



Achieving Equitable Community and Participant Engagement in the *All of Us* Research Program

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Disclosure Information

I have no relevant financial relationships to disclose.

This presentation will not include discussions of off-label, experimental, or investigational use of drugs or devices.

Achieving Equitable Engagement: Citizen Scientists

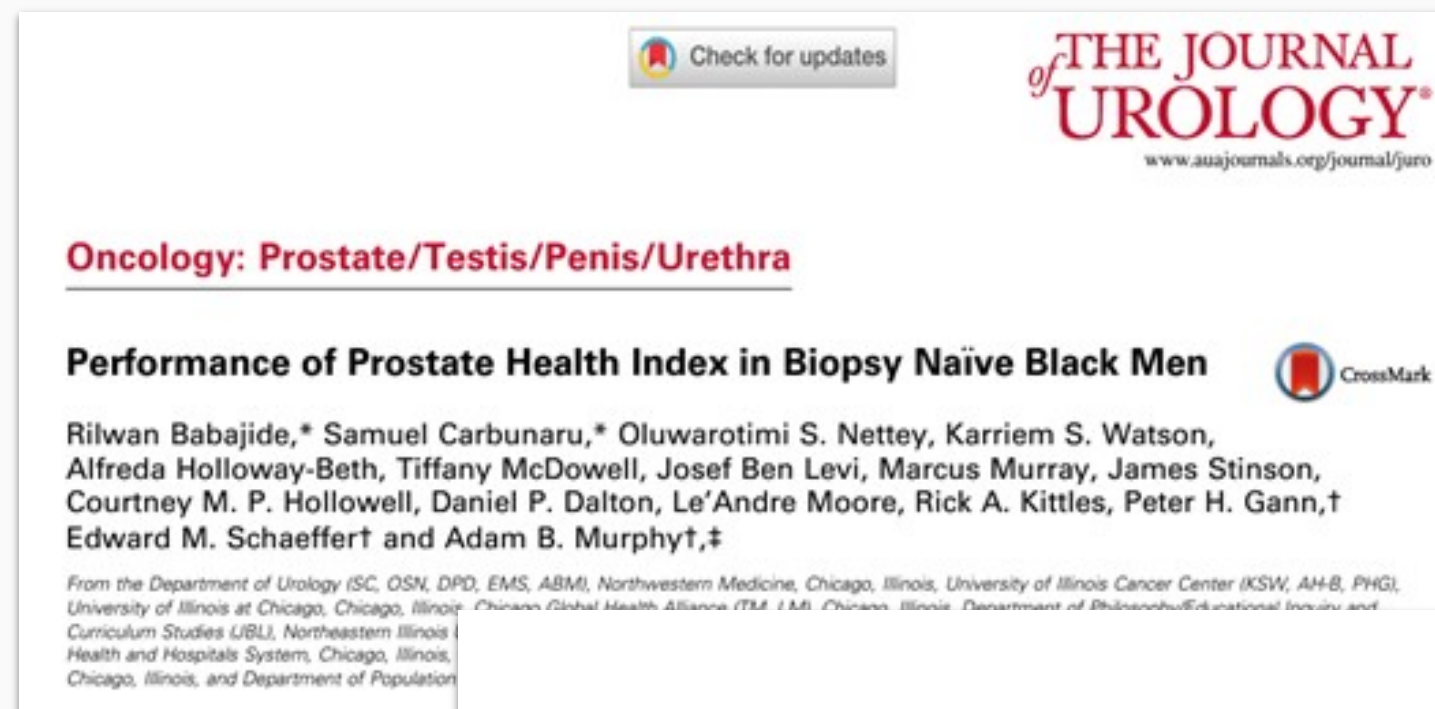
Improving prostate and lung cancer screening among African American men through the engagement of citizen scientists.



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Northwestern University



ROBERT A. WINN, M.D.
Virginia Commonwealth University



JOSEF BEN LEVI, ED.D
Northeastern Illinois University

Engaging African American Men as Citizen Scientists to Validate a Prostate Cancer Biomarker: Work-in-Progress

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PHOENIX A. MATTHEWS, PHD, MS, BS, LCP
Columbia University



CURTIS ESKRIDGE
Cut It Out Curt



MARCUS MURRAY, MPH
Project Brotherhood

The NIH *All of Us* Research Program



The NIH *All of Us* Research Program is a historic, longitudinal effort to gather data from one million or more people living in the United States and territories to accelerate research and improve health.

