



Agenda

PPRN Partner Meeting

January 22nd, 2014
The Brookings Institution
1775 Massachusetts Ave,
NW
Washington, DC 20036

January 23rd, 2014
1828 L Street, NW
Suite 900
Washington, DC 20036

January 22nd, 2014

- 3:30 PM Welcome**
Rachael Fleurence, Patient-Centered Outcomes Research Institute
- 3:45 PM PCORnet Data Infrastructure and PPRN Needs**
Jeffrey Brown, Data Standards, Security, and Network Infrastructure Task Force
Lesley Curtis, Data Standards, Security, and Network Infrastructure Task Force
- 5:00 PM Adjourn**

January 23rd, 2014

- 8:00 AM Welcome**
Rachael Fleurence, Patient-Centered Outcomes Research Institute
- PPRNs and Patient Engagement Practices, Challenges, Opportunities – A Review of the PPRN Data**
Sarah Daugherty, Patient-Centered Outcomes Research Institute
- 8:30 AM Governance**
Alison Rein, AcademyHealth, Moderator
Seth Ginsberg, Ar-PoWER PPRN
Michael Kappelman, CCFA PPRN
Barbara Kroner, REN PPRN
- 9:30 AM Break**
- 9:45 AM Outreach and Sustaining Engagement**
Sean Tunis, Patient and Consumer Engagement Task Force, Moderator
Andrew Nierenberg, MOOD PPRN
Susan Redline, Sa-PCON PPRN
Kathleen Sullivan, PI-CONNECT PPRN
- 10:45 AM Research Issues:**
1) Conducting Observational and Experimental Research
Rich Platt, Harvard Pilgrim Health Care Institute
- 2) Navigating Informed Consent and IRBs
Rob Califf, Duke Translational Medicine, Moderator
Mark Pletcher, Health eHeart Alliance PPRN
John Walsh, COPD PPRN

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11:45 AM	Break
12:00 PM	Box Lunch – PCORI Pipeline to Proposal Award/Ambassadors Program Sue Sheridan, Patient-Centered Outcomes Research Institute
12:30 PM	Establishing Effective Partnerships Across the Network 1) CDRN/PPRN Collaborations 2) PPRN Communication Sarah Greene, Patient-Centered Outcomes Research Institute
1:00 PM	Cross-Cutting Collaborations: Break-Out Sessions 1) Stakeholder Engagement – Engaging Clinicians and Families/Caregivers Patricia Deverka, Center for Medical Technology Policy, Moderator Elizabeth Cope, NephCure Kidney Network PPRN Florian Eichler, ALD Connect PPRN Holly Peay, DuchenneConnect PPRN Rebecca Sutphen, ABOUT Network PPRN 2) Integrating PROs with Clinical Data Laura Schanberg, PARTNERS Consortium PPRN Michael Seid, ImproveCareNow PPRN 3) Standardized PCORnet Talking Points Bray Patrick-Lake, Duke Translational Medicine Institute, Moderator Robert McBurney, MS PPRN Megan O’Boyle, Phelan-McDermid Syndrome PPRN Sharon Terry, CENA PPRN 4) Ad Hoc Topic PPRN Partners: TBA
2:00 PM	Presentation of New Initiatives and Establish Working Groups Sarita Wahba, Patient-Centered Outcomes Research Institute
2:30 PM	Debrief and Closing Remarks Rachael Fleurence, Patient-Centered Outcomes Research Institute
3:00 PM	Adjourn