

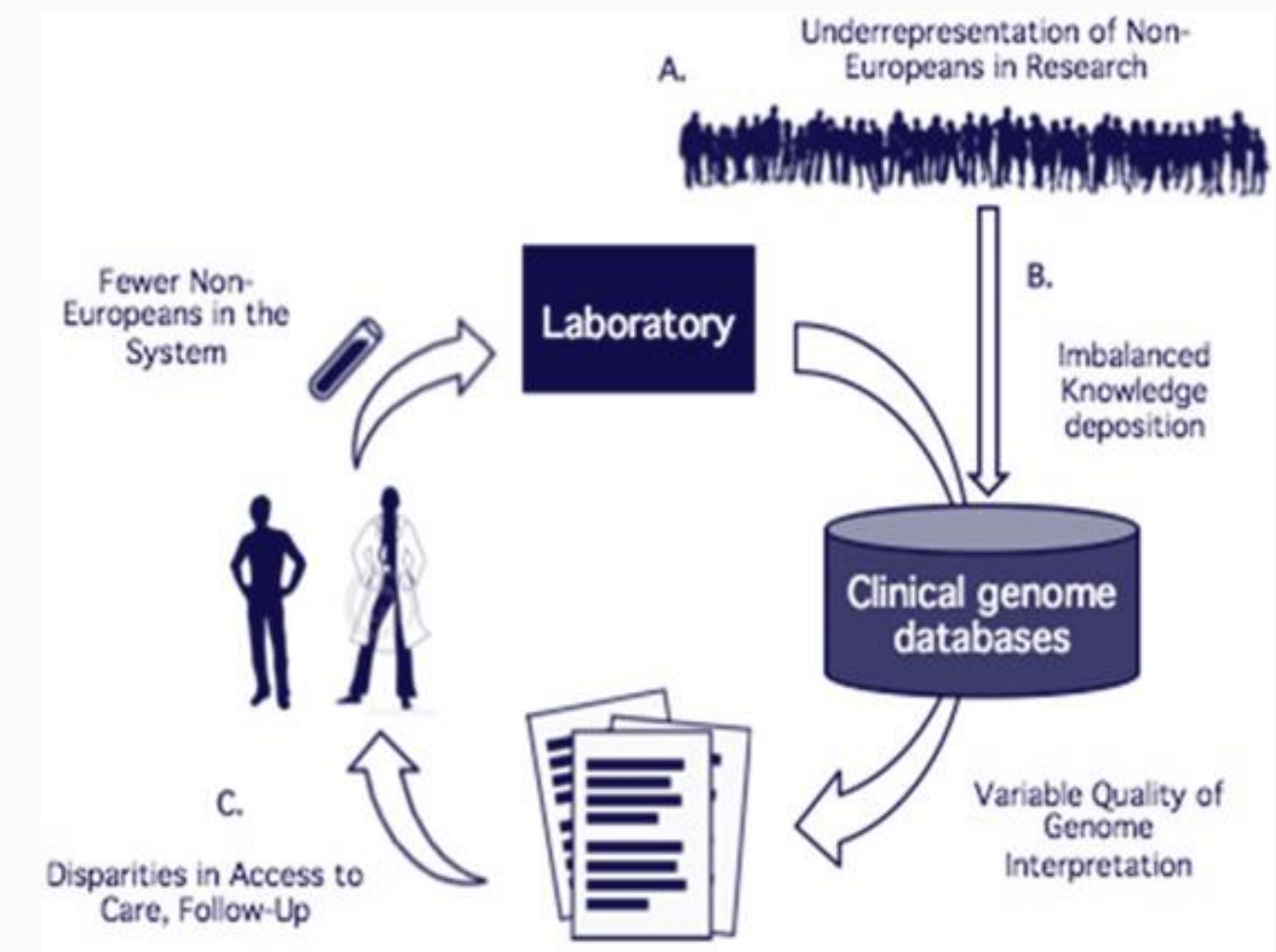
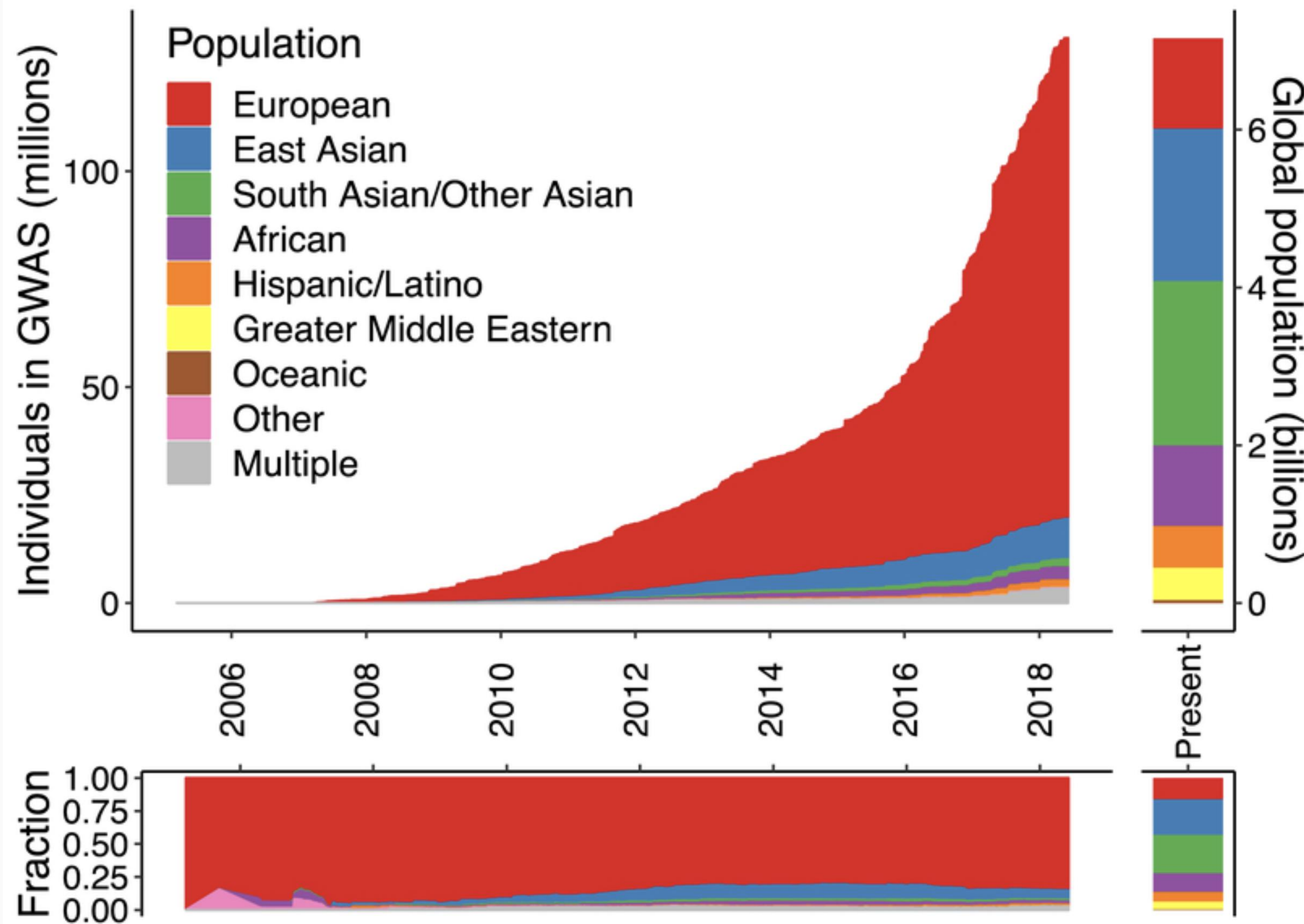


