Author(s): Charles Friedman

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Where are We?

• Channel 1
• Domain Lectures
  1. National health information infrastructure
  2. Provision of health care by clinicians
  3. Personal/individual health and wellbeing
  4. Biomedical and other health-related research
  5. Public health
National Health Information Infrastructure and the “Learning Health System”

Prof. Charles P. Friedman
Introduction to Health Informatics (Fall 2013)
University of Michigan
September 4, 2013
Warm-up: What Does This Picture Say to You?
Questions to be Addressed

1. What do we mean by infrastructure?
2. What is a learning health system and why do we need it?
3. How does a learning health system work and how to envision it as infrastructure?
4. How can we achieve it?
An infrastructure is...

• Persistent: you can count on it being there
• Transparent: you know what it does
• Reliable: it does what it does almost all the time
• Routine: using it requires no special effort
• Versatile: it serves a wide range of needs
• Scalable: requires one connection
• Fertile: Capable of growth
Remember this Slide! Infrastructure and Scale

N (N – 1) / 2 connections vs. N connections
Questions to be Addressed

1. What do we mean by infrastructure?
2. What is a learning health system and why do we need it?
3. How does a learning health system work and how to envision it as infrastructure?
4. How can we achieve it?
Big Problem!

• The U.S. does not have a health information infrastructure

• The consummate health informatics challenge
We Can’t Fix This Without an Infrastructure
What Infrastructure Can Enable

- A **needed** virtuous cycle of study, learning and improvement
- This requires assembly of data, analysis, and feedback

```
Assemble    Analyze    Interpret    Feedback    Change
```

# The Challenge: Studying a Rare Disease

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Outcome</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient 1</td>
<td>A</td>
<td>2</td>
</tr>
<tr>
<td>Patient 2</td>
<td>B</td>
<td>1</td>
</tr>
<tr>
<td>Patient 3</td>
<td>B</td>
<td>2</td>
</tr>
<tr>
<td>Patient 4</td>
<td>A</td>
<td>1</td>
</tr>
<tr>
<td>Patient 5</td>
<td>B</td>
<td>1</td>
</tr>
<tr>
<td>Patient 6</td>
<td>B</td>
<td>2</td>
</tr>
</tbody>
</table>
But Look What Might Be Possible
The Learning Health System

• The nation’s health system is going digital 30% now → 80% by 2019
• If each care provider, patient, researcher, used his/her/its own data only for immediate needs, these efforts will undershoot their potential
• Sharing of data can enable a virtuous cycle of study, learning and improvement
• A learning health system is infrastructure that enables this to be done routinely and continuously.
Adoption of “Basic” Electronic Health Records Among Office-based Physicians

Source: National Center for Health Statistics, Centers for Disease Control, NAMC (National Ambulatory Medical Care) Survey
Deployment of “Basic” EHRs in Non-Federal Acute Care Hospitals

Perspective: Jan 3, 2013

“Code Red and Blue — Safely Limiting Health Care’s GDP Footprint”

Arnold Milstein, M.D., M.P.H.

...U.S. health care needs to adopt new work methods, outlined in the Institute of Medicine’s vision for a learning health system... Such methods would enable clinicians and health care managers to more rapidly improve value by continuously examining current clinical workflows, management tools from other service industries, burgeoning databases, and advances in applied sciences (especially health psychology and information, communication, and materials technologies). They could then use the insights gained to design and test innovations for better fulfilling patients’ health goals with less spending and rapidly scaling successful innovations.
Questions to be Addressed

1. What do we mean by infrastructure?
2. What is a learning health system and why do we need it?
3. How does a learning health system work and how to envision it as infrastructure?
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A National-Scale Learning Health System
The LHS Must Work Bi-Directionally: Afferent and Efferent Arms
A Learning System Will Make These Things Possible

“17 years to 17 months, or maybe 17 weeks or even 17 hours…“

• Nationwide post-market surveillance of a new drug quickly reveals that personalized dosage algorithms require modification. A modified decision support rule is created and is implemented in EHR systems.

• During an epidemic, new cases reported directly from EHRs. As the disease spreads into new areas, clinicians are alerted.

