiologic monitoring devices to their home computer via standard hardware interfaces (e.g., firewire, USB, rs232, etc.) and download monitoring data. This data should then be able to be displayed in table format, in graphical formats, and sent to institutionally owned systems if appropriate. Support communication and presentation of data captured from remote monitoring devices, such as glucometers. Support remote health care services such as telehealth and remote device monitoring by integrating records and data collected by these means into the patient's PHR for care management and public health reporting purposes.	DC.3.2.5 S.3.1.4	
53	Drug interactions checking	Provide consumers with ability to check a specific drug against his or her current medication list to check for drug-drug, drug-allergy interactions.	DC.2.3.1.1	
54	Formulary and generic availability lookup	Provide ability for the patient to look up a specific prescription medication to determine under what tier it is covered in the patient's pharmacy benefit. For all current medications in the patient's record, provide indications of the availability of therapeutic equivalent generic medications, if any.	DC.1.3.1	
55	Rx refill requests	Enable the patient to request a prescription refill through secure messaging that gets routed to appropriate desks.	DC.3.2.2	
56	Electronic EOB	Provide the financial data from medical and prescription services typically delivered in Explanation of Benefits, such as information about co-pays, co-insurance, amounts covered by insurance benefit, payment status and dispute information.		
57	Account tracking tools, such as deductibles, OOP max, flex spending accounts, etc)	Provide current balances for health-related accounts or thresholds including but not limited to deductibles, out-of-pocket or co-insurance limits, flexible spending accounts, health savings accounts.		
58	Cost transparency tools	Provide regional fee information for common medical services and medications based on reliable aggregate data, usual and customary fee scales.		

59	Cost modeling tools	Provide the ability for consumers to model their anticipated care utilization needs and estimate their out-of-pocket costs and potential savings from tax-sheltered accounts.	S.3.2.3	
60	Other data storage capabilities	Provide mechanisms for incorporating external clinical documentation, such as image documents, and other clinically relevant data are available. Data incorporated through these mechanisms is presented alongside locally captured documentation and notes wherever appropriate.	DC.1.1.7.1	
61	Scanned paper documents	Provide the ability to upload and store securely in the PHR scanned paper documents.	DC.1.1.7.1	
62	Scanned images	Provide the ability to upload and store securely in the PHR scanned medical images.	DC.1.1.7.1	Patient Health Status: Procedures/ Imaging
63	Clinical trial recruitment	Support the identification and notification (via secure messaging with appropriate opt-ins) of people who match the recruitment criteria of clinical trials.	DC.2.2.1.5	
64	Aggregate data analysis	Support clinical health state monitoring of aggregate patient data for use in identifying health risks from the environment and/or population.	DC.2.6.1 I.2.4	

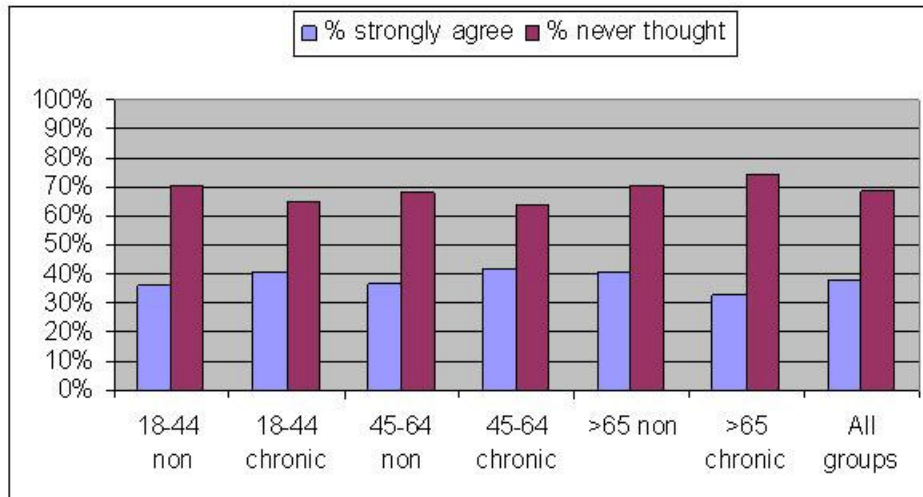
Appendix C: 2004 Telephone survey results for 12 PHR promotional messages

The following charts show the percentages of respondents who "strongly agreed" with the message and the percentage of respondents who reported that they had "never thought about it before," broken out by age and self-reported presence of a chronic condition. (The abbreviation "chronic" is used for populations who reported having a chronic condition. The abbreviation "non" corresponds with those respondents who said they did not have a chronic condition.)

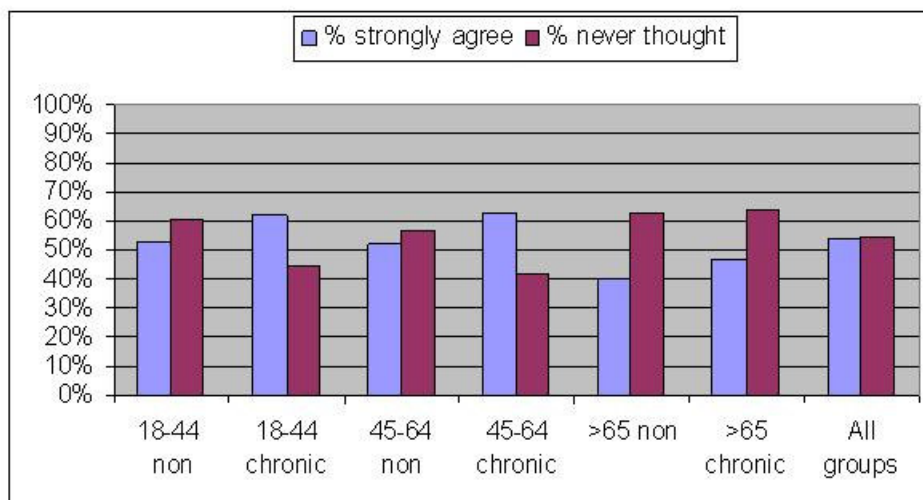
"It's my health information. I should have access to it anywhere, any time."



