



**ELECTRONIC INFRASTRUCTURE FOR THE LEARNING HEALTHCARE SYSTEM:  
THE ROAD TO CONTINUOUS IMPROVEMENT IN HEALTH AND HEALTH CARE**

An Institute of Medicine Workshop Series  
Sponsored by the Office of the National Coordinator for Health Information  
Technology

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**WORKSHOP #1: OPPORTUNITIES, CHALLENGES, PRIORITIES**

JULY 27–28, 2010

VENABLE CONFERENCE FACILITY  
575 Seventh Street NW, WASHINGTON DC 20001

A LEARNING HEALTHCARE SYSTEM ACTIVITY  
IOM ROUNDTABLE ON VALUE & SCIENCE-DRIVEN HEALTH CARE

**Agenda**

**Day One: Tuesday July 27th**

8:00 am Coffee and light breakfast available

8:30 am	<b>Welcome, Introductions and Overview</b>
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Welcome, framing of the meeting and workshop series, agenda overview

- Michael McGinnis (Institute of Medicine)
- Charles Friedman (Office of the National Coordinator)
- Laura Adams (Planning Committee Chair)

9:00am	<b>Session 1: Visioning perspectives on the electronic health utility</b>
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National leader/decision-maker from each of several key areas will offer a perspective on the vision and opportunities for the electronic health utility, briefly describe the current state of the infrastructure, its use relative to the potential, and the key actions and priorities moving forward.

Moderator: Laura Adams (Rhode Island Quality Institute)

- **Individual and patient perspective**  
Adam Clark (Armstrong Foundation)
- **Practicing clinician perspective**  
James Walker (Geisinger)
- **Quality and safety perspective**

- Janet Corrigan (National Quality Forum)
- **Clinical research perspective**  
Christopher Chute (Mayo Clinic)
- **Population health perspective**  
Martin LaVenture (Minnesota Department of Health)

**Framing questions:**

These questions identify major strategic issues relevant to this session, and are meant as reference points for presentations, discussion, and follow-up. Presenters are not expected to address all issues.

- **Gain by 2020:** If well designed and implemented, what might be among the most striking health and healthcare outcomes by 2020 from the strategy for using IT to transform progress in your area? What is your (non-binding) quantitative “guesstimate” of the potential impact?
- **Key IT issue:** For your area, what IT issue represents the most important rate limiting factor for progress, and what simply must be part of the strategy to address it?
- **Collaborative priorities:** Who are the key players for driving change, and how can the national strategy best foster their collaborative engagement?
- **ACA platform:** From what you know of the health reform legislation (“ACA, or Accountable Care Act” for short), what emphases in the ACA implementation are particularly important components of the strategy to grow the electronic infrastructure for health and health care?
- **Other policy opportunities:** Are there other important policy opportunities that should be part of the strategy to advance progress on the technical dimensions of the learning platform?
- **Public messaging:** Since progress on each of these perspectives requires public demand at some level, what do you think should be the focus/approach of the messaging component of the national strategy?

**OPEN DISCUSSION**

11:00am	<b>Session 2: Technical strategies: data input, access, use—and beyond</b>
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Presentations to consider issues, needs, and approaches related to data input, access and use—as well as infrastructure requirements to foster web-mediated remote-site interventions—for continuous learning and improvement in health and health care.

Moderator: Chris Greer (Office of Science and Technology Policy)

- **Building on the foundation of meaningful use**  
Doug Fridsma (Office of the National Coordinator for Health IT)
- **Interoperability for the learning healthcare system**

- Rebecca Kush (Clinical Data Interchange Standards Consortium)
- **Grids, federations and clouds**  
Jonathan Silverstein (University of Chicago)
- **Innovative approaches to information diversity**  
Shaun Grannis (Regenstrief Institute)

A panel of responders from the quality, clinical research, and population health communities to respond to presentations, share their experiences, and propose solutions.

Ida Sim (University of California, San Francisco)

John Halamka (Beth Israel Deaconess Medical Center)

Robert Kahn (Corporation for National Research Initiatives)

