Connecting Americans to Their Health Care:
Empowered Consumers, Personal Health Records and Emerging Technologies

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Connecting Americans to Their Health Care:
Empowered Consumers, Personal Health Records
and Emerging Technologies

2006

PHRs 101
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Purpose of today’s PHR 101 session

- Provide basic understanding of PHRs
- Assess the current landscape
- Understand key stakeholders
- Discuss key barriers
- Explore possible solutions and the future
Examples of consumer-based transformation

• Communications
  – Email, internet calls, cell phones
• Search
  – Google, Yahoo!
• Content
  – Wikipedia, YouTube
• E-commerce
  – Books, travel, real estate, eBay, Craigslist, etc.
• Personal finance
  – Quicken, Online banking
• Entertainment
  – iPod
Consumers can’t leverage power of health care networks

- Changes in other sectors rely on a fresh openness toward consumer access to — and contribution of — information
- Yet, health care today is not “networked”
- Consumers go through the “system” one data silo at a time
- And much of the important information remains on paper or in the consumer’s head

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Retrieving your health information

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

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The person as an information hub

Personal Health Record

Hospital X

Pharmacy Q

Pharmacy R

Hospital System Data Hub

Hospital Y

Pharmacy Data Hub

Laboratory

Primary Care Doctor

Specialist Doctor

School Nurse

Payer Data Center (health plan, Medicare)

Home Monitoring Device

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What are personal health records?

- PHRs enable people to **collect, view, manage, or share** copies of their health information or health-related transactions electronically.

- PHRs facilitate an individual’s ability to track personal health information and services through an application that the individual (or a designee) controls.

- Over 100 such applications on the market.
PHRs are not EHRs

- Electronic health records are tools for *health professionals*:
  - Designed to improve upon the paper “chart”
  - Clinicians have a legal and professional obligation to maintain patient records

- Personal health records are tools for *consumers*:
  - Consumers have no similar legal obligation to maintain their health information
  - PHRs do not replace EHRs or paper charts
  - PHRs may include copies of data from EHRs

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Common functions of PHRs

- Patient education, self-care content, 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
- Rx refills
- Financial information, such as Explanation of Benefits

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Conduct secure and private email communication with your doctor or doctors.

<table>
<thead>
<tr>
<th>Services Tested</th>
<th>% Yes</th>
</tr>
</thead>
<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>
</tr>
<tr>
<td>Conduct secure and private email communication with your doctor or doctors.</td>
<td>57%</td>
</tr>
<tr>
<td>19% Would not use the service for any of these items.</td>
<td></td>
</tr>
</tbody>
</table>

“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.”

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Now, overall, would you favor or oppose the creation of this type of secure online "personal health record" service?

**Majority of Americans favor concept of PHR service**

- **Total Favor**: 60%
- **Total Oppose**: 37%

- **Strongly Favor**: 29%
- **Somewhat Favor**: 31%
- **Somewhat Oppose**: 13%
- **Strongly Oppose**: 24%
- **Don't Know**: 3%

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You have three seconds to remember every doctor you’ve ever seen, every procedure you’ve ever undergone and every medicine you’ve ever taken.

You could do just that if your medical history was all together, safe and sound and in one place. That’s why online medical records are such a great idea. They mean you can get to your medical information instantly. That could be a real life saver in the event of an accident or sudden illness.
Potential of personal health records

• Giving individuals access to and control over their personal health information enables:
  – More reliable care, e.g., in emergency situations
  – Patients better able to maintain health and manage their care
  – Greater efficiency, less duplication of tests and quicker access
  – Improved health care quality and safety
  – More effective communication and collaboration between patients, doctors, pharmacies, and others
  – Opportunities for new service delivery models
Public concerns about PHRss

- Security of the data system
- Keeping data private
- Keeping data accurate and current
- Controlling and monitoring PHR access
- Business motives of sponsor
The identity of anyone using the system would be carefully confirmed to prevent any unauthorized access or any cases of mistaken identity.  

An individual would be able to review who has had access to their personal health information.  