The All of Us Research Program: Diverse Participation in Arizona

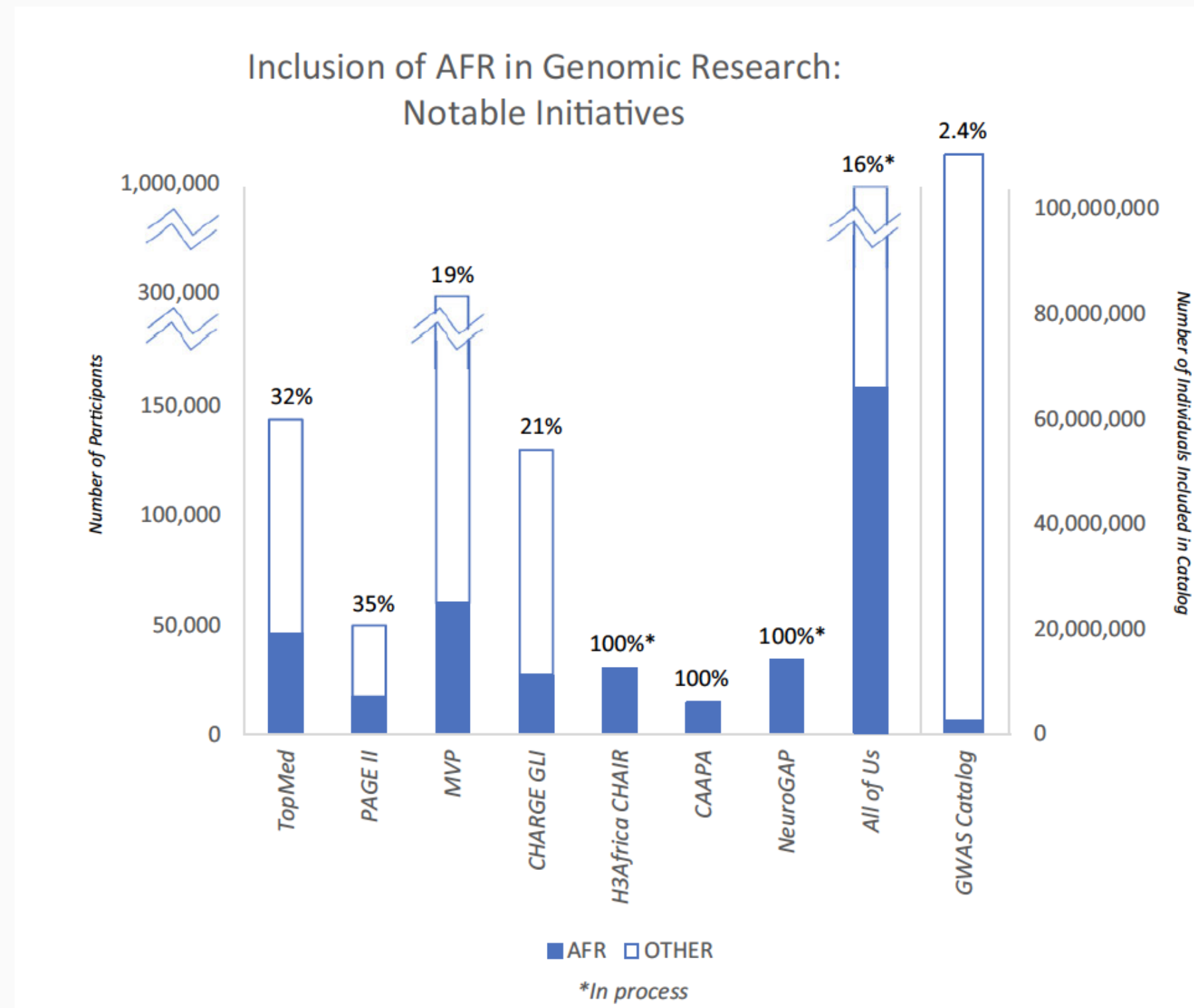
Francisco A. Moreno, Carrie Simmons, Gregory McAteer
Engagement Team



Ancestry of GWAS participants over time compared to global population (GWAS Catalog 76)