### **Framing questions:**

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- **Major data strategies:** Taking the Meaningful Use provisions as the starting point, what are the primary issues and approaches to assuring the quality and capture of clinical data, including accommodation of emerging and novel information and data for continuous learning?
- **Interoperability strategies:** What improvements can be made in current approaches to clinical data base interoperability? What might disruptive innovation look like on this dimension?
- **Dealing with information heterogeneity:** What strategies are important to promote the capacity and utility of data from increasingly diverse sources—e.g. genetic profiles, patient-generated input, and mobile health devices?
- **Accommodating the multiple facets of the electronic utility:** What strategies are important to promote the capacity and utility of the infrastructure for multiple purposes—e.g. effective patient care, near- and remote-site clinical decisions and interventions, informing patients, public health responses, and real-time and virtual research?
- **Standards-based priorities and alternatives:** Given the various efforts underway on standards to guide the development, adoption, interoperability, effectiveness, efficiency, and utility of electronic health records, what are the strategic priorities for innovation-friendly adoption of those standards? What alternatives exist to standards-based approaches that deserve particular emphasis in the strategic options?
- **Fostering innovation:** What strategic opportunities exist in identification and promotion of novel technologies and approaches to the use of our electronic infrastructure in health—e.g. data aggregation,

process automation, real-time learning and adaptation, electronic clinical trials, pattern- and signal-recognition technologies, clustering algorithms? Are there insights from other industries in these areas that could be extended to health data? How can this cross pollination be cultivated?

## OPEN DISCUSSION

1:00pm	<b>Lunch Available</b>
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1:10pm	<b>Session 3: Ensuring engagement of population and patient needs</b>
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Presentations to consider issues, needs, and approaches in use of the electronic infrastructure to address compelling priorities in patient and population health improvement.

Moderator: Patricia Brennan (University of Wisconsin)

- **Transparency on cost and outcome at individual and population levels**  
Mark McClellan (Brookings Institution)
- **Integrated use of personal and population-wide data sources**  
Ken Mandl (Harvard University)
- **Optimizing chronic disease care & control**  
Sophia Chang (California Health Care Foundation)
- **Targeting population health disparities**  
Christopher Gibbons (Johns Hopkins University)

Panel of responders respond to presentations, share their experiences, and propose solutions.

Don Kemper (Healthwise)  
Eric Larson (Group Health)  
Jim Hansen (Dossia)

### **Framing questions:**

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- **Promoting better value in health care:** How can the nation's electronic health infrastructure identify and draw attention to health care activities that are most wasteful, as well as those that deliver the highest value? How can outcome and cost data be more seamlessly and reliably linked to produce needed insights and awareness on value from health care?

- **Effectiveness in health care:** What strategy options for our electronic health infrastructure are most important to continuous and accelerated insights on the effectiveness—and comparative effectiveness—of health interventions and services?
- **Social- and income-related disparities:** Which dimensions of the electronic health infrastructure are key to better understanding and acting to address the actionable elements of social- and income-related health disparities? What might be disruptive innovations targeted to unique characteristics of these populations?
- **Chronic disease management:** What options—within and among providers, and between clinical and community efforts—are most compelling for using our electronic infrastructure to improve the control and management of the growing burden of chronic diseases in the nation (and globally)? For example, how can work on the following be best facilitated?
  - o Overweight and obesity control
  - o Management of multiple co-occurring conditions
  - o End-of-life care
  - o Self care promotion
  - o Team care and facilitated clinical decision-making
  - o Clinical and community delivery of recommended preventive services
- **Integrating clinical and other input:** What ways might be envisioned for the integration and use of clinical and population health data to accelerate progress in improving health care and health outcomes on priority health challenges? What strategies are most important for this to occur?
- **Communicating the possibilities:** What will be the best approach to engaging the population and educating them to these opportunities? Since progress on each of these perspectives requires public demand at some level, what should be the focus/approach of the messaging component of a national strategy?
- **ACA platform:** From what you know of the health reform legislation (“ACA, or Accountable Care Act” for short), what emphases in the ACA implementation offer particularly important support for ensuring that our electronic infrastructure is optimally positioned to improve health and health care outcomes?

## OPEN DISCUSSION

Presentations to consider issues, needs, and approaches related to building the broad scale confidence necessary for operation of the electronic infrastructure for continuously learning and improving health and health care programs.

Moderator: Mark Frisse (Vanderbilt)

➤ **Facilitating and chronicling data use for better health and health care**

Edward Shortliffe (American Medical Informatics Association)

➤ **Privacy and consent strategies**

Deven McGraw (Center for Democracy and Technology)

➤ **HIPAA and a learning healthcare system**

Bradley Malin (Vanderbilt)

➤ **System security**

Ian Foster (Argonne National Lab)

A panel of responders from ongoing collaborative efforts and experts with big-picture perspectives respond to presentations, share their experiences, and propose solutions.

