The Learning Health System in the U.S.

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September 24, 2015
Disclosure

I am the chair of the Interim Steering Committee of the Learning Health Community, a grassroots not-for-profit organization.
Two Parts to This Talk

1. An “American” conception of the LHS.
2. Progress in the U.S. along seven channels
Health systems--at any level of scale--become learning systems when they can continuously 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...
Checklist: A Health System That Can Learn

✓ Every consenting patient’s characteristics and experience are available to learn from

✓ 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
Macro View: An Ultra-Large Scale System

- Trusted
- Decentralized
- All-Inclusive
- Reciprocal

Governance
Engagement
Data Aggregation
Analysis
Dissemination
Learning Systems Can Exist at Any Level of Scale

Mono-organizational, inter-organizational, state/regional, national, global...
Many Use Cases… A Learning System *Routinely* Enables:

- Pursuit of Best and Safer Care at Lower Cost
- Enhanced Public Health
- Consumer Empowerment
- Streamlined, Efficient Research
How Learning Happens: “Virtuous Cycles” of Study and Change

A Problem of Interest

- Decision to Study
- Take Action
- Tailored Messages to Decision-Makers
- Interpret Results
- Analyze Data
- Assemble Experience Data

Experience Data

Assemble

Take

Interpret

Analyze

Tailored Messages to Decision-Makers
The Afferent and Efferent Sides of the Learning Cycle

A Problem of Interest

Afferent (BD2K)  Efferent (K2P)

Learning = BD2K + K2P
Example of A Virtuous Learning Cycle

Reducing Falls in Nursing Homes

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

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

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...

Decision to study falls
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
Assemble Relevant Data

Analyze Data

Interpret Results

Not This

A Problem of Interest

Take Action to Change Practice

Deliver Tailored Message

Decision to Study

Journals?
LHS Infrastructure
A Single Socio-Technical Platform Supports Multiple Simultaneous Learning Cycles

Different Problems

SUPPORTING PLATFORM

People
Technology
Process
Policy
The Scale of the System = The Scope of the Platform
So What’s in a Complete Platform?

A Problem of Interest

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

Mechanisms for managing communities of interest

Technology and policy for making knowledge persistent and sharable

Technology for aggregating and analyzing data

Policies governing access to data

Mechanisms for tailoring messages to decision makers

Mechanisms for capturing changed practice

Decide to Study
Two Parts to This Talk

1. An “American” conception of the LHS.

2. Progress in the U.S. along seven channels
Elements of a National Learning System are Assembling

1. Words: calls and reports
2. Digital data
3. “Learning Islands”
4. Data federations and networks
5. Grant programs
6. A grassroots coalition of the willing
7. An emerging research community, a journal, and an academic department

“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
Progress: Grassroots Movement

- 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*
- 73 organizations have formally endorsed
- Giving rise to a Learning Health Community
86 Endorsements of the LHS Core Values*
(As of 8/12/2015)

*To be included on the www.LearningHealth.org website.
Progress: A Research Community

- A national workshop to explore the *research challenges* inherent in realizing a high functioning LHS
- April, 2013 in Washington, DC
- 55 attendees: 45 invited participants plus federal liaisons
- Many disciplines represented: computer science to epidemiology to economics
Outcomes of the 2013 Workshop

Reflected in report and JAMIA article:

• A vision of a high-functioning system
• 106 research questions organized into 4 broad categories and 19 sub-categories
• A sense that a scientific community of interest might form around the LHS
Further Progress

- Follow-up symposium at HICSS 2015
- Interaction with the NSF and NIH
- A White Paper on a science of cyber-social learning systems
- Interest from the Computing Community Consortium in a series of visioning workshops
A unique, collaborative department:

- **Research:** Generate and communicate new knowledge that advances the sciences of learning applied to health
  - *New academic journal*
- **Education:** Prepare a next generation of learning scientists; fold learning science into health professional curricula
  - *New PhD program*
- **Service:** Promote learning and learning systems at all levels of scale
New Open-Access Journal

Learning Health Systems

Published in collaboration with the University of Michigan
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