• A patient faces a difficult medical decision. She bases that decision on the experiences of other patients like her.
The National LHS: One Infrastructure that Supports

• Research
  – Clinical
  – Comparative effectiveness
  – Translational

• Public Health
  – Surveillance
  – Situational Awareness

• Quality Improvement
  – Health process and outcomes research
  – Best practice dissemination

• Consumer Engagement
  – Knowledge-driven decision making
How the LHS Works: Falls in Nursing Homes

Interpret findings:
Are the results credible?
What advice should be given?

Analyze Data
What practices associate with lower fall rates?

Assemble Data:
How do we prevent falls?
What is the fall rate?

Feedback:
Based on your current practice, you might want to consider...

Decision to study falls

Change Current Practice:
In whole or part...

Efferent
The LHS Must Meet Infrastructure Requirements

- **Persistent:** you can count on it being there
- **Transparent:** you know what it does
- **Reliable:** it does what it does almost all the time
- **Routine:** using it requires no special effort
- **Versatile:** it serves a wide range of needs
- **Scalable:** requires one connection
- **Fertile:** Capable of growth
The National LHS as Currently Envisioned

- A federation of some type
  - *Not* a centralized database
- Grounded in public trust and patient engagement
- Participatory governance
- A “Complex Adaptive System”
- An “Ultra Large Scale” System
  - “Just enough” standardization
  - Supports innovation around standards
Exhibit 1.2: Health Informatics: The Transforming Power of HIT

Health Informatics Methods, Techniques, and Theories

Basic Research

- Bioinformatics
- Imaging Informatics
- Clinical Informatics
- Public Health Informatics
- Health Systems Informatics

Applied

- Molecular and Cellular Processes
- Tissues and Organs
- Individuals (Patients)
- Populations and Society
- Complex Adaptive Systems

includes...Learning Health System
The LHS as a Fractal

• At every level of scale, it looks pretty much the same
• Local, regional, national, global
Questions to be Addressed

1. What do we mean by infrastructure?
2. What is a learning health system and why do we need it?
3. How does a learning health system work and how to envision it as infrastructure?
4. How can we achieve it?
LHS: A Pillar of the 2011 Federal Health IT Strategic Plan BUT the Government Can’t Build It

**Goal I:** Achieve Adoption and Information Exchange through Meaningful Use of Health IT

**Goal II:** Improve Care, Improve Population Health, and Reduce Health Care Costs through the Use of Health IT

**Goal III:** Inspire Confidence and Trust in Health IT

**Goal IV:** Empower Individuals with Health IT to Improve their Health and the Health Care System

**Goal V:** Achieve Rapid Learning and Technological Advancement

Transform Health Care

Better Information

Better Technology
Digital Infrastructure for the Learning Health System: The Foundation for Continuous Improvement in Health and Health Care

Best Care at Lower Cost: The Path to Continuously Learning Health Care in America
The LHS Summit: May 17-18, 2012

Engaging a critical mass of key stakeholders, to be, for the LHS, what the Dumbarton Oaks Conference was for the United Nations (see [http://LearningHealth.org](http://LearningHealth.org))

- ~ 70 organizations represented at the National Press Club
- Resulted in 10 consensus Core Values
- 52 organizations have formally endorsed
- Giving rise to national “Learning Health Community”
Learning Health System *Core Values*

1. Person-Focused
2. Privacy
3. Inclusiveness
4. Transparency
5. Accessibility
6. Adaptability
7. Governance
8. Cooperative and Participatory Leadership
9. Scientific Integrity
10. Value
A Growing National Movement

• Achieving multi-stakeholder endorsement of LHS Core Values (54 endorsements received to date)
• Building a self-organizing, multi-stakeholder “learning health community”, to develop as a coalition of the willing
• National workshops
• Catalyzing, leading, and participating in initiatives
  – Standards
  – Governance,
  – Technology
Public Health LHS Workshop

• Workshop in Ann Arbor, March 12-13

PUBLIC HEALTH AND THE LEARNING HEALTH SYSTEM
A National Invitational Meeting at the University of Michigan

… state and local public health have been underrepresented at discussions of the Learning Health System, and there is general agreement that the voice of public health needs to be heard as this national movement rolls forward. Accordingly, this meeting is designed to lay the groundwork for a community of public health leaders who share an interest in learning about the LHS and enriching its current status…
1. What do we mean by infrastructure?

2. What is a learning health system and why do we need it?

3. How does a learning health system work and how to envision it as infrastructure?

4. How can we achieve it?