Robert Shelton (Private Access)

Kristen Rosati (Coppersmith Schermer & Brockelman PLC)

Richard Platt (Harvard Pilgrim)

**Framing questions:**

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- **Patient control, use and demand:** Assuming the level of consumer confidence in and comfort with elements of the e-health infrastructure is an important element of the trust fabric, what ought to be the central strategic priorities for increasing consumer/patient control, use and demand for stronger infrastructure capacity?
- **Transparency of benefits and risks:** If trust derives from clarity of understanding of the relative benefits and risks attendant to the state of infrastructure function, who should take responsibility for assessment and reporting on these dimensions?
- **Knowledge generation:** What are the most effective approaches to increasing the availability and reliable use of data for clinical research and new knowledge?
- **Regulatory and audit streamlining:** How should the national strategy work to avoid unnecessarily restrictive and duplicative regulatory activities related to safeguarding access and use of data for improved patient care and knowledge development?
- **Expanding the public utility notion:** What are the implications and options for positioning the nation's electronic infrastructure for health as

a public utility, in ways akin to the basic utilities such as water, electricity, roads?

- **Lessons from other sectors:** In shaping strategies to improve the trust fabric for the e-health infrastructure, what are the most salient lessons from other sectors—e.g. financial services?

## OPEN DISCUSSION

5:00pm	<b>Concluding Keynote</b>
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David Blumenthal (National Coordinator for Health Information Technology)

5:30pm	<b>Adjourn to reception</b>
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## Day Two: Wednesday July 28<sup>th</sup>

8:00 am Coffee and light breakfast available

8:30am	<b>Welcome and Re-cap of First Day</b>
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9:00am	<b>Session 5: Stewardship and governance in the learning health system</b>
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Presentations on issues, needs, approaches, and arrangements—formal and informal, public and private, national and international—necessary to steward the development of an electronic infrastructure to deliver health data and information which is timely, user-friendly, secure, reliable, research-ready, supports continuous learning and accelerated improvements in health and health care.

Moderator: Michael Kahn (Children's Hospital Denver)

- **Governance coordination, needs and options**  
Laura Adams (Rhode Island Quality Institute)
- **Leveraging the need for consistency and reliability in reporting for regulators**  
Theresa Mullin (Food and Drug Administration)
- **Research access and prioritization issues**  
Shawn Murphy (Partners HealthCare)
- **A case study in governance: The National Information Governance Board for Health and Social Care (UK)**  
Harry Cayton (National Information Governance Board)

Panel of responders from ongoing efforts and experts with big-picture perspectives respond to presentations, share their experiences, and propose solutions.

Rachel Nosowsky (University of California)

Don Detmer (University of Virginia)

Meryl Bloomrosen (American Medical Informatics Association)

Doug Peddicord (Oldaker, Belair & Wittie)

### **Framing questions:**

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- **Priority governance needs/goals:** What's needed? On which dimensions of importance to the emergence of the electronic health utility do you feel governing guidance or requirements will be most facilitative in addressing rate limiting factors?

- **Operational principles:** In contemplating the issues and approaches most important for facilitative governance, what do you feel are the primary principles that should guide the choice of focus, structure, and operation?
- **Public engagement:** How and on what dimensions can the public be best engaged to provide ongoing input, counsel and guidance?
- **Other implementation issues:** In shaping the agenda, approaches, and activities, how should each of the following be addressed?
  - o Overlapping mandatory and voluntary governance responsibilities
  - o Accommodating existing standards bodies
  - o Role(s) of government(s)
  - o Enforcement approaches, requirements, and mandates
  - o Support for, and investment in, innovation and local initiative
  - o International harmonization
- **Structural options and models:** What structural options should be considered, e.g. federated and intergovernmental, collaborative and professional, central and formal or loosely relational? Are there existing approaches in this or other arenas that might serve as models for consideration?
- **Approach forward:** Given the various issues in play, what do you feel might be the key next steps for progress on the governance front?

## OPEN DISCUSSION

11:00am	<b>Session 6: Fostering the global dimension of the health data trust</b>
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Presentations to consider issues, needs, and approaches related to setting the stage for evolution of an electronic infrastructure that can serve as a global resource for continuous learning and improvement for health and health care programs.

Moderator: Michael Ibara (Pfizer)

- **Transform**  
Brendan Delaney (Kings College)
- **HealthGRID/SHARE**  
Tony Solomonides (University of the West England, Bristol)
- **Global collaborative safety strategies**  
Ashish Jha (Harvard University)
- **Global public health strategies**  
David Buckeridge (McGill University)

**Framing questions:**

These questions identify major strategic issues relevant to this session, and are meant as reference points for presentations, discussion, and follow-up. Presenters are not expected to address all issues.

