

Roundtable Summary Report

Personal Health Records and Electronic Health Records: Navigating the Intersections

Sponsored by:

*The Agency for Healthcare Research and Quality • American Medical Informatics Association
• Kaiser Permanente Institute for Health Policy • The Robert Wood Johnson Foundation*

I. Introduction

On September 28 and 29, 2006 public and private sector professionals convened to discuss ways to better integrate personal health records and electronic health (medical) communications and records. The roundtable had three goals:

- Identify the transformative potential of integrated Personal Health Records (PHRs)
- Identify barriers to realizing this potential
- Identify a framework for action to move integrated PHRs closer to the health care mainstream

The format of the roundtable included facilitated large discussion and small group breakout sessions. This report summarizes the discussion and suggested action steps from the roundtable.

II. Background

PHRs are consumer-centric tools that, ideally, engage consumers in managing their own health and healthcare through an integrated and comprehensive view of their health information, including medical history, medications, immunizations, allergies and other personal health information. PHRs can offer

useful tools and services to make personal health information meaningful and actionable for consumers. Some PHRs are paper-based, some computer-based, some stand-alone, and some highly integrated into the information and communication systems of the care provider. If they are to reap their transformative potential, PHRs must at least be capable of electronic data exchange with the disparate sources of relevant health information. Integrated PHRs are electronic records that are capable of communications, data exchange, and full integration with health care information systems (i.e., provider-based electronic health records and other relevant sources of personal health information). Whether the full potential of integrated PHRs can be realized, however, is uncertain in view of significant technology hurdles, as well as a number of organizational, cultural and policy challenges. The group agreed that the potential of integrated PHRs for improving health and healthcare is sufficiently important to take on these challenges.

III. Identifying the Transformative Potential of Integrated PHRs

Transformative health technologies are innovations that fundamentally change care, including self-care,

and health care delivery in ways that add substantial value to individuals and society. Participants explored the transformative potential that can be realized when PHRs allow iterative communications between patients and providers as well as exporting data to and importing data from other information systems. Discussion identified the following potential benefits of integrated PHRs:

Transformation of Care Processes

- Provide stakeholders (e.g., patients, providers, and other informal caregivers) with tools for interactive communication and decision-making
- Enable communication between stakeholders, which can support innovations in care management, including self-care
- Foster health knowledge promotion and lifestyle modification
- Enable comprehensive care that is ‘virtually’ accessible, continually available, and patient-centered, which includes the concepts of a “medical home” and “health care team”
- Support and disseminate “best practices” in both clinical care and self care

Interactive Communication

- Permit asynchronous communication between patients and providers
- Improve the availability of patient information at the point of care
- Improve the continuity of care with communication beyond physical encounters through common access to test results and shared tracking
- Facilitate accessible, accurate, and cost-effective communication of data to authorized stakeholders (e.g., public health, research, performance measurement and reporting entities)

Information Transformation

- Improve the accuracy and completeness of health information
- Support the delivery of personalized, patient-centric/interest-specific information
- Shift the control of health information from providers to patients or to a more “shared control” model

- Increase the portability of health information, such that consumers have access to relevant sources of content from a single interface accessible anywhere, anytime
- Serve as a potential source of outcomes and other data for health system performance measurement, monitoring, and reporting

Consumer Activation

- Shift the health and health care locus of control to a consumer orientation
- Empower consumers to “own” and jointly manage their health information
- Translate clinical data into consumer-friendly health information

Convenience & Efficiency

- Reduce redundant transactions and tests by sharing patient and administrative information among otherwise closed health care systems
- Promote more efficient use of time and facilitate substitution of online consultation for in-person visits
- Enable home monitoring to remotely record patient data
- Reduce the time practitioners spend gathering patient history
- With patient permission, allow approved informal caregivers or geographically distant family members to track a loved one’s care and health status

IV. Barriers to Realizing the Full Potential of Integrated PHRs

Roundtable participants engaged in discussion about the factors that impede integrated PHR adoption and the challenges to realizing their full potential. The discussion focused on four major themes:

Changing Health System Roles and Responsibilities

- Concerns (real and perceived) about liability risk
- Predominance of and reliance on ‘limited’ proprietary systems
- Presence of an adverse incentive system - absence