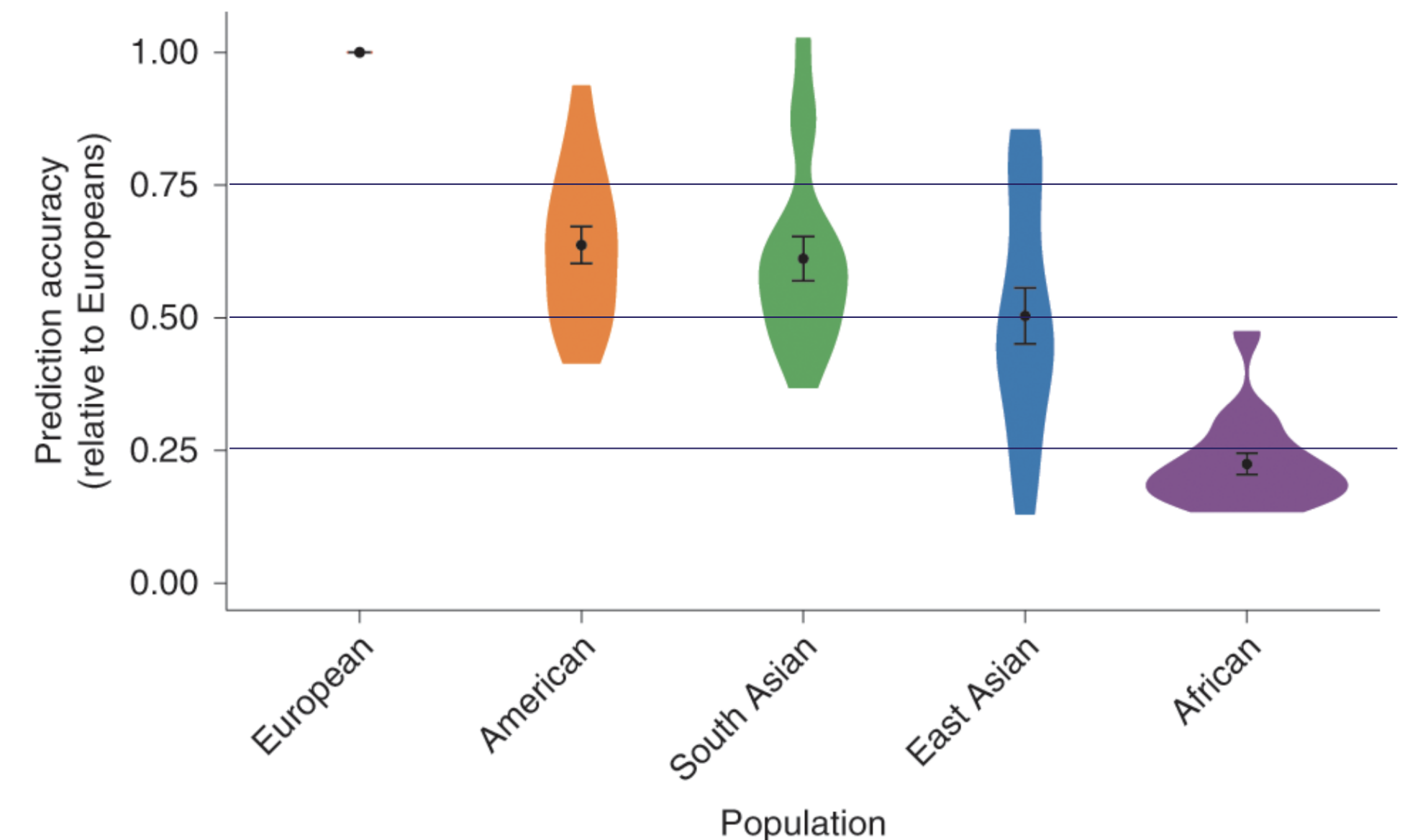


Prediction accuracy relative to European-ancestry individuals across 17 quantitative traits in 5 continental populations in the UKBB.



Bentley, A.R., Callier, S.L. & Rotimi, C.N. Evaluating the promise of inclusion of African ancestry populations in genomics. *npj Genom. Med.* **5**, 5 (2020).
<https://doi.org/10.1038/s41525-019-0111-x>

From: Evaluating the promise of inclusion of African ancestry populations in genomics

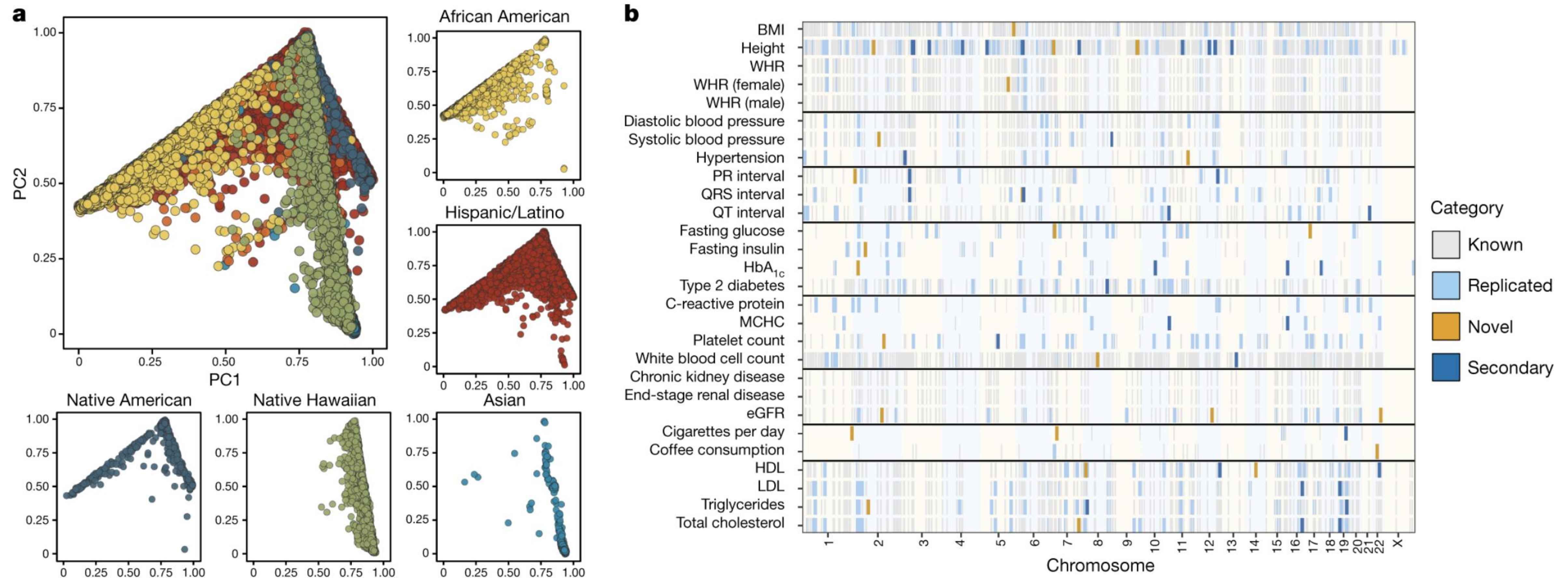


Prediction target individuals do not overlap with the discovery cohort and are unrelated. Violin plots show distributions of relative prediction accuracies, points show mean values, and error bars show s.e.m. values. [Reprinted by permission from Springer Nature Customer Service Centre GmbH: Springer Nature, Nature Genetics, "Clinical use of current polygenic risk scores may exacerbate health disparities", Alicia R. Martin et al.⁴²].