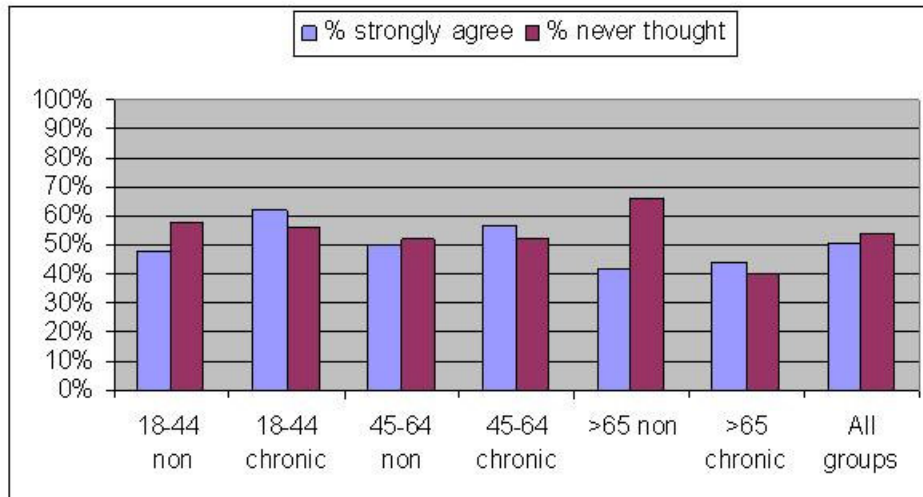
"I'd like to have all my health information in one place - and get to it with the click of a mouse."



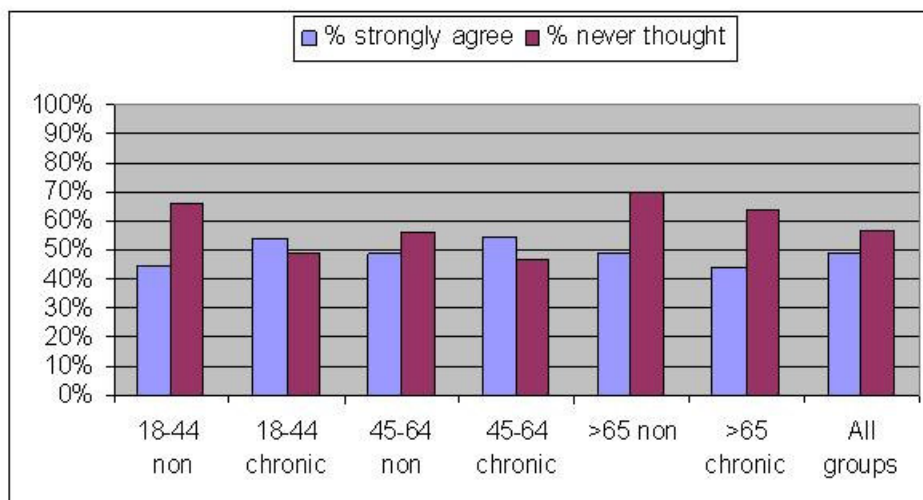
"Anybody can make a mistake. I'd like to double-check what's in my medical records."



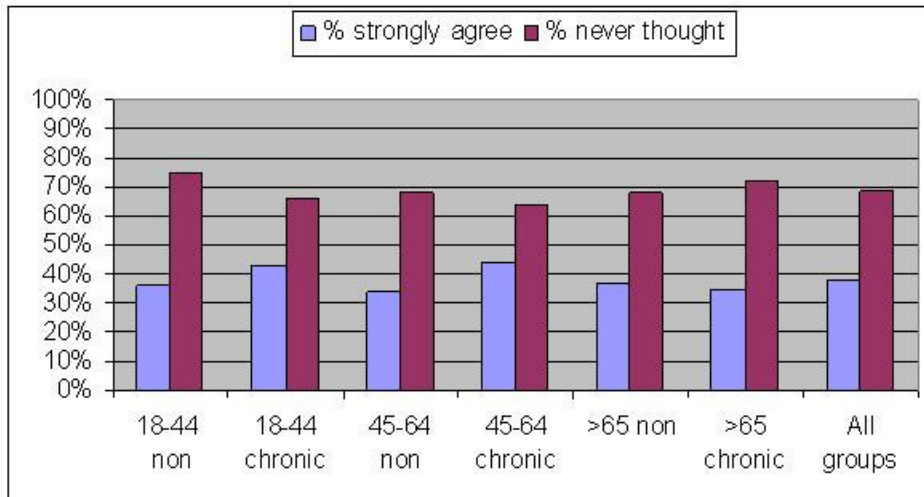
“It’s hard to remember everything my doctor says. I’d like to get an automatic copy of my doctor’s notes and records after each visit.”



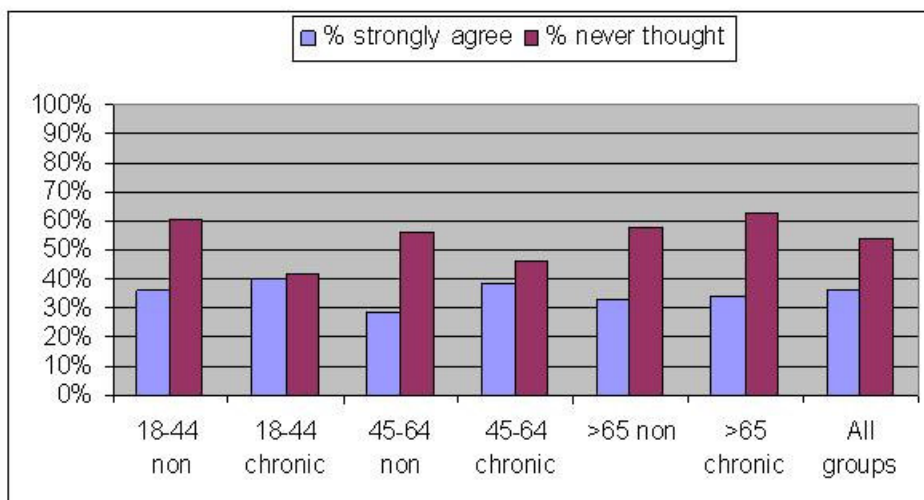
“I want to be involved in medical decisions that affect me. Having my own medical record would help me make better decisions.”



