Personal Health Records: An Overview
First in a 3-part Series

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Functions, Architecture, Emerging Issues

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Retrieving Your Health Information

- Hospital X
- Pharmacy Q
- Pharmacy R
- Laboratory
- Hospital Y
- School Nurse
- Payer Data Center (health plan, Medicare)
- Primary Care Doctor
- Specialist Doctor
- Home Monitoring Device
Being Your Own Information Hub

- Hospital X
- Pharmacy Q
- Pharmacy R
- Hospital Y
- Pharmacy Data Hub
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- Payer Data Center (health plan, Medicare)
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National Landscape - 2008

- President’s 10-year commitment (2014?)
- HHS: American Health Information Community – Consumer Empowerment “Breakthrough”
- Congress – Carper, Porter bills for federal employees; Brownback Health Record Banks
- AHIP and BCBS – 100 million Americans
- Global internet companies – Microsoft, Google, Intuit …
- Major employers – IBM, PepsiCo, Wal-Mart, Dossia
- Major providers – VA, Kaiser, Partners
- Consumer organizations – AARP, American Heart…
PHR Services Today

• Patient education, self-care content and consensus guidelines
• Secure messaging
• Appointment scheduling and reminders
• Preventive service reminders
• Adherence messaging
• Patient diaries (pain, symptoms, side effects)
• Longitudinal health tracking tools (charts, graphs)
• Drug interactions checking
• Financial information, such as Explanation of Benefits
• Rx refills
There is strong interest among consumers in using health information technology to more fully participate in their own health care.

<table>
<thead>
<tr>
<th>Statement</th>
<th>% Yes</th>
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<tbody>
<tr>
<td>Check for mistakes in your medical record.</td>
<td>69%</td>
</tr>
<tr>
<td>Check and fill prescriptions.</td>
<td>68%</td>
</tr>
<tr>
<td>Get results over the Internet.</td>
<td>58%</td>
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<tr>
<td>Conduct secure and private email communication with your doctor or doctors.</td>
<td>57%</td>
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Now let's imagine that a new secure online service was made available to you allowing you to locate your medical records and view them through your own secure online "personal health record" account. Now I am going to read you some things this secure online "personal health record" service would allow you to do after I read each item, please tell me, yes or no, whether or not you would use this secure online "personal health record" service for each activity.

Despite these high levels of support for health information technology, keeping electronic medical information private and secure remain chief consumer concerns.

<table>
<thead>
<tr>
<th>Statement</th>
<th>% Absolute Top Priority</th>
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<tr>
<td>The identity of anyone using the system would be carefully confirmed to prevent any unauthorized access or any cases of mistaken identity.</td>
<td>91%</td>
</tr>
<tr>
<td>An individual would be able to review who has had access to their personal health information.</td>
<td>81%</td>
</tr>
<tr>
<td>Only with an individual’s permission could their medical information be shared through this network.</td>
<td>79%</td>
</tr>
<tr>
<td>Employers would NOT have access to the secure health information exchange networks.</td>
<td>68%</td>
</tr>
</tbody>
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I am going to read you different attributes that could be part of this exchange or network and I would like you to rate the importance of each. As you respond, please keep in mind that not every attribute can be a top priority.

The Many Flavors of PHR – c. 2008

1. Institutional/IDN provider portal (e.g., Epic)
2. Individual provider portal (e.g., Medem)
3. Untethered – USB, desktop, PDA (e.g., CapMed)
4. Populated from claims data (e.g., Aetna)
5. Population oriented (e.g., LifeLedger)
6. Condition oriented (e.g., PeopleLikeMe)
7. Service oriented (e.g., MyPyramidTracker)
8. And… health 2.0 sites (e.g., SophiasGarden)
What Do We Know About Adoption and Use?

- Provider portals reach 15-50% of patients to whom offered
  - Computer skilled
  - High users (visits, meds)
- Most other approaches with small uptake, except incentivized (e.g., IBM - $150)
- Transactions heavily used
- Specialized products seem to have more user interest
People Vary in their Preference for PHR media

As of 3/07, 29% of seniors reported regular use of the Internet. (65% of people age 50-64)

Business data streams of Millie’s information

What about me?