819,000+
Participants

578,000+
Biosamples

559,000+
Completed
initial steps of
the program

451,000+
Electronic Health
Records

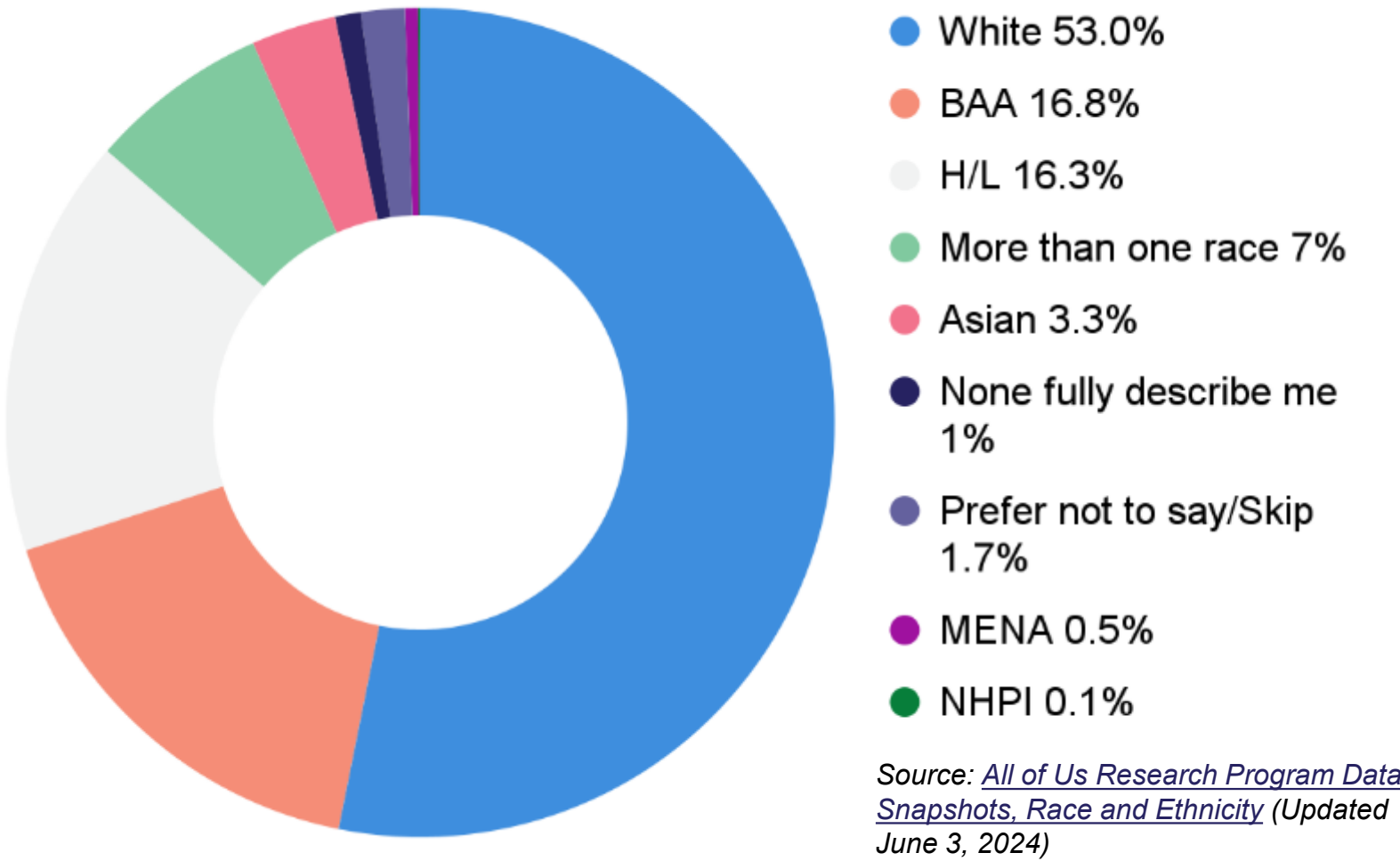
Current as of July 5, 2024

The data and research generated by *All of Us* may:

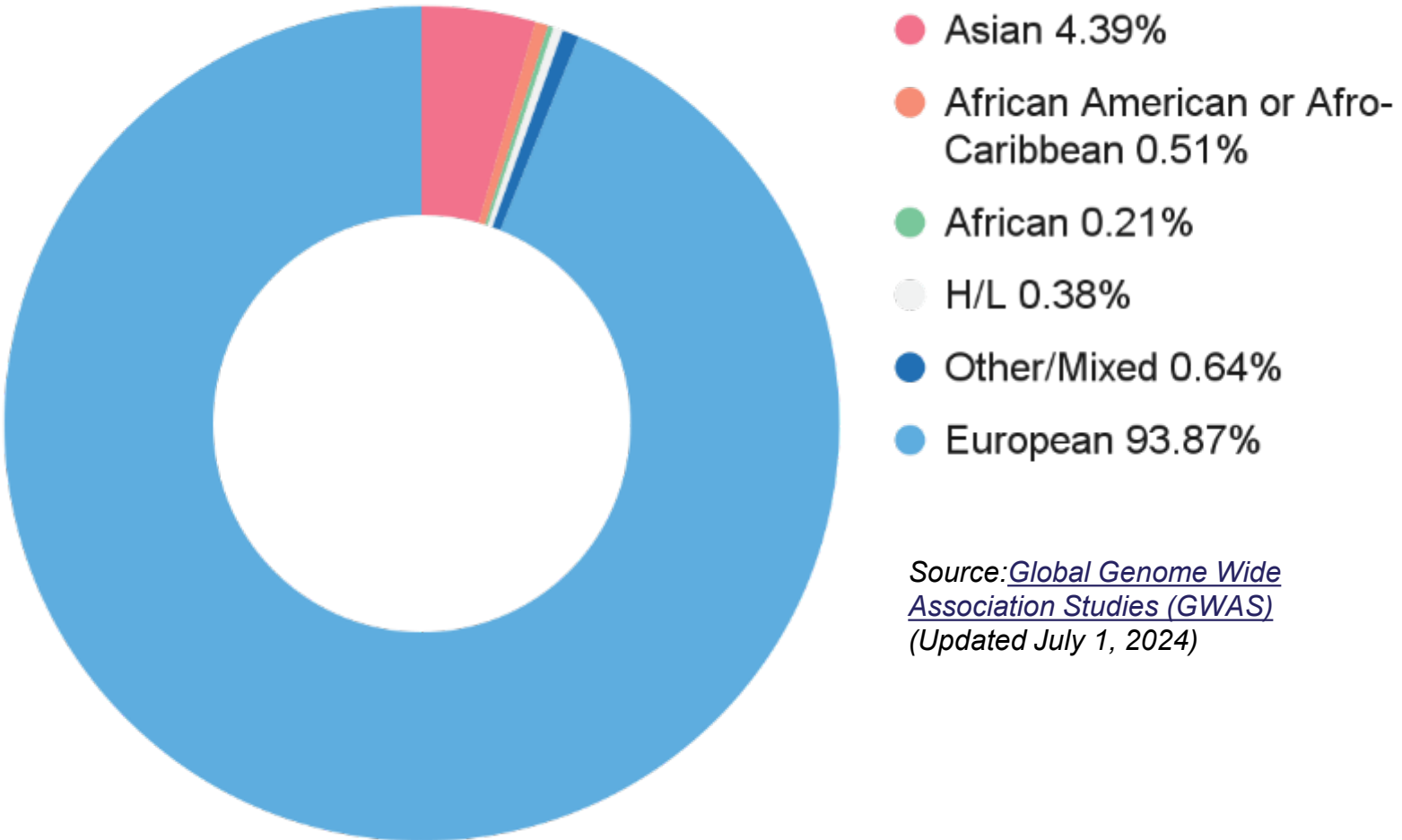
- Fill a **critical gap in precision medicine research** by contributing **valuable genetic and health data** from communities underrepresented in biomedical research (UBR).
- **Enable disaggregated analyses** to identify health disparities specific to UBR communities.

