

# Innovating Ourselves for the Era of Precision Health

National Committee on Vital and Health Statistics

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## The All of Us Research Program

- One million or more volunteers, reflecting the broad diversity of the U.S.
- Opportunities for volunteers to provide data (deep clinical, environmental, lifestyle, & genetic data) on an ongoing basis
- Opportunities for researchers from citizen scientists to university researchers to access one of the world's largest biomedical databases to accelerate breakthroughs
- Not a study on any one disease, but a data resource to inform many research studies on a wide variety of health conditions



### All of Us Mission and Objectives

### **Nurture relationships**

with one million or more participant partners, from all walks of life, for decades



of researchers and funders hungry to use and support it



Deliver the largest, richest biomedical dataset ever

that is easy, safe, and free to access

#### **Core Values**

- Participation in the All of Us Research Program will be open to interested individuals.
- The Program will reflect the rich diversity of America.
- Participants will be partners in the Program.
- Trust will be earned through robust engagement and full transparency.
- Participants will have access to information and data about themselves.

- Data from the Program will be broadly accessible to empower research.
- The Program will adhere to the PMI Privacy and Trust Principles and the PMI Data Security Policy Principles and Framework.
- The Program will be a catalyst for innovative research programs and policies.

# Major Building Blocks of the All of Us Research Program

# DATA AND RESEARCH CENTER (DRC)

Big data capture, cleaning, curation, & sharing in secure environment

Vanderbilt, Verily, Broad Institute

#### **BIOBANK**

Repository for processing, storing, & sharing biosamples (35+M vials)

Mayo Clinic

#### PARTICIPANT CENTER

Direct volunteer participant enrollment, digital engagement innovation, & consumer health technologies

Scripps Research Institute (with multiple partners)

# PARTICIPANT TECHNOLOGY SYSTEMS CENTER

Web & phone-based platforms for participants

Vibrent Health

# HEALTH CARE PROVIDER ORGS (HPOs)

Clinical & scientific expertise network, enrollment & retention of participants

20+ regional med centers, FQHCs, VA, future awards to grow network

# COMMUNICATIONS & ENGAGEMENT

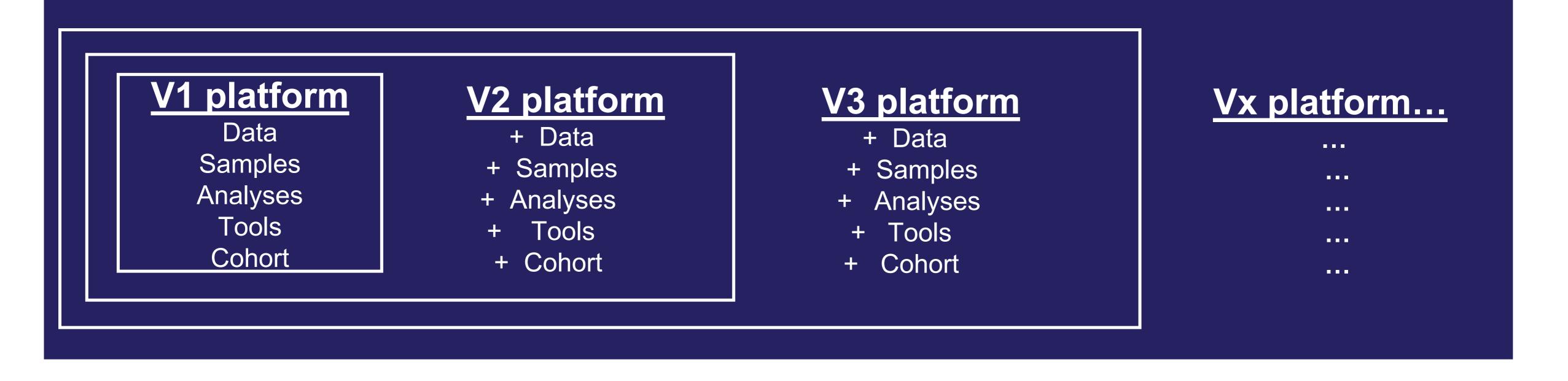
Comms, marketing, & design expertise; Engagement coordination & community partners network Wondros, HCM, network of community partners

## All of Us Research Program Data

The Program will start by collecting a limited set of standardized data from sources that will include:

- Participant questionnaires
- Electronic health records
- A baseline physical evaluation
- Biospecimens (blood and urine samples)
- Mobile/wearable technologies
- Geospatial/environmental data

Data types will grow and evolve with science, technology, and trust.



# All of Us Research Program Participant Activities



1. Learn



2. Discuss



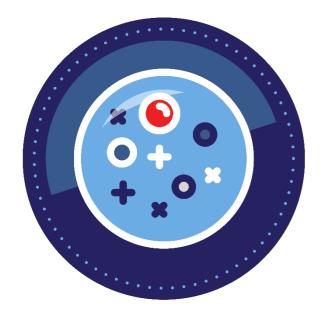
3. Enroll & Consent



4. Questionnaires



5. Physical Measures



6. Bio-Samples



7. Lifestyle & Health Data Contributions



8. Research Projects & Publications



9. Return of Information



10. Duration

## Right Now

Now in beta phase of enrollment: More than 2800 participants across ten sites

- Invite-only, slow, iterative enrollment across the national network over 3-4 months
- Focused on the user experience; phased implementation as we pilot, iterate, and scale
- Evaluating engagement approaches

...All leading to a national launch in late 2017/early 2018

# Questions?

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