

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

Steven Goodman, MD, MHS, PhD, Associate Dean for Clinical and Translational Research, Stanford University School of Medicine, Member, PCORI Methodology Committee

8:15 - 8:45 a.m.

What Are We Looking For?

Joe Selby, MD, MPH, Executive Director, PCORI

- 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

Francis Collins, MD, PhD, Director, National Institutes of Health, Member, PCORI Board of Governors

9:00 - 9:45 a.m.

Survey of the Landscape – Governmental, NGO, Methodological Perspectives

Erin Holve, MPH, MPP, PhD, Director of Research and Education in HSR, Academy Health

Lucila Ohno-Machado, MD, PhD, Chief of the Division of Biomedical Informatics, Associate Dean for Informatics and Technology, University of California, San Diego

9:45 - 10:10 a.m.

Questions and Discussion

10:10 - 10:30 a.m.

Break (*meeting and webcast will resume at 10:30 a.m.*)

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, LL.M, 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:

- 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:

- **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:

- 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

Sherine Gabriel, MD, MSc, Professor of Medicine and of Epidemiology, Mayo Clinic, Chair, PCORI Methodology Committee

Steven Goodman, MD, MHS, PhD, Associate Dean for Clinical and Translational Research, Stanford University School of Medicine, Member, PCORI Methodology Committee

Joe Selby, MD, MPH, Executive Director, PCORI

Allen Douma, MD – CEO, Empower, LLC, Member, PCORI Board of Governors

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.