How Community Engagement Has Advanced Precision Medicine and Genomics in the *All of Us* Research Program

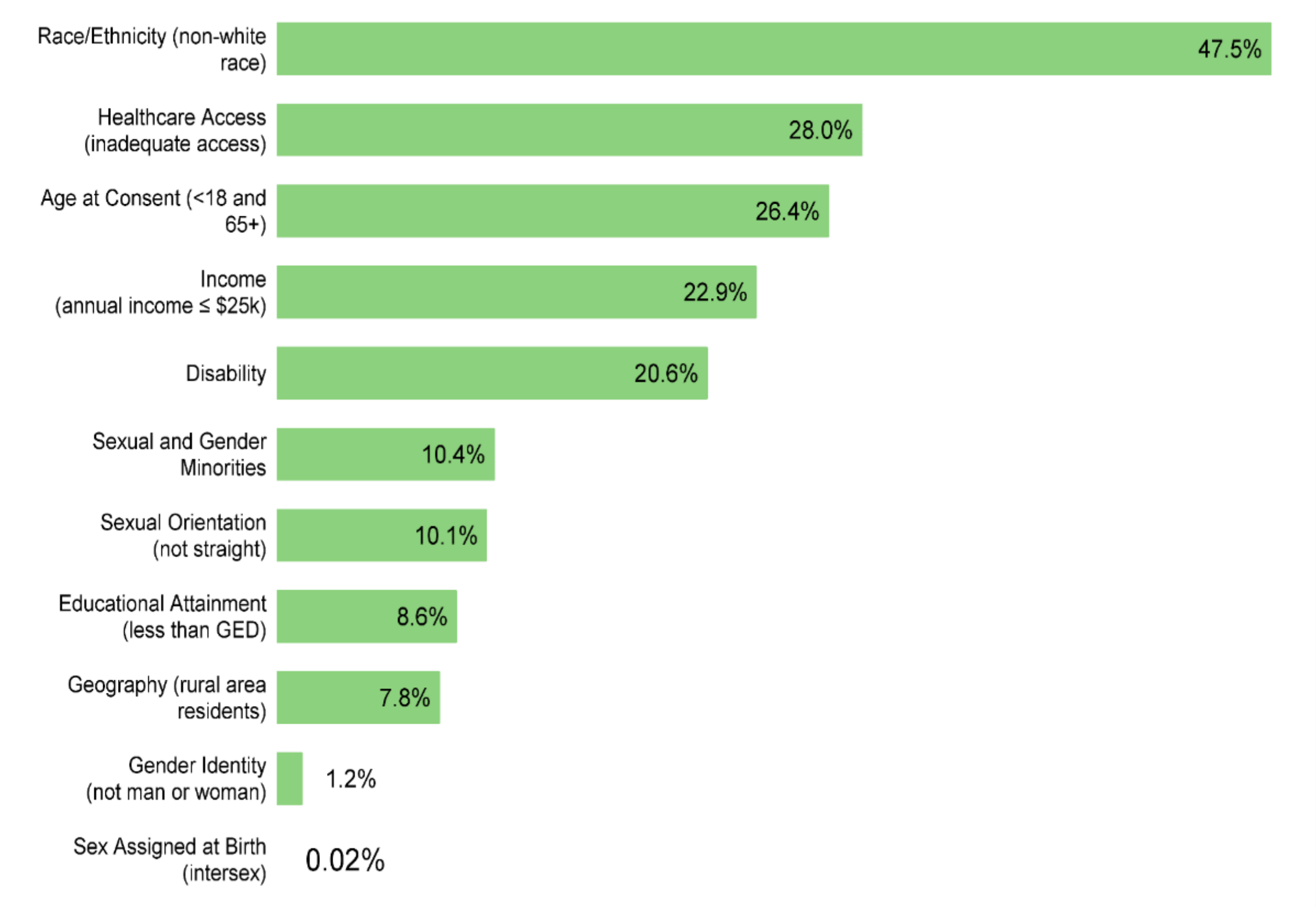
All of Us Research Program



Other Genomic Studies



Underrepresented in Biomedical Research (UBR)



