



DATA HARMONIZATION FOR PATIENT-CENTERED CLINICAL RESEARCH

*An Institute of Medicine Workshop
Sponsored by Patient-Centered Outcomes Research Institute*



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

OCTOBER 31-NOVEMBER 1 2013
THE NATIONAL ACADEMY OF SCIENCES
2101 CONSTITUTION AVENUE, NW
WASHINGTON, DC

Meeting goals

1. Inform the work of the Patient Centered Outcomes Research Institute’s (PCORI) National Patient-Centered Clinical Research Network (NCRN) awardees and coordinating center in working toward inter-network data harmonization.
2. Reflect on past efforts and current state of the art approaches to help identify barriers and challenges, share best practices, and identify options for progress in the area of data harmonization.
3. Identify strategic priorities for accelerating data interoperability between PCORI NCRN awardees and existing national data sharing activities.

Day 1: Thursday October 31, 2013

8:00 am Coffee and light breakfast available

8:30 am	Welcome, Introductions, and Overview
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Welcome from the IOM
Michael McGinnis, Institute of Medicine

Opening remarks and meeting overview
Joe Selby, Patient-Centered Outcomes Research Institute
Michael Kahn, University of Colorado

8:45 am	Context setting
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This session will serve to lay out the context for the meeting and orient all participants to the tasks which will be carried out during the small group work.

Setting up NCRN grantees for success

Joe Selby, Patient-Centered Outcomes Research Institute

Perspective of NCRN coordinating center

Lesley Curtis, Duke University

Experiences with cohort counts across networks

Jeff Brown, Harvard Pilgrim Health Care Institute

Experiences with cohort summary statistics across networks

Martijn Schuemie, Janssen Research and Development

Experiences with cohort lists for re-identification and recruitment across networks

Jim Cimino, National Institutes of Health

Experiences with expanded data sources for cohorts and outcomes

Sally Okun, PatientsLikeMe

Q&A and Open Discussion

11:00 am

Lunch and small group work

Lunch boxes will be provided so participants can pick up their lunch and eat in their breakout group rooms.

Participants will be broken into 3 groups focusing on the following components of the data harmonization effort:

1. **Data models and terminology** (including meaningful use, assessing models)
Moderator: Patrick Ryan, Janssen Research and Development and OMOP
2. **Data harmonization implementation and sustainability** (including data model governance)
Moderator: Michael Kahn, University of Colorado
3. **Strategies for dealing with expanded data sources** (including patient reported outcomes, remote monitoring)
Moderator: Sharon Terry, Genetic Alliance

For their respective areas, groups are asked to:

- Using the example use cases to frame (and contain) your discussions to the data harmonization task, review the basic work plan developed by the planning committee
- Identify, for their topic, where they think barriers will be, lay out options and alternatives for addressing barriers (including pros and cons), and highlight most important components
- Suggest who could be responsible for taking on approaches suggested (Awardees, coordinating center)

- Add any missing components of draft work plan
- Select one member of the group to report back on the progress of the breakout group to the whole meeting, and one member to keep track of and report back on areas where participants expressed differing views

1:30 pm	Report back and discussion
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Each breakout group will report back on progress and areas of differing perspectives.

Group will be led in brief initial discussion of reports and prioritize areas for further discussion the next day.

3:30 pm	Summary and instructions for Day 2
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Comments from the Chair

Michael Kahn, University of Colorado

4:00 pm **Adjourn to Reception**

Day 2: Friday November 1, 2013

9:00 am Coffee and light breakfast available

9:30 am	Welcome and Overview
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Brief reminder of task at hand and summary of discussion on Day 1.

Michael Kahn, University of Colorado

9:45 am	Discussion
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This session will continue the discussion from the day before, focusing on areas in need of continued discussion, integration of recommendations and key barriers, synthesis of key execution milestones to achieve the use cases.

10:45 am	Priorities and strategies for progress
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The goal of this session will be to identify priorities and strategies for the work of the Coordinating center and awardees toward data harmonization.

12:00 pm	Summary and next steps
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Michael Kahn, University of Colorado
Joe Selby, Patient-Centered Outcomes Research Institute

Comments and thanks from the IOM

Michael McGinnis, Institute of Medicine

12:30 pm **Adjourn (Box lunches available)**

Planning Committee

Michael Kahn, MD, PhD, University of Colorado (Chair)
Christopher G. Chute, MD, DrPH, MPH, Mayo Clinic
James J. Cimino, MD, National Institutes of Health
Lesley H. Curtis, PhD, Duke Clinical Research Institute, Duke University
Rachael Fleurence, PhD, Patient-Centered Outcomes Research Institute
Doug Fridsma, MD, PhD, Office of the National Coordinator for Health IT
Betsy L. Humphreys, MLS, National Library of Medicine, NIH
Rebecca D. Kush, PhD, Clinical Data Interchange Standards Consortium
Shawn N. Murphy, MD, PhD, Partners HealthCare System
Patrick Ryan, PhD, Janssen Research and Development
Joe V. Selby, MD, MPH, Patient-Centered Outcomes Research Institute
Sharon Terry, Genetic Alliance

Staff officer: Claudia Grossmann PhD

cgrossmann@nas.edu

(202) 334-3867