

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

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

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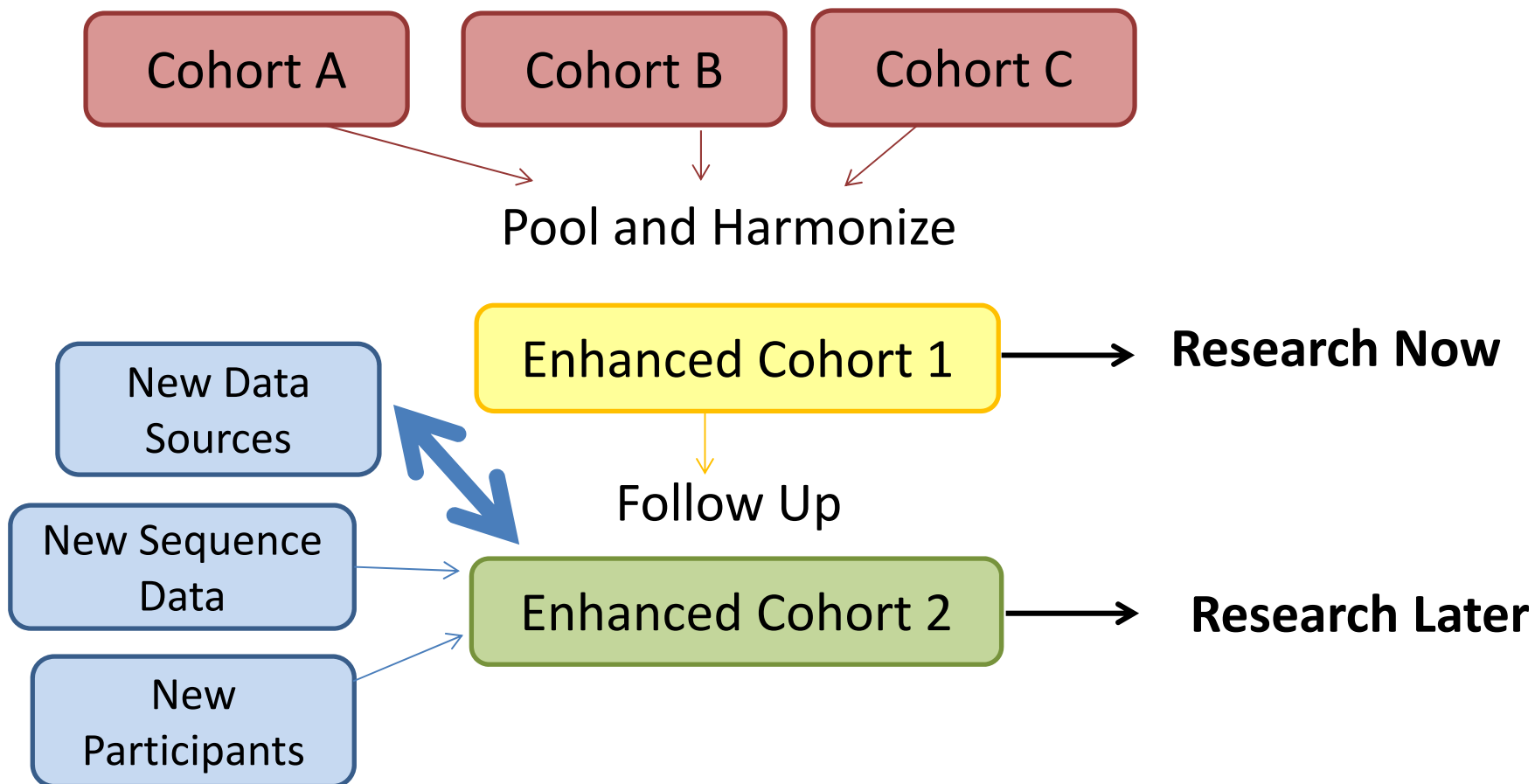
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Current Landscape: Resources

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)

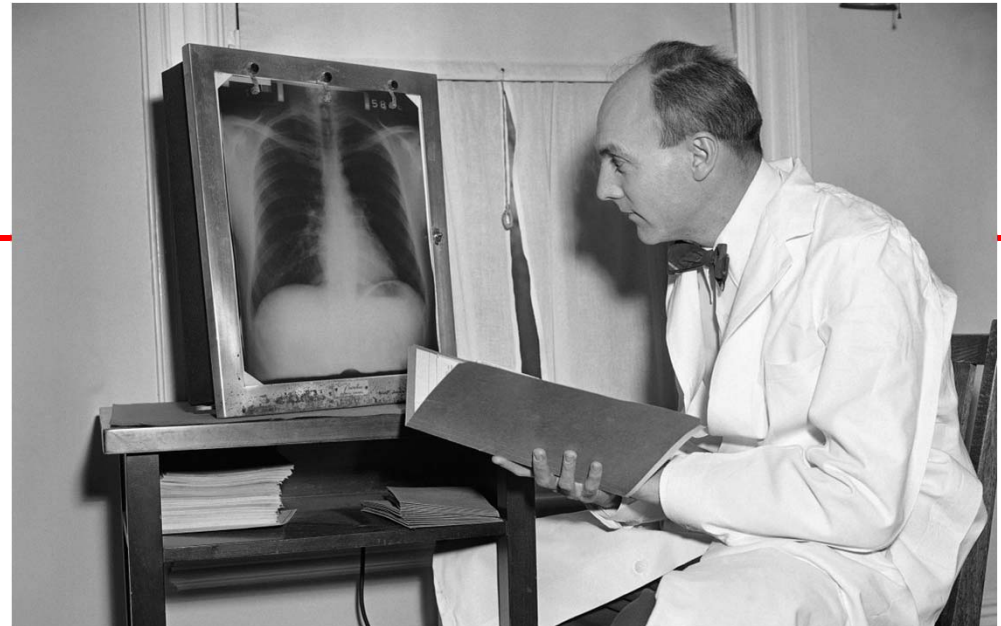
Construction of a National Cohort



Enable short-term and long-term research studies

Challenges

- Feasibility and \$
- Technologies
- Fragmentation
 - coordination
 - data platforms
 - delivery systems
- Incentives



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