

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

Mobile and Personal Technologies in Precision Medicine

July 27-28, 2015
Intel Corporation
Santa Clara, California

Agenda – Updated July 20, 2015

Overarching Workshop Questions

1. What are the potential benefits and barriers of employing mobile technologies in a large cohort study using the experiences of current smaller cohort studies that have incorporated these technologies? What are some of the anticipated issues of scaling up to a cohort of 1 million or more participants?
2. What is the desired functionality for a national research cohort mobile health app that would facilitate participant engagement and retention?
3. What are some examples of the status of mobile technologies to measure a wide range of PMI cohort relevant variables (e.g. physiological, behavioral, and environmental)?
4. What are the social and technical challenges that will be faced in using these technologies in a large cohort (including sampling bias/diversity, privacy/security, feasibility/validity, and data management/integration)?
5. What are some practical uses of mobile technologies based on relevant national research cohort use cases?
6. What are examples where the cohort might be used as a test bed for new and emerging technologies that will advance precision medicine?

Day 1 – Monday, July 27

- 8:00 - 8:15 a.m. **Welcome and Overview**
Eric Dishman, Ph.D. (Intel Corporation)
Francis Collins, M.D., Ph.D. (NIH)
Kathy Hudson, Ph.D. (NIH)
- 8:15 - 8:30 a.m. **Mobile and Related Technologies and their Potential for Advancing Precision Medicine**
Keynote Speaker: *Jessica Mega, M.D., M.P.H. (Google Life Sciences)*
- 8:30 - 10:15 a.m. **Session 1: Lessons Learned from Cohorts Implementing Mobile Technologies –**
Moderated by Josh Denny, M.D., M.S. (Vanderbilt University)
- Presentations (10 min each):*
- Framingham Health Study - *Rhoda Au, Ph.D. (Boston University)*
 - Childhood Cancer Survivor Study - *Greg Armstrong, M.D. (St Jude Children's Research Hospital)*
 - The Nurses' Health Study 3 - *Jorge Chavarro, M.D. (Harvard)*

Open discussion (1 hour)

10:00 - 10:15 a.m. Break

10:15 a.m. - 12:00 p.m. **Session 2: Mobile Technologies for Participant Engagement** - Moderated by Bray Patrick-Lake, M.F.S. (Duke University)

Presentations (10 min each):

- Human Computer Interface (HCI) for Feedback and Sustained Engagement - *Maribeth Gandy Coleman, Ph.D. (Georgia Tech)*
- Social Support Apps for Engagement – *Bonnie Spring, Ph.D. (Northwestern University)*
- Example of Digital Engagement and Retention - *Anand Iyer, Ph.D. (WeIDoc)*
- Participant Perspective - *Kathy Sigona (Health eHeart Study Participant & Alliance Steering Committee Member)*

Open Discussion (1 hour)

12:00 - 1:00 p.m. Lunch

1:00 - 3:00 p.m. **Session 3: Variables Measurable Via Mobile Technologies** - Moderated by Spero Manson, Ph.D. (University of Colorado Denver)

Presentations (10 min each): Environment

- Environmental Data - *Michael Jerrett, Ph.D. (University of California, Los Angeles)*
- Contextual Data (location, social context, activity) – *Kevin Patrick, M.D., M.S. (UCSD)*
- Data Acquired in the Home - *Jeff Kaye, M.D. (Oregon Health & Science University)*

Open Discussion (30 min)

Presentations (10 min each): Behavior

- Wearable Physiological Sensors – *Emre Ertin, Ph.D. (Ohio State University)*
- Passive Measurements of Behavior - *Andrew Campbell, Ph.D. (Dartmouth College)*
- Self-Reported Data – *Arthur Stone, Ph.D. (University of Southern California)*

Open Discussion (30 min)

3:00 - 3:15 p.m. Break

3:15 - 4:45 p.m. **Session 4: Social Challenges for Mobile Technologies in the PMI Cohort** - Moderated by Esteban Gonzalez Burchard, M.D., M.P.H. (University of California San Francisco)

Presentations (10 min each):

- Ensuring Cohort Diversity and Minimizing Sample Bias – *Gary Bennett, Ph.D. (Duke University)*
- Use in Child and Adolescent Populations - *Donna Spruijt-Metz, Ph.D. (University of Southern California)*
- Use in Elderly Populations - *David Gustafson, Ph.D. (University of Wisconsin-Madison)*

Open Discussion (1 hour)

4:45 - 5:00 p.m. **Wrap-up and Summary of Day 1** – Kathy Hudson, Ph.D. (NIH)

Day 2 – Tuesday, July 28

8:00 - 8:15 a.m. **Welcome and Overview of Day 2** – Kathy Hudson, Ph.D. (NIH)

8:15 – 9:45 a.m. **Session 5: Technical Challenges in Using Mobile Technologies in a PMI Cohort** - Moderated by Eric Dishman, Ph.D. (Intel)

Presentations (10 mins each):

- Data Quality and Variability-*Mani Srivastava, Ph.D., M.S. (UCLA)*
- Interoperability and Interpretability - *Ida Sim, M.D., Ph.D. (University of California, San Francisco/Open mHealth)*
- Data Integration and Validation – *Deborah Kilpatrick, Ph.D. (Evidation Health)*
- Privacy and Security - *David Kotz, Ph.D. (Dartmouth College)*

Open Discussion (50 min)

9:45 - 10:00 a.m. Break

10:00 - 10:45 a.m. **Session 6: Panel Discussion: Precision Medicine Initiative Cohort Potential Pilot Platforms** – Moderated by Sachin Kheterpal, M.D., M.B.A. (University of Michigan)

Panelists: Ram Fish, M.B.A. (Samsung), Andrew Kasarskis, Ph.D. (Mount Sinai), Anmol Madan, Ph.D. (Ginger.io), Ray Dorsey, M.D., M.B.A. (University of Rochester)

10:45 - 11:30 a.m. **Session 7: Panel Discussion: Mobile Technologies in Precision Medicine Initiative Cohort Use Cases** - Moderated by Sue Siegel (GE Ventures & Healthymagination)

Panelists (from prior session): Rhoda Au, Ph.D. (Boston University), Anand Iyer, Ph.D. (WellDoc), Michael Jerrett, Ph.D. (University of California, Los Angeles), Arthur Stone, Ph.D. (University of Southern California), Ida Sim, M.D., Ph.D. (University of California, San Francisco/Open mHealth), Gary Bennett, Ph.D. (Duke University)

11:30 - 11:45 a.m. **Concluding Remarks** – Kathy Hudson, Ph.D. (NIH)

11:45 a.m. **Adjourn Public Workshop**