**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, Room 620-640
National Institutes of Health
Bethesda, Maryland

Final Agenda – Last revised July 1, 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

8:00–8:45 a.m.   **Welcome and Meeting Overview**
Welcome and PMI Background from the NIH Director — Francis Collins, M.D., Ph.D.
Meeting Overview — Bray Patrick-Lake, M.F.S. (Duke University)

8:45–9:15 a.m.   **Session 1: Envisioning a Cohort that Is Participant-Driven, Inclusive, and Diverse** — Moderated by Tony Coles, M.D. (Yumanity)
Presenter: Vernal Branch (Patient Research Advocate)
Followed by interactive audience discussion (15 minutes)

9:15–10:00 a.m.   **Session 2: Public Perspectives about a PMI Cohort** — Moderated by Kathy Hudson, Ph.D. (NIH)
Presenters: Vence Bonham, J.D. (NHGRI), Dave Kaufman, Ph.D. (NHGRI)
Followed by interactive audience discussion (15 minutes)

10:00–10:15 a.m.   Break

10:15–11:15 a.m.   **Session 3: Inclusion and Engagement Goals Related to Health Equity** —Moderated by Shiriki Kumanyika, Ph.D., M.P.H. (University of Pennsylvania)
Panelists: Sarah Gehlert, Ph.D. (Washington University in St. Louis), Rick Kittles, Ph.D. (University of Arizona), James Perrin, M.D., M.P.H. (American Academy of Pediatrics/Harvard Medical School)
Followed by interactive audience discussion (30 minutes)

11:15 a.m.–12:30 p.m.	**Session 4: Challenges in Recruiting and Retaining Disadvantaged and Underrepresented Populations and Best Practices for Overcoming Them** — Moderated by Esteban Gonzalez Burchard, M.D., Ph.D. (University of California, San Francisco) *Panelists: Lucile Adams-Campbell, Ph.D. (Georgetown University), Carol Horowitz, M.D., M.P.H. (Icahn School of Medicine at Mount Sinai), Kiang Liu, Ph.D. (Northwestern University)* Followed by interactive audience discussion (20 minutes)
12:30–1:30 p.m.	Lunch
1:30–3:00 p.m.	**Session 5: Establishing Collaborative and Inclusive Governance in a Large Study** — Moderated by Spero Manson, Ph.D. (University of Colorado, Denver) *Presenters: Al Richmond, M.S.W. (Community-Campus Partnerships for Health), Sue Sheridan, M.B.A. (PCORI), Consuelo H. Wilkins, M.D., M.S.C.I. (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, M.B.A. (Multiple Myeloma Research Foundation) *Panelists: Susan Love, M.D., M.B.A. (Dr. Susan Love Research Foundation), Megan O'Boyle (Phelan-McDermid Syndrome Data Network), Sally Okun, RN, M.M.H.S. (PatientsLikeMe), Sharon Terry, M.A. (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, M.D., MBA (University of Michigan) *Panelists: Laura Jean Bierut, M.D. (Washington University in St. Louis), Matt Might, Ph.D. (University of Utah/NGLY1.org), Robert Ring, Ph.D. (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, M.F.S. (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, M.F.S. (Duke University)
8:10-8:30 a.m.	**White House Vision for the Precision Medicine Initiative** – Introduction to Mr. Deese by NIH Director Francis Collins, M.D., Ph.D. Brian Deese, J.D. (Senior Advisor to the White House)
8:30–9:15 a.m.	**Session 8: Interagency Proposed Privacy and Trust Framework for a PMI Cohort** — Moderated by Pearl O'Rourke, M.D. (Partners Health Care System) *Presenters: Christina Heide, J.D. (Office for Civil Rights), Tania Simoncelli, M.S. (Office of Science and Technology Policy)* 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, M.F.S. (Duke University)
Panelists: Kelly Edwards, Ph.D. (University of Washington), Sue Friedman, D.V.M. (FORCE),
Sohini Chowdhury (Michael J. Fox Foundation for Parkinson's Research), Holly Peay, Ph.D., CGC
(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, M.D. (Food and Drug Administration)
Speakers: Donna Antoine-LaVigne, M.S.Ed., M.P.H., Ph.D. (Jackson Heart Study Community
Outreach Center), Catherine Schaefer, Ph.D. (Kaiser Permanente Division of Research),
Maureen Smith, M.S., CGC (NUgene Biobank)
Followed by interactive audience discussion (30 minutes)

12:00 –12:30 p.m.   **Reflections and Next Steps**
Bray Patrick-Lake, M.F.S. (Duke University)

12:30 p.m.   Adjourn Workshop