A National Learning Health System

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Briefing Slides for NSF Workshop
One Metaphor and One Lesson from History
Main Themes

1. What is a Learning Health System (LHS)?
   – What it can do to promote individual and population health
   – What it may look like and how it can work

2. A growing national movement
   – Reports and publications
   – How an LHS can be achieved
   – Developments nationally and locally
A Learning Health System (LHS)

“... one in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and health care.” (Institute of Medicine)
In Simpler Language

• The health system is going digital
  ~30% now
  ~80% by 2019

• If each care provider, patient, researcher, used his/her own data only for immediate needs, we are undershooting the potential

• If comparable data are shared, we can learn and improve

• The key is to figure out how to do this routinely.
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
The National LHS as Currently Envisioned

• A federation of some type
  – *Not* a centralized database

• Grounded in public trust and patient engagement

• Participatory governance

• An “Ultra Large Scale” System
  – “Just enough” standardization
  – Supports innovation around standards
How Will the LHS Actually Work?

*Example of stakeholder initiative:*

1. An entity in the system poses a question
2. Data-holding entities agree to participate
3. Relevant standardized data are exposed outside firewalls
4. “Agents” conduct distributed analysis
5. Results of analysis are expressed and disseminated in actionable form
6. Decisions are made/actions are taken
7. Results are archived for ongoing access by others
The LHS as a Fractal

• At every level of scale, it looks pretty much the same
• Local, regional, national, global
The LHS as an Ultra-Large-Scale System

- Including people and technology
- Decentralization
- Innovation around minimal (but essential) standards
- Diverse requirements
- Continuous evolution and deployment
- Diverse and changing elements
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LHS: A Pillar of the 2011 Federal Health IT Strategic Plan

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
IOM Reports

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
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.
NIH to recruit Associate Director for Data Science

National Institutes of Health Director Francis S. Collins, M.D., Ph.D., today announced plans to recruit a new senior scientific position, the Associate Director for Data Science. The associate director will lead a series of NIH-wide strategic initiatives that collectively aim to capitalize on the exponential growth of biomedical research data, such as from genomics, imaging, and electronic health records…
Current State: An Archipelago
"Carrying the nation the rest of the way to achieving a broadly participatory and functioning learning system will require coordination of effort, within and outside the federal government, of individual organizations that will inevitably be investing their own resources to advance their own capabilities as learning organizations. To the extent that these efforts align with progress toward a national system, they will advance a national agenda as much as each organization’s unique mission.”

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)

- ~ 70 organizations represented at the National Press Club
- Resulted in 10 consensus Core Values
- 45 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
So What’s Next?

• Achieving multi-stakeholder endorsement of LHS Core Values (45 endorsements received to date)
• Building a “chaordic”, self-organizing, multi-stakeholder “learning health community”, to develop bottom-up as a coalition of the willing
• Catalyzing, leading, and participating in initiatives
  • Beginning with standards (CDISC), governance (NeHC), a technology “sandbox”
• Identifying key research challenges
43 Endorsements of the LHS Core Values*
(As of 2/28/2013)

*To be included on a Learning Health Community public website that will list all organizations that have endorsed the LHS Core Values.
Standards Initiative

- Essential Standards to Enable Learning (ESTEL)
- Initial face to face meeting in Austin, Feb 6-7
- 30 participants
- Formation of a strategy and several working groups
- Report available soon
- Next meeting to be hosted by Duke
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...
LHS Research Challenges Workshop

• Grant awarded to the University of Michigan in September
• To convene national workshop to explore the research challenges inherent in building LHS as an ultra large scale system
• April 11-12 in Washington, DC
• Broad domain coverage: computer science to economics
• 45 participants committed to attend
Thanks and Write to Me
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