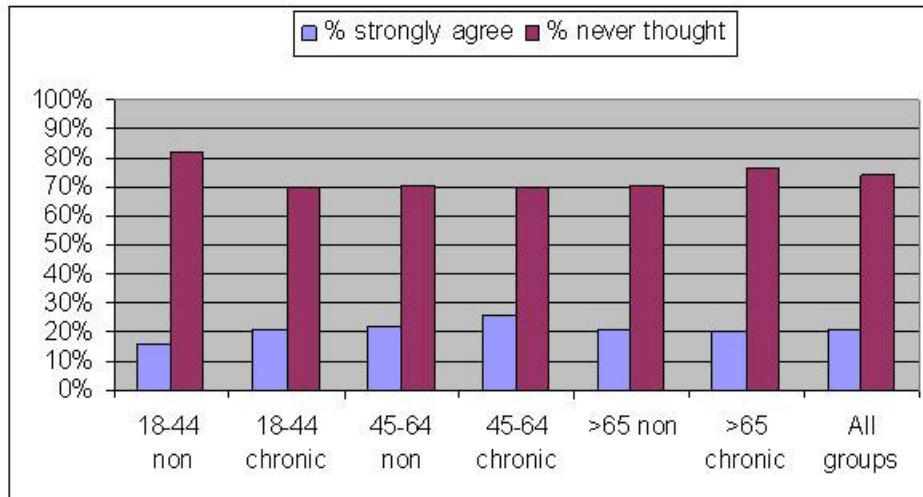
“My own online medical record would help me get all my doctors on the same page when they treat me.”



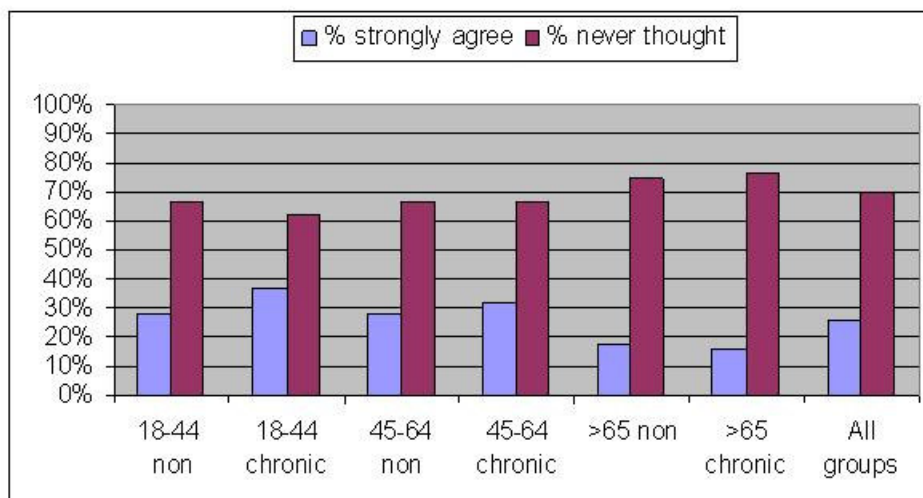
“I get the feeling that doctors don't want me to look at my file. It's my health and I have a right to know what's going on.”



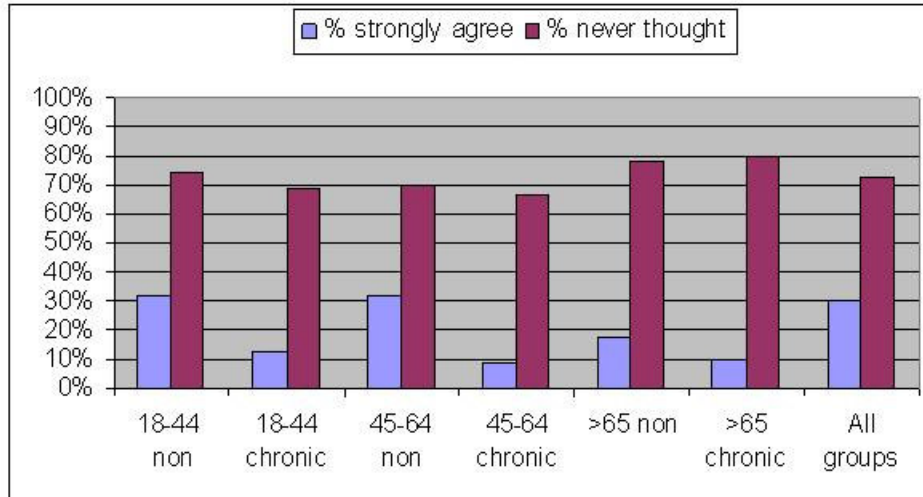
"I've often felt the health care system has all the power. Having my own online health record seems to even it out a little bit."



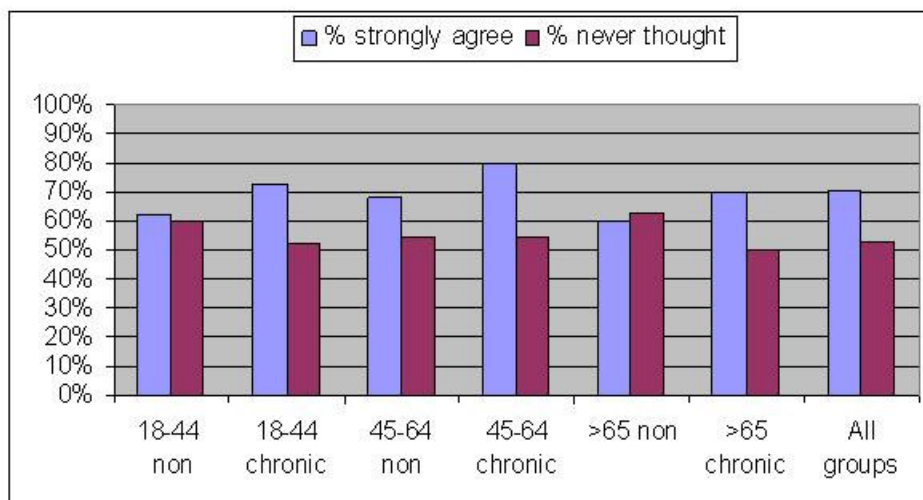
"I'm tired of playing 'telephone tag' with doctors and filling out the same forms. Why can't I do some of this stuff online?"



"I can access my bank account online. Why not my medical records?"



