An Introduction to the

All of Us

Research Program

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@AllofUsResearch  #JoinAllofUs

Presented on behalf of NIH “All of Us” by

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Overview of the *All of Us* Research Program
Why do we need the All of Us Research Program?

**People/ Patients**
- Treatment often targeted to the “average” patient, not individual
- Health problems can take years to unravel, with hard trial & error
- No one to drive “whole person care” except you

**Professional Providers**
- Too few conditions w/ evidence & options for precision today
- Medical records & key data scattered in different silos
- Pace rarely allows for complex analysis of each patient

**Biomedical Researchers**
- Enormous time/cost spent building IT systems/tools vs. doing research
- Siloed data resources and funding opportunities
- Challenges acquiring large and diverse sample sizes
- Incentives not aligned for data sharing & large scale collaboration
All of Us Mission and Objectives

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

Our mission
To accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us

Deliver the largest, richest biomedical dataset ever that is easy, safe, and free to access

Catalyze a robust ecosystem of researchers and funders hungry to use and support it
Summary of the *All of Us* Research Program

- **Rich, Longitudinal Resource**: Deliver a national resource of deep clinical, environmental, lifestyle, & genetic data from one million participants who are consented & engaged to provide data on an ongoing, longitudinal basis (60+ years!)

- **Diversity of Participants**: Reflect the broad diversity of the U.S.—all ages, races/ethnicities, gender, SES, geographies, & health status—by over-recruiting those underrepresented in biomedical research

- **Diversity of Researchers**: Build the tools & capabilities that make it easy for researchers from citizen scientists to premier university labs to make discoveries using the data & biosamples and through ancillary studies w/ the cohort
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.

**Core Values: “Quadruple Diversity”**

- Building relationships with diverse communities & participants is foundational to the program!
What makes *All of Us* unique?

- **Breadth**: at least 1 million participants
- **Data depth**: diversity of data types, including biospecimens, EHR, surveys, wearables
- **Longitudinal**: ongoing data acquisition for at least a decade
- **Diverse**: participants will reflect the rich diversity of the U.S.
- **Accessible and democratic**: data will be available to all researchers, including citizen scientists for “more brainpower per problem”
Major building blocks of the 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
30+ regional med centers, FQHCs, VA, future awards to grow network

COMMUNICATIONS & ENGAGEMENT
Comms, marketing, & design expertise; Engagement coordination & community partners network
Wondros, HCM, 4 community partner orgs, future awards to grow network
Current Consortium Members

DV Network
(Direct Volunteers)

- Scripps Translational Science Institute
- DXC Technology
- National Hollywood Collaborative Network
- A Leander Company
- Walgreens
- Blue Cross Blue Shield
- WONDROS

HPO Network
(Health Care Provider Organizations)

- California Precision Medicine Consortium
- The University of Arizona
- Marshfield Clinic
- BloodCenter of Wisconsin

RMCs

- Illinois Precision Medicine Consortium
- Northwestern University
- The University of Chicago
- NorthShore University Health System
- Advocate Health Care
- University of Illinois at Chicago

- New England Precision Medicine Consortium
- Partners Healthcare
- Brigham and Women’s Hospital
- Massachusetts General Hospital
- Beth Israel Deaconess Medical Center

- Trans-American Consortium for the Health Care Systems Research Network
- University of Pittsburgh Medical Center
- University of California, Los Angeles
- New York Presbyterian Hospital
- Weill Cornell Medicine

- New York City Precision Medicine Consortium
- Columbia University Medical Center
- Montefiore Medical Center
- New York Presbyterian Hospital

- Southern All of Us Network
- VA Medical Centers
- Southern All of Us Enrollment Center
- Marshfield Clinic
- BloodCenter of Wisconsin

Community Partners

- FQHCs (Federally Qualified Health Centers)
- VA Medical Centers
- U.S. Department of Veterans Affairs

Communication & Engagement

- WONDROS
- HCM

Platform Development

- Scripps Translational Science Institute
- Sage
- Vanderbilt University
- WONDROS
- vibrent
Towards “Anywhere & Everywhere” Researcher Access

**Traditional Way:** Bring data to researchers

**All of Us Way:** Bring researchers to the data

**Problems**
- Security (data handoffs)
- Data sharing = data copying
- Huge infrastructure needed
- Fixed amount of compute
- Slow & cumbersome access

**Advantages**
- Threat detection and auditing
- Cost
- Increased Accessibility
- Elastic compute
- Fast access
Recent Announcements

- **Children’s Enrollment Scientific Vision WG**
  - Announced on 7/17
  - 4 meetings so far; report expected October

- **Initial Community Partner Awards**
  - 4 community partner awards announced on 7/25
  - Additional awards expected in September timeframe

- **Protocol**
  - Posted on allofus.nih.gov on 8/4

- **Genomics WG**
  - Announced on 8/15
  - 4 meetings so far; report expected 10/1

Purpose & Status of “Closed Beta Phase”
What is the purpose of the “Closed” Beta Phase?

- Enroll initial 10-15,000 participants who can give feedback on all aspects before national launch
- Ramp over 100 locations around the country slowly, carefully week by week
- Test the initial protocol, call center, online tools & interfaces, language of consent & questionnaires, workflow for staff at each location, biobank shipments, etc.

“Closed” means only those given a special code can enroll right now—will be removed for nat’l launch

Click “We’re in beta” at top of https://www.joinallofus.org/
How is it going so far?

- **Over 3000 full participants**

- **Participants** are joining, going through the protocol on the participant portal, & giving useful feedback in beta

- **Local staff** learning & ramping quickly, finding ways to improve as they “get into it”

- Good progress on **rolling out locations**

- Limited ability to test engagement methods in a closed beta & no local PR

An expanded beta phase will run from November through national launch (Spring 2018)
Looking Ahead
Plans for Launch and Beyond

- We’re working like a technology platform company, centered on the user experience
- Will launch when ready and right
- Phased implementation as we pilot, iterate, and scale
- Over time, anticipate new technologies, protocols, and assays
- Will provide transparency and open access to our protocols to enhance interoperability with other cohorts
Questions?

Sign up for updates:
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