



# DIGITAL DATA PRIORITIES FOR CONTINUOUS LEARNING IN HEALTH AND HEALTH CARE

*An Institute of Medicine Workshop*

*Sponsored by the Office of the National Coordinator for Health Information Technology*

MARCH 23, 2012

KECK CENTER

500 FIFTH STREET NW, WASHINGTON DC 20001

A LEARNING HEALTH SYSTEM ACTIVITY

IOM ROUNDTABLE ON VALUE & SCIENCE-DRIVEN HEALTH CARE

## Meeting objectives

1. Discuss the current quality status of digital health data.
2. Explore challenges, and identify key questions related to data quality in the use of EHRs, patient registries, administrative data, and public health sources for learning—continuous and episodic—and for system operational and improvement purposes.
3. Engage individuals and organizations leading the way in improving the reliability, availability, and usability of digital health data for real-time knowledge generation and health improvement in a continuously learning health system.
4. Identify and characterize the current deficiencies and consider strategies, priorities, and responsibilities to address the deficiencies.
5. Initiate the development of a strategic framework for integrated and networked stewardship of efforts to continuously increase digital data utility.

## Agenda

7:30 am Coffee and light breakfast available

8:00 am	<b>Welcome, introductions and overview</b>
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Welcome, framing of the meeting and agenda overview

- Michael McGinnis (Institute of Medicine)
- Farzad Mostashari (Office of the National Coordinator)
- Jim Walker (Planning Committee Chair)

8:15 am	<b>Characteristics, challenges, and determinants of data quality</b>
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- **Session Description:** This session includes brief comments on the data quality challenges that lie ahead and a longer discussion of the characteristics and determinants of digital health data quality.

➤ **Key Topics:**

- Challenges on the horizon  
*Doug Fridsma (ONC)*
- Characteristics and determinants of data quality  
*Marc Overhage (Siemens)*

**OPEN DISCUSSION**

9:00am	<b>Performance assessment</b>
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- **Session Description:** This session focuses on the quality of digital health data needed to evaluate clinical care delivery, population management and the business and operating processes that make up a learning health system

➤ **Key Topics:**

- Assessing value  
*Carol McCall (GNS)*
- Managing populations and processes  
*Mark Leenay (OptumHealth)*

**OPEN DISCUSSION**

10:00am	<b>Break</b>
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10:15am	<b>Enabling research</b>
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- **Session Description:** This session focuses on the quality of digital health data needed to enable research.

➤ **Key Topics:**

- Clinical research  
*Rebecca Kush (Clinical Data Interchange Standards Consortium)*
- Translational informatics  
*Mia Levy (Vanderbilt)*

**OPEN DISCUSSION**

11:15am	<b>Supporting public health and surveillance</b>
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- **Session Description:** This session focuses on the quality of digital health data needed to support of public health functions, including surveillance

- **Key Topics:**

- Public health surveillance and management  
*James Buebler (CDC)*
- State-level perspective  
*Martin LaVenture (Minnesota Dept of Health)*

### OPEN DISCUSSION

12:15pm	<b>Lunch keynote</b>
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Who is your customer?  
*James Heywood, PatientsLikeMe*

1:00pm	<b>Approaches to continuous improvement using large-scale data sets</b>
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- **Session Description:** Session presentations will focus on the implications of digital health data quality on the potential for learning from large amounts of health data.

- **Key Topics:**

- Using distributed data/ Query Health  
*Rich Platt (Harvard) and Rich Elmore (ONC)*
- Data analysis and discovery of significant patterns  
*David Madigan (OMOP/ Columbia)*

### OPEN DISCUSSION

2:00pm	<b>Innovative approaches to addressing data challenges</b>
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- **Session Description:** This session will focus on innovative approaches to overcoming some prominent challenges associated with using health data.

- **Topics:**

- Data harmonization  
*Chris Chute (Mayo)*
- Linking data across time and sources  
*Vik Khetarpal (CareEvolution Inc)*

## OPEN DISCUSSION

3:00pm	<b>Strategies going forward</b>
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➤ **Session Description:** This session will include a rapid-fire, moderated discussion to identify the top 10 actions necessary for progress discussed during the course of the meeting.

1. Identification of potential action steps - 20 min. (45 seconds each)
2. Rapid identification of pros and cons - 15 min.
3. Identification of top ten leading action steps - 25 min.

## OPEN DISCUSSION

4:00pm	<b>Next steps</b>
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➤ **Session Description:** This session will build off of the ten action steps identified in the previous session and outline options to move forward.

5:00pm	<b>Adjourn</b>
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### Planning Committee

James Walker (chair)	Geisinger Health System
Justine Carr	Steward Health Care
William DuMouchel	Oracle
Jamie Heywood	Patients Like Me
Rebecca D. Kush	Clinical Data Standards Interchange Consortium
Lisa M. Lee	Centers for Disease Control and Prevention
Theresa M. Mullin	Food and Drug Administration
Lucila Ohno-Machado	University of California San Diego
Richard Platt	Harvard University
Jim Scanlon	U.S. Department of Health and Human Services
Paul Stang	Johnson & Johnson
Walter Suarez	Kaiser Permanente