"In an emergency, getting my medical records quickly could mean the difference between life and death."



Here are the data in table form:

		N=298	N=172	N=161	N=509	N=76	N=504	N=1750
		18-44 non	18-44 chronic	45-64 non	45-64 chronic	>65 non	>65 chronic	All groups
"It's my health information. I should have access to it anywhere, any time."	% strongly agree	55%	60%	62%	66%	55%	60%	61%
	% never thought	62%	48%	48%	45%	57%	63%	54%
"In an emergency, getting my medical records quickly could mean the difference between life and death."	% strongly agree	62%	73%	68%	80%	60%	70%	71%
	% never thought	60%	52%	55%	55%	63%	50%	53%
"I'd like to have all my health information in one place - and get to it with the click of a mouse."	% strongly agree	36%	41%	37%	42%	41%	33%	38%
	% never thought	71%	65%	68%	64%	71%	74%	69%
"Anybody can make a mistake. I'd like to double-check what's in my medical records."	% strongly agree	53%	62%	52%	63%	40%	47%	54%
	% never thought	61%	45%	57%	42%	63%	64%	55%
"It's hard to remember everything my doctor says. I'd like to get an automatic copy of my doctor's notes and records after each visit."	% strongly agree	48%	62%	50%	57%	42%	44%	51%
	% never thought	58%	56%	52%	52%	66%	40%	54%
"I get the feeling that doctors don't want me to look at my file. It's my health and I have a right to know what's going on."	% strongly agree	36%	40%	29%	39%	33%	34%	36%
	% never thought	61%	42%	56%	46%	58%	63%	54%
"I want to be involved in medical decisions that affect me. Having my own medical record would help me make better decisions."	% strongly agree	45%	54%	49%	55%	49%	44%	49%
	% never thought	66%	49%	56%	47%	70%	64%	57%

"I've often felt the health care system has all the power. Having my own online health record seems to even it out a little bit."	% strongly agree	16%	21%	22%	26%	21%	20%	21%
	% never thought	82%	70%	71%	70%	71%	77%	74%
"I can access my bank account online. Why not my medical records?"	% strongly agree	32%	13%	32%	9%	17%	10%	30%
	% never thought	74%	69%	70%	67%	78%	80%	73%
"I'm tired of playing 'telephone tag' with doctors and filling out the same forms. Why can't I do some of this stuff online?"	% strongly agree	28%	37%	28%	32%	17%	16%	26%
	% never thought	67%	62%	67%	67%	75%	77%	70%
"My own online medical record would help me get all my doctors on the same page when they treat me."	% strongly agree	36%	43%	34%	44%	37%	35%	38%
	% never thought	75%	66%	68%	64%	68%	72%	69%
"I'm concerned about privacy. But if my credit card number can be kept secure online, then my health information can be, too."	% strongly agree	31%	32%	36%	36%	36%	36%	34%
	% never thought	71%	62%	63%	56%	60%	65%	62%

Appendix D: Excerpts from consumer focus groups regarding electronic personal health records

On April 13 and 14, 2004, FACCT – Foundation for Accountability conducted a series of focus groups designed to reach the following goals:

1. To better understand how consumers think about their current state of personal health information.
2. To better understand how consumers perceive any benefits of keeping such information online.
3. To better understand consumer demand for a more connected health care system, in which their information can move electronically to various providers as needed.

Four focus groups were conducted – two in Atlanta, GA, and two in Chicago, IL. In each city, one group was comprised of people from the general population. In Atlanta, the second focus group was made up of people who were caregivers of a friend or family member. In Chicago, the second group was made up of people who had a chronic illness. In all cases, effort was made to ensure that the groups were representative in terms of gender, race and age.

As part of the focus group procedure, participants were asked to rank nine different reasons a person may want to keep their medical records online. The following benefit statements were the top three selected in each of the four groups:

1. Gives me better access to all my health information.
2. Allows me to see if my health information is complete and accurate.
3. Puts me in better control of my health and health care decisions.

Although the concept of interoperability was not directly identified as a top benefit of online health records, several participants' stories revealed a strong perception of a problem with communication among the various parties of the health care system. Another notable concept that emerged was a concern over privacy of identity and information, which was largely mitigated in the discussions once the online banking analogy was raised.

The following pages feature quotes from these focus groups, categorized according to some of the key benefit statements and themes that emerged from the session.

FOCUS GROUP QUOTES

Gives me better access to all my health information

We have one drawer set aside for everything that comes from the doctor. But it's mostly for the kids because I don't keep up with mine that often. I don't go to the doctor that often. But the kids—you have to keep them up to date. – *Atlanta caregiver group*

I count on them <doctors> to keep the records more than myself. Because they have their records all on computers so I'm good to go with that. – *Atlanta caregiver group*

If they're taking care of me, why can't I know what's going on with me? – *Atlanta general population*

And when you're traveling and sometimes you might need – you might lose your medicine and you need a refill. And they say, "Carry your refill with you." Well what if you lose that too? And then you're stuck in a foreign hospital. Half the time they may have a different name for the type of medications you're on and it would just make things a lot easier if you could do things by computer where they wouldn't have to wait until it was – **I mean it could be somewhere where you're in a different time zone and your doctor over here, their office isn't open. And so what are you going to do? In eight hours you might die.** – *Atlanta caregiver group*

I'd like to have it all together like that. I love it. **I would love to have all the information and say, "Gosh, the neurologist said, and then the orthopedist said," you know, that kind of thing. I'd like it all together.** – *Atlanta caregiver group*

When my mother was sick and pretty much dying what I didn't like was that I could never, ever talk with the doctor and I really never, ever really found out how she was doing day to day or even week to week and she was in Florida and I could never have that information available to me. So in terms of information – information is very important to me and my family. And I believe as we move forward, **it is inevitable that computers are going to provide a service to guys like me or families that want to check on their parents and find out what is going on** and not wait until the very end for you to tell me that my mom had this or that. I don't want to hear that now. I could have challenged you a little earlier. I got have gotten more involved with that. And so would my family also... Or a neighbor. Or a buddy. If I can find out what's happening, I maybe need to call somebody else and say check this out. Are you sure this is right? So there's some added value in that. – *an Atlanta caregiver*

I recently wanted my doctor's records from a doctor, and they gave me a hard time about it, and they made me pay for them. And they wanted to know what I wanted them for. – *Chicago general population*

