

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)

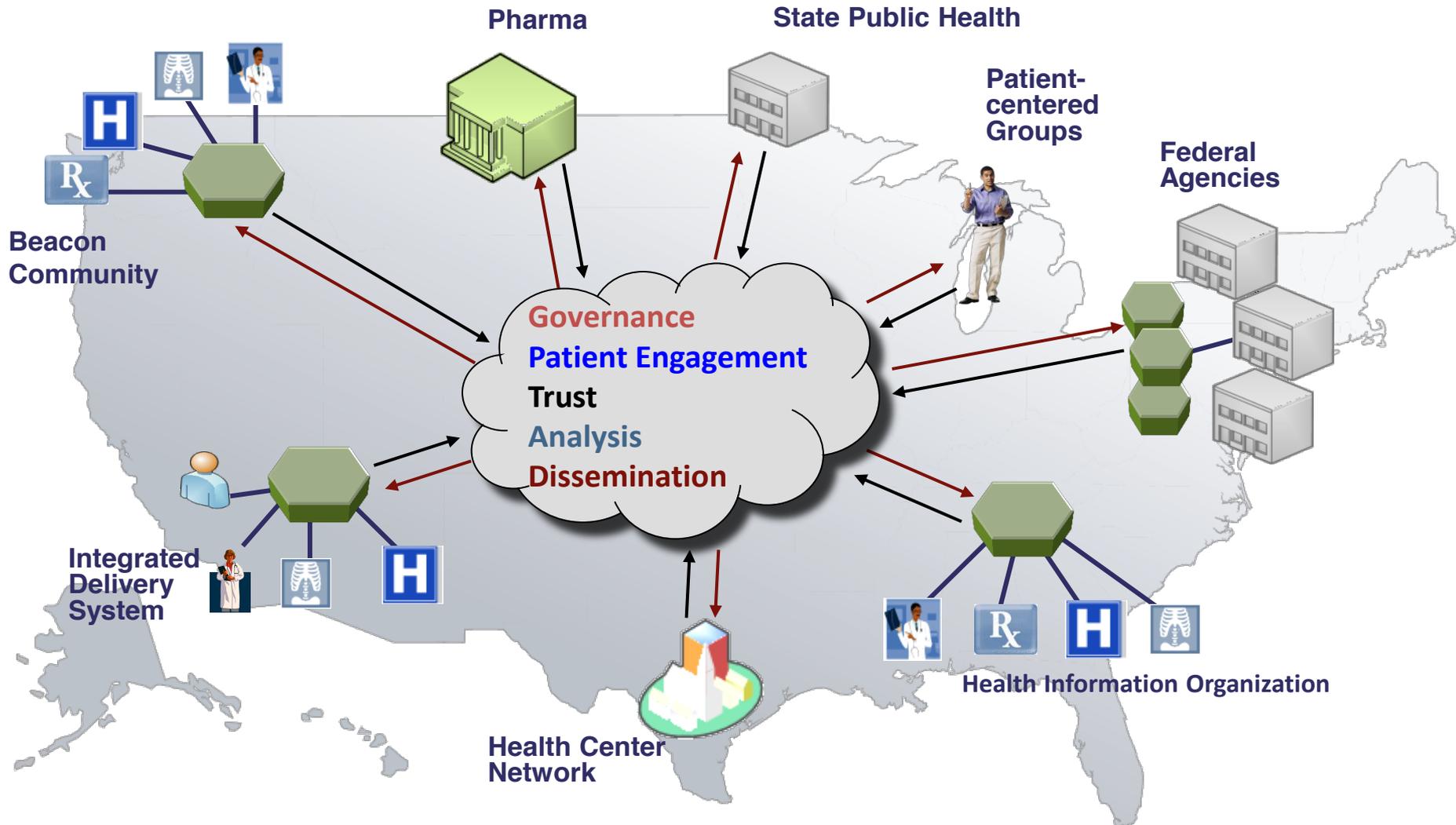
“ ... one in which progress in science, informatics, and care culture align to generate new knowledge as an ongoing, natural by-product of the care experience, and seamlessly refine and deliver best practices for continuous improvement in health and health care.”
(Institute of Medicine)



