THE PRECISION MEDICINE INITIATIVE

and why Health Literacy matters... a lot

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# Disclosures

**Federal**
- NIH  
  - NCI  
  - NIA  
  - NIDDK  
  - NINR  
  - NHLBI  
  - OBSSR  
- AHRQ  
- FDA

**Private**
- ACOG  
- California Endowment  
- California Healthcare Foundation  
- Missouri Foundation for Health  
- PCORI

**Industry**
- Abbvie  
- Amgen  
- Deborah Adler Design  
- Eli Lilly  
- Emmi Solutions  
- Luto UK  
- Merck  
- UnitedHealthcare  
- Vivus
Getting It Right with the Precision Medicine Initiative: The Role of Health Literacy

Ruth M. Parker, MD; Suzanne Bakken, RN, PhD; and Michael S. Wolf, PhD, MPH

February 2, 2016
A $215 Million Investment (for 2016)
What is the ‘ask’ to PMI Participants?

- Agree to a long-term relationship
- Undergo a research medical exam + RX assessment
- Get blood drawn
- Complete health surveys
- Use and share environmental exposure and lifestyle information via mobile tech
- Share electronic health record (EHR) information
Do I Understand the ‘Why’?

Can we convey its purpose, importance, & value for community and n of 1?
What 3 Decades of Research Has Told Us...

Repeatedly

1. Many people, especially those with limited health literacy, misunderstand health information, ranging from:

   - Prevention
   - Disease etiology
   - Treatment
   - Research consent
   - Insurance Coverage
   - Genetics
What 3 Decades of Research Has Told Us...

2. For many reasons, health literacy cannot be easily separated from demographic and socioeconomic factors.

Racial Disparities in Participation in Biomedical Research

Nancy R. Kressin, PhD, Mark Meterko, PhD, and Nancy J. Wilson, MD, MPH
Bedford, Massachusetts
3. Most psychometric tests in wide use today have not been appropriately validated for use among lower literate audiences.

- Differential Item Functioning (DIF)
4. Retention in cohort studies is challenging, and participants with limited health literacy are at greatest risk for attrition.
5. Individuals with limited health literacy have lower rates of health & mobile technology use.
“For God’s sake, stop researching for awhile and begin to think”.

- Sir Walter Hamilton Moberly
  British Scholar, Philosopher, 1949
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The PMI: Important...Just Do It Right!

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- Get the messages right (test them)
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- Should/could we measure health literacy?
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GET INVOLVED