I had to get medical records twice. Once my husband's, and once mine. And both times was unsuccessful. And it was from – one was for my husband's employer. He had back surgery and they wanted to make sure that he could lift things, subsequent to this back surgery, which was several years previous, and he could, but they wanted documentation about the surgery. And **the hospital just kind of refused in a real round-about-way to give us the information. And then I had surgery a few**

years ago and I needed to have it repeated and my doctor had left the practice, and the practice would not give him the documentation, and they argued with me about it. – *Chicago general population*

I think you should get copies of all your records at time of service. Because when you go back for them, they think you want to sue them for something, or you want to go to another doctor for something. It's always all about money, always. But you can get copies of everything they do to you while you're seeing that doctor. And get them right then. – *Chicago general population*

Doctors don't want you in your chart. The ones that I know don't want you in your chart. – *Chicago general population*

I never got caught looking at my medical record, but you do feel like you shouldn't be looking at it, like it's not yours to look at. Even though it's all about you...It's like I was almost eavesdropping on something I shouldn't be. – *Chicago general population*

Well, if you have gotten the flu, or a bad cold, several times over the last couple of years, and you know certain antibiotics you've already taken, which ones work well, and which ones didn't, it may help. I'm sure the doctor would look at that, but he may not know what worked for you. Maybe you took something and it did nothing for you, and you remembered that, and you never told the doctor, and you just sort of let it heal on its own. – *Chicago general population*

I think that goes too with allergies. I have one son with many allergies to medication, and some or more severe than others, and every time we go to the doctor, or I've been in the emergency room with him, they want to know what those medications are, and how severe his allergies are. Fortunately now, he's old enough to actually know what the medications are, and he can help me remember, because I can't remember the severity. **It would be easier if it were someplace, so that it was just always there,** so that it always existed for him. – *Chicago general population*

I had to do get my medical records because I changed doctors, and I needed them sent to the other doctor. And I wanted to come and pick them up and they wouldn't let me. What they did is they sent them themselves. They didn't want me to sue them I guess. – *Chicago chronically ill group*

At Mayo Clinic there are no charts anymore. They're completely gone. There's no paper. Everything is computerized and you said how hard it was to read. All prescriptions are printed. They come out of a prescription thing. There is no more hand writing anything, so it does away with that—that shield of mystery that doctors have always created. It allows complete visibility and in English. – *Chicago chronically ill group*

Allows me to see if my health information is complete accurate

I think, too, it's like where you see – like if you have a place where you can go and look at your information – like you read stories, and like I said, see things on the news, you read things in the paper about doctors who write a prescription, say, and **they write one thing wrong and the pharmacist reads it wrong one way or the other and**

you get the wrong medication or the wrong dosage and like a lot of times now, if a doctor prescribes something for me, before I even get it, I'll go on the Internet and see what it is and make sure that it's something that's indicated for the problem I have and see what I can find out about it and think, "Hmm, is that something I really want to take or not?" – *Atlanta caregiver group*

Well, for one thing you want to see what the doctor's saying about you. **I think one of the problems with the healthcare system is that doctor's have typically always kept that information close to their vest. You don't ever get to see the inside of that folder.** How many of you have ever seen the inside of the folder, right? -- *Atlanta general population*

Wouldn't you like to know what the doctor is saying? -- *Atlanta general population*

They don't want the patient to see what they write. Because the patient might see something wrong and say, "Why did you say this?" -- *Chicago general population*

If you have more access to your health information and the complete and accurate information you can see all your past and present illnesses and what they treated you with. And if anything is wrong then you can update it with your physician. – *Chicago chronically ill group*

Puts me in better control of my health and health care decisions

The best thing we can do is just to be knowledgeable overall in medical things. **I can just think of one example when my son sees a lot of specialists and when they don't – they're supposed to send everything back to the pediatrician and a lot of times I'll ask the pediatrician, "Do you have all that? He went to this guy, this guy." "No, I don't have that." So it really should be up to me. Unfortunately it has to be up to me to ask the specialist—make sure you send a copy to the pediatrician, and when you ask them like that then things get done. When you remind them. Because they have a lot to do too. It's just one of those things—a lot of paperwork. So I think if we're knowledgeable, that helps.** – *Atlanta caregiver group*

It's a little odd, but you know what? It's funny because the more and more we talk, the more and more it seems okay. And I don't know why. I always try to keep an open mind but it's like, if you can go to the computer and you can just – you never know. You may be having a bad day. I don't know. And you could forget. I know I do it a lot. **I stay busy so sometimes I could forget what's really bothering me sometimes and I could...you've been to the doctor for this, that and the other—it may make a little sense. It may help me figure out what's bothering me and it may even, I don't know, it could eliminate some doctor visits** because if I could identify with what I'm feeling and why I'm feeling, maybe I could do what I did last time and get better. – *Atlanta caregiver group*

If you had like access to the medical records, I think that it would be very important because you could research like maybe a condition or a term or like some kind of medicine. Okay, they said I need this. Well, let me go to the computer and see what that is. I would like that. – *Atlanta general population*

The best care would be knowing and having all the information...And knowing what questions to ask and what professionals to go see. – *Atlanta general population*

I can never remember, like years, like months, I can never, never, never, never remember. So I would like, if I am going to the doctor, maybe print out a copy of it so when they ask me some of my history, I can give them some of the exact times. Because I never can remember. – *Chicago general population*

I have migraines. I have been taking medicine for migraines since I was like ten. **I've seen a thousand doctors. I have a lot of medications, and I be needing to know, because the medication has to constantly change, I can never remember.** I can never remember what medicines I've had, what doctors I've seen. I can remember the tests, **but I can never remember the doctors, because I've seen a lot. And right now it's even bugging me because it's important, I need to know.** – *person with chronic illness from Chicago*

It's good to know, when you have children, if they have a reoccurring illness. **You may not realize that your kid had four ear infections in the last year. You might find that excessive.** I'm just using that as an example. You may read something that says children that have excessive ear infections develop difficulty with their hearing later in life; you may want to adhere to that. – *Chicago general population*

If you want a second opinion on something, it may be a lot of red tape, or you may be afraid of offending your physician if you want a second opinion on something. **And to be able to get a complete record of whatever transpired, if it's right there, it's accessible. You can get that second opinion a lot quicker, and not have fear of offending your doctor.** – *Chicago general population*

