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, 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,** Program 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 Fritsma, 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, Venroc

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
\textit{Sherine Gabriel, MD, MSc, Professor of Medicine and of Epidemiology, The Mayo Clinic, Chair, PCORI Methodology Committee}
\textit{Steven Goodman, MD, MHS, PhD, Associate Dean for Clinical and Translational Research, Stanford University School of Medicine, Member, PCORI Methodology Committee}
\textit{Joe Selby, MD, MPH, Executive Director, PCORI}
\textit{Allen Douma, MD – CEO, Empower, LLC, Member, PCORI Board of Governors}

11:45 – 11:50 p.m.  Wrap Up and Adjourn

\textbf{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 \url{www.pcori.org}. 