

SYMPOSIUM PROGRAM

THURSDAY, MAY 14

8:00 - 9:00 **REGISTRATION AND LIGHT BREAKFAST**

9:00 - 9:20 **WELCOME**

Kevin Patrick (UCSD)
Stephen J Downs (RWJF)
Gary Wolf (QS Labs)

9:20 - 10:00 **SESSION 1: ACCESS & EQUITY**

THEME: Let's dig deeper together to uncover what we mean when we talk about equity and access. What should we be exploring together as we build systems of inquiry and data collection? How can we support access to not just the tools of the trade, but also the process of generating questions that are important to our personal and public lives.

Dawn Nafus (Intel Research)
Jose Gomez-Marquez (Little Devices / Maker Nurse)

10:00 - 10:30 **BREAK**

10:30 - 11:30 **SESSION 2: LARGE SCALE PARTICIPATORY RESEARCH**

THEME: Over last year there have been major advances to bring forth new mechanisms for participating in health research. From using our phones to contribute our data to the creation of communities of willing participants, we are seeing rapid increase in the scale of engagement. What can we learn from pioneering projects in the field?

Michael Kellen (Sage Bionetworks)
Heidi Dohse (Google, Health eHeart Study)
Madeleine Ball (Personal Genomes, Open Humans)
Bob Evans (Google, PACO)

11:30 - 12:00 **SESSION 3: HUMAN-CENTERED DESIGN FOR HEALTH & RESEARCH**

THEME: What happens when we bring the principles of human-centered design into the realm of participatory research?

Don Norman (Design Lab, UCSD)
Susannah Fox (RWJF)

12:00 - 1:00

LUNCH & TOOLMAKER TABLES

Enjoy a wonderful lunch and take some time to meet with the various Toolmakers in attendance. If you have time, pop into the VR Cave to experience “Health in the Home” with Patti Brennan.

1:00 - 2:00

SESSION 4: PERSONAL & PUBLIC KNOWLEDGE

THEME: We know that individuals all over the world are using self-tracking to understand themselves. How can the novel methods and practices of self-trackers inform scientific and clinical discovery?

Brian Levine (Tap2, Inc.)

Mark Drangsholt (University of Washington)

Dawn Lemane (Individual Metabolic Research Group)

2:00 - 2:30

BREAK

2:30 - 3:30

SESSION 5: THE WEALTH OF DATA

THEME: How does data flow from consumer tools into medical and research platforms? What cultural changes must occur to make this data accessible and useful?

Drew Schiller (Validic)

Andrei Pop (Human API)

Aaron Coleman (Fitabase)

3:30 - 4:00

BREAK

4:00 - 5:00

SESSION 6: A COMMUNITY OF PRACTICE

THEME: Personal self-collected data is part of everyday life for individuals living with diabetes. What can we learn from these pioneers about solving thorny issues of access, regulation, collaboration, and day-to-day disease management?

Dana Lewis (#OpenAPS, #DIYPS)

Howard Look (Tidepool)

Joyce Lee (University of Michigan)

Nate Heintzman (Dexcom)

5:30 - 6:00

SESSION 7: WHAT'S AT STAKE?

THEME: We're all working together to deliver on the promise of personal data from personal and public benefit. Can government and philanthropy help?

Lori Melichar (RWJF)

Bryan Sivak