Building the Health Informatics Chunnel:
The PHR Meets the EHR

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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
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!
- Almost 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
Self-Care (off the map)

INDUSTRIAL AGE MEDICINE

INFORMATION AGE HEALTHCARE

idoctom@doctom.com, www.fergusonreport.com
• How might we engage patients in their health?
• What benefits might arise from that?

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.
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.”
What Patients Want

Communication

Involvement in Care

Information

Convenience
Personal Health Record

“The [PHR] is an **electronic, universally available, lifelong resource** of health information needed by individuals to make health decisions. Individuals own and manage the information in the PHR, which comes from healthcare providers and the individual. The PHR is maintained in a secure and private environment, with the **individual determining rights of access**. The PHR is separate from and does not replace the legal record of any provider.”
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.”
- Tool for patient
- Data source for EMR

- Tool for clinician
- Data source for PHR

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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

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

Source: Markle Foundation

Figure by MIT OCW.
The person as an information hub

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

Source: Markle Foundation
Figure by MIT OCW.
HIE between the PHR, EHR, & RHIOs

Personal Health Record System (PHR-S)

Physician Office EHR-S
Hospital EHR-S
LTC, Behavioral Health EHR-S
Home, Community Health EHR-S

Referral Data
Referral Data
Referral Data

Data stays where it is. Longitudinal EHR distributed over multiple (federated) EHR-S, but still episodic.

RHIO Record Locator Service

RHIO: transaction oriented
PHR: record oriented

Courtesy Donald T. Mon, PhD, AHIMA

Courtesy of AHIMA. Used with permission.
Hypertension

High blood pressure
Facilitating Patient Understanding

The patient’s hypertension is poorly controlled...

Hypertension is another name for High blood pressure...

Reference Libraries

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

Automatic Translation (appropriate to patient literacy)

Figure by MIT OCW.
Trust Requirements

- Encrypted communication
- Integrity
- Authentication
- Non-repudiation
- Time-stamps
- Withheld data flagged
- Standard terminology, when possible
<table>
<thead>
<tr>
<th>Data Source</th>
<th>Data Type</th>
<th>Subjective</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>Manual entry or results of online data capture (e.g., symptoms scores, qualitative descriptions)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Instrumentation</td>
<td>Manual entry (e.g., blood pressure, weight)</td>
<td></td>
<td></td>
</tr>
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<td>Clinicians</td>
<td>Automated interface with medical records</td>
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<td></td>
<td>N/A</td>
<td>Automated interfaces (e.g., blood pressure from interfaced home BP monitor)</td>
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</table>
An Empty Vessel Strategy Is Not Viable
Maintaining Security of PHR Data is a Public Priority

<table>
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<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.”

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
Claims Data is Not Perfect…

But It Can Prime the Pump
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
A Continuum of Interoperability

• Who enters the data?
• Who controls the data?
• Who controls access?
• Who depends on the record?
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.ihealthrecord.com/

Image removed due to copyright restrictions. Screenshot of iHealthRecord web service.
Image removed due to copyright restrictions.
Screenshot of iHealthRecord web service.
A Continuum of Interoperability

- Who enters the data?
- Who controls the data?
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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?
Majority Interested in Accessing Information Online

Interest in Accessing Health Information Online

- 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

Health Information Online Will Give People More Control Over Own 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%)

Not sure
5%

Agree
68%

Disagree
27%

Courtesy of the Markle Foundation. Used with permission.
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)

Courtesy of the Markle Foundation. Used with permission.
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)

Courtesy of the Markle Foundation. Used with permission.
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

Privacy and Access Concerns

- Identity theft/fraud: 80% somewhat concerned, 12% very concerned
- Marketing firms gaining access: 77% somewhat concerned, 12% very concerned
- Employers gaining access: 56% somewhat concerned, 18% very concerned
- Health insurance companies gaining access: 53% somewhat concerned, 26% very concerned

Source: D. Z. Sands
Issues with Payor Involvement

- No enduring relationship with payor
  - So payor should not be destination site
- Claims data ≠ clinical data
  - So translations and caveats important
- Patient needs to own and control data
  - So payor can be data source, with data stored in portable record
- Patient privacy must be upheld
  - Data must flow from plan to patient only
Research Agenda

- What do patients want from PHRs?
- What are they willing to pay for?
- What are business models for PHRs?
- How can PHRs help patients create personal health plan?
- How do we assess/assure the accuracy and completeness of patient-entered info?
- What issues arise when providers use patient-entered data?
- What is the concordance of patient-entered and provider-entered data (e.g., problem list)?
Research Agenda

- What consumer health vocabularies do we need?
- How do we best present data for patient use?
- How does it vary by:
  - General literacy level?
  - Health literacy level?
  - Disease state?
- What is the impact of PHR on health status?
- What standards are necessary for PHR?
- What is physician’s liability for reviewing data from PHR?
- What are optimal workflows, both for clinicians and for patients?
Image removed due to copyright restrictions.

http://www.jamia.org
Other Resources

- AHIMA’s MyPHR.com
  - http://www.myphr.com/
- Connecting for Health
  - http://connectingforhealth.org/phti/
- Informatics Review
  - http://informatics-review.com/records.html
- MedlinePlus
  - http://medlineplus.gov/personalmedicalrecords
PHR Conclusions

- 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.”
Questions?

Please submit your evaluations!