Building Trustworthiness in PCORnet
March28-29, 2016
Marriott Wardman Park Hotel
Washington DC

Workshop Objectives:
- Describe the characteristics of trustworthy engagement
- Examine successes and failures in building trustworthiness in research initiatives
- Begin a robust dialogue around trustworthiness within PCORnet
- Createrecommendations for PCORnetand its stakeholders
- Create recommendationsfor the networks and stakeholders that comprise PCORnet

DAY ONE: March 28, 2016

7:30-8:30 AM **Registration and Breakfast**
Registration B

8:30-8:45AM **Welcoming remarks**
Thurgood Marshall Ballroom North/East
Joe Selby, *Executive Director, PCORI*
Rachael Fleurence, *PCORnet Director, PCORI*

8:45-9:00AM **Charge to workshop speakers and participants**
Sharon Terry, *PCORnet Engagement Committee Chair*

Follow @PCORnetwork for live updates from the event!
Contribute to the conversation through the hashtags #BuildingTrust and #PCORnet.

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SESSION I: CURRENT LANDSCAPE

Thurgood Marshall Ballroom North/East

9:00-10:15 AM

Moderator: Kemp Battle, *Genetic Alliance Scaling Trust Project*

Keynote: What constitutes trustworthiness?
    Ruha Benjamin, *Princeton University*

How can we learn from our failures?
    Jane Kaye, *HeLEX - Centre for Health, Law and EmergingTechnologies,University of Oxford, UK*
    Rosalina James, *Cedar Rose Consulting*
    David Lacks Jr.,*Lacks Family*

Discussion with presenters and participants

10:15-10:45AM

Break

SESSION II: ESSENTIAL ELEMENTS OF TRUSTWORTHINESS

Thurgood Marshall Ballroom North/East

10:45-11:45 AM

Attributes of trustworthiness

Moderator:
    Jocelyn Samuels, *Director,HHS Office for Civil Rights*
Respect:
    Casey Quinlan, *Mighty Casey Media*
Privacy:
    Ivette Torres, *GRACIAS Texas*
Transparency:
    Hugo Campos, *Patient Co-PI, pSCANNERCDRN*

Discussion with speakers and participants

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SESSION III: SPECIAL ISSUES FOR SPECIAL POPULATIONS

Thurgood Marshall Ballroom North/East

11:45-1:00 PM   **Contextualizing trust: Act locally**

Moderator: James O'Leary, *Genetic Alliance*
Underserved communities:
   Neely Williams, *Community Engagement Strategist,
   Mid-South CDRN*
Sexual and gender minorities:
   Annesa Flentje, *Mental Health Lead,PRIDEnet PPRN*
Children:
   Jennie David, *ImproveCareNow PPRN*
Decisionally compromised and caregivers:
   Meryl Comer,*Co-Principal Investigator, AD-PCPRN*
Mental health and other stigmatizing issues:
   Deborah C. Peel, *Founder,Patient Privacy Rights*

Discussion with speakers and participants

1:00-2:00PM   **Networking lunch**
Thurgood Marshall Ballroom South

SESSION IV: POLICY APPROACHES AND LEGAL FRAMEWORK

Thurgood Marshall Ballroom North/East

2:00-3:15 PM   **Accelerators and roadblocks in national policies and
guidance**

Moderator: Kelly Edwards,*University of Washington*

OHRP Policies:
   Jerry Menikoff, *Director, HHS Office for Human
   Research Protections*

IRB issues:
> Camille Nebeker, *Assistant Professor, Family Medicine and Public Health School of Medicine, University of California, San Diego*

Information blocking:
> Claudia Williams, *Senior Health and Health IT Advisor, White House Office of Science and Technology Policy*

PMI White House privacy guidance:
> Eleanor Celeste, *Policy Analyst, Medical and Forensic Science, White House Office of Science and Technology Policy*

Community-Campus Partnerships for Health rewrite of Common Rule and Belmont Report:
> Alan Richmond, *Executive Director, Community-Campus Partnerships for Health*

Discussion with speakers and participants

3:15-3:20PM   **Shameless promotion of the session 5 breakouts**

3:20-3:45 PM   **Break**

SESSION V: BREAKOUTS

3:45-4:45PM   **Being Trustworthy:** *Essential elements, barriers to overcome, resources to employ, resources needed, and next steps for deploying tools and solutions broadly*