- **Global public health networking:** Based on recent experiences such as those with H1N1, what technical or process breakthroughs are required to steward the evolution of a global public health network?
- **Global safety and effectiveness networking:** Based on your experience in promoting international cooperation and data sharing in patient safety and bio-surveillance, what steps are necessary to take the outcomes to the next level and beyond?
- **Global clinical research networking:** Since clinical research may require navigating more complex data sets than those required to detect safety and outbreak signals, what priority steps might best help build toward a global clinical research network for real-time learning?
- **Global collaborative vehicles/mechanisms:** What vehicles are in place, or need to be created, to address challenges of the sort you have confronted and to accelerate the emergence of what might be called the global data trust for health improvement? Can we garner insights from any other sectors?
- **Protocols for data quality and security:** What are the key steps to ensuring the quality of data from so many marginally compatible systems and sources as well as its security?
- **Protocols for finding authentication/validation:** What approaches might be considered to assess the constraints on comparative data from different cultures?

## OPEN DISCUSSION

12:30 pm	<b>Lunch</b>
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1:00pm	<b>Session 7: Perspectives on Innovation</b>
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Thought leader participants from across stakeholder groups as well as from outside the health field to reflect on the meeting's discussions, respond to questions, and offer unique insights and novel perspectives on innovation strategies for the electronic infrastructure supporting continuous learning and improvement in health and health care.

Moderator: John Halamka (Beth Israel Deaconess Medical Center)

Daniel Friedman (Population and Public Health Information Services)

Molly Coye (Public Health Institute)

Matthew Holt (Health 2.0)

Michael Liebhold (Institute for the Future)

### **Framing questions:**

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- **Stewardship of the technologic frontiers:** What strategy options might be most productive in creating, identifying and fostering the application to health of emerging concepts, approaches and functionalities in information technology?
- **Shortening the cycle time:** With the goal of continuous and real-time learning and application for health improvement, what strategy options might be most productive in shorting the input-output-feedback cycle time?
- **Role of the public/patient:** How can the public and the patient best be positioned simultaneously as the central focus of and a promoter and designer for the electronic infrastructure.
- **Role of the clinician:** Similarly, what are the potential strategic options for assuring optimal support for the clinician contending simultaneously with dynamic changes in the science and resource base for care content, and with team- and patient-driven elements of care culture?
- **Fostering investment:** What are the most promising strategic options, approaches and sources for investment support in the development, operation, and innovation in the national electronic infrastructure for health?
- **Disruptive innovation:** On what dimension might disruptive innovation be most likely for our electronic health infrastructure, and what are the implications for shaping a dynamic national e-health utility strategy?

### **OPEN DISCUSSION**

2:30pm	<b>Session 8: Breakout Sessions</b>
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Five small groups will assemble with representation spanning the affinity groups of interest—individual and patient, practicing clinician, quality improvement experts, clinical researchers, and population health—to identify key principles and strategies for development of the electronic infrastructure envisioned—including identification of questions addressed to the panel of responders.

4:00pm	<b>Session 9: Reporting back to the group</b>
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This session will feature reports back from small groups on proposed strategic approaches, followed by discussion across groups, and identification of common themes across approaches, challenges, and solutions.

## OPEN DISCUSSION

5:30pm	<b>Summary, Next Steps and Concluding Remarks</b>
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6:00pm	<b>Adjourn</b>
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### Upcoming sessions

- September 7–8, 2010: WORKSHOP #2: THE SYSTEM AFTER NEXT
- September 28, 2010: WORKSHOP #3: STRATEGY SCENARIOS

### Series objectives

1. Foster a shared understanding of the vision for the electronic infrastructure for continuous learning and quality-driven health and health care programs.
2. Explore current capacity, approaches, incentives, and policies; and identify key technologic, organizational, policy, and implementation priorities.
3. Discuss the characteristics of potentially disruptive, breakthrough developments.

### Issues motivating the discussion (cont.)

- Meaningful Use criteria and health reform provisions that provide starting points and incentives for the development of a learning system for quality improvement and population health, while underscoring the need to be strategic on issues and opportunities, while maintaining flexibility to accommodate breakthrough capacities.
- Need for careful attention to limiting the burden for health data collection to the issues most important to patient care and knowledge generation.
- Requirement for governance policies that foster the data utility for the common good, cultivate the trust fabric with the public and between data sharing entities, and accelerate collaborative progress.
- Availability of standards for aggregation of large pools of data for purposes such as CER, biomarker validation, disease modeling and improving research processes.

### Approach

- Three meetings in the series: the first will engage the overall vision and consider the priority issues to current opportunities for a data infrastructure, the second will look to the future prospects as innovation proceeds, and the third will be devoted to developing strategy options that will best accelerate progress.
- The flow of the first meeting will:
  - Begin with presentations on the vision of the possibilities for our electronic infrastructure to enable continuous learning and improvement in health and

## **Planning Committee**

Laura Adams (chair), National eHealth Collaborative  
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 Interchange Standards Consortium  
Martin LaVenture, Minnesota Department of Health  
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 and Quality