U.S. Healthcare “System”

- Fragmented
- Expensive
  - ~ US$2 trillion = 16% of GDP
  - Key stakeholders don’t care about costs!
- Unacceptable quality
  - Errors 8th leading cause of death
  - Recommended care 50% of time
  - 37th best in the world!
  - No incentives to provide quality care!
- Inefficient
### Ways to “Fix” the System

- The system
- The practitioners
- The patients
E-mpowered Consumers

- 80% of online adults
- Rising over time
- Each day, more people search for health information than see a physician!
- More than half acted on information

Source: www.pewinternet.org

Shifting Paradigm?

- Information asymmetry
  - Physician as oracle
  - Comfortable
  - A burden?
- Information symmetry
  - Physician as partner
  - Threatening vs. liberating
  - Physician as healer
Non Sequitur by Wiley Miller

Image removed due to copyright restrictions.
Cartoon: “Non Sequitur” by Wiley Miller.
Two food vendors with carts: one labeled “Health” has no customers, and the other labeled “Shmealth (Deep Fried Stuff)” has a long line of enthusiastic buyers.

• How might we engage patients in their health?
• What benefits might arise from that?

Personal Health Record

“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.”

Connecting for Health 2004
What Patients Want

Communication

Involvement in Care

Information

Convenience

Electronic Health Record

“An Electronic Health Record (EHR) is a medical record or any other information relating to the past, present or future physical and mental health, or condition of a patient which resides in computers which capture, transmit, receive, store, retrieve, link, and manipulate multimedia data for the primary purpose of providing health care and health-related services.”

Wikipedia 2005
PHR Benefits to Patient

- Better medication adherence
- More engagement in health → better health outcomes
  - Is this true for broad populations?
- Health management tools
- Asynchronous secure e-communication
- Facilitated enrollment in clinical trials
- Disease management w/ patient involvement
### PHR Benefits to Clinician

- Better clinical database
- Transferability of health records
- Asynchronous e-communication

---

**PHRs May Bridge the Gaps**
PHR Benefits to Health System

- Bridging the gaps among info silos
- Safety
- Public health
  - Advisories
  - Surveillance
- Clinical trials recruitment
- Clinical research
- Reduced testing redundancy

Image removed due to copyright restrictions.
Cartoon: two mice looking up for their hole-in-the-wall home at two humans; one mice says “Oh no! We've got people!”
Are PHRs *data sources* for health information exchange or are PHRs the *vehicles* for health information exchange?

Retrieving your health information

![Diagram showing interconnected healthcare providers and personal devices](Source: Markle Foundation)

Source: Markle Foundation

Figure by MIT OpenCourseWare.
The person as an information hub

Source: Markle Foundation

Figure by MIT OpenCourseWare.

High blood pressure

Hypertension
Facilitating Patient Understanding

Reference Libraries

Context-sensitive hyperlinks and help

The patient's hypertension is poorly controlled...

Hypertension is another name for High blood pressure...

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

Automatic Translation (appropriate to patient literacy)

Trust Requirements

- Encrypted communication
- Integrity
- Authentication
- Non-repudiation
- Time-stamps
- Withheld data flagged
- Standard terminology, when possible
### Data
- Medications
- Problems
- Procedures
- Hospitalizations
- Test results
- Immunizations
- Adv. directives
- Physiologic monitoring
- Home
- Clinician

### Connectivity
- E-messaging
- Data exchange
- With:
  - Providers
  - Institution
  - Health plans

### Resources
- References
- Context-sensitive
- Static
- Dynamic
- Coaching

### Tools
- Health risk assessment
- Symptom monitoring
- Health status assessment
- Convenience:
  - Rx renewals
  - Appointments
  - Self-care

### Opportunity
- Clinical trials
- Disease mgmt
- Selling data

### Community
- Links to online communities

### Financial
- Benefits
- Expenses
- Deductibles
- Claims

### Data Type
<table>
<thead>
<tr>
<th>Data Source</th>
<th>Subjective</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td></td>
<td>home BP monitoring</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Copyright © 2006 D. Z. Sands
Maintaining Security of PHR Data is a Public Priority

<table>
<thead>
<tr>
<th>Attribute Statement</th>
<th>Rating</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.”

Courtesy: Markle Foundation
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
**PHR Media**

- **Paper**
- **Web**
  - Standalone
  - Interconnected
  - Tethered
- **Removable media**
  - CD-ROM
  - USB drive
- **Linkages**
  - Standalone
  - Interconnected

Collage of three images removed due to copyright restrictions.