Martin, A.R., Kanai, M., Kamatani, Y. et al. Clinical use of current polygenic risk scores may exacerbate health disparities. *Nat Genet* **51**, 584–591 (2019).
<https://doi.org/10.1038/s41588-019-0379-x>

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

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



Enacted with significant bipartisan support



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**
RESEARCH PROGRAM

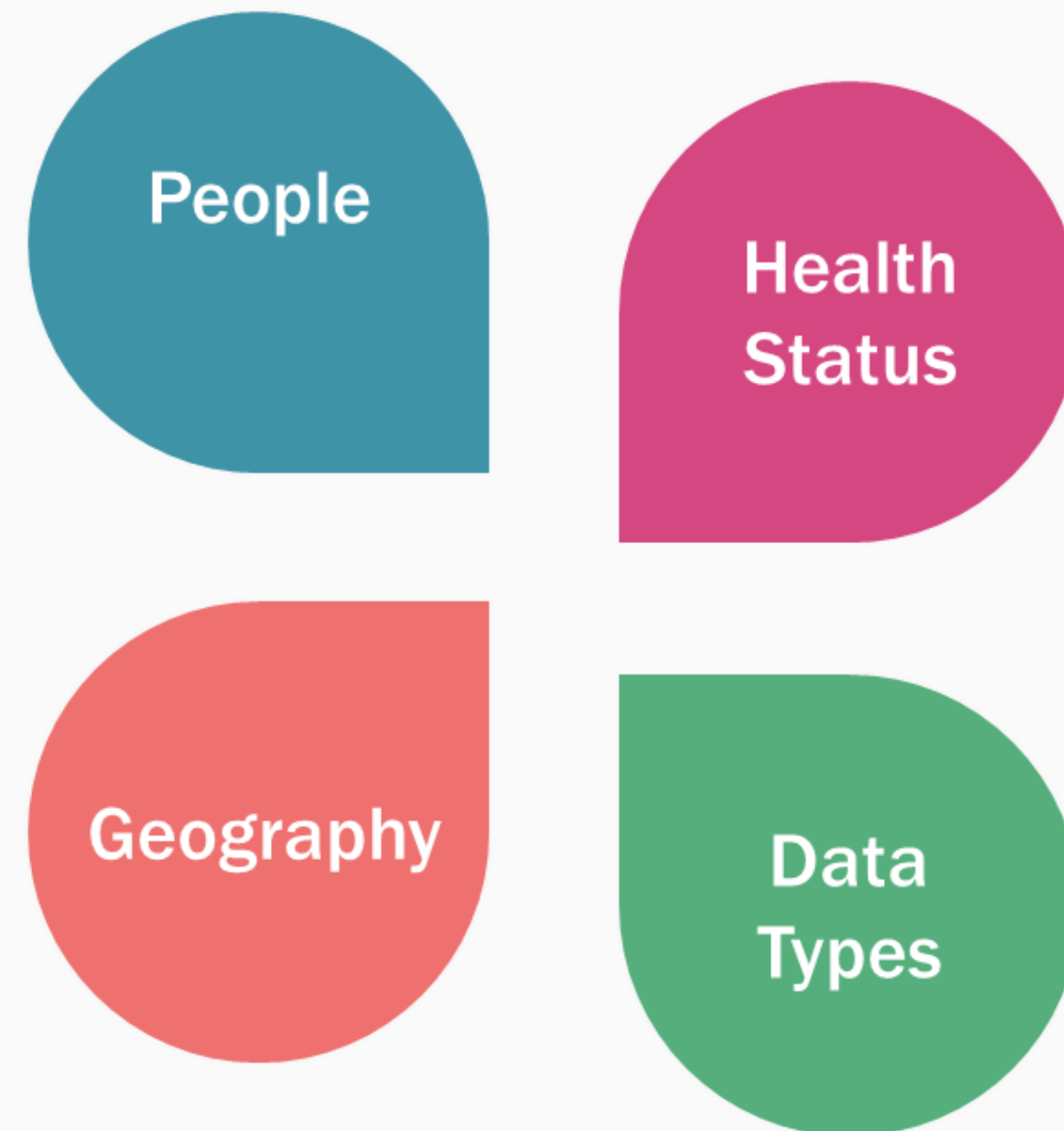


All of Us Core Values

- 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.

Portfolio of Actions and Investments To Achieve Diversity

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

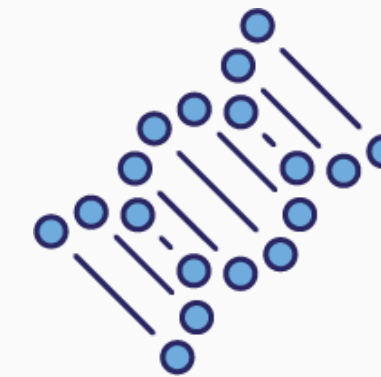
Additional surveys will be released on an ongoing basis



