

**Upcoming Workshop on Enabling Precision
Medicine: The Role of Genetics in Clinical
Drug Development
March 8, 2017**

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*
- *Age*
- *Ethnicity*
- *Geography*
- *Culture*
- *Values*

Personal Story



1950



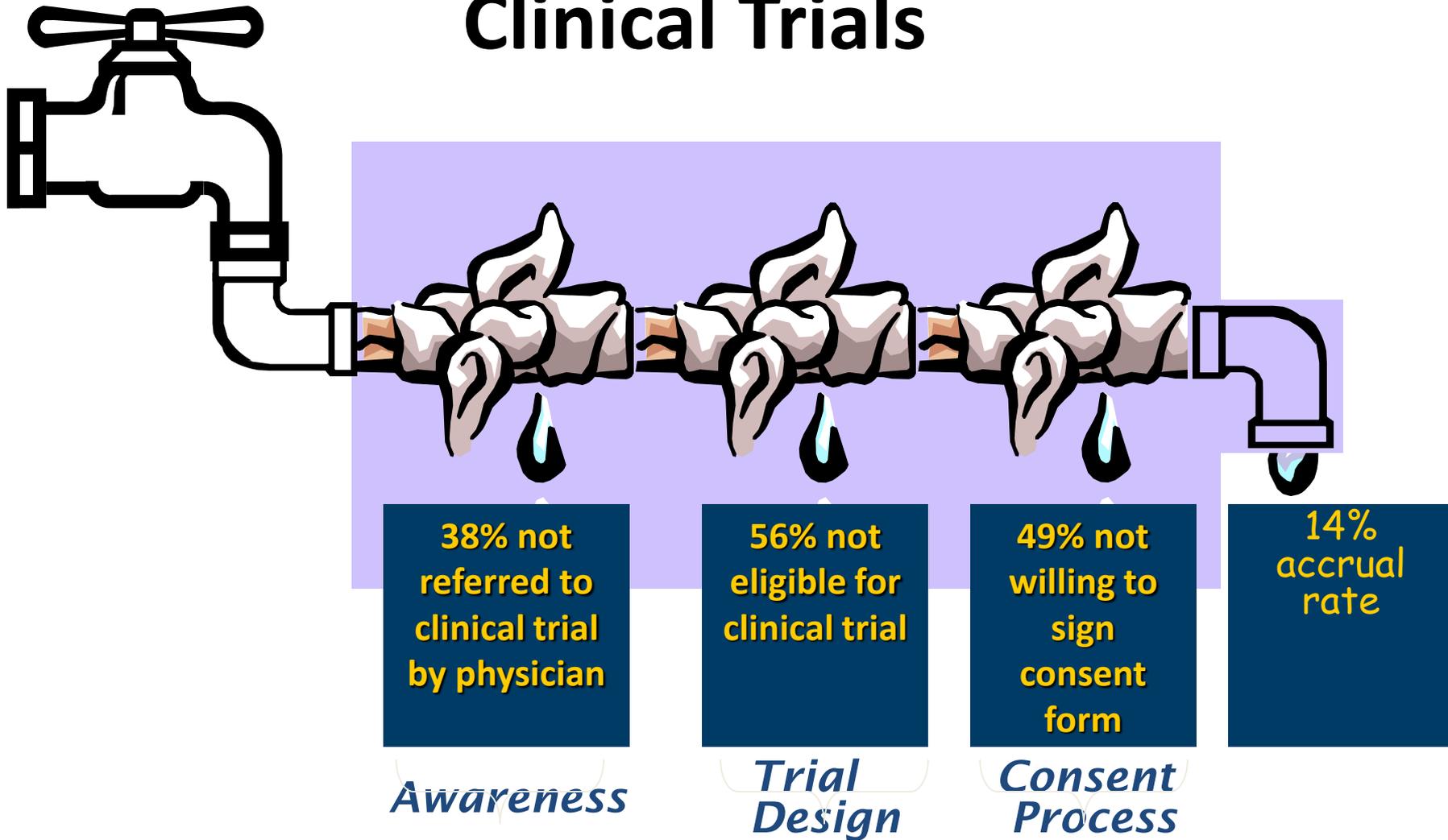
2016

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 health care providers



Why Patients Don't Participate in Clinical Trials



Lara, P.N., Jr., et al., Prospective evaluation of cancer clinical trial accrual patterns: identifying potential barriers to enrollment. *J Clin Oncol*, 2001. **19(6)**: p. 1728-33.

Patient Concerns: Privacy/Security



Patient Concerns: Data Sharing



Questions

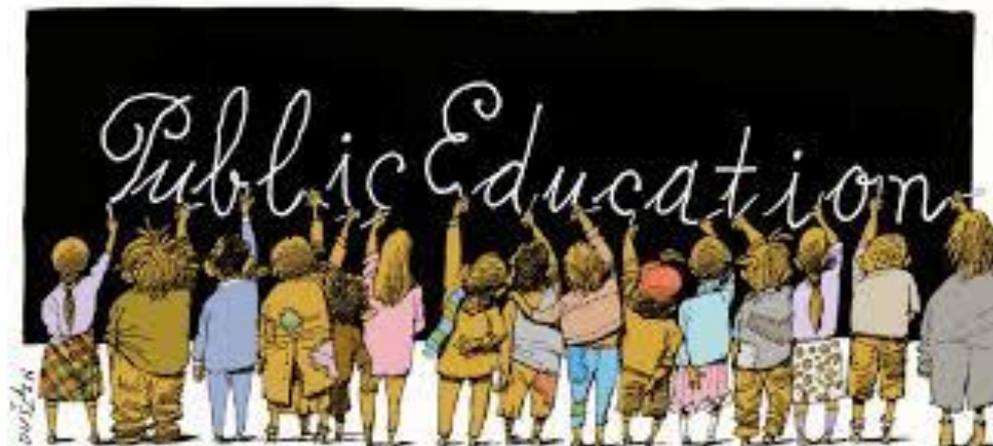
- What are the perspectives of patients and trial participants with regard to the use of genetic data in clinical drug development?



- **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?

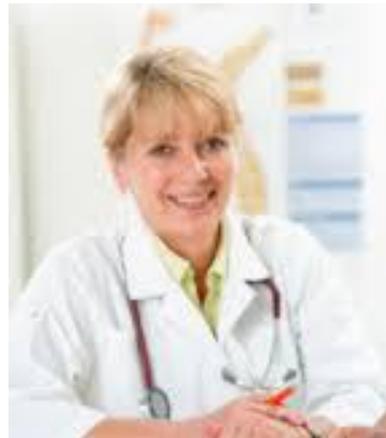
Phase 1 first in
human trial

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



