The All of Us Research Program: Diverse Participation in Arizona

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Engagement Team
Ancestry of GWAS participants over time compared to global population (GWAS Catalog 76)
Prediction accuracy relative to European-ancestry individuals across 17 quantitative traits in 5 continental populations in the UKBB.


Inclusion of multi-ethnic samples enables discovery and replication in GWAS

From: Genetic analyses of diverse populations improves discovery for complex traits

MISSION: To enable a new era of medicine through research, technology, and policies that empower patients, researchers, and providers to work together toward development of individualized care
All of Us Anthem
Personalized Medicine
All of Us Core Values

- Participation is open to all.
- Participants reflect the rich diversity of the U.S.
- Participants are partners.
- Trust will be earned through transparency.
- Participants have access to their information.
- Data is accessed broadly for research purposes.
- Security and privacy are of highest importance.
- The program may be a catalyst for positive change in research.
Vision: Reflect the country’s rich diversity to produce meaningful health outcomes for communities historically underrepresented in biomedical research.

- Incentivize HPO Network to Focus on UBR Communities
- Build Up FQHC Research Capacity as Valuable HPO Partners
- Invent Network of Direct Volunteer Partners
- Grow a Network of National and Local Community Partners
- Develop Specific Plans for Special Population Engagement
- Build a User/Participant-Centered Design Culture and Process
Current Protocol: Participant Journey

Enroll, Consent and Authorize EHR
- Recruiting 18+ years old initially; plan to include children in future
- Online, interactive consent
- Includes authorization to share EHR data

Answering Surveys
- Initial surveys:
  - The Basics
  - Overall Health
  - Lifestyle
  - Health Care Access & Utilization
  - Family Medical History
  - Personal Medical History
- Additional surveys will be released on an ongoing basis

Physical Measurements*
- Blood pressure
- Heart rate
- Height
- Weight
- BMI
- Hip circumference
- Waist circumference
*Based on diverse sampling and capacity

Provide Biosamples*
- Blood (or saliva)
- Urine specimen
- Biosamples will be stored at the program’s biobank
*Based on diverse sampling and capacity

Wearables and Digital Apps
- Share data from wearable fitness devices, starting with Fitbit
- Coming soon: Integrated apps to track mood & cardio-respiratory fitness
All of Us Research: How it works

1. Participants share their data with the All of Us Research Program through multiple sources. These data are sent to a secure cloud environment, managed by the Data and Research Center.

2. Participant data is received and funneled through a curation pipeline within a secure repository that connects to the Research Hub tools.

3. Anyone can visit the Research Hub to learn more about the types of data All of Us makes available for research. The Survey Explorer and Data Browser offer more information about the unique data elements and let visitors browse aggregated participant data.

4. Researchers register and apply for access to the Researcher Workbench to analyze data.

5. Registered researchers in the Researcher Workbench can create research projects using collaborative workspaces, cohort-building tools, interactive notebooks, and more.

6. Research underway can be viewed on the Projects Directory. Publications related to All of Us Research Program data are posted on the Publications page.
Data Snapshots: Participants at a Glance

Enrollment Numbers

This graph represents participants who have consented to join the program and those who have completed all initial steps of the program. The initial steps are consenting, agreeing to share electronic health records, completing the first three surveys, providing physical measurements, and donating at least one biospecimen to be stored at the biobank.

The following numbers are approximated to protect participants’ privacy.
Numbers are updated as of June 8, 2022.

499,000+
Participants

342,000+
Participants who have completed initial steps of the program
Racial and Ethnic Diversity of Participants

- **White**: 48.0%
- **Asian**: 2.9%
- **Black, African American or African**: 20.8%
- **Hispanic Latino or Spanish**: 16.9%
- **More than one race/ethnicity**: 6.5%
- **Other**: 2.9%
- **Prefer not to say**: 0.6%
Age of Participants at the Time of Enrollment

- 18-29: 10.3%
- 30-39: 15.1%
- 40-49: 14.3%
- 50-59: 19.5%
- 60-69: 21.6%
- 70-79: 14.6%
- 80-89: 4.1%
- 89+: 0.5%
## Arizona Enrollment and Diversity Dimensions

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Arizona</th>
</tr>
</thead>
<tbody>
<tr>
<td>As of 1/13/2022 Total Numbers Core</td>
<td>51,440</td>
</tr>
<tr>
<td>Overall diversity</td>
<td>81.2%</td>
</tr>
<tr>
<td>Racial-Ethnic Identity</td>
<td>52.7%</td>
</tr>
<tr>
<td>Age</td>
<td>17.9%</td>
</tr>
<tr>
<td>Sexual and Gender Minority</td>
<td>9.5%</td>
</tr>
<tr>
<td>Income</td>
<td>34.9%</td>
</tr>
<tr>
<td>Education</td>
<td>14.0%</td>
</tr>
<tr>
<td>Geography</td>
<td>6.0%</td>
</tr>
</tbody>
</table>

How does the *All of Us* Research Program relate to individuals from diverse backgrounds?
Community Engagement

- Community engagement is grounded in the principles of community organization: fairness, justice, empowerment, participation, and self-determination...
- ...the process of working collaboratively with and through groups of people to address issues affecting their well-being
- It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members
- It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices

(CDC, 1997, p 9)
Precision Engagement Approach

**Identify** individuals, communities, and stakeholders who will be targeted for engagement locally.

**Develop** locally tailored and culturally congruent clear and uncomplicated messaging.

**Pursue** meeting with partner organization employees/learners/constituencies to participate in the research program.

**Plan** to share ongoing process of the study in meaningful useful formats to maintain communities, participants, participant families, providers informed.