I think you have to be in control of your medical history, your medical records, and your care. – *Chicago chronically ill group*

You can get more out of the doctor's visit—if you know more and have more information, you can talk with your doctor easier and he can understand more what might be going on and I think it's more complete that way. – *Chicago chronically ill group*

I'm just glad that I've taken stock of my medical health for many, many years and collaborated with healthcare professionals to keep a complete record because I think I'm the mistress of my own destiny that way. – *Chicago chronically ill group*

INTEROPERABILITY

I think they keep it more on computers. Maybe it's because like, you know, if you go to a doctor in a big medical center where there are a number of them together, it's just more efficient for them to keep everything now on computers and then you just give them your name and your identifying number and they can punch up and see exactly what you had done, how many times you've been there, you know, for X amount of time, what was done at each visit, what the results were and they keep it more on computers. – *Atlanta caregiver group*

I don't think anything's flawless, but I think that this – but I think just in general the healthcare insurance industry is getting so disconnected. **You talk about files and I remember an article years ago but some 18 or 19-year-old kid that came up with an idea, essentially a credit card, that if you were in an accident or out-of-state or whatever, any doctor or emergency room could swipe this card and pull up all of your information on this national database. I thought what brilliant idea. But I think it died out to a degree because there's all these different healthcare systems have their own proprietary systems** and I think getting that all into one basket where everyone could access it is probably more difficult than most people think and then taking all that historical data from millions of people and getting it transferred over. If you started today and said, okay, here's a new system. You know our kids would probably benefit from that, but your previous medical history it would be almost impossible to update and make accessible to everybody. – *Atlanta general population*

I think that's the issue with the healthcare is that they say all these different insurance companies and everything else have their own databases, but none of them talk to each other. – *Atlanta general population*

You have to have some sort of standardization of the records because I'm sure every hospital or healthcare system has their own recordkeeping and any detected differences in software and technologies and the fact that healthcare is far behind the rest of the world, than say financial services in terms of IT infrastructure. – *Atlanta general population*

When I had to have a tumor removed a couple years ago, and the surgeon and my doctor were on the same network, it just, it seemed like they weren't talking. One was telling me one thing and the other guy was telling me something else, so the communication was terrible. – *Chicago general population*

If it was like a common system—you could put it in and whoever needed it could, you know, have access to it. That would be easier. You wouldn't have to transfer it back and forth – *Chicago chronically ill group*

PRIVACY

I think shared is sort of a concern a lot of times because maybe there are things that are regarding your health that you might not want someone to know like a future employer or something like that if it might in some way reflect negatively on you. – *Atlanta general population*

You don't want anybody knowing your personal medical history. I mean I wouldn't if I was a recovering alcoholic. I wouldn't want that if I was going to go get another job somewhere. **I mean that's in the past and I've got it under control. I wouldn't want anybody else to know about that.** – *Atlanta general population*

But that is something that would be a concern of mine. Also when you think about what can happen with your credit history as far as you hear about people where their records get married with someone else's because of a transposed social security number. **I mean what happens if your medical records are married with someone else's and someone were to go and pull up your information and think you have a**

condition when you don't. That's something else to think about. – *Atlanta general population*

I think with the HIPAA Privacy Act now, too, it's hard; it's more difficult for people to get records. – *Chicago general population*

I think HIPAA makes it a little more difficult. Because I couldn't get my records from my doctor's office. They didn't have them there, they're in the – and they're all in the computer. But I had to go to a different building and it cost them – that would have made it a little more difficult. – *Chicago general population*

I don't believe that the HIPAA is doing anything except saving the doctors and the hospitals from lawsuits. – *Chicago chronically ill group*

They can be hacked. Actually it's probably less safe at your doctor's office than if it was on a centralized database that had firewalls up the yazoo that even the best hacker couldn't get into. You can use the same type of firewalls that you would use in a major – I work for a major bank, and trust me, the best hacker in the world would have a real hard time. I'm not saying that it's impossible, but we've had very few problems. So, and someone is more interested in stealing your money than your medical records, believe me. – *Chicago general population*

It bothers me that an EMR compromises your privacy in that – I have a very severe, chronic, life-threatening condition. And for years I have not shared that with any of the employers for whom I've been hired because I felt that it would be a condition that would not allow for them to hire me. – *Chicago chronically ill group*

"Oh my gosh—my privacy." That's the thing – that's raising my hair right now listening to all of you all, I'm like, "Oh God. I never thought about my healthcare privacy. – *Chicago chronically ill group*

I'm just not comfortable with – unless it's an emergency situation I'm not comfortable with accessibility and my privacy and certain information being just given to you. If I give it to you – it should be my choice of what I want you to know, what I don't want you to know—unless it's an emergency. If I am incapacitated, if I am in a coma, then I can see you passing on all of my medical information, but... – *Chicago chronically ill group*

OTHER

For one, **I don't know that my doctor has mine <health records> online. And come back to the question why it's not online—I think that's personally that's something that hasn't caught on with the doctors yet.** If they're doing it and if it's an extra cost, you know, for them to do that. You know, maybe another three, four, or five years down the line that might be more common. You know, but personally I think it they haven't caught on to that yet. – *Atlanta caregiver group*

For the patients it's great. The doctors might be a little bit more fearful of having all that on there. You know? Because they have their own legality – legal issues...If they did make a mistake you would have it right there on a printout. . – *Atlanta caregiver group*

Well, if it's all electronic, you're eventually going to end up with a huge cost savings anyway. One of the huge expenses in our healthcare system is all these pieces of paper. You have this piece paper and three people touch it and enter the exact same information at three different places...Or the incorrect information in three different places. – *Atlanta general population*

My medical records are at the doctor's office, but they won't give you a copy of them. You have to go to medical records, which is in a different part of – in a different building. It's something, because they still share them amongst each other. Even though they say they're not supposed to, they still do. They – doctors share with the insurance, the insurance share with whoever call and ask for the information. They're not supposed to release that information without consent of the person, period. Ever. – *Chicago general population*

What I'm saying being the age of computers, it shouldn't be so difficult. It should be efficient. . – *Chicago general population*