Only with an individual’s permission could their medical information be shared through this network.

<table>
<thead>
<tr>
<th>Attribute Statement</th>
<th>% Absolute Top/High Priority</th>
</tr>
</thead>
<tbody>
<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>
</tbody>
</table>

“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.”

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Attributes of an ideal PHR

1. Controlled by the individual
2. Contain information from one’s entire lifetime
3. Contain information from all health care providers
4. Are accessible from any place at any time
5. Are private and secure
6. Are transparent
   • Individuals can see who entered each piece of data, where it was transferred from, and who has viewed it
7. Permit easy exchange of information across health care systems

URL: http://www.connectingforhealth.org/resources/final_phwg_report1.pdf
Consumer and patient principles endorsements

- AARP
- ACOR – Association of Cancer Online Resources
- AFL-CIO
- American Hospice Foundation
- Center for Medical Consumers
- Consumers Union
- Families USA
- Health Privacy Project
- International Association of Machinists and Aerospace Workers
- Maternity Center Association
- National Coalition for Cancer Survivorship
- National Consumers League
- National Partnership for Women and Families
- SEIU – Service Employees International Union

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Consumer- and patient-focused principles

1. Individuals should be guaranteed access to their own health information

2. Individuals should be able to access their personally identifiable health information conveniently and affordably

3. Individuals should know how their personally identifiable health information may be used and who has access to it

Markle Foundation. Personal Health Technology Council letter to Secretary Leavitt, March 6, 2006.
URL: http://www.connectingforhealth.org/resources/AHIC_Principles_PHTC_Letter.pdf
4. Individuals should have control over whether and how their personally identifiable health information is shared

5. Systems for health information exchange must protect the integrity, security, and confidentiality of an individual’s information

6. The governance and administration of health information exchange networks should be transparent and publicly accountable
New Connecting for Health survey

• Results will be released tomorrow
Six ‘dimensions’ by which to study PHRs

- **Population** - Who are the targeted users?
- **Integration** - What systems are connected?
- **Data** - What information is stored?
- **Platform** - What type of application is offered?
- **Sponsors** - Who is promoting the application to end users?
- **Business** - What is the financial model or value proposition?
Who are the targeted users?

General population

Selected populations

- By health plan
- By provider system
- By condition
- By age group
What systems are connected?

System Integration

Not integrated with other health information systems
- E.g., self-report data, or monitoring device data

Integrated with other health information systems
- E.g., EHR, pharmacy, disease management, etc.
What information is stored?

Data Integration

- **Consumer-sourced**
  - E.g., patient’s symptom diary

- **Professional-sourced**
  - E.g., EHR data, doctor’s notes, labs, prescriptions

- **Device sourced**
  - E.g., blood glucose monitor

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What type of application?

Application Platform

Web-based
- E.g., WebMD, patient portals, etc.

Device-based
- E.g., USB key, smart card, cell phone, chip implant, etc.

PC-based
- E.g., Intuit, personal spreadsheet, etc.
Heterogeneous preferences for PHR platform

- **Age 18-44**
- **Age 45-64**
- **Age 65+**

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Who is promoting the application to end users?

Possible sponsors:

- Employers
- Integrated delivery system
- Small practice doctors
- Dot-coms
- Regional Health Information Orgs
- Insurance Plans
- Affinity groups
- Pharmacies or PBMs
- Disease management or device companies
- Search engines

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What is the financial model or value proposition?

Business model or value proposition

Direct revenue (vendor)
- License fees
- User fees
- Ads

Indirect value (sponsor)
- Loyalty
- Efficiency
- Aggregate data
- Behavior & Outcomes

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Categories not mutually exclusive

- Many existing models are blended
- For example, a PHR can have all three types of data sources or have several different business objectives
Type 1: Integrated with EHR

- **Population** - Patients of a practice or health system
- **Integration** - Direct “tether” to EHR
- **Data** - Mostly read-only from EHR
- **Platform** - Web portals
- **Sponsors** - Physicians, health systems, possibly RHIOs
- **Business value** - Loyalty, marketing, service, messaging, behavior, process efficiency
PHR vs. EHR