**Sustain** community engagement by mobilizing identified community assets and strengths.

**Conduct** workforce assessment of congruence of skill and resources with local community engagement priorities. Does your team share the culture and/or languages preferred by target communities? Are our efforts meeting the community where they are at?

**Revise** and optimize training and supervision processes to ensure fidelity to jointly developed localized approaches. This includes participating in tracking and evaluation processes.

**Participate** in network wide engagement discussions to facilitate integration of co-learned strategies, contribute to All of Us empowering communication and inclusive decision making process.

**Potential Partnerships**
Potential participants and respective families, community-based, non-profit, governmental, and non-governmental organizations, faith-based organizations, churches, FQHC, Coalitions, advocacy groups, community centers, hospitals and providers and Spanish and English media outlets.
Participant and Community Engagement Strategy

Awareness  Education  Credibility  Trust  Relationship  Support  Participation
Partner Development: Selection Criteria

- Demonstrate reach into and experience working with at least one priority UBR community
- Serve as a validator, an organization with a trusted brand within a priority community
- Share an aligned goal to with *All of Us*
- Active communication channels (traditional and social media)
- Experience developing, implementing and evaluating outreach, education, and awareness campaigns to targeted populations
- Reach and ability to develop and implement activities in priority geographic regions
- Documented interest in *All of Us*
NIH has created *All of Us* community engagement partners to help motivate the diverse communities they serve to join and remain in the program. Some also engage and educate health care professionals, researchers, and others about the program.
Personalized Medicine and Hispanic Health: Recommendations by Avilés-Santa et al., 2017

- Improve data collection strategies through existing networks
- Require inclusion of race/ethnicity data
- Strengthen guidance to researchers in regard to inclusive study designs
- Integrate genetic and epigenomic data into EHR
- Prioritize research on Hispanic populations not represented
- Integrate Hispanic research in clinics
- Engage stakeholders at multiple levels of research
- Increase Hispanic scientific workforce
• Collaboration with Mexican Consulates in Arizona
• Collaboration with community service partners
• Bilingual personnel
• Cultural understanding of the local population
• Informational materials in Spanish and English
• Ability to support informed decision making consistent with the participant’s language, literacy level, or cultural needs
• Community activities: Use of Promotores, Mobile Units, participants who serve as champions
• Return of value tailored to the community
• Meeting potential participants where they are at
Designing the Spanish Speaking Participant Experience

1. From the beginning, participants are welcomed into the program in Spanish through Spanish-speaking staff and the signage within the facilities.

2. All participant-facing materials are printed double-sided in English and Spanish so that every participant feels welcome into the program.

3. Participant fears about privacy are addressed through the display of our Certificate of Confidentiality at every site and used by program staff in participant education.

4. After enrollment, participants have the opportunity to let others know why they joined AoU. The sign is written in both languages to signal both languages are welcome.

5. Appreciation is shown to participants through digital enrollment anniversary and birthday cards in both languages.
Native American Engagement Team

Miguel Flores, Jr.  
(Pascua Yaqui and Tohono O’odham)  
traditional healer and counselor.

Mary S. Koithan, PhD, associate dean, Anne Furrow endowed professor of Integrative Nursing, UA College of Nursing.

John Molina, MD, JD, LHD, (Pascua Yaqui and Yavapai-Apache) Corporate Compliance Officer for Native Health of Phoenix, an Urban Indian health center in Phoenix.

Teshia Solomon, PhD  
(Choctaw), co-investigator, American Indian Community Engagement Director, UA College of Medicine.

Monica Yellowhair, PhD, (Navajo) assistant research scientist, UA Cancer Center.
All of Us Research Program
Tribal Consultation Report

NIH
National Institutes of Health
Turning Discovery into Health
Sexual and Gender Minorities: NIH Research Goals

Expand knowledge of SGM Health / Well-being
Remove barriers to SGH research planning, conducting, reporting
Strengthen the community of SGM researchers / scholars
Evaluate progress
LGBT Recruitment and Research Efforts

Mitchell R. Lunn (right), MD, MAS, and Juno Obedin-Maliver, MD, MPH, MAS, co-direct PRIDEnet, which engages sexual and gender minorities in research. Their expertise will be used as UCSF and Zuckerberg San Francisco General Hospital take part in the All of Us Research Program. *Photo by Susan Merrell*

All of Us Consortium Members (earlier in 2021)

The Participant Center
- Scripps Research Translational Institute
- Bloodworks
- patientslikeme

Communications & Engagement
- RTI International
- PRECISION

HPO Network (Health Care Provider Organizations)
- All of Us California
  - UC San Diego Health
  - UCI Health
- U.C. Davis Health
- Cedars Sinai
- USCS/University of Southern California
- UI Health

HPO Lite
- UTHealth
- VCU Health
- Washington University and its affiliates

RMCs
- All of Us California
- California Precision Medicine Consortium
- All of Us New England
- Trans America Consortium
- New York City Consortium
- All of Us Southern Network
- All of Us SouthEast Enrollment Center

Illinois Precision Medicine Consortium
- Northwestern Medicine
- Brigham Health
- Mass General Brigham
- University of Chicago Medicine
- Rush University Medical Center
- Cook County Health
- UI Health

University of Arizona and Banner Health
- University of Pittsburgh
- University of Arizona
- Banner Health

FQHCs (Federally Qualified Health Centers)
- Cherokee
- Community Health Systems
- Sun River Health

VA Medical Centers
- VA Wisconsin

Participant Technology Systems Center (PTSC)
- Participant Technology Systems Center (PTSC)

Biobank
- Biobank

Data & Research Center (DRC)
- Data & Research Center (DRC)

Genomics Partners
- Genomics Partners

Mass General Brigham

University of Washington

Columbia
Thank You!
fmoreno@arizona.edu

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Visit AllofUs.nih.gov
Call AoU National Support: 1 (844) 242-2855

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