



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Patient-Centered Outcomes Research Institute

National Workshop to Advance the Use of Electronic Data in Patient-Centered Outcomes Research

July 2-3, 2012 | Palo Alto, CA

AGENDA

A webcast will be provided for this workshop. Details on registering for the webcast will be posted in the Meetings & Events section of the PCORI website: www.pcori.org/meetings-events.

All Times Pacific

Monday, July 2, 2012

8:00 - 8:15 a.m.	Welcome and Introduction <i>Steven Goodman, MD, MHS, PhD, Associate Dean for Clinical and Translational Research, Stanford University School of Medicine, Member, PCORI Methodology Committee</i>
8:15 - 8:45 a.m.	What Are We Looking For? <i>Joe Selby, MD, MPH, Executive Director, PCORI</i> <ul style="list-style-type: none">• PCORI's "Desirable Characteristics" in developing data infrastructure for the conduct of patient-centered outcomes research?
8:45 - 9:00 a.m.	A Vision for a National Research Network <i>Francis Collins, MD, PhD, Director, National Institutes of Health, Member, PCORI Board of Governors</i>
9:00 - 9:45 a.m.	Survey of the Landscape – Governmental, NGO, Methodological Perspectives <i>Erin Holve, MPH, MPP, PhD, Director of Research and Education in HSR, Academy Health</i> <i>Lucila Ohno-Machado, MD, PhD, Chief of the Division of Biomedical Informatics, Associate Dean for Informatics and Technology, University of California, San Diego</i>
9:45 - 10:10 a.m.	Questions and Discussion
10:10 - 10:30 a.m.	Break (<i>meeting and webcast will resume at 10:30 a.m.</i>)

10:30 - 11:30 am

Lessons from the Field

Sebastian Schneeweiss, MD, ScD, Associate Professor, Harvard Medical School, Department of Epidemiology, Member, PCORI Methodology Committee

Case Studies:

- HMO Research Network (HMORN) – **Eric Larson, MACP, MD, MPH**, Executive Director, Group Health Research Institute
- Sentinel – **Patrick Archdeacon, MD**, Medical Officer, Food and Drug Administration

Respondents:

- **Regina Greer-Smith, MPH, FACHE**, Healthcare Coordinator, Enhanced Medical Services Collaboration
- **Deven McGraw, JD, LLM, MPH**, Director of Health Privacy, Center for Democracy and Technology
- **Richard Platt, MD, MSc**, Director Harvard Pilgrim Healthcare/DEcIDE Network, HMO
- **Gurvaneet Randhawa, MD, MPH**, Medical Officer, Agency for Healthcare Research and Quality

11:30 - 12:30 p.m.

Lessons from the Field

Robin Newhouse, PhD, RN, FAAN, NEA-BC, Chair and Associate Professor, University of Maryland School of Nursing, Member, PCORI Methodology Committee

Case Studies:

- DARTNet – **David West, PhD**, Director Colorado Health Outcomes
- SCANNER – **Michele Day, PhD**, Program Manager, SCANNER

Respondents:

- **Suzanne Bakken, DNSc, RN, FAAN, FACMI**, Professor, Director for the Center for Evidence-Based Practice in the Underserved, Columbia University
- **Doug Fridsma, MD, PhD**, Chief Scientist, Office of the National Coordinator for Health Information Technology
- **Tracy Lieu, MD, MPH**, Director, Division of Research, Kaiser Permanente
- **Paul Tang, MD, MS**, Vice President, Chief Innovation and Technology Office, Palo Alto Medical Foundation

12:30 - 1:30 p.m.

Lunch (meeting and webcast will resume at 1:30 p.m.)

1:30 - 1:50 p.m.	Survey of the Landscape – Industry Perspective Bob Kocher, MD, Partner, Venrock
1:50 - 2:50 p.m.	Lessons from the Field Rick Kuntz, MD, MSc, Senior Vice President and Chief Scientific, Clinical and Regulatory Officer, Medtronic, Member, PCORI Board of Governors
Case Studies:	
	<ul style="list-style-type: none">• C3N – Peter Margolis, MD, PhD, Co-Director, Center for Health Care Quality, Director of Research, James M. Anderson Center, Cincinnati Children's Hospital• Registry of Registries – Rich Gliklich , MD, President, Quintiles Outcomes
Respondents:	
	<ul style="list-style-type: none">○ Basit Chaudhry, MD, PhD, Medical Scientist, IBM○ Ben Heywood, MBA, President, PatientsLikeMe○ Bob Jesse, MD, PhD, Principal Deputy Under Secretary for Health, Department of Veterans Affairs, Member, PCORI Board of Governors
2:50 - 3:10 p.m.	Break **Webcast will not be available for Breakout Groups or Poster Session**
3:00 – 5:00 p.m.	Breakout Groups: <ul style="list-style-type: none">• Governance – Including models of governance structure, and key issues such as data ownership and data availability• Data Standards and Interoperability• Architecture• Privacy and Ethical Issues – Including IRB issues, informed consent, and HIPAA• Methods – With an eye towards overcoming imperfect data• Unconventional Approaches• Incorporating Patient Reported Outcomes
5:30 – 6:30 p.m.	Poster Session

Tuesday, July 3, 2012

8:00 - 8:15 a.m.	Welcome, Review of Agenda and Recap of Poster Session Steven Goodman, MD, MHS, PhD, Associate Dean for Clinical and Translational Research, Stanford University School of Medicine, Member, PCORI Methodology Committee
8:15 - 10:45 am	Charting the Course – Exploring Top Proposals from Poster Sessions Harlan Krumholz, MD, Harold H. Hines Jr. Professor of Medicine, Yale University School of Medicine, Member, PCORI Board of Governors

10:45 - 11:00 a.m.	Break
11:00 - 11:45 am	PCORI-Attendee Dialogue <i>Sherine Gabriel, MD, MSc, Professor of Medicine and of Epidemiology, Mayo Clinic, Chair, PCORI Methodology Committee</i> <i>Steven Goodman, MD, MHS, PhD, Associate Dean for Clinical and Translational Research, Stanford University School of Medicine, Member, PCORI Methodology Committee</i> <i>Joe Selby, MD, MPH, Executive Director, PCORI</i> <i>Allen Douma, MD – CEO, Empower, LLC, Member, PCORI Board of Governors</i>
11:45 – 11:50 p.m.	Wrap Up and Adjourn

About PCORI

The Patient-Centered Outcomes Research Institute (PCORI) is an independent, non-profit organization authorized by Congress. Its mission is to fund research that will provide patients, their caregivers and clinicians with the evidence-based information needed to make better-informed health care decisions. PCORI is committed to continuously seeking input from a broad range of stakeholders to guide its work. More information is available at www.pcori.org.