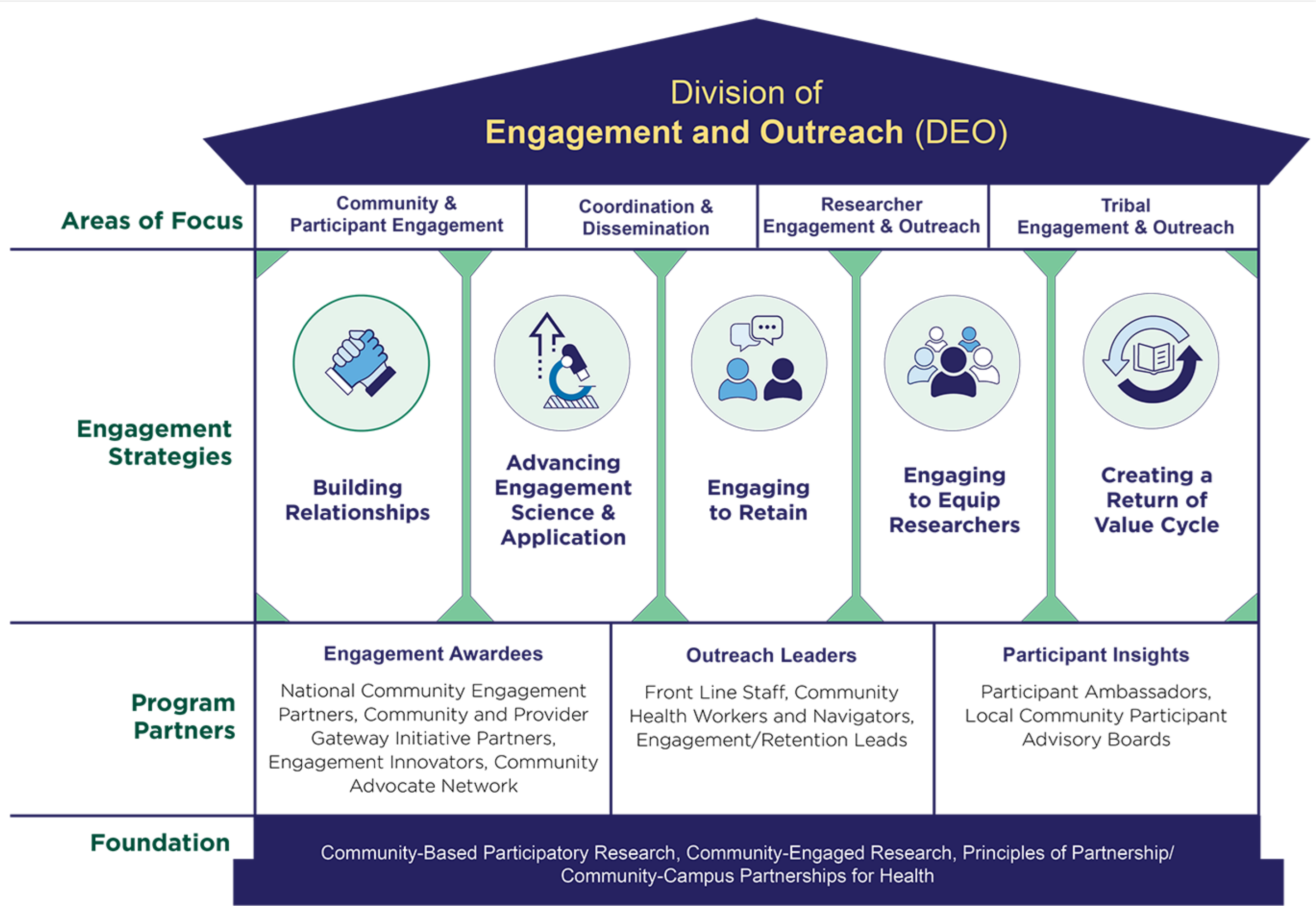
Source: [All of Us Research Program Data Snapshots](#) (Updated July 2, 2024)