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*

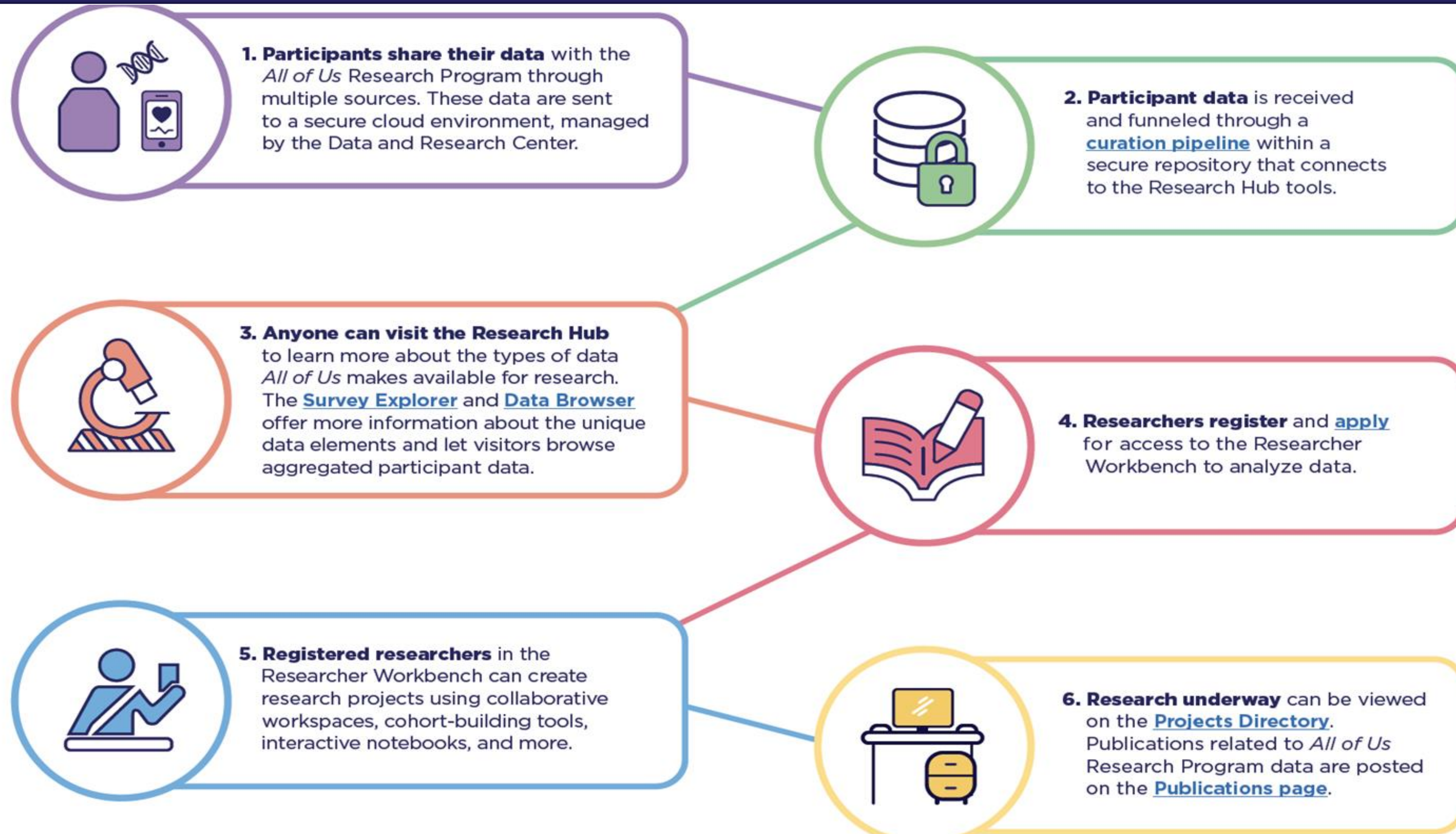


Wearables and Digital Apps

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

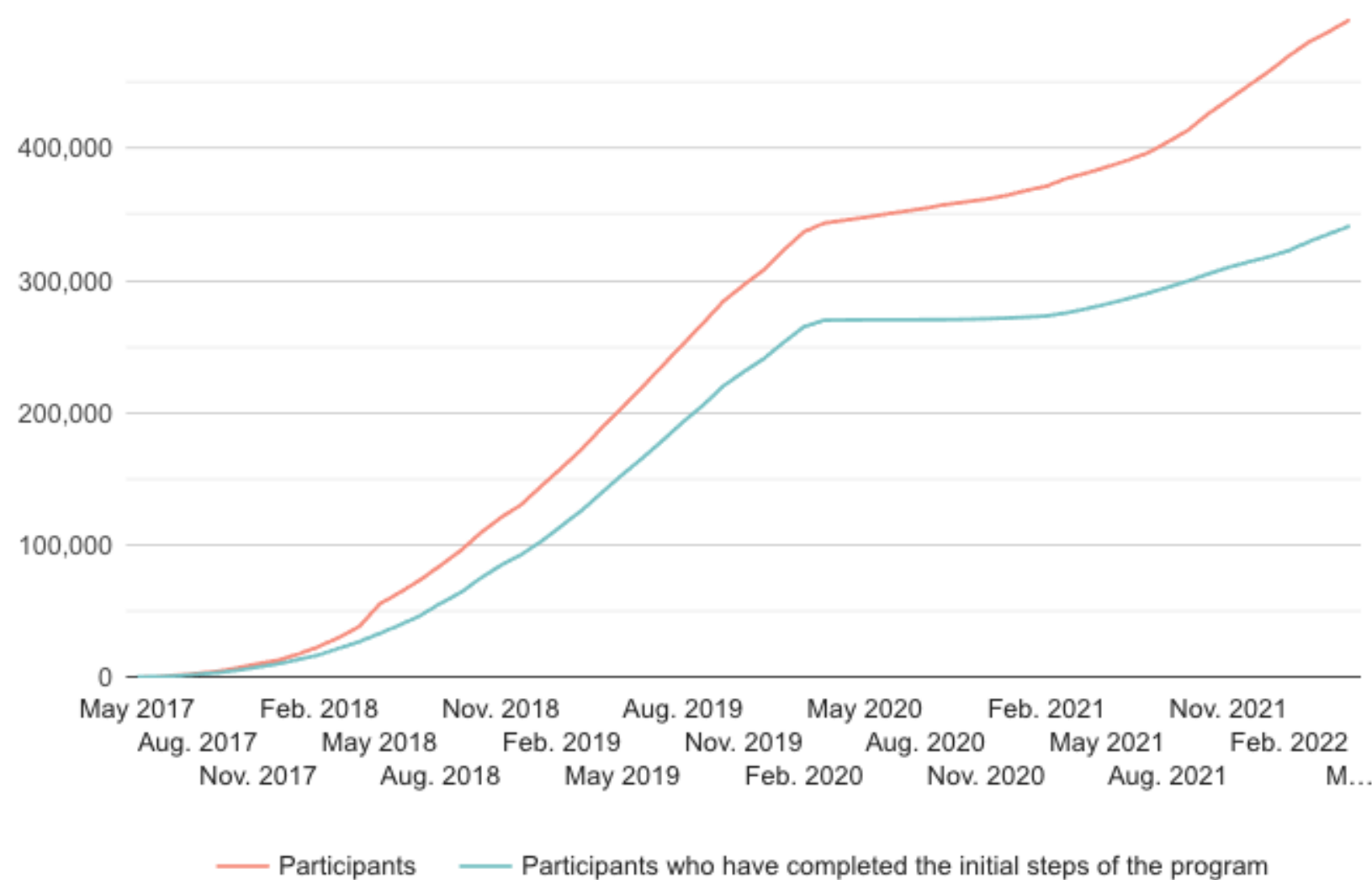


Data Snapshots: Participants at a Glance

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.*

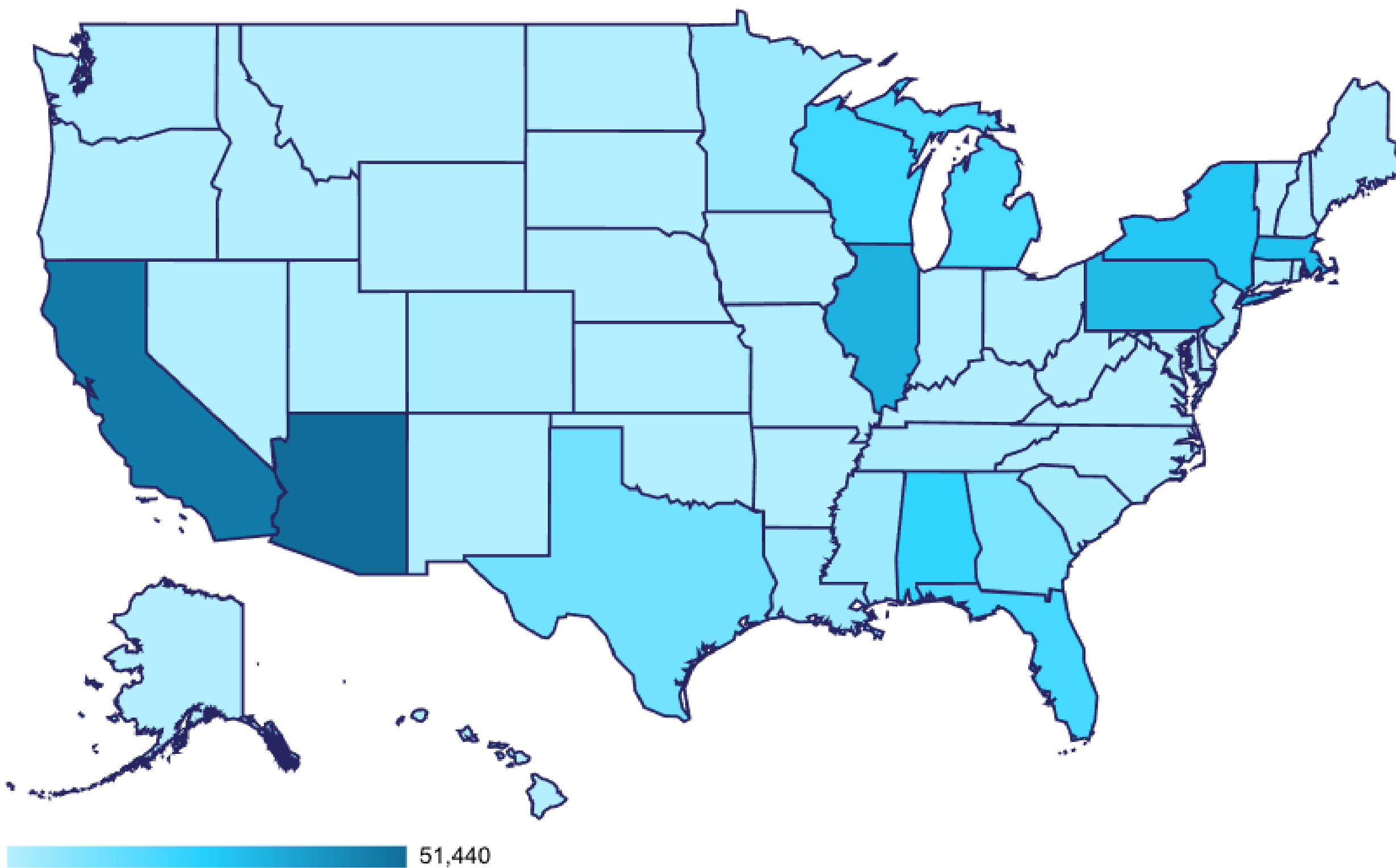


499,000+

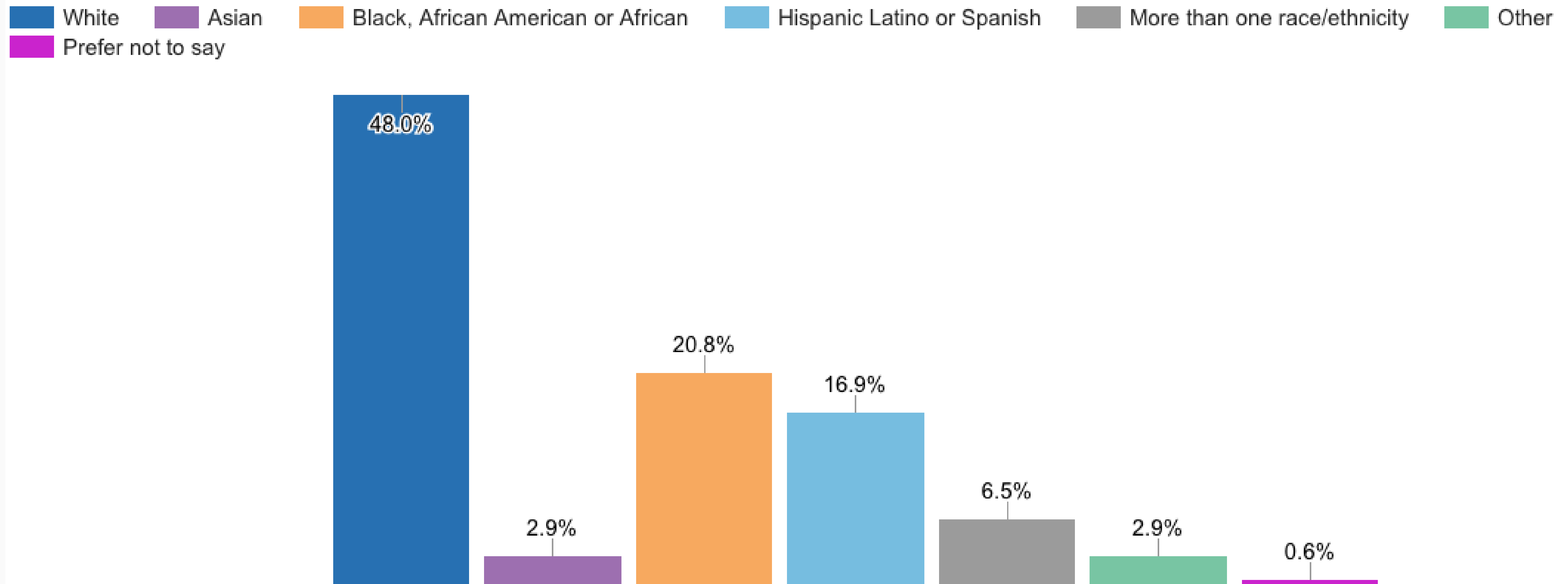
Participants

342,000+