- of incentives/presence of disincentives
- Absence of appropriate reimbursement system
- Perceptions of adverse effects for stakeholders, including increased workload
- Concerns about staff training/regulations about scope of work
- Concerns about patient inertia, e.g. focus on existing model of care with limited acceptance of PHR approach
- Concerns about provider inertia

Creating a Common Framework

- Limited investments to support an infrastructure
- Presence of conflicting motivations among stakeholders
- Absence of organizational process standards
- Absence of agreement on relevant standards
- Gaps in technical standards and lexicon
- Limitations of the health information system architecture

Building Trust and Confidence in the System

- Concerns about privacy and security
- Concerns about secondary uses of information and second-order users
- Fears about new electronic systems (both technophobia and limitation of skills)
- Absence of policies to increase the transparency and accountability of data use
- Absence of privacy/security control mechanisms, e.g., policies, procedures, and/or system capabilities
- Absence of consumers in the role of PHR designers and evaluators

Uncertain Market Demand

- Absence of information about whether there is adequate patient knowledge as well as demand for the integrated PHR or its applications
- Absence of information about whether there is adequate knowledge as well as demand by other stakeholders
- Absence of information about whether there is adequate value for each stakeholder
- Concerns about who should pay and how much they should pay
- Concerns about the distribution of payoffs, its equity and desirability

- Absence of aligned incentives in the majority of the US, given fragmented delivery system
- Concerns about strong incentives for some stakeholders to develop proprietary systems with limited functionalities
- Absence of information about the sustainability of the value of integrated PHRs
- Concerns about the need for a critical mass of data sources and level of integration
- Absence of information on how workforce and work processes will change

V. Primary Findings

The primary findings that emerged from the roundtable discussions are summarized as follows:

Definition of an Integrated PHR

The roundtable participants did not attempt to create a consensus definition of an integrated PHR. They did, however, identify a number of features and functions that point toward a rough 'working model' for the Integrated PHR:

- Maintains a comprehensive, accurate, privacy-protected, multi-sourced record about an individual's health
- Provides endorsed, understandable knowledge, advice, and health status data for an individual to act upon
- Promotes access and portability of personal health information
- Facilitates a personalized experience, promotes health and wellness, and supports the health care of an individual
- Facilitates asynchronous communication between a patient, authorized stakeholders (e.g., family members, other informal care givers) and the health professional(s) who are providing care services
- Allows individuals to see much, if not most, of the information that health professionals have and use to support the patient's care
- Allows the patient to add personal health information to the provider's formal EHR and to 'flag' potential error(s)
- Accumulates a 'longitudinal' electronic health record that incorporates a 'memory' of essential

- communications among all involved parties
- Allows individuals to create a unique health identifier for purposes of more efficient and safe authentication
 - Allows the patient, should they so choose, to be contacted for possible participation in IRB approved biomedical or social research projects.

Need for additional research and continued development: While there has been a welcome expansion of research on the use of PHRs and PHR systems, there are key areas of evaluation and development that deserve attention. For example, targets of additional research and development include:

- Identifying and understanding the applications and devices that hold the greatest transformative potential
- Evaluating models of care delivery that are integrated with PHRs and PHR systems
- Continuing to develop integrated PHRs as a promising model for health communications and care.

The transformative potential is realized through functionality: The data within an electronic PHR record alone is not sufficient to realize improvements that can be considered transformative. Significant value will be realized only when PHRs incorporate systems, tools, and other resources that leverage the data in the record and engage consumers to play a more active role in their health and health care. PHR system functionality can activate consumers by transforming clinical measurements and observations into meaningful and actionable information. Some of these functionalities exist today; other applications are yet to be developed. Meanwhile, the market is waiting for PHR functionality that can deliver the compelling value of a “killer” application.

VI. Steps Towards Realizing the Full Potential of Integrated PHRs

After exploring the opportunities and challenges in realizing the full potential of integrated PHRs, participants identified potential directions for action. While consensus was not a goal, some common themes did emerge from the discussion. Participants offered the following suggestions for next steps:

1. The American Medical Informatics Association’s (AMIA) “Got EHR?” Initiative and other groups should promote industry standards for integrated PHR data portability and integrated PHR standards of practice. For example:
 - Standards & mechanisms must be developed to integrate PHRs fully into EMR systems to support care (e.g., portals, etc.).
 - Standard policies and procedures must be developed for data management and exchange.
 - A common set of utilities must be developed to assure that items a. and b. function appropriately.
2. Encourage national entities that broadly promote EHRs to explicitly address integrated PHRs.