Sources of information about Millie

Millie

Millie’s Apps
Consumer data streams of Millie’s information

Personal Health Data Requested

Millie Using PHR → Consumer Access Services → Health Data Source

Personal Health Data Received
Consumer data streams

Personal Health Data Requested

- Consumer Using PHR
- Consumer Access Services
- Consumer Using a Different PHR
- Health Data Source
- Health Data Source

Personal Health Data Received
Consumer data streams

- Millie’s Apps
- Mobile Phone
- Blood Pressure Device

Millie Using PHR

Employer Sponsored

Hospital System (Aggregator)

- Doctor’s Office
- Hospital
- Health Plan
- Retail Pharmacy
- PBM

Consumer Access Services

- Consumer Using a Different PHR

Claims Warehouse (Aggregator)

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Creating a networked PHR environment that achieves sustainable consumer confidence
Individual Consumers Will Need Mediating Bodies to Facilitate their Access to the Network

Functions:

• Distribute services to populations of consumers.

• Issue individuals’ identity credentials and “vouch” for them as network users.

• Help consumers access and aggregate their personal health data and connect with various services.

• Assure that network-wide policies (e.g., privacy and information practices) are followed.
Potential Sponsors of Consumer Access Services

- Affinity groups (e.g., AARP, labor unions)
- “Retail” PHR providers (e.g., WebMD, Intuit, Medem)
- Consumer portals (e.g., Google, Yahoo)
- Data clearinghouses (e.g., SureScripts)
- Retail pharmacies (e.g., Walgreens, Wal-Mart)
- Health plans (e.g., AHIP, BCBS)
- Provider organizations (e.g., VA, Kaiser Permanente)
Keys to Success?

- Defining a Consumer Access Service that is trusted by consumers
- Defining a Consumer Access Service that is trusted by other participants on the network
- Determining minimum necessary privacy and security policies and practices
Needed Policy Framework for Consumer Access Service

- Does HIPAA address privacy and security concerns?
- Authentication
- Authorization
- Consent and notification
- Consumer control of information sharing, including audit
- Rules for secondary use, data mining
- Annotating and editing data
- Data management systems
- Governance, transparency, remedies
Big Questions – 2008

• Will Consumer Access Services succeed?
• Will common information practices create a trustworthy environment?
• Will data holders release data to the new intermediaries – or become aggregators themselves?
• Will high-value consumer applications emerge?
• Which business models will emerge?
Patient Controlled Health Records: National, Regional, and Local Update

Presenter:
John D. Halamka
Beth Israel Deaconess Medical Center
Themes

- National Perspective from HITSP
- New Vendor products
- BIDMC's Patientsite
HITSP and the PHR

• What standards were chosen?
• What is the impact on architecture?
• What are the next steps?
**CCD:** collection of templates that represent the core content for healthcare summary documents

**CDA:** foundation standard enabling the definition of templates for a broad range of healthcare documents
New Vendor Products

• Dossia/Indivo
• Google
• HealthVault
PatientSite

- Patientsite over the past 5 years
- 2.5 million transactions and 40,000 monthly patient users
- All the worries about provider and patient information overload have not occurred
Patient Access to Record

• What should they see?
• When should they see it?
• Who else should have access?
• How should we present it?
Personal Health Record

• Patient-entered and maintained
• Data types:
  – Text
  – Numeric data
  – Documents and other objects
Educational Partners

• PreOp – Patient Education
• UpToDate – Provider Edition
• UpToDate – Patient Edition
• Medical Dictionary
• Multum – medication information database
• Lab Test Online
Messaging Volume

- Clinical messages: 27.8*
- Prescription renewals: 3.1*
- Referrals: 2.1*
- Appointment requests: 2.6*

*monthly volume per 100 patients
Patients

- 57% female
- Median age ~43
- 4% over 70 years old
Patient Drivers

• Secure Messaging with Provider
• Access to Medical Records
• Convenience
  – Request Appointments
  – Medication Refills
  – Referrals to Specialists
  – Review Bills Online
• Education
  – Disease specific content by experts at CareGroup
  – Links to medication information
  – Personalized drug interaction information
Summary

• The ideal PHR prepopulates data from hospitals, clinics, payers, labs, and pharmacies

• HITSP will help catalyze PHR interoperability among stakeholders

• New vendor products will enable patients to be stewards of their own data