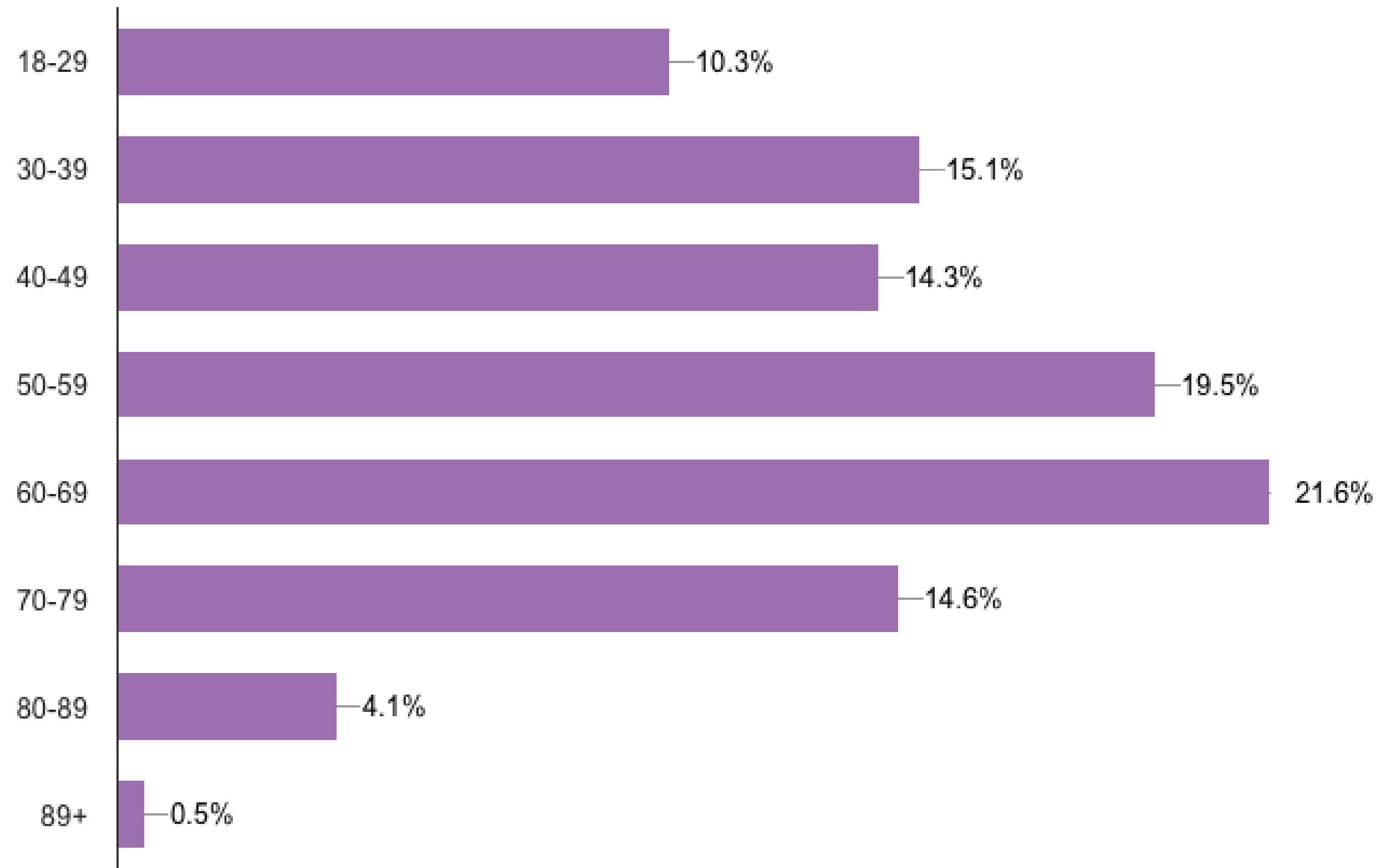
Participants who have completed initial steps of the program



Racial and Ethnic Diversity of Participants



Age of Participants at the Time of Enrollment



Arizona Enrollment and Diversity Dimensions

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

Reference: Ilori TO, Viera E, Wilson J, Moreno F, Menon U, Ehiri J, Peterson R, Vemulapalli T, StimsonRiahi SC, Rosales C, Calhoun E, Soka A, Karnes JH, Reiman