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

Digital Health Data in a Million-Person Precision Medicine Initiative Cohort

May 28-29, 2015
Vanderbilt University
Nashville, Tennessee

AGENDA*
All times noted are in Central Time.
Draft updated on May 26, 2015; subject to change.

Principal Workshop Questions
- What existing cohorts can we leverage?
- What resources can we leverage outside of health care delivery and research settings?
- How will we ascertain health information prospectively?
- What baseline information and samples should be collected?
- How will we manage the data generated by PMI?

Day 1 - Thursday, May 28

8:30–8:45 a.m.   **Welcome and Meeting Overview**
Welcome from the Vice Chancellor for Health Affairs - Jeff Balser, M.D., Ph.D. (Vanderbilt University)
Meeting Overview – Kathy Hudson, Ph.D. (NIH)

8:45–9:15 a.m.   **Special Session with Senator Lamar Alexander**
Introduction from the NIH Director – Francis Collins, M.D., Ph.D.
Remarks – Senator Lamar Alexander (Tenn.)
Discussion: The Promise of a National Research Cohort – Moderated by Francis Collins, M.D., Ph.D. (NIH)
Panelists from ACD PMI Working Group

9:15–9:30 a.m.   **Overview of Public Input: Responses to the NIH Request for Information**
Gina Wei, M.D., M.P.H. (National Heart, Lung, and Blood Institute)

9:30–10:45 a.m.   **Session 1: Heath Care Delivery Network Cohorts**—Moderated by Rory Collins, FMedSci (University of Oxford)
Panelists: J. Michael Gaziano, M.D., M.P.H. (Harvard Medical School; Department of Veterans Affairs), Hakon Hakonarson, M.D., Ph.D. (Children's Hospital of Philadelphia), Larry Kushi, ScD (Kaiser Permanente), Peggy Peissig, Ph.D., M.B.A. (Marshfield Clinic), Marylyn Ritchie, Ph.D. (Geisinger Clinic), Raj Srivastava, M.D., M.P.H. (Intermountain Healthcare), A. Keith Stewart, M.B., Ch.B. (Mayo Clinic)

10:45–11:00 a.m.   Break

11:00 a.m.–12:00 p.m.   **Session 2: Research Cohorts** – Moderated by Sekar Kathiresan, M.D. (Massachusetts General Hospital)
Panelists: *Danny Benjamin, M.D., Ph.D., M.P.H. (Duke University), Eric Boerwinkle, Ph.D. (University of Texas, Houston), Will Dere, M.D. (University of Utah), Susan Gapstur, Ph.D., M.P.H. (American Cancer Society), Jeff Olgin, M.D. (University of California, San Francisco/Health eHeart Study), Robert Ring, Ph.D. (Autism Speaks)*

12:00–1:00 p.m.   Lunch

1:00–2:00 p.m.   **Session 3: Ensuring Inclusion** — Moderated by Esteban Burchard, M.D., M.P.H. (University of California, San Francisco)
Panelists: *Sonia Anand, M.D., Ph.D. (McMaster University), William Blot, Ph.D. (Vanderbilt University), Jen DeVoe, M.D., D.Phil. (OCHIN), Herman Taylor, M.D., M.P.H. (Morehouse School of Medicine),*

2:00–3:00 p.m.   **Session 4: Cross-Institutional Digital Health Data Sharing for Research** – Moderated by Josh Denny, M.D., M.S. (Vanderbilt University)
Speakers: *Mark Frisse, M.D., M.S., M.B.A. (Vanderbilt University), Sachin Kheterpal, M.D. (University of Michigan), Abel Kho, M.D. (Northwestern University), Russ Waitman, Ph.D. (University of Kansas Medical Center)*

3:00–3:15 p.m.   Break

3:15–4:00 p.m.   **Session 5: White House and Office of the National Coordinator Vision for Future U.S. Health Data Infrastructure** – Moderated by Pearl O'Rourke, M.D. (Partners Health Care System, Inc.)
Speakers: *Karen DeSalvo, M.D., M.P.H., M.S.C. (Office of the National Coordinator), Mina Hsiang (The White House)*

4:00–5:00 p.m.   **Session 6: HIT Developer Solutions for Data Sharing Across Institutions** – Moderated by Eric Dishman (Intel)
Panelists: *Paul Bleicher, M.D., Ph.D. (Optum Labs), Eric Just (Health Catalyst), David McCallie Jr., M.D. (Cerner Corporation), Scott Moss (Epic)*

5:00–5:30 p.m.   **Summary of Day 1**
Kathy Hudson, Ph.D. (NIH)

5:30 p.m.   Adjourn Day 1

Day 2 - Friday, May 29

8:00–8:25 a.m.   **Introduction and Goals for Day 2**
Kathy Hudson, Ph.D. (NIH)

8:25–8:45 a.m.   **Special Session with Representative Marsha Blackburn**
Introduction from the NIH Director – Francis Collins, M.D., Ph.D.
Remarks – Representative Marsha Blackburn (Tenn.)
Open Discussion

8:45–9:45 a.m.	**Session 7: Core Data Elements and Where They Reside** —Moderated by Rob Califf, M.D. (FDA) Panelists: *Rory Collins, FMedSci. (University of Oxford), Tom Glass, Ph.D. (John Hopkins University), Brad Malin, Ph.D. (Vanderbilt University), Herman Taylor, M.D., M.P.H. (Morehouse School of Medicine)*
9:45–10:00 a.m.	Break
10:00–11:00 a.m.	**Session 8: Possibilities for Direct-from-Participant Data**— Moderated by Shiriki Kumanyika, Ph.D., M.P.H. (University of Pennsylvania) Panelists: *Adam Amdur (American Sleep Apnea Association), Christopher Burrow, M.D. (Humetrix), John Wilbanks (Sage Bionetworks)*
11:00 a.m.–12:00 p.m.	**Session 9: Perspectives on Centralized and Federated Data Models** - Moderated by Josh Denny, M.D. (Vanderbilt University) Panelists: *Jeff Brown, Ph.D. (Harvard Pilgrim Health Care Institute/Harvard Medical School), J. Marc Overhage, M.D., Ph.D. (Siemens Health Services), John Walsh (COPD Foundation)*
12:00–12:30 p.m.	**Summary and Next Steps** Kathy Hudson, Ph.D. (NIH)
12:30 p.m.	Adjourn Workshop