Upcoming Workshop on Enabling Precision Medicine: The Role of Genetics in Clinical Drug Development
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The Perspective of a Patient and Patient Advocate
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Questions

• What are the perspectives of patients and trial participants with regard to the use of genetic data in clinical drug development?

• How can drug developers better engage with, and recruit trial participants?
Patients

All The Same

- Frightened
- Want to live long
- Want to live well

Each Unique

- Biology
- Ethnicity
- Culture
- Age
- Geography
- Values
Personal Story

1950

2016
Most Patients

• Don’t know much about:
  – Genetics and genomics
  – Drug development and clinical trials

• May not value science

• Are frightened and not comfortable talking to healthcare providers
Why Patients Don’t Participate in Clinical Trials

Patient Concerns: Privacy/Security

I APPRECIATE HOW YOU’VE PROTECTED MY PRIVACY, DOC. I’M GONNA TELL EVERYBODY ABOUT IT ON MY MEDICAL RATING WEBSITE!
Patient Concerns: Data Sharing

Here, we are firmly committed to the OPEN DATA initiative. Please address all your requests to our new data sharing officer, Mr. Snoopy!
Questions

• What are the perspectives of patients and trial participants with regard to the use of genetic data in clinical drug development?

• How can drug developers better engage with, and recruit trial participants?
Educate the Public More Effectively and Before they Become Patients

• Knowledge of genetics and genomics
• Understanding of medical research process
• Appreciation of protections of patients involved in clinical trial and their value
• Respect for science
• Less hype; more reality
Be Careful of Hype and Different Use of Language

When Will this Be in the Clinic?
Be Careful of Hype and Different Use of Language

When Will this Be in the Clinic?

Phase 1 first in human trial
2 years

Available from my doctor
15 years, MAYBE

Medical Researcher/Clinician Thinks

Patient/Public Thinks
Make it Friendly; Engage the Community

*All of Us* Research Program announces funding opportunity for community partners.

PMI Cohort Program announces new name: the *All of Us* Research Program
Clinical Trials Volunteers Deserve

• Fast turnaround of test results
• Aggregate and individual results, and genetic counseling, when appropriate
• Eligibility in an experimental arm or cross-over
  – Umbrella/Basket trials
• Minimal financial toxicity in a clinical trial
  – Tests for eligibility should be covered by the trial
• Plan for care after the trial is over
  – Experimental agents if effective for the patient
Involve Patients/Advocates
To Make Trials Patient-Centric

1. Design patient-centric trials
   - Select the right endpoints
   - Minimize patient burden
   - Maximize potential patient benefit

2. Implement trials in a patient-centric manner
   - Develop patient friendly informed consents and educational material
   - Train staff in patient communication

3. Disseminate results to patients
   - Overall findings
   - Individual results