

**Workshop of the Precision Medicine Initiative  
Working Group of the Advisory Committee to the NIH Director**

**Participant Engagement and Health Equity**

July 1-2, 2015

John Porter Neuroscience Center  
National Institutes of Health  
Bethesda, Maryland

Final Agenda – Last revised June 29, 2015

**AGENDA**

**Principal Workshop Questions**

- 1) What are the key design features of a participant-driven, inclusive and diverse cohort?
- 2) What are inclusion and engagement goals and best practices related to health equity?
- 3) How can PMI build and sustain public trust through governance, policy, and implementation?
- 4) What would a direct-from-participant cohort look like?
- 5) What would it take to implement new models of active engagement in existing cohorts?

**Day 1 - Wednesday, July 1**

- 8:00–9:00 a.m.      **Welcome and Meeting Overview**  
Welcome and PMI Background from the NIH Director – Francis Collins, MD, PhD  
Meeting Overview – Bray Patrick-Lake, MFS (Duke University)
- 9:00–9:30 a.m.      **Session 1: Envisioning a Cohort that is Participant-driven, Inclusive and Diverse** – Moderated  
by Tony Coles, MD (Yumanity)  
*Presenter: Vernal Branch (Patient Research Advocate)*  
Followed by interactive audience discussion (15 minutes)
- 9:30–10:15 a.m.      **Session 2: Public Perspectives about a PMI Cohort** – Moderated by Kathy Hudson, PhD (NIH)  
*Presenters: Vence Bonham, JD (NIH/NHGRI), Dave Kaufman, PhD (NIH/NHGRI)*  
Followed by interactive audience discussion (15 minutes)
- 10:15–10:30 a.m.      Break
- 10:30–11:30 a.m.      **Session 3: Inclusion and Engagement Goals Related to Health Equity** —Moderated by Shiriki  
Kumanyika, PhD, MPH (University of Pennsylvania)  
*Panelists: Sarah Gehlert, PhD (Washington University in St. Louis), Rick Kittles, PhD (University of  
Arizona), James Perrin, MD, MPH (American Academy of Pediatrics/Harvard Medical School)*  
Followed by interactive audience discussion (30 minutes)

- 11:30 a.m.–12:45 p.m. **Session 4: Challenges in Recruiting and Retaining Disadvantaged and Underrepresented Populations and Best Practices for Overcoming Them** - Moderated by Esteban Gonzalez Burchard, MD, PhD (University of California, San Francisco)  
*Panelists: Lucile Adams-Campbell, PhD (Georgetown University), Carol Horowitz, MD, MPH (Mt. Sinai), Kiang Liu, PhD (Northwestern University)*  
Followed by interactive audience discussion (20 minutes)
- 12:45–1:30 p.m. Lunch
- 1:30–3:00 p.m. **Session 5: Establishing Collaborative and Inclusive Governance in a Large Study** - Moderated by Spero Manson, PhD (University of Colorado, Denver)  
*Presenters: Al Richmond, MSW (Community-Campus Partnerships for Health), Sue Sheridan, MBA (PCORI), Consuelo H. Wilkins, MD, MSCI (Vanderbilt University)*  
Followed by interactive audience discussion (45 minutes)
- 3:00–3:15 p.m. Break
- 3:15–4:15 p.m. **Session 6: What Would a Direct-from-Participant (DFP) Cohort Model Look Like?** - Moderated by Kathy Giusti, MBA (Multiple Myeloma Research Foundation)  
*Panelists: Susan Love, MD, MBA (Dr. Susan Love Research Foundation), Megan O’Boyle (Phelan McDermid Syndrome), Sally Okun, RN, MMHS (PatientsLikeMe), Sharon Terry, MA (Genetic Alliance)*  
Followed by interactive audience discussion (30 minutes)
- 4:15–5:15 p.m. **Session 7: Participant Perspectives on Data Sharing and Data Use** - Moderated by Sachin Kheterpal, MD, MBA (University of Michigan)  
*Panelists: Laura Jean Bierut, MD (Washington University in St. Louis), Matt Might, PhD (University of Utah & NGLY1.org), Rob Ring, PhD (Autism Speaks), Nancy Roach (Fight Colorectal Cancer)*  
Followed by interactive audience discussion (30 minutes)
- 5:15–5:30 p.m. **Day 1 Wrap up**  
Bray Patrick-Lake, MFS (Duke University)
- 5:30 p.m. Adjourn Day 1

## **Day 2 - Thursday, July 2**

- 8:00–8:10 a.m. **Introduction and Goals for Day 2**  
Bray Patrick-Lake, MFS (Duke University)
- 8:10-8:30 a.m. **White House Vision for the Precision Medicine Initiative**  
Brian Deese, JD (Assistant to the President and Senior Advisor)
- 8:30–9:15 a.m. **Session 8: Interagency Proposed Privacy and Trust Framework for a PMI Cohort** – Moderated by Pearl O’Rourke, MD (Partners Health Care System)  
*Presenters: Christina Heide, JD (Office for Civil Rights) and Tania Simoncelli, MS (Office of Science and Technology)*  
Followed by interactive audience discussion (20 minutes)

- 9:15–10:30 a.m.      **Session 9: Keys to Building and Sustaining Participant Engagement in the PMI Cohort** -  
Moderated by Bray Patrick-Lake, MFS (Duke University)  
*Panelists: Kelly Edwards, PhD (University of Washington), Sue Friedman, DVM (FORCE), Sohini Chowdhury (Michael J. Fox Foundation for Parkinson’s Research), Holly Peay, PhD (DuchenneConnect Registry)*  
Followed by interactive audience discussion (40 minutes)
- 10:30 – 10:45 a.m.      Break
- 10:45 a.m. –12:00 p.m.      **Session 10: Case Study - Given a Set of Assumptions What Would It Take to Integrate Existing Cohorts into PMI?** - Moderated by Rob Califf, MD (US Food and Drug Administration)  
*Speakers: Donna Antoine-LaVigne, MSED, MPH, PhD (Jackson Heart Study), Catherine Schaefer, PhD (Kaiser Permanente), Maureen Smith, MS, CGC (NUgene Biobank)*  
Followed by interactive audience discussion (30 minutes)
- 12:00 – 12:30 p.m.      **Reflections and Next Steps**  
Bray Patrick-Lake, MFS (Duke University)
- 12:30 p.m.      Adjourn Workshop