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CONNECTING AMERICANS TO THEIR HEALTHCARE

Executive Summary

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

July 2004

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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:

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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 <u>means</u> 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 <u>incremental steps</u> 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:

    o Common means of correctly identifying each person and ensuring privacy protections.
    o Common data sets, common secure data exchange standards, and common data coding vocabularies.
    o 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:
    o 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.
    o 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.

o 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.

o 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.

o The sharing of PHR information between patients and clinicians should generate time-stamped, source-stamped transactions that are traceable in audit trails.

o 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.

o 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.

o 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 <u>structured data</u> 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 <u>set of common data fields</u>. (In other words, what will PHRs and EHRs talk **about**?)

  2. Establishing a secure <u>protocol for electronic information exchange</u>. (**How** will the PHR and EHR talk?)

  3. Establishing common <u>clinical vocabularies</u>. (**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 <u>for the core health information repository functions of the PHR</u>, 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 <u>should be the default set of fields that any PHR developer should always try first to use to drive any of its functions</u>. 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.

- <u>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</u>**.** Critical criteria for any such common data set should be:

  - o Acceptance by the medical community and consumers.
  - o An HL7-compliant platform for secure data transfers.
  - o 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. <u>This underscores the importance of simplicity in language and user interface in the PHR</u>. 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 <u>only</u> 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 <u>subset</u> 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:

o Email my doctor	75 percent
o Track immunizations	69 percent
o Note mistakes in my record	69 percent
o Transfer information to new doctors	65 percent
o 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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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.