There's no incentive for the doctors to do it. Or the insurance companies. Banking institutions have incentives to have online services to attract customers. And, a lot of people go to a doctor because that's within their healthcare group. So, they're not going to select a doctor because he has online services. It would be nice if they did, but that's probably not going to be the deciding factor for a lot of people. So there is no incentive. . – *Chicago general population*

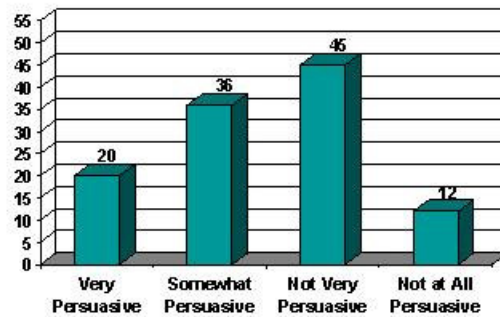
I think I'm going to ask my doctor how my records are kept next time I go. I think they're just kept on paper, but I really don't know. So I have some questions for the office. I would be interested in how accessible my records are right now. For all I know, this is already in place in some places. And I don't even know that my doctor has my records available, accessible, or able to email my doctor. So, I'm going to ask those questions. I never thought about electronic communication with my doctor before. – *Chicago general population*

I didn't even know they keep records on computer. I have not ever seen that. I've seen the paper. The only things I've ever seen anybody do on a computer is lock me in—check me in, and check me out. That's it. For medical records or anything, it's always been on paper. – *Chicago chronically ill group*

Appendix E: Testing of creative advertising concepts

At the end of the telephone survey, participants with online access were asked to go to a Web site and rank the nine visual ads on a 4-point scale, with 1 being "very persuasive" and 4 being "not at all persuasive." Nearly all of the 116 respondents reported having a chronic illness. Of the 1750 telephone participants, 116 (nearly all of whom reported a chronic illness) went online to complete this portion of the survey. Although this number represents only 6.6 percent of the sample, not all telephone participants "qualified" for the online portion since 29 percent stated they did not have access to the Internet and 41 percent stated that they did not have an active email account. After removing these respondents from the pool of possible online participants, the response rate for the sample was a more respectable 11 percent.

Below are the visual ads with their results of the online portion of the survey:

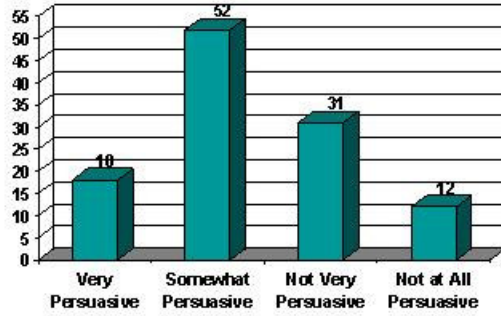




Get a better handle on your medical records.

In today's busy world, who has time to collate and organize all your medical information and keep it accurate and up to date? You do. Now you can do all that and more thanks to online medical information. You have secure and easy access on the World Wide

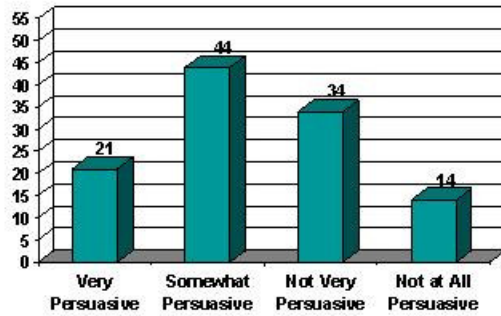
Web that makes controlling and organizing your family's health care much simpler. You're able to check the data for accuracy and completeness. And, in the event of a medical emergency, you can get hold of it from anywhere around the world at anytime, night or day.



Whose medical information is it anyway?

Your medical information is the most sensitive and personal information there is. That's why you want more control of it. With online medical information, you have secure and easy access to that information on the World Wide Web. It makes controlling and

organizing your family's health care much simpler. You're able to check the data for accuracy and completeness. And, in the event of a medical emergency, you can get hold of it from anywhere around the world at anytime, night or day.

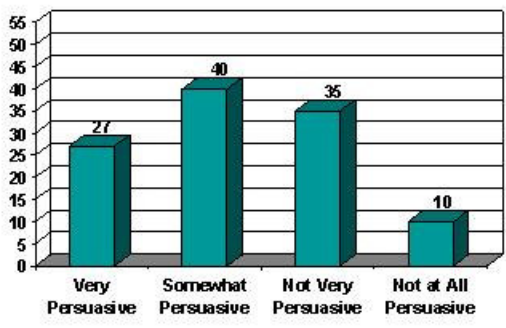


“ So much about today’s health care makes me feel powerless. Online medical records put me back in control. ”

Joanne Tibbels
Houston, TX

My medical information is the most sensitive and personal information there is. That’s why I want more access to it and more control of it. With online medical information I have secure and easy access via the World Wide Web. It really helps me keep track of things and it makes my family’s health care much simpler to organize. I’m able to check the data for accuracy and completeness. And, in the event of a medical emergency, I can get hold of it from anywhere around the world at anytime, night or day.



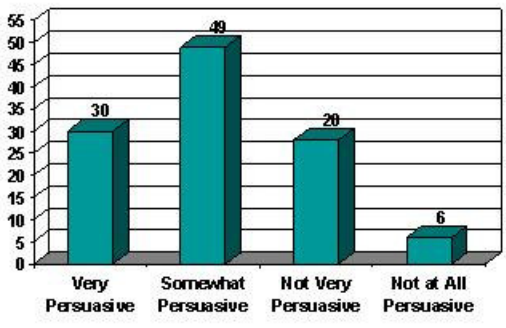




“ Anybody can make a mistake. I’d like to double-check what’s in my medical records. ”

