The Learning Health System & The Learning Health Community

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April 7, 2015
Disclosure

I am the chair of the Interim Steering Committee of the Learning Health Community, a grassroots not-for-profit organization.
Main Menu for Today

1. What is the LHS and how does it learn?

2. The Learning Health System is infrastructure.
   - The Learning Health System is bigger than Big Data.

3. Progress toward an LHS at local, state, and national levels.
   - With emphasis on the Learning Health Community
Health systems--at any level of scale--become learning systems when they can, continuously and routinely, study and improve themselves.

The NEW ENGLAND JOURNAL of MEDICINE
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...
A National Learning Health System

Large Scale

Decentralized

All-Inclusive

Reciprocal

Insurers

Pharma

Patient Groups

Tech Industry

Universities

Government/Public Health

Governance

Engagement

Data Aggregation

Analysis

Dissemination

Healthcare Delivery Networks

Research Institutes
A Health System That Can Learn

• Every patient’s characteristics and experience are available for study

• Best practice knowledge is immediately available to support decisions

• Improvement is continuous through ongoing study

• This happens routinely, economically and almost invisibly

• All of this is part of the culture
A Learning System *Routinely* Enables:

- **Pursuit of Best and Safer Care at Lower Cost:** Communities of interest discover what interventions are most cost-effective and are supported in implementing them.

- **Enhanced Public Health:** During an epidemic, new cases are reported directly from EHRs, the spread of the disease is predicted, and clinicians are alerted.

- **Consumer Empowerment:** Patients facing difficult health decisions discover the experiences of other patients like them.
How To Learn: “Virtuous Cycles” of Study, Learning and Improvement

A Problem of Interest

Assemble Experience Data

Analyze Data

Take Action

Tailored Messages to Decision-Makers

Interpret Results

Decision to Study
Example of A Virtuous Learning Cycle

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

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

Analyze Data:
What practices associate with lower fall rates?

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

Take Action:
Change Current Practice:
In whole or part...

Decision to study falls

Reducing Falls in Nursing Homes
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How Do We Convert?

• A set of learning loops, each addressing a different problem:

• Into an efficient large scale system:
We Build an Infrastructure!

• Learning loops enable learning but do not create a Learning Health System

• If you want to get 350,000 people per day across a river, do you build 350,000 rowboats?

• No, you build a:
LHS Infrastructure: A Single Platform Supports Multiple Simultaneous Learning Cycles

Different Problems

Rapid Cycle

Slower Cycle

SUPPORTING PLATFORM
Why a Platform?

• Without a platform:
  – Every cycle requires its own agreements, technology, staffing, analytics, dissemination mechanisms
  – No economy of scale
  Cost of 10 cycles = 10 x (Cost of one)

• With a platform:
  – All cycles are supported by the infrastructure
  – Big economy of scale
  Cost of 10 cycles << 10 x (Cost of one)
So What’s in the Platform?

1. Collect Data
2. Assemble Data
3. Analyze Data
4. Interpret Results
5. Deliver Tailored Message
6. Take Action to Change Practice

Technology and policy for making knowledge persistent and sharable

Mechanisms for managing communities of interest

Mechanisms for tailoring messages to decision makers

Mechanisms for capturing changed practice

Technology for aggregating and analyzing data

Policies governing access to data
Learning Systems Can Exist at Any Level of Scale

- The scale of the system = the scope of the platform
- Local, state, national, global
The LHS and Big Data

• The **LHS** is bigger than **Big Data**

• Big Data addresses only the blue side of the learning cycle

• The LHS infrastructure must support complete learning cycles
The LHS Must Do This

A Problem of Interest

- Assemble Relevant Data
- Analyze Data
- Interpret Results
- Deliver Tailored Message
- Take Action to Change Practice
- Decision to Study
Not This

A Problem of Interest

Assemble Relevant Data

Analyze Data

Interpret Results

Take Action to Change Practice

Deliver Tailored Message

Journals?

Decision to Study
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Elements of a National Learning Systems are Assembling

1. Words: calls and reports
2. Digital data
3. “Learning Islands”
4. Data federations and networks
5. Grant programs
6. An emerging research community
7. The Learning Health Community: A grassroots coalition

“In the Big Data era, AHCs should strive to become “learning health systems” by making clinical data “research grade” and lowering the costs of data acquisition and knowledge generation.”

10-Year Agenda:
The Learning Health System
Progress: Health Data are Increasingly in Digital Form

Figure 1. Percentage of office-based physicians with EHR systems: United States, 2001–2013

NOTES: EHR is electronic health record. “Any EHR system” is a medical or health record system that is either all or partially electronic (excluding systems solely for billing). Data for 2001–2007 are from in-person National Ambulatory Medical Care Survey (NAMCS) interviews. Data for 2008–2010 are from combined files (in-person NAMCS and mail survey). Estimates for 2011–2013 data are based on the mail survey only. Estimates for a basic system prior to 2006 could not be computed because some items were not collected in the survey. Data include nonfederal, office-based physicians and exclude radiologists, anesthesiologists, and pathologists.

SOURCE: CDC/NCHS, National Ambulatory Medical Care Survey and National Ambulatory Medical Care Survey, Electronic Health Records Survey.
Progress: Learning “Islands”

• Organizations that have become Learning Health Systems at their level of scale.
• But don’t routinely connect with other islands.
Progress: Inter-organizational Data Federations and Networks
Progress: Grant Programs

- NIH “Big Data to Knowledge”
- PCORI Research Networks
- NSF Smart and Connected Health
Toward a Community: 2013 “Research Challenges” Workshop

• Invitational meeting with 45 participants
• Result 1: 106 research questions organized into 4 broad categories and 19 sub-categories
• Result 2: A sense that a scientific community of interest might form around the LHS
  – A new science of “cyber-social ecosystems”
  – And a second meeting to begin building the community

Toward a science of learning systems: a research agenda for the high-functioning Learning Health System

Charles Friedman,¹ Joshua Rubin,¹ Jeffrey Brown,² Melinda Buntin,³ Milton Corn,⁴ Lynn Etheredge,⁵ Carl Gunter,⁶ Mark Musen,⁷ Richard Platt,² William Stead,³ Kevin Sullivan,⁸ Douglas Van Houweling¹
The Learning Health Community

• National “Summit” convened in May 2012 to envision LHS as set of shared beliefs
• A Dumbarton Oaks Conference for the LHS
• ~ 70 organizations represented at the National Press Club
• Resulted in 10 consensus Core Values
• 72 organizations have formally endorsed the Core Values
LHS 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
73 Endorsements of the LHS *Core Values* (3/23/2015)

*To be included on the [www.LearningHealth.org](http://www.LearningHealth.org) website.
Learning Health Community Initiatives

• Essential Structures/Standards to Enable Learning (ESTEL)

• LHS Governance
Thanks & Write to Me

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