

# An Annotated Agenda for – Precision Medicine 2015: Patient Driven

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## CONFERENCE AGENDA DAY 1 (JUNE 24)

9:00-9:15 am      **Opening Remarks** by Jeffrey Flier, *Dean of Harvard Medical School*  
❖ [Introduction video](#)

9:15-9:30 am      **Welcome** - Zak Kohane, *Harvard Medical School*  
❖ The welcome talk begins the [Day 1, part 1 video](#).

9:30-10:15am      **Keynote** – Matt Might, *University of Utah*  
“An algorithm for precision medicine: What do you do when n=1?”  
❖ This talk begins at 23 minutes 24 seconds into [Day 1, Part 1 video](#).

**Summary:** The speaker focused on his experience as a father of a child who was diagnosed with a condition doctors said was one of a kind, and lays out the steps he took: getting basic data (exome sequencing of himself, wife and son), using Google, PubMed and social media and talking to researchers, to learn more about the cause, to find others whose children had similar characteristics, and to press researchers to undertake studies of possible therapies. His talk was, in a sense, a cookbook for how to start a patient advocacy group, beginning with one person. The talk is followed by a Q&A session for about 10 minutes.

10:15-11:15am      **SESSION 1A:** Hitting the ground running at the frontlines  
**THEME 1- YES WE CAN: HOW PATIENTS ARE THE RIGHT LEADERS FOR PRECISION MEDICINE.**  
❖ This panel begins at 72 minutes in the [Day 1, Part 1 video](#).

### Panelists:

- Kathy Giusti, Founder and Executive Chairwoman, *Multiple Myeloma Research Foundation*
- Megan O’Boyle & Paul Avillach, *Harvard Medical School: Phelan-McDermid Syndrome Foundation*
- George Church, *Harvard Medical School, Director, PersonalGenomes.org*

**Summary:** Session 1 panelists presented their unique perspectives on the issues surrounding patient access to all health data about them and helping patients understand and accept what is there and what is not there. After this panel, and every other panel, there was a lively dialogue with audience members covering a wide range of topics related to the theme of the panel.

11:15-11:30Am BREAK

11:30-12:45pm **SESSION 2:** Whose data is it anyway?

**THEME 2: INJECTING PRECISION MEDICINE INTO MEDICAL PRACTICE.**

❖ Session 2 begins at 135 minutes 35 seconds into [Day 1, Part 1 video](#).

**Panelists:**

- Susan M. Wolf, *University of Minnesota*  
“The big picture: Rules in flux”
- Henry Greely, *Stanford Law School*  
“Privacy issues, potential for discrimination, and needed solutions”
- Barbara J. Evans, *University of Houston Law Center*  
“Reconciling patient access to data with quality oversight”
- Ellen Wright Clayton, *Vanderbilt University*  
“Proceed with caution: Translating precision medicine research into clinical care”
- Gary E. Marchant, *Arizona State University College of Law*  
“Liability issues in precision medicine”

**Summary:** These panelists explored the legal ethical and practical issues around patient ownership of their own health data and pointed out the need to “fix” a number of frameworks, such as HIPAA, NIGA, IRBs and health organization governance practices that work against it.

12:45-1:45pm LUNCH

1:45-3:15pm **SESSION 1B:** Hitting the ground running at the frontlines

**THEME 1- YES WE CAN: HOW PATIENTS ARE THE RIGHT LEADERS FOR PRECISION MEDICINE.**

❖ This Panel begins the [Day 1, Part 2 video](#).

**Panelists:**

- Susan Love, Chief Visionary Officer, *Dr. Susan Love Research Foundation*
- Jeff Hammerbacher, Founder and Chief Scientist, *Cloudera*
- Stephen Friend, President, *SAGE Bionetworks*
- Eric Minikel & Sonia Vallabh (prion scientists), *Broad Institute*

**Summary:** This panel continues topics that were raised earlier in Session 1A. This panel included representatives from technology development, who talked about the tools and organizational structures that patients might need to house and visualize personal health data.