George Flemer
San Diego, CA

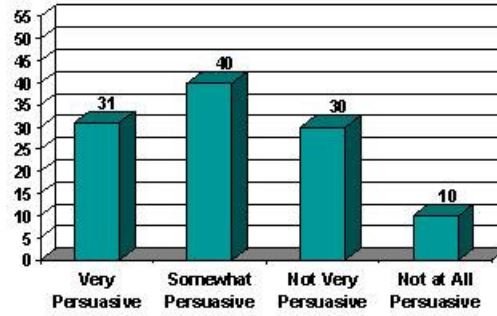
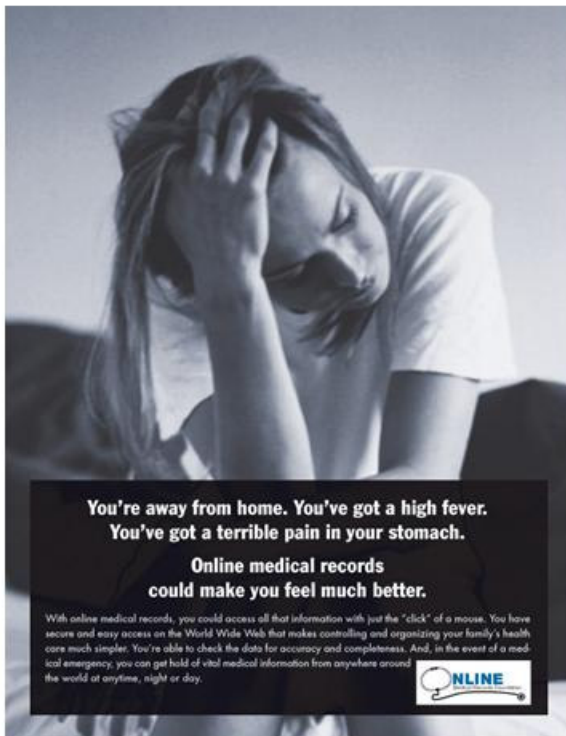
My medical information used to be scattered among many different doctors’ offices, clinics and hospitals. It’s so much better to have everything together in one place, where it’s accessible to me. That’s why online medical records are such a great idea. I really like that I can go online and check that the medical information in my life is accurate and up to date.

“I can access my bank account online, why not my medical records?”

Charles Foley
Springfield, MA


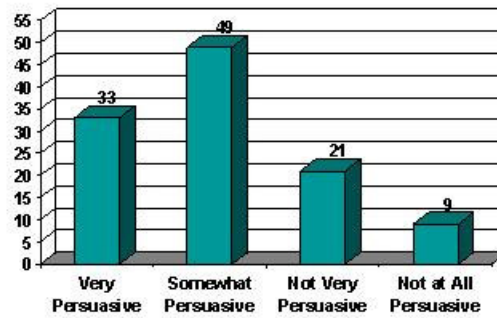
I like being able to take charge of my life. Online medical records are another way that I'm able to do that. I pay all my bills online. I bank online. And now, I can keep track of all my vital health care information online too.

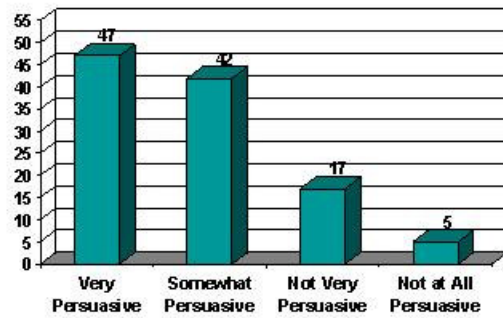
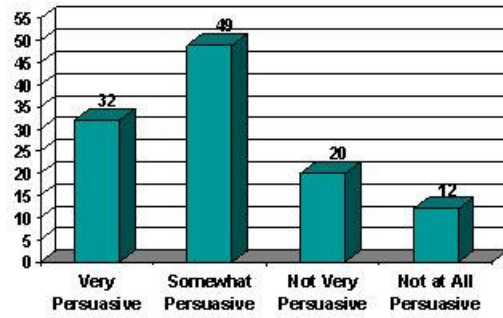
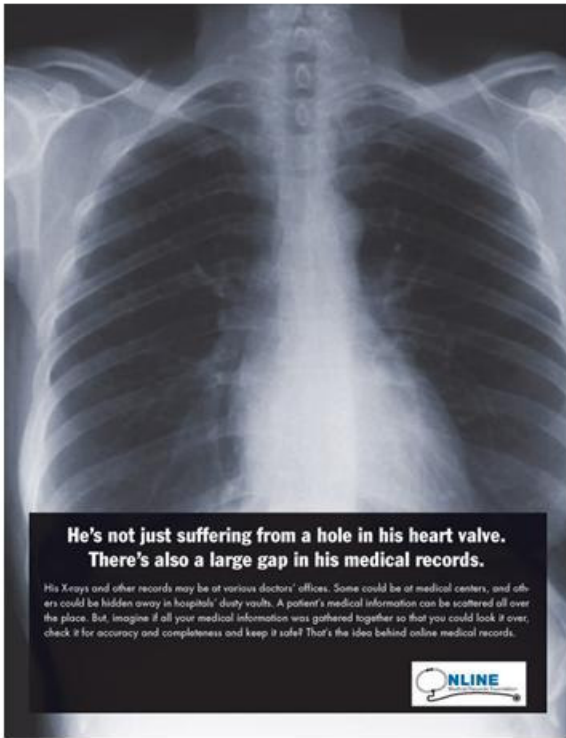




You're away from home. You've got a high fever. You've got a terrible pain in your stomach.

Online medical records could make you feel much better.

With online medical records, you could access all that information with just the "click" of a mouse. You have secure and easy access on the World Wide Web that makes controlling and organizing your family's health care much simpler. You're able to check the data for accuracy and completeness. And, in the event of a medical emergency, you can get hold of vital medical information from anywhere around the world at anytime, night or day.



CONNECTING FOR HEALTHSM
MARKLE FOUNDATION *A Public-Private Collaborative*

Connecting for Health is an unprecedented collaborative of over 100 public and private stakeholders designed to address the barriers to electronic connectivity in healthcare. It is operated by the Markle Foundation and receives additional support from The Robert Wood Johnson Foundation. Connecting for Health is committed to accelerating actions on a national basis to tackle the technical, financial and policy challenges of bringing healthcare into the information age. Connecting for Health has demonstrated that blending together the knowledge and experience of the public and private sectors can provide a formula for progress, not paralysis. Early in its inception, Connecting for Health convened a remarkable group of government, industry and healthcare leaders that led the national debate on electronic clinical data standards. The group drove consensus on the adoption of an initial set of standards, developed case studies on privacy and security and helped define the electronic personal health record.

For more information, see www.connectingforhealth.org.