Precision Medicine:

Building a Large U.S. Research Cohort

Workgroup:

Electronic Health Records and Informatics

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Session outline

- Revisiting informatics and EHR issues from yesterday's discussion in more detail:
  - "Precision Participant Engagement" methods
  - Motivations to contribute clinical data
  - Lessons learned in using EHR data for genome-phenome correlation
  - Blue Button to S4S (Synch for Science) functionality
- Q&A with working group members

Precision Participant Engagement

- Principle: Individuals, however expert, who serve as surrogates for a group's opinions and preferences can at best be only approximately correct. To be precisely correct, you have to ask each individual in the group.

- Concept of Operations for the PM cohort:
  - Use experts for first approximation of what to do
  - Use informatics infrastructure (social media, polls) to:
    vote (if something can be done only one of several different ways) and to
    record and use individual preferences (if something can be done more than one way simultaneously)