1) Paper notebook: “My Personal Health”
2) Screenshot from website WebMD
3) Photo of USB drive
Image removed due to copyright restrictions.
A patient’s personal health card, containing:
Family, doctor, and pharmacy contacts
Social service contacts (e.g. elder care)
List of conditions being tracked
Medications – dosages, times of day, purpose

http://www.patientsite.org
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

Image removed due to copyright restrictions.

Image removed due to copyright restrictions.
Website screenshot.

https://healthmanager.webmd.com
http://www.capmedphr.com

Courtesy of CapMed. Used with permission.

Courtesy of CapMed. Used with permission.
Courtesy of CapMed. Used with permission.

Courtesy of CapMed. Used with permission.
A Continuum of Interoperability

Images removed due to copyright restrictions.

- Who enters the data?
- Who controls the data?
- Who controls access?
- Who depends on the record?

Paper notebook: "My Personal Health Diary"
Beth Israel Deaconess Medical Center "PatientSite"
Photo of USB Flash drive.

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When is a PHR not a PHR?

When it’s a receptacle for PHR Data.

E.G. Microsoft's HealthVault

Website screenshot image removed due to copyright restrictions.

http://www.healthvault.com
HealthVault Privacy

Website screenshot image removed due to copyright restrictions. HealthVault's "Privacy Commitment" statement.

HealthVault Contributions

- Privacy policy
- Interoperability through API
- A storage area for:
  - PHR
  - Other data sources
  - Various applications
**Who Will Use PHR?**

- Truly well and worried well
- Engaged patients chronic conditions
- Parents of young children (esp. ill)
- Grown children caring for ill parent
- Possibly anyone with incentives?

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**Majority Interested in Accessing Information Online**

<table>
<thead>
<tr>
<th>Interest in Accessing Health Information Online</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not interested: 34%</td>
</tr>
<tr>
<td>Not sure: 1%</td>
</tr>
<tr>
<td>Interested: 65%</td>
</tr>
</tbody>
</table>

- Majority of all subgroups express interest, even seniors (53%)
- Most interested include:
  - Under 40 (72%)
  - Daily Internet users (71%)
  - Parents (70%)

Courtesy of the Markle Foundation. Used with permission.
Online Access as a Way to Gain More Control Over Care

Most likely to agree:
- 18 to 29 year olds (81%)
- African Americans (79%)
- Daily Internet users (76%)
- Parents (74%)
- Frequent users of health care system (74%)

Ways to Manage Own Care With Secure Network

- Tracking symptoms or changes in health (90% say would be important personally)
- Tracking financial aspects of health care (80% interested)
- Tracking child’s health records and services, like immunization dates (82% of parents interested)
Benefits Relating to Quality of Care and Cost

- Checking doctor’s chart to make sure situation is understood (91% important)
- Checking medical records for mistakes (84% interested)
- Looking at test results (82% interested)
- Reducing unnecessary or repeated tests and procedures (88% important)

Willingness to Share Information, If Safeguards in Place

- To detect disease outbreaks (73% willing)
- To improve quality of care (72%)
- To detect medical fraud (71%)
- To detect bio-terrorist attacks (58%)

Courtesy of the Markle Foundation. Used with permission.
Who Will Fund PHR?

- Individuals (limited population)
- Health care institutions (tethered)
- Employers (self-insured)
- Health plans

Yet There Is Very High Concern About Unwanted Access

<table>
<thead>
<tr>
<th>Privacy and Access Concerns</th>
<th>Somewhat Concerned</th>
<th>Very Concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity Theft &amp; Fraud</td>
<td>80%</td>
<td>12%</td>
</tr>
<tr>
<td>Marketing firms gaining access</td>
<td>77%</td>
<td>12%</td>
</tr>
<tr>
<td>Employers gaining access</td>
<td>56%</td>
<td>18%</td>
</tr>
<tr>
<td>Health insurance companies gaining access</td>
<td>53%</td>
<td>26%</td>
</tr>
</tbody>
</table>

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Patient engagement may be helpful
PHR may be route to engagement
Business case is evolving
Benefits need to be studied
PHR is an important, potentially disruptive health information technology
SF 61 y.o. M Minister with Diabetes, Chronic Pain Syndrome, and Multiple Medical Issues

“I have a lot of medical issues. This system has left me feeling comfortable and in good hands! Otherwise, I would feel as cold, depleted, and alone, as the lifeless tree in my front yard in the deepest of winter!”

Image removed due to copyright restrictions. Cartoon: “Herman” by Jim Unger, 7/19/2002. Two cavemen, one holding a burning stick, the other saying “That’s fantastic! I can’t keep up with all this modern technology.”