The American Health Information Community (AHIC), the National Committee on Vital and Health Statistics (NCVHS), the Certification Commission for Healthcare Information Technology (CCHIT), and any other relevant agencies or regulatory bodies dealing with electronic health records should acknowledge that integrated Personal Health Records are an integral component of health care communications and record-keeping by including appropriate policy, standards, demonstration projects, educational, and training as well as research efforts into their work agendas. And while several of these organizations are currently addressing PHR related issues, moving toward a higher level of interconnectivity should be earmarked as a priority.

Work plans of these entities should reflect this dimension in 2007 at the latest.

data security & privacy, lifelong care education and management, etc.

3. Make the development of standards for PHR certification a priority.

CCHIT should begin to certify security and confidentiality standards for integrated PHRs as soon as possible and should certify integrated PHR/EHR systems by 2012. This effort can build on minimum standards development underway relating to data elements and a platform of basic functions.

4. Develop and disseminate a compendium that highlights standards of practices in PHR deployment, administration, and use.

Issues addressed in the compendium might include:

- Authentication policies and procedures
- Email response time for patient messages
- Communication policies regarding abnormal lab results
- Longitudinal record modeling
- Informed consent and perspectives on consumer rights
- Work in this area may build on the American Medical Informatics Association (AMIA) "Guidelines for the use of Clinic-Patient Electronic Mail" and should complement the efforts of the Markle Foundation's Connecting for Health initiative.

5. The Markel Foundation's Connecting for Health PHR Initiative or the Robert Wood Johnson Foundation should be urged to conduct an in-depth survey assessment of:

- Consumers regarding their views of the value of integrated PHRs, including desired PHR functionalities
- A sufficiently large sample of those patients who now get care through the use of integrated PHRs to compare their views/perceptions of value, issues relating to authentication, management of chronic illness, potential lifestyle changes, views relating to

6. The AMIA "Got EHR?" Initiative should seek to analyze the effectiveness of PHRs through a systematic review of business cases and clinical use cases.

7. The AMIA "Got EHR?" Initiative should work with stakeholders to encourage vendors to support integrated PHRs by:

- Including PHR functionality in their products by 2008
- Agreeing upon common PHR standards for electronic data importation and exportation and other core functionality by 2012.

8. The AMIA "Got EHR?" Initiative should encourage the eHealth Initiative and the Agency for Healthcare Research and Quality (AHRQ) to persuade RHIO initiatives to include PHR integration into their planning and development efforts.


RHIOs are a potential enabler of integrated PHRs because of their ability to serve as a focal point for authentication, authorization and data exchange among PHR and EHR stakeholders.

9. The Markel Foundation's Connecting for Health PHR Initiative should conduct an analysis of liability issues and other legal barriers that integrated PHRs confront.

This analysis can support the development of principles of responsibility for integrated PHR stakeholders.

10. Encourage the NCVHS to develop a critical research agenda for integrated PHRs.

The research agenda should identify future desired functionalities for integrated PHRs including studies that carefully solicit future functionalities from the perspectives of patients, special populations, payers, providers, regulators, patient advocacy groups, etc.



The agenda should be used to inform publicly funded research agencies and research funding agencies such as the National Institutes of Health, the Centers for Medicare and Medicaid services, the Office of the National Coordinator for Health Information Technology, and the AHRQ. This research agenda should also be shared with similar advisory groups of other nations.

11. Develop a research and educational agenda to address the needs of special populations including rural, minority, central city poor, physically handicapped, and non-English speaking citizens.
12. Identify opportunities to include quality improvement measurement in integrated PHR use.
13. Conduct a human factors assessment of integrated PHR use.
14. Explore informed consent use with integrated PHR as a process for individuals to authorize the exchange of personal health information for various purposes (e.g., health care, public health, research).

VII. Roundtable Participants

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VIII. Endnotes

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