3:15-3:30pm

BREAK

3:30-5:00pm

**SESSION 3:** Scaling up for populations

**THEME 2: INJECTING PRECISION MEDICINE INTO MEDICAL PRACTICE.**

- ❖ This panel begins at 97 minutes 35 sec into the [Day 1, Part 2 video](#).

**Panelists:**

- Isaac (Zak) Kohane, Harvard Medical School  
“Undiagnosed Diseases Network”
- David Glazer, Director of Engineering, *Google Genomics*
- Ken Mandl, *Harvard Medical School*  
“SMART Apps for Genomics”
- Arjun (Raj) Manrai, *Harvard Medical School*  
“Taking Care of All Ethnicities”

**Summary:** In the final panel session of Day 1 panelists discussed issues of connecting practicing clinicians with research data in the health system, how apps might help, pointed out some problems inherent in research data that need to be addressed, and identified the difficulty in some cases of classifying an interaction as research or care (impacting who pays).

## CONFERENCE AGENDA DAY 2 (JUNE 25)

9:00-9:15am

**Day 2 Opening Remarks** by Isaac Kohane, *Harvard Medical School*

- ❖ These remarks begin the [Day 2 video](#).

- 9:15-10:00am **Keynote #2** - Linda Avey  
Co-founder & CEO, *We Are Curious* and Co-Founder of *23andMe*  
“Who will lead in Precision Medicine?”  
This keynote talk begins 8 minutes into the [Day 2 video](#).
- Summary:** Linda Avey presented a fascinating account of how she became interested in research technology, which led to her co-founding of 23andMe as a way of crowd-sourcing data that could be used for research. Her long-term focus, helping people ask questions against their own health data, led her away from *23andMe*, to another start-up, *We are Curious*, and stimulated her interest in creating a trackable sensor.
- 10:00-11:30am **SESSION 4:** How much does it cost and who will pay for Precision Medicine?  
**THEME 2: INJECTING PRECISION MEDICINE INTO MEDICAL PRACTICE.**  
❖ This panel begins at 28 minutes 16 seconds into the [Day 2 video](#).
- Panelists:**
- Greg Steinberg, *Aetna*
  - Howard Golub, *Care-Safe*
  - Brian Kelly, *Quintiles*
  - Patrick Warren, *Covance*
  - Murali Prahalad, *Epic Sciences*
- Summary:** In this panel presenters discussed the value propositions around precision medicine, such as ‘how much will it cost’ and ‘who will pay for it.’ One speaker asked the provocative question: should health insurance payers fund collection of data for research? Another spoke about the need to change the structure of clinical trials toward more adaptive designs.
- 11:30-11:45am BREAK
- 11:45-12:30pm **Closing Keynote** – Arlene Sharpe  
Microbiology & Immunology, *Harvard Medical School*  
“How basic research can jumpstart precision treatments: Immunotherapy for cancer”  
❖ The final keynote address of the conference begins at 156 minutes 59 seconds into the [Day 2 video](#).

**Summary:** Arlene Sharpe provided a step-by-step overview of groundbreaking research in immunology that led to a cancer tumor blockade therapy which has found considerable success against a number of different kinds of tumors, and which is less toxic to the patient than chemotherapy. She concluded that predictive biomarkers are needed, so the number of patients who respond to therapy can be increased.

12:30pm            CONFERENCE ENDS

## VIDEO LINKS:

Introduction

<http://ecommons.med.harvard.edu/MediaPlayer/Player.aspx?v={7107D054-D959-4F9D-886D-DCB86FE7E7AB}>

Day 1 part 1

<http://ecommons.med.harvard.edu/MediaPlayer/Player.aspx?v=%7bCE3444F1-A4BA-44DA-A2E2-B86CA48D3400%7d>

Day 1 part 2

<http://ecommons.med.harvard.edu/MediaPlayer/Player.aspx?v=%7b6ECFC217-AA55-49AC-9F8C-A8FAE0171CC3%7d>

Day 2

<http://ecommons.med.harvard.edu/MediaPlayer/Player.aspx?v=%7b61E1B30B-EC78-4C45-B094-631509ED8F28%7d>