- Tool for patient
- Data source for EMR

- Tool for clinician
- Data source for PHR

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Mail:
- Secure
- Automated routing
- Task assignment

Services:
- Prescription refills
- Appointment requests
- Referrals
- View bill

Records:
- Secure
- All CG records
- Upcoming appointments
- Meds/Problems/Results...
- Personal records

Education:
- Info prescriptions
- Patient selected links
- Predefined collections
- Videos

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Type 2: Integrated with other health information systems

- **Population** - Members of health care services

- **Integration** - Direct “tether” to a specific service or database

- **Data** - Mostly read-only from specific database, e.g., pharmacy data, claims data

- **Platform** - Web portals

- **Sponsors** - Payers, employers, pharmacy services, software companies, not-for-profits

- **Business value** - Aggregate data, messaging, behavior change, outcomes, impact utilization, process efficiency
Data strategy: Low-hanging fruit

- Claims data: medications
- Claims data: diagnoses
- Home monitor interfaces
- Immunization registries
- Pharmacies?
- Commercial labs?
Issues with claims data

- Medications (see MedsInfo-ED experience)
  - Limited history duration
  - No instructions
  - No self-pay
  - No OTCs
  - May require filtering due to legal restrictions
- Diagnoses
  - May not reflect reality
  - May not have secondary diagnoses
  - May require filtering due to legal restrictions
- Tests
  - No results
Claims data is not perfect...

But it can prime the pump
Type 3: Independent

- **Population** - General population or specific segments, e.g., diabetes

- **Integration** - Generally little integration with health care entities

- **Data** - Mostly consumer self-reported

- **Platform** - Web portals, devices, PC-based

- **Sponsors** - Software companies, not-for-profits, affinity groups

- **Business value** - User fees, license fees, advertisements, messaging, behavior change

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Accelerators of PHR trend

- Internet, digital lifestyle increases information demand
  - E.g., DTC ads, online banking, “Googling,” iPods, wi-fi
- Demographics
  - “Baby Boomers”
  - Chronic diseases
  - “Sandwich Generation” (particularly females)
- Competitive pressures
  - Most big EHR vendors now have a PHR portal product
  - Many health care institutions, payers, and employers now offer PHRs
- Market forces
  - “Consumer driven” plan designs
Consumer demand limitations and barriers

- Privacy concerns — access by government, plans, employers, marketers, identify thieves, etc.
- Small, diffuse populations with highly specific needs
- Low literacy, poor access to technology, lack of experience with health decision-making
- Limited portability or integration
- Limited patient “control”
- Low awareness and lack of a trusted, transcendent national “brand”
- Low level of public trust in health information services not connected to personal physician.
Hypertension

High blood pressure

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Facilitating Patient Understanding

Reference Libraries

Context-sensitive hyperlinks and help

The patient’s hypertension is poorly controlled...

The patient’s high blood pressure is poorly controlled...

Hypertension is another name for High blood pressure...

Automatic Translation (appropriate to patient literacy)

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Health professional barriers to PHR trend

- Limited number of EHRs with which to connect
- Lack of reimbursement for:
  - Adopting health IT in general
  - For supplying PHR data
  - For incorporating PHR data into practice.
- Workflow concerns
- Liability concerns
- Paternalism and preference for ‘passive’ patients

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Major barriers to consumer health IT in general

- Revenue sustainability still not established
- Data sharing not rewarded
- Inability to locate patient information across multiple care settings.
- Authenticating each individual
- No standards for patient-contributed info.
- Health information is complex
- Lack of an iconic brand or market winner
Major new initiatives

• Healthcare providers
  – Delivery systems
  – Pharmacies and “retail” services

• Health insurers
  – Individual health plans
  – AHIP/BCBSA

• Government
  – National use cases, AHIC
  – CMS
  – VA
  – Congress
Major new initiatives

• Regional initiatives & RHIOs
• Employers
  – Intel-led coalition
  – Other major employers (IBM, American Airlines, etc.)
• New entrants?
  – Software companies
  – Consumer organizations
AHIC “Breakthroughs”