How Our Engagement Framework Is Rooted in Evidence-Based Science



Community-Campus Partnerships for Health

Promoting Health Equity and Social Justice

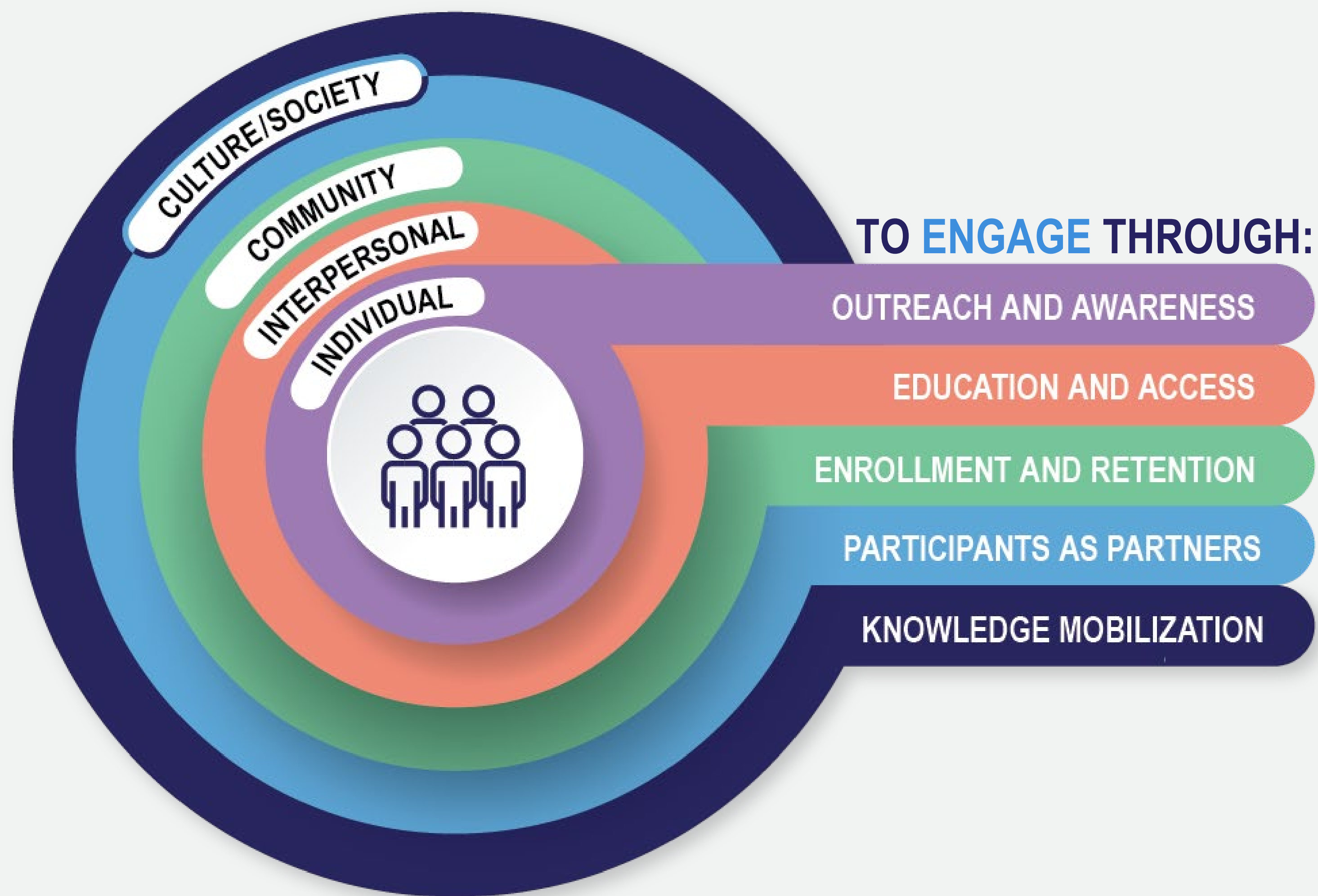


Foundational Expectations for Partnerships in Research, 2014 PCORI Engagement Rubric