Health systems: Vance Bauer, *ADVANCE CDRN*
> *Lincoln Room 5*

Clinicians and Researchers: Bowen Chung*, CPPRN*
> *Lincoln Room 2*

Affinity communities–social, ethnic, racial, disease: Donna Appell, *Founder and CEO, Hermansky-Pudlak Syndrome Network*

Lincoln Room 3

The public good: Stephen B. Thomas, *Maryland Center for HealthEquity, University of Maryland School of Public Health*

Lincoln Room 4

4:45-5:05 PM	**Report back** *Thurgood Marshall Ballroom North/East*
5:05-5:30 PM	**Concluding remarks**

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DAY TWO: March 29, 2016

7:30-8:30 AM	**Breakfast** *Registration B*
8:30-8:40 AM	**Recap of day 1 and opportunities for day 2** Sharon Terry, *Chair, PCORnet Engagement Committee*

SESSION VI: BUILDING TRUST

Thurgood Marshall Ballroom North/East

8:40-10:00 AM	**Case study for building trust: Community Partnered Participatory Research Network Centers of Excellence (CPPRN)** **Moderator:** Bray Patrick Lake, *PCORnet Coordinating Center*

Panelists:
Bowen Chung, *Co-PI, CPPRN*
Felica Jones, *Patient Stakeholder, CPPRN*
Ashley Wennerstrom, *Co-PI, CPPRN*
Catherine Haywood, *Community Engagement Program Manager, CPPRN*

Discussants:
Peter Margolis,*Principal Investigator, ImproveCareNow PPRN*
Kiely Law,*Principal Investigator,Interactive Autism NetworkPPRN*

Discussion with presenters and participants

10:00-10:30 AM   **BREAK**

SESSION VII:TRUST IN OTHER CONTEXTS

Thurgood Marshall Ballroom North/East

10:30-11:40 AM   **Moderator:** Whitney Bowman-Zatzkin, *Flip the Clinic*

Mobile technology and education:
>   Luisa Soaterna-Castañeda, *Text4baby*

Community places to play:
>   Joy Hathaway, *Director of Community Outreach, KaBOOM!*

Police and the community:
>   Ronald E. Hampton, *Retired Police Officer, DC Metropolitan Police Department*

Cultural competency-bridge to trust:
>   Keith Colston, *Administrative Director, Maryland Commission on Indian Affairs*

Discussion with speakers and participants

11:40-12:45 PM   **Networking lunch**
Thurgood Marshall Ballroom South

SESSION VIII: TRUSTWORTHINESS WITHIN PCORNET

Thurgood Marshall Ballroom North/East

12:45-2:15 PM	**Moderator:** Andrew Nierenberg, *Principal Investigator, MOOD Network*

Models of trustworthy engagement in communitiesand health systems
Holly Peay, *Principal Investigator, DuchenneConnect PPRN*
Mitchell R. Lunn, *Principal Investigator, PRIDEnet PPRN*
Emily Kontos, *SAPCON*
Katherine Bevans, *PEDSnetCDRN*
Consuelo Wilkins, *Director, Stakeholder Engagement, Mid-South CDRN*
Rebekah Angove,*Engagement Director, REACHnet*

Lessons learned in designing PCORnet demo projects
Adaptable: Madelaine Faulkner,*Program Director, Health eHeart Alliance*
Obesity: Neely Williams, *Community Engagement Strategist, Mid-South CDRN*

Discussion with Speakers and Participants

2:15-2:45 PM   Break

SESSION IX: RECOMMENDATIONS FOR PCORNET

2:45-3:45 PM   **Breakouts considering topics that emerged and crafting draft recommendations for PCORnet**
(See the back of your badge for your breakout room)
Breakout A   *Thurgood Marshall Ballroom North/East*
Breakout B   *Lincoln Room 2*
Breakout C   *Lincoln Room 3*
Breakout D   *Lincoln Room 4*

| 3:45-4:00 PM | **Break** |

| 4:00-4:45 PM | **Report outs** |

Thurgood Marshall Ballroom North/East

Moderator: Sharon Terry, *Co-PI, Coordinating Center, and Chair, Engagement Committee*

Respondents:
Rachael Fleurence, *PCORnet Director, PCORI*
Peter Margolis, *Principal Investigator, ImproveCareNow PPRN and Chair of the PCORnet Council*
Thomas Carton, *Principal Investigator, REACHnet CDRN*
Adrian Hernandez, *Co-Principal Investigator, PCORnet Coordinating Center*

SESSION X: CONCLUSION

| 4:45-5:00 PM | **Concluding remarks** |

Thurgood Marshall Ballroom North/East

| 5:00 PM | **Adjourn** |