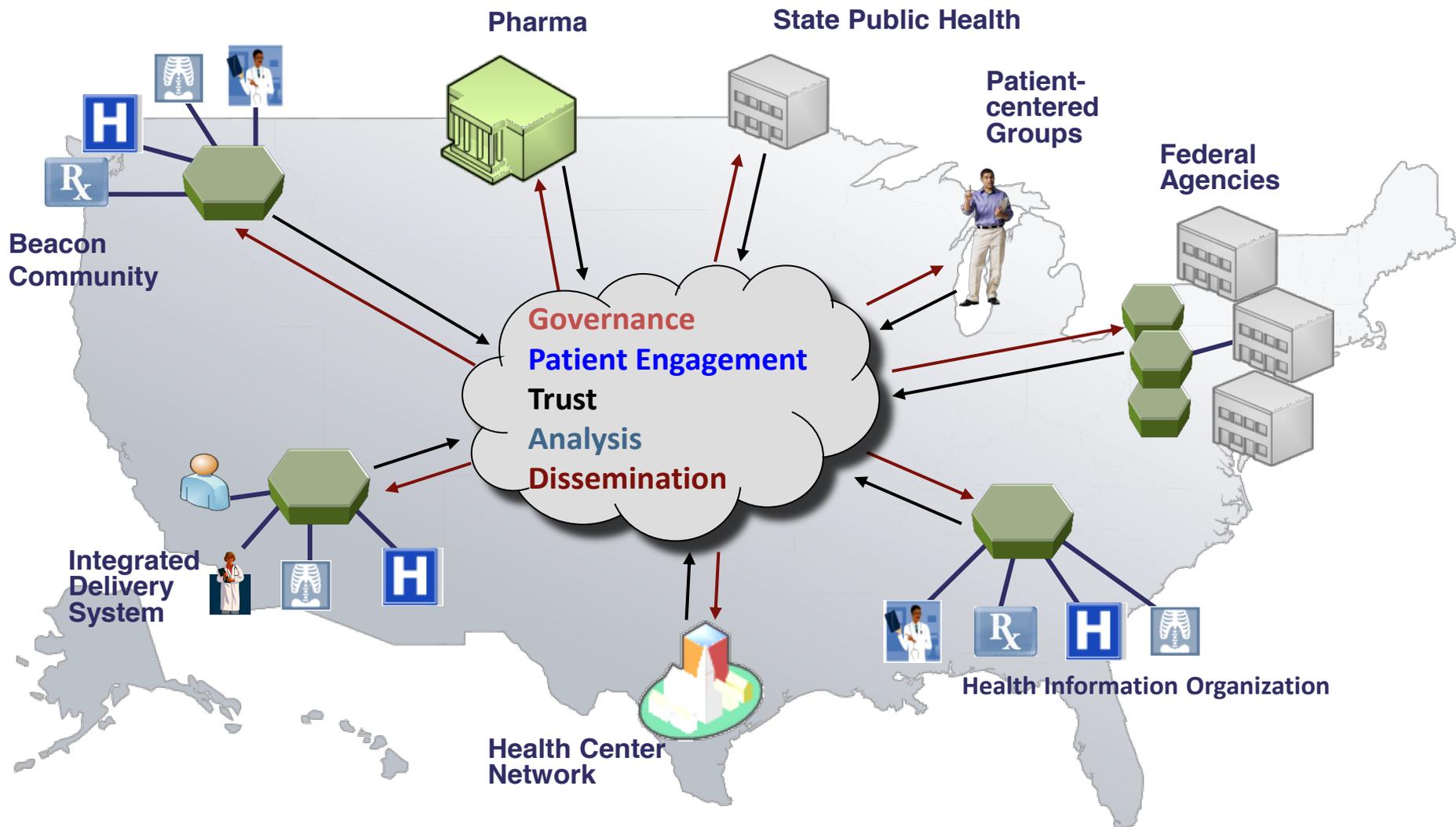
In Simpler Language

- 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 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

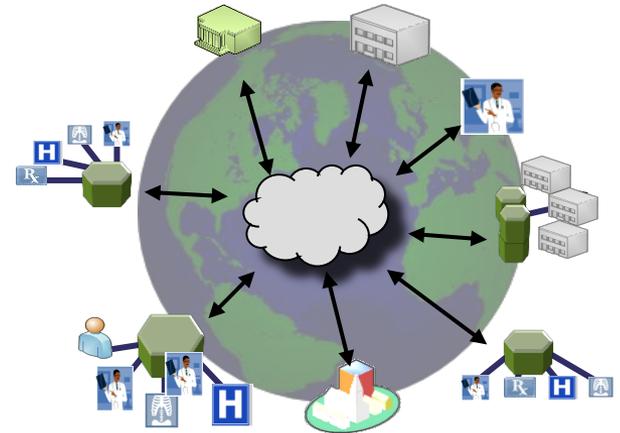
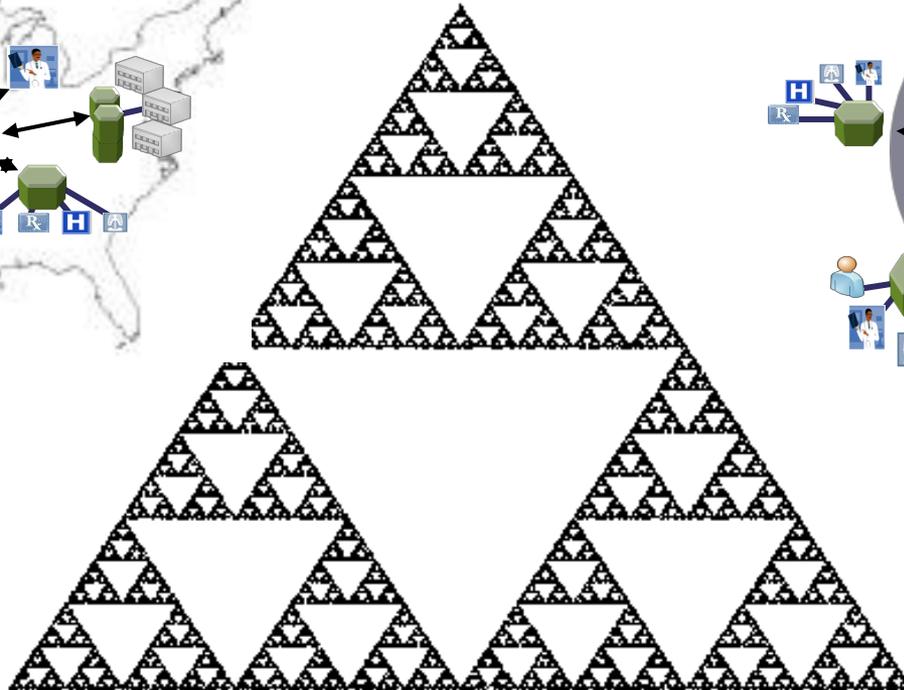
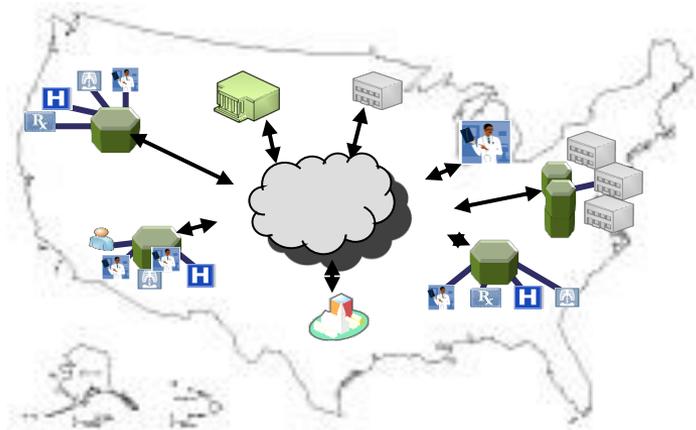
How Will the LHS Actually Work?

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

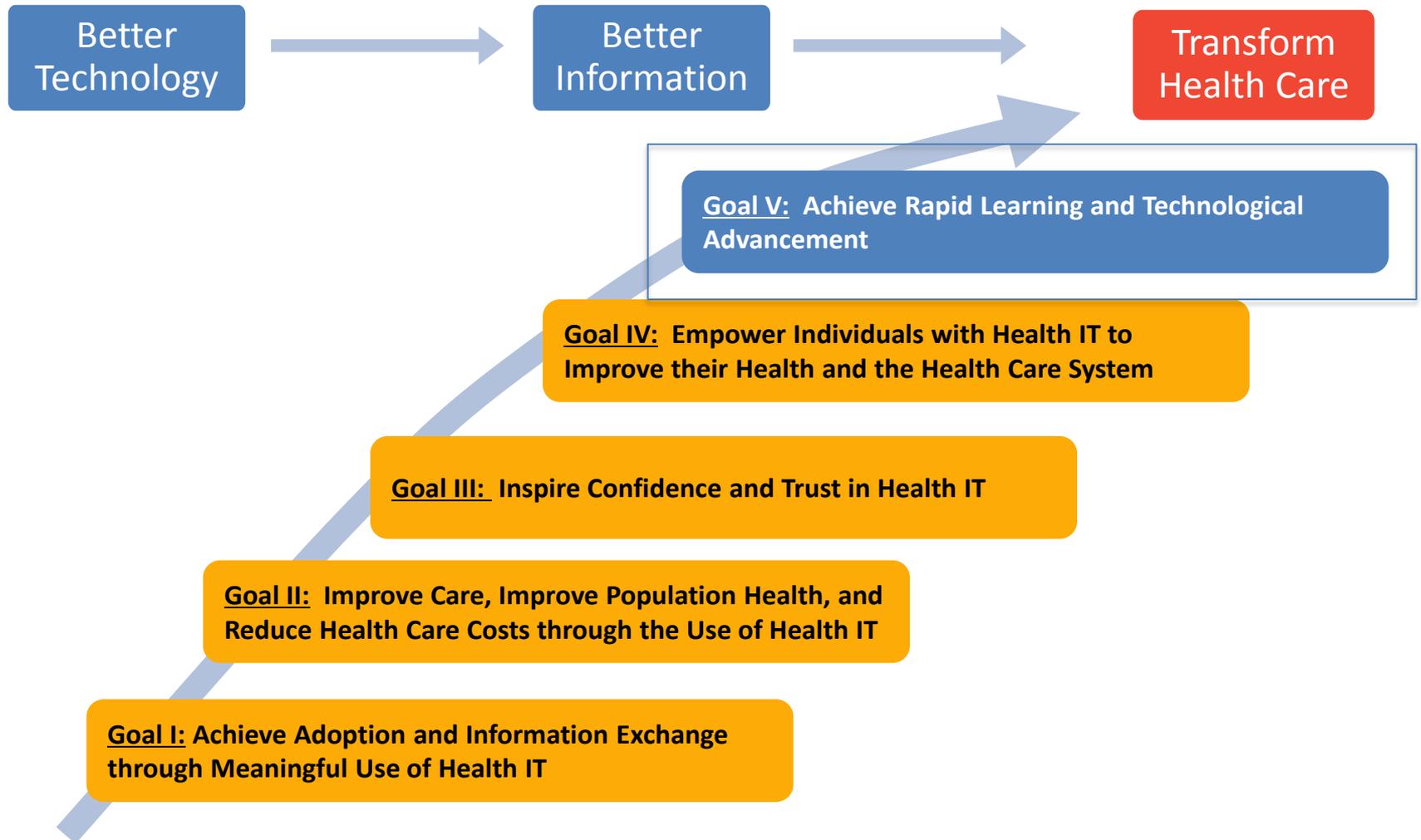
- Including people and technology
- Decentralization
- Innovation around minimal (but essential) standards
- Diverse requirements
- Continuous evolution and deployment
- Diverse and changing elements



Main Themes

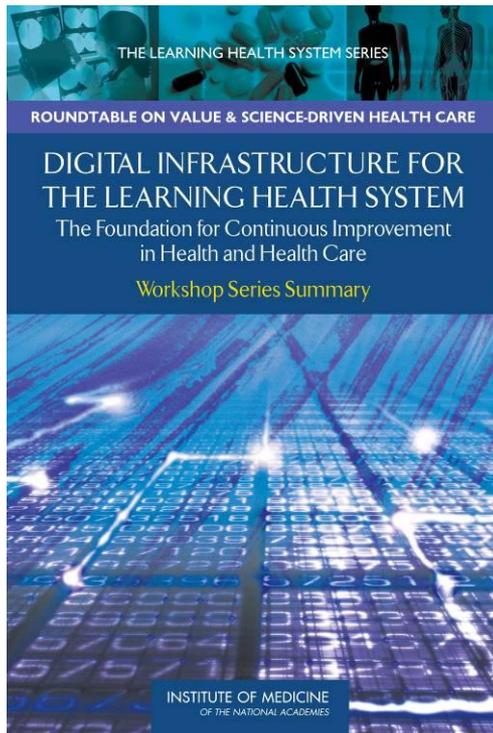
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LHS: A Pillar of the 2011 Federal Health IT Strategic Plan

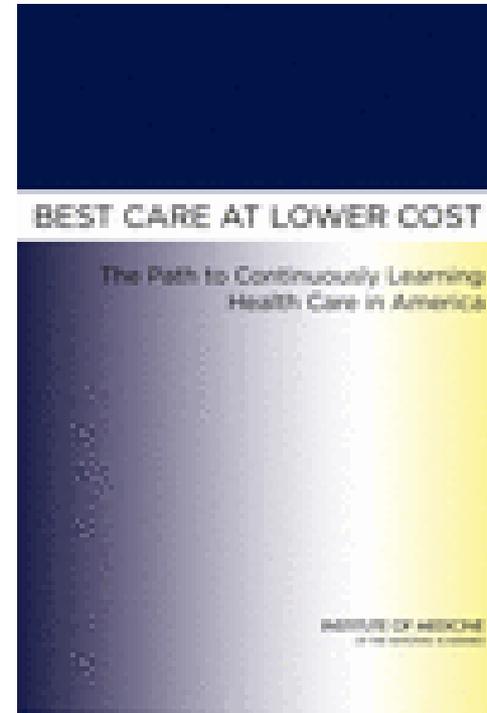


IOM Reports

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





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... 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.

And News from NIH...

NIH to recruit Associate Director for Data Science

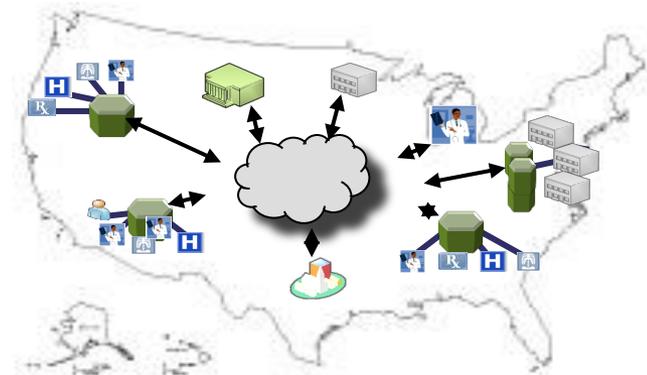
National Institutes of Health Director Francis S. Collins, M.D., Ph.D., today announced plans to recruit a new senior scientific position, the Associate Director for Data Science. The associate director will lead a series of NIH-wide strategic initiatives that collectively aim to capitalize on the exponential growth of biomedical research data, such as from genomics, imaging, and electronic health records...



Current State: An Archipelago



Toward a Federated 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

43 Endorsements of the LHS Core Values* (As of 2/28/2013)

NCHICA
North Carolina Healthcare Information and Communications Alliance, Inc.

patientslikeme

MedDATA FOUNDATION

GEISINGER HEALTH SYSTEM

ANA AMERICAN NURSES ASSOCIATION

Open Health Tools

THE CDI GROUP

NorthShore University HealthSystem

AMIA
INFORMATICS PROFESSIONALS. LEADING THE WAY.

Lewin and Associates LLC

Ursus Technologies (SDVO SB)

Minnesota e-Health

MDH DEPARTMENT OF HEALTH

SANOFI

INHS
IOWA AND NORTHWEST HEALTH SERVICES

AZZLY
One Click Patient Care Management™

SIEMENS Siemens Health Services

HealthCore

WELLPOINT

KANTER HEALTH
JOSEPH H. KANTER FAMILY FOUNDATION

M

ALTARUM INSTITUTE
SYSTEMS RESEARCH FOR BETTER HEALTH

CRITICAL PATH INSTITUTE

Rhode Island Quality Institute

Open mHealth

Duke Clinical Research Institute
DUKE UNIVERSITY MEDICAL CENTER
The Center for Learning Health Care

e-Patient Dave
A Voice of Patient Engagement

HIZ INTERNATIONAL

Genetic Alliance

COUNT US IN

Harvard Pilgrim HealthCare

2311

DANA-FARBER CANCER INSTITUTE

gsk GlaxoSmithKline

ASCO

sas

HIMSS
transforming healthcare through IT

GE Healthcare IT

University of Pittsburgh
School of Dental Medicine
Center for Dental Informatics

Medical Advocacy Mural Project
Let's change the "face" of healthcare.

*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



Robert Wood Johnson Foundation

... 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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