Precision Medicine Initiative: Building a Large U.S. Research Cohort
February 11-12, 2015

AGENDA

DAY 1: Patient/Participant Centered

8:30 am – 8:40 am	Welcome and Meeting Overview – *Kathy Hudson & Eric Green*
8:40 am – 9:10 am	Vision for the Cohort and the Precision Medicine Initiative – *Francis Collins*
9:10 am – 11:10 am	**Reports from Workshop Planning Teams** – *Moderated by Rick Lifton*

1. Building a consortium of cohorts: cohort identification and participant recruitment – *Chaired by Mike Lauer & Eric Boerwinkle*

2. Participant engagement, data privacy, and novel ways of returning information to participants – *Chaired by Laura Lyman Rodriguez & Pearl O'Rourke*

3. Data collection and mobile technologies – *Chaired by Roderic Pettigrew & Kevin Patrick*

4. Opportunities and challenges related to the use of electronic health records data for research – *Chaired by Daniel Masys & Rex Chisholm*

11:10 am – 11:30 am	Break
11:30 am – 12:00 pm	**Creation of a Large U.S. Research Cohort** – *Moderated by Teri Manolio*

Report of NIH Cohort Inventory Findings – *Dave Kaufman*

The Million Veteran Program Cohort: An Example of a Large-Scale Health System-Based Cohort – *Michael Gaziano*

Building a Consortium of Cohorts – *Eric Boerwinkle*

12:00 pm – 1:15 pm	Discussion
1:15 pm – 2:15 pm	Lunch
2:15 pm – 2:45 pm	**Participants as Partners** – *Moderated by Pearl O'Rourke*

Fair Information Practices: Building Trust with Consumers– *Dixie Baker*

New Ways of Engaging Research Participants and Novel Consent Models – *Sharon Terry*

Participant Perspectives on Data Sharing: What is Important and Why – *Andrea Downing*

2:45 pm – 4:00 pm	Discussion

4:00 pm – 4:30 pm	Recap of Day 1 – *Eric Green*
4:30 pm	Adjourn

DAY 2: Informatics/Data Centered

8:30 am – 8:40 am	Welcome and Goals for Day 2 – *Mike Lauer*
8:40 am – 9:10 am	**mHealth Technologies** – *Moderated by Bill Riley*

>How Americans Use Technology to Track and Understand Their Health – *Peter Tippett*
>
>Choosing Wisely: What Should be Measured in a Cohort this Large? – *Kevin Patrick*
>
>Testing the Devices: Using the Cohort to Assess Efficacy – *Santosh Kumar*

9:10 am – 10:30 am	Discussion
10:30 am – 10:45 am	Break
10:45 am – 11:15 am	**Informatics Requirements and Electronic Health Records (EHRs)** – *Moderated by Daniel Masys*

>Motivations to Participate – *Rex Chisholm*
>
>Technical Issues in Aggregating and Analyzing Data from Heterogeneous EHR Systems– *Josh Denny*
>
>Enhancing "Blue Button" functionality for Research – *Doug Fridsma*

11:15 am – 12:15 pm	Discussion
12:15 pm – 1:00 pm	Lunch
1:00 pm – 1:20 pm	**Data Access for Researchers: Guiding Principles for Data Access and Sharing** – *Moderated by Phil Bourne*

>Data Access: Who Can Access the Data and How? – *Rory Collins*
>
>What Protections are Needed – *David Ledbetter*

1:20 pm – 2:00 pm	Discussion
2:00 pm – 3:00 pm	**Discussion: Emerging Ideas from the Workshop** – *Moderated by Eric Green*
3:00 pm – 3:30 pm	Formulating Next Steps – *Rick Lifton & Kathy Hudson*
3:30 pm – 4:00 pm	Closing Remarks – *Francis Collins*
4:00 pm	Adjourn