Precision Medicine: Building a Large U.S. Research Cohort

WORKGROUP: Building a Consortium of Cohorts – Cohort Identification and Participant Recruitment

Co-chairs: Eric Boerwinkle and Michael Lauer
Group Members: Rebecca Baker, Greg Burke, Rory Collins, J. Michael Gaziano, and Teri Manolio

February 11, 2015
Current Landscape: Resources

Numerous cohorts already exist and are:

• Richly phenotyped and ethnically diverse
• Enriched with valuable longitudinal data
• Invested in materials, including DNA samples
• Supported by enthusiastic researchers and informed consenting participants
• But ... are not harmonized (data, rules)
Construction of a National Cohort

- Cohort A
- Cohort B
- Cohort C

Pool and Harmonize

- Enhanced Cohort 1
  - Research Now
  - Follow Up
  - Enhanced Cohort 2
    - Research Later

New Data Sources
New Sequence Data
New Participants

Enable short-term and long-term research studies
Challenges

• Feasibility and $
• Technologies
• Fragmentation
  – coordination
  – data platforms
  – delivery systems
• Incentives

http://files.itproportal.com/wp-content/uploads/photos/iphone5_vs_galaxy_s3_600_original.jpg
Expense, time, and feasibility:

**Concern:** Costly, lengthy, and logistically challenging.

**Proposed Solution:** Leverage existing resources

- Extensive genomic/-omic data
- Recruitment complete or ongoing
- Electronic data, digital communities
- Enable new participants and methods
Technology:

**Concern:** Rapidly evolving technologies

**Proposed Solution:** Leverage and grow with

- Bidirectional internet and cloud-based services
- Mobile devices (smartphones, sensors)
- Home monitoring devices, web-based portals
- Electronic health records and digitized registries
Coordination, transparent governance:

**Concern:** A *common infrastructure is lacking.*

**Proposed Solution:** *Coordinating center to*
- Harmonize existing data
- Facilitate testing of new data collection methods

**Proposed Solution:** *Steering committee to advise on*
- Policy, management, and scientific direction
- Approaches to reduce marginal cost of new studies
Incentives:

**Concern:** What is the new value (vs threat)?

**Proposed Solution:** Offer new value

– Whole genome sequencing
– Digital patient-reported outcomes
– Data derived from novel devices and apps
– Larger harmonized samples for analyses
– Analyze findings within broader contexts
Opportunities & Big, Audacious Ideas

A Large US Research Cohort could make possible

• An enormous, versatile “scientific commons”
• Dialogues of researchers and participants
• Studies of health and well-being
• Platforms for rapid, efficient randomized trials
• Evidence-based precision medicine as reality