- Consumer empowerment (medication list and ‘clipboard’)
- Biosurveillance (data to identify disease outbreaks, bioterror)
- Electronic health records (lab results)
- Chronic care coordination (messaging)
- Quality
- Privacy, security, confidentiality
- Personalized medicine

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### Medication Summary

<table>
<thead>
<tr>
<th>Date</th>
<th>Medication</th>
<th>Dosage</th>
<th>Instructions</th>
<th>Provider</th>
<th>Refill</th>
</tr>
</thead>
<tbody>
<tr>
<td>02/22/2000</td>
<td>Folic Acid 1 mg PO</td>
<td></td>
<td>One tablet by mouth every day</td>
<td>Rind David</td>
<td></td>
</tr>
<tr>
<td>03/29/2000</td>
<td>Ibuprofen 400 mg PO</td>
<td></td>
<td>One by mouth three times a day as needed – take with food</td>
<td>Mitchell Nancy</td>
<td></td>
</tr>
<tr>
<td>02/22/2000</td>
<td>Nitroglycerin 400 mcg</td>
<td></td>
<td>One under the tongue as needed for chest pain, may repeat every 5 minutes x 2, then got to ER if pain persists</td>
<td>Rind David</td>
<td></td>
</tr>
<tr>
<td>08/09/2000</td>
<td>Levothyroxine 50 mcg PO</td>
<td></td>
<td>One tablet by mouth every day</td>
<td>Looney, Maureen</td>
<td></td>
</tr>
<tr>
<td>02/22/2000</td>
<td>Prednisone 2.5 mg PO</td>
<td></td>
<td>2 by mouth every morning and one by mouth every evening</td>
<td>Looney, Maureen</td>
<td></td>
</tr>
<tr>
<td>08/28/2000</td>
<td>Aspirin E.C. 325 mg PO</td>
<td></td>
<td>One tablet by mouth every day</td>
<td>Rind David</td>
<td></td>
</tr>
<tr>
<td>08/28/2000</td>
<td>Fluoxetine 10 mg PO</td>
<td></td>
<td>One by mouth every day</td>
<td>Looney, Maureen</td>
<td></td>
</tr>
<tr>
<td>08/28/2000</td>
<td>Verapamil SH 240 mg PO</td>
<td></td>
<td>One tablet by mouth every day</td>
<td>Looney, Maureen</td>
<td></td>
</tr>
<tr>
<td>08/28/2000</td>
<td>Atorvastatin Calcium 10 mg PO</td>
<td></td>
<td>One tablet by mouth every day</td>
<td>Looney, Maureen</td>
<td></td>
</tr>
</tbody>
</table>
Some of the high priority policy issues

1. Patient notification and consent
2. Authentication
3. Authorization for access and proxies
4. Patient ability to control sharing of data
5. Data standards
6. Data integrity
7. Application requirements
8. Clinician workflow, financial and liability concerns
9. Secondary uses and breaches
10. Consumer awareness and value proposition
Status of PHRs today

- High public interest in features and services coupled with concern about privacy
- There’s no “it” out there yet—diverse, complex market
- Many significant offerings in the works
- All will face common challenges:
  - Standards issues
  - Architecture issues
  - Policy issues
- Common policy and technical framework will be essential to achieve “networked” personal health record—and avoid another set of silos

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Charting a path forward

• Each stakeholder must make a commitment to enable portability of personal health data with the consumer in control.

• Organizations should make the data that they hold available — at the consumer’s request — to applications offered by other entities, as long as those entities comply with a common set of rules and practices for information stewardship.
Charting a course forward

• A networked PHR environment cannot be achieved without collaborative efforts and consensus agreements among all stakeholders
• We need to agree on the characteristics of the network and the means by which personal health information will be shared and managed
• We must create an environment of trust and confidence
• Without a common set of policies for information stewardship, even a thousand interesting projects and product offerings are not likely to produce a trustworthy, interoperable PHR
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