E, Ojo A, Theodorou A, Ojo T. Approach to High Volume Enrollment in Clinical Research: Experiences from an All of Us Research Program Site. Clin Transl Sci. 2020 Jul;13(4):685-692. doi: 10.1111/cts.12759. Epub 2020 Mar 17. PMID: 32004412; PMCID: PMC7359931.



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

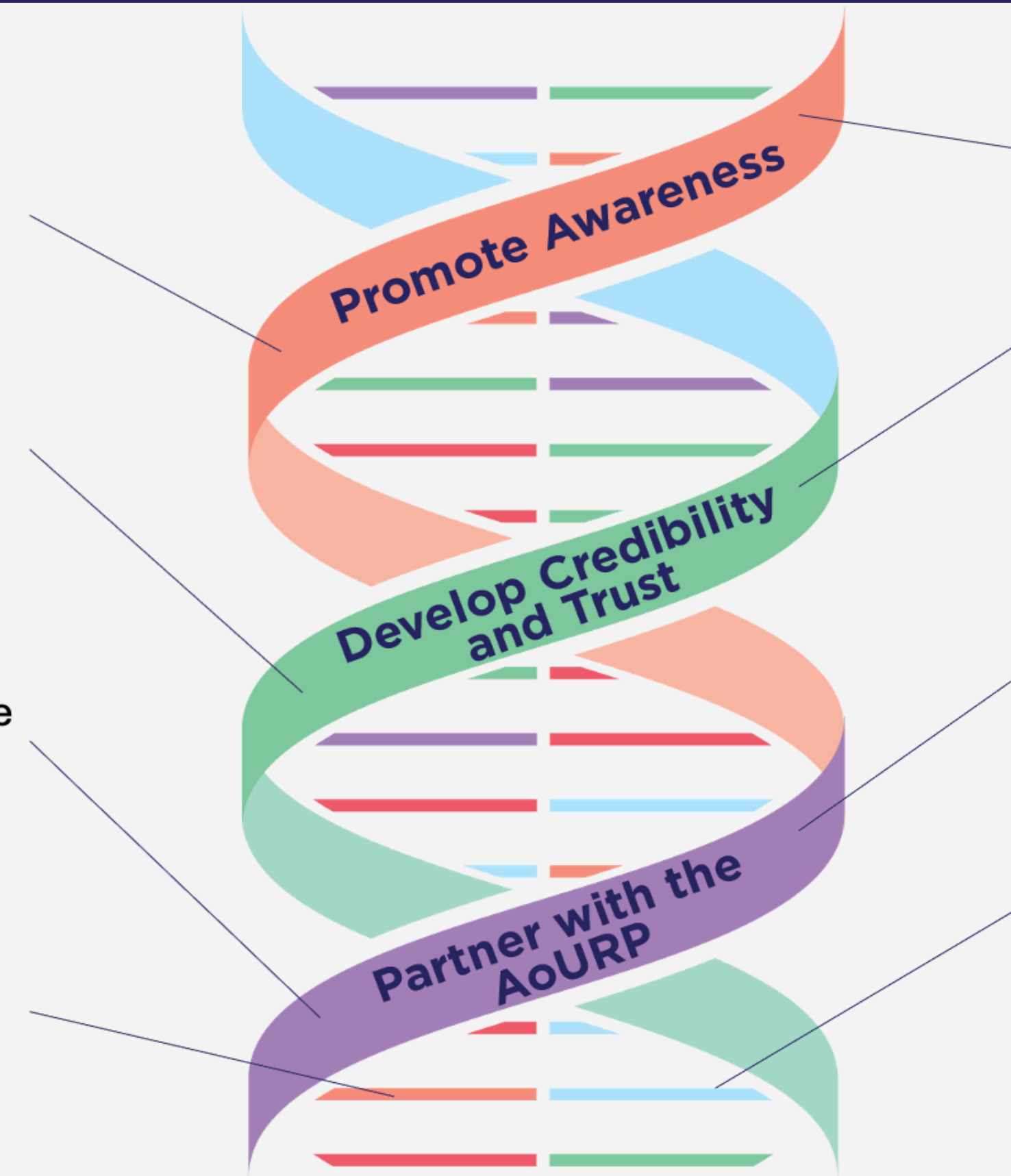
Precision Engagement Approach

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.

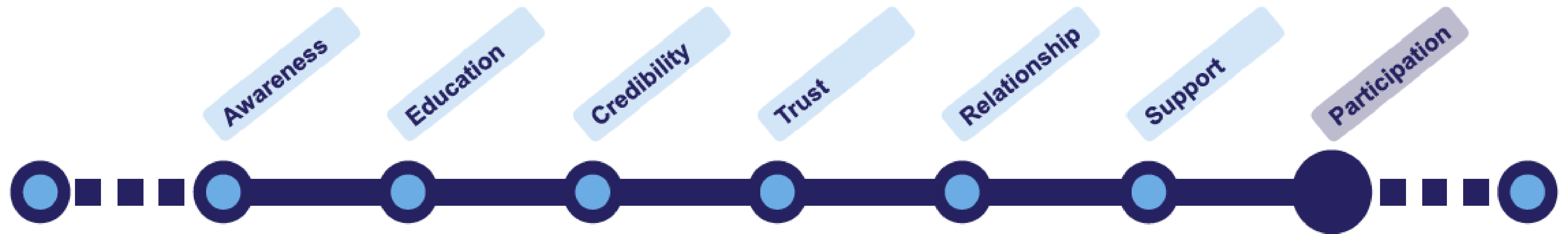
Potential Partnerships

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.

Community Congruent Clinical Research and Engagement Staff



Participant and Community Engagement Strategy



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*

All of Us Community and Provider Partner Network *(earlier in 2021)*



Community Engagement Partners


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.



We are an
Arizona Champion
for the
All of Us
RESEARCH PROGRAM
partnering to pave the
way to a healthier future.




1 (877) 268-2684
Visit AllofUsAZ.org
#JoinAllofUs

   All of Us is a service mark of the U.S. Department of Health and Human Services.



We are an
Arizona Champion
for the
All of Us
RESEARCH PROGRAM
partnering to pave the
way to a healthier future.

1 (877) 268-2684
Visit AllofUsAZ.org
#JoinAllofUs

   All of Us is a service mark of the U.S. Department of Health and Human Services.



We are an
Arizona Champion
for the
All of Us
RESEARCH PROGRAM
partnering to pave the
way to a healthier future.

1 (877) 268-2684
Visit AllofUsAZ.org
#JoinAllofUs

   All of Us is a service mark of the U.S. Department of Health and Human Services.

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**



Hispanic Engagement in Arizona

- 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



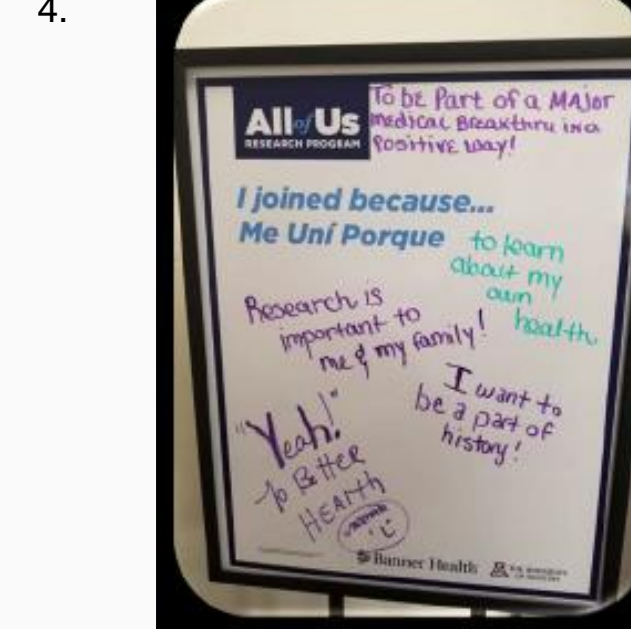
From the beginning, participants are welcomed into the program in Spanish through Spanish-speaking staff and the signage within the facilities.



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



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.



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.



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.



**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.



**Monica
Yellowhair,
PhD**, (Navajo)
assistant
research
scientist,
UA Cancer
Center.



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



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



All of Us Research Program Tribal Consultation Report



Sexual and Gender Minorities: NIH Research Goals

Sexual and Gender Minorities (SGM) are officially designated as a Health Disparity Population (HDP) for NIH research.



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*

<https://www.joinallofus.org/en/videos/nancy-vanreece-lgbtq-inclusion-all-us-research-program>

All of Us Consortium Members (earlier in 2021)

The Participant Center



Communications & Engagement



HPO Network

(Health Care Provider Organizations)

RMCs

All of Us California



Illinois Precision Medicine Consortium



All of Us New England



Trans America Consortium



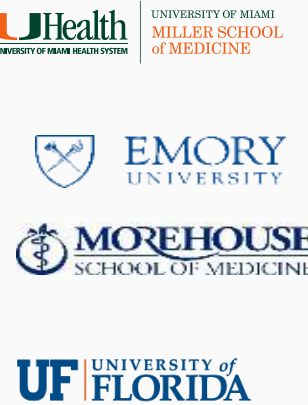
New York City Consortium



All of Us Southern Network



All of Us SouthEast Enrollment Center



HPO Lite



All of Us Wisconsin



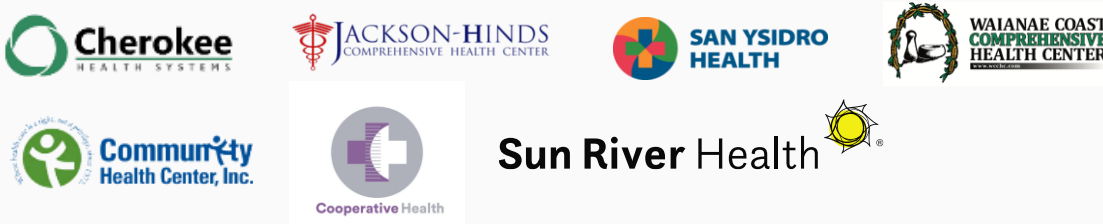
All of Us Pennsylvania



University of Arizona and Banner Health



FQHCs (Federally Qualified Health Centers)



VA Medical Centers



Participant Technology Systems Center (PTSC)



Biobank



Data & Research Center (DRC)



Genomics Partners



Thank You!
fmoreno@arizona.edu



*Scan Code with Your
Mobile Device to Visit
Our Website!*



Visit AllofUsAZ.org
Call AoU UArizona-Banner:
1 (877) 268-2684



National Institutes
of Health

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

Follow Us on Social Media! @All of Us AZ

