

Digital Infrastructure for a Learning Health System:

The Foundation for Continuous Improvement in Health and Health Care



INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the nation / Improving health

The Learning Health System is..

..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.

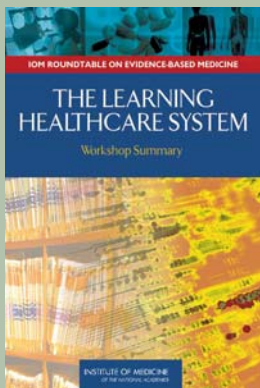


Learning Health System Characteristics

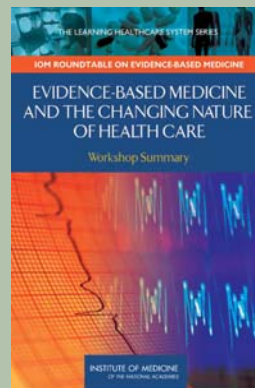
- ***Culture***: team-oriented and participatory
- ***Design and processes***: patient-anchored and tested
- ***Participants***: continuously and actively-engaged
- ***Decisions***: seamlessly-linked, informed, and facilitated
- ***Care***: starting with best practice, every time
- ***Quality and outcomes***: assessed and reported in real-time
- ***Knowledge***: ongoing by-product of care delivery and research
- ***Health information***: a reliable, secure, and reusable resource
- ***Learning utility***: data stewarded and used for the common good
- ***Information technology***: the engine for continuous learning
- ***Trust fabric***: strong, secure, and constantly nurtured
- ***Leadership***: multi-focal, networked, and dynamic



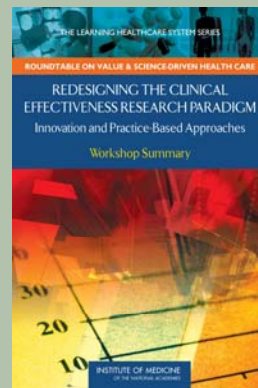
Learning Health System Series



Vision
(2007)



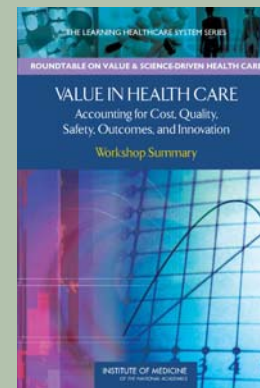
Evidence
(2008)



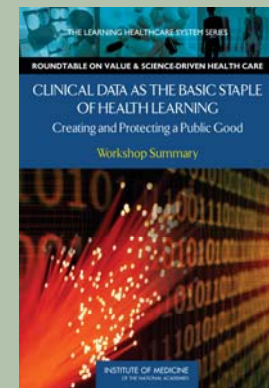
Research
(2010)



Leadership
(2010)



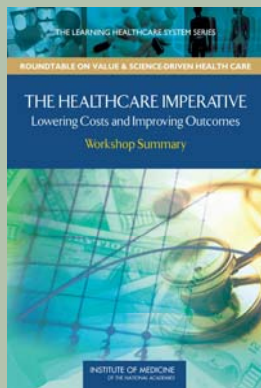
Value
(2010)



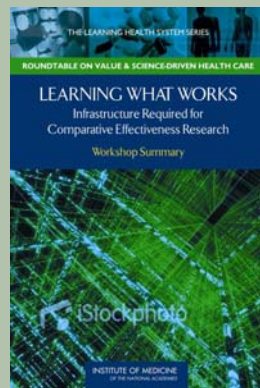
Clinical Data
(2010)



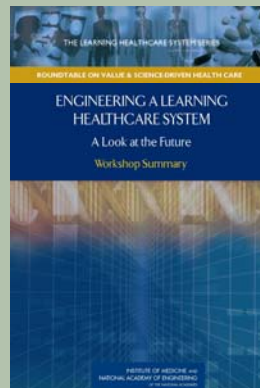
The Learning Health System Series



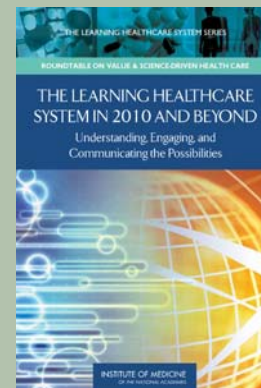
Cost
(2011)



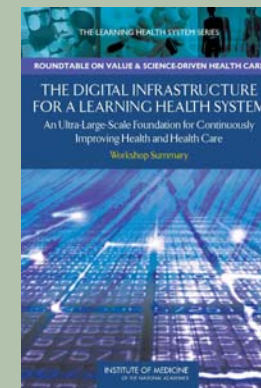
CER
Infrastructure
(2011)



Engineering
(2011)



Patients
(2011)



Digital
Infrastructure
(2011)



Planning Committee

Laura Adams	Rhode Island Quality Initiative
Ken Buetow	National Institutes of Health
Janet Corrigan	National Quality Forum
Greg Downing	Health and Human Services
Chris Greer	Office of Science and Technology Policy
John Halamka	Beth Israel Deaconess Medical Center
Rebecca Kush	Clinical Data Standards Interchange Consortium
Ken Mandl	Children's Hospital Boston
Dan Masys	Vanderbilt University
David McCallie	Cerner Corporation
Anthony Rodgers	Centers for Medicare and Medicaid Services
David Ross Public	Health Informatics Institute
Ted Shortliffe	American Medical Informatics Association
Jonathan Silverstein	University of Chicago
James Walker	Geisinger Health System
Jon White	Agency for Healthcare Research & Quality



Workshop Series Aims

- Foster a shared understanding of the vision for the digital infrastructure
- Explore current state of the system
- Identify priorities for future work
- Discuss the characteristics of potentially disruptive, breakthrough developments
- Consider strategy elements and priorities for accelerating progress

Workshops

- *Opportunities, Challenges, Priorities*
Focus on overall vision and prominent issues and opportunities.
- *The System After Next*
Deeper dive into areas identified during the first workshop.
- *Strategy Scenarios*
Reviewed common themes and extended into consideration of strategy elements, opportunities, responsibilities, and next steps.
- Focus in 4 areas:
 - **Technical progress**
 - **Knowledge generation and use**
 - **Patient and population engagement**
 - **Governance**

Report

- Introduction and Overview
- Common Themes and Principles
- Opportunities, Challenges, and Priorities
 - Visioning perspectives on the digital health utility,
 - Technical issues for the digital health infrastructure,
 - Engaging patient and population needs,
 - Weaving a strong trust fabric,
 - Stewardship and governance in the learning health system,
 - Perspectives on innovation,
 - Fostering the global dimension of the health data trust,
- Growing the Digital Health Infrastructure
- Accelerating Progress



Common Themes and Principles

- Build a shared learning environment
- Engage health and health care, patient and population
- Enable active knowledge generation and delivery loop
- Anchor in an ultra-large-scale system approach
- Leverage on the foundation of existing programs and policies
- Foster a socio-technical perspective, focused on the population
- Emphasize decentralization and specifications parsimony
- Keep barriers low and complexity incremental
- Weave a strong and secure trust fabric among stakeholders
- Provide continuous evaluation and improvement

Priority Action Targets Discussed

- Making the case
- Stakeholder involvement
- Embedded quality measures
- Distributed clinical research
- Functionality standards
- Interoperability
- Identity resolution
- Technical acceleration
- ULS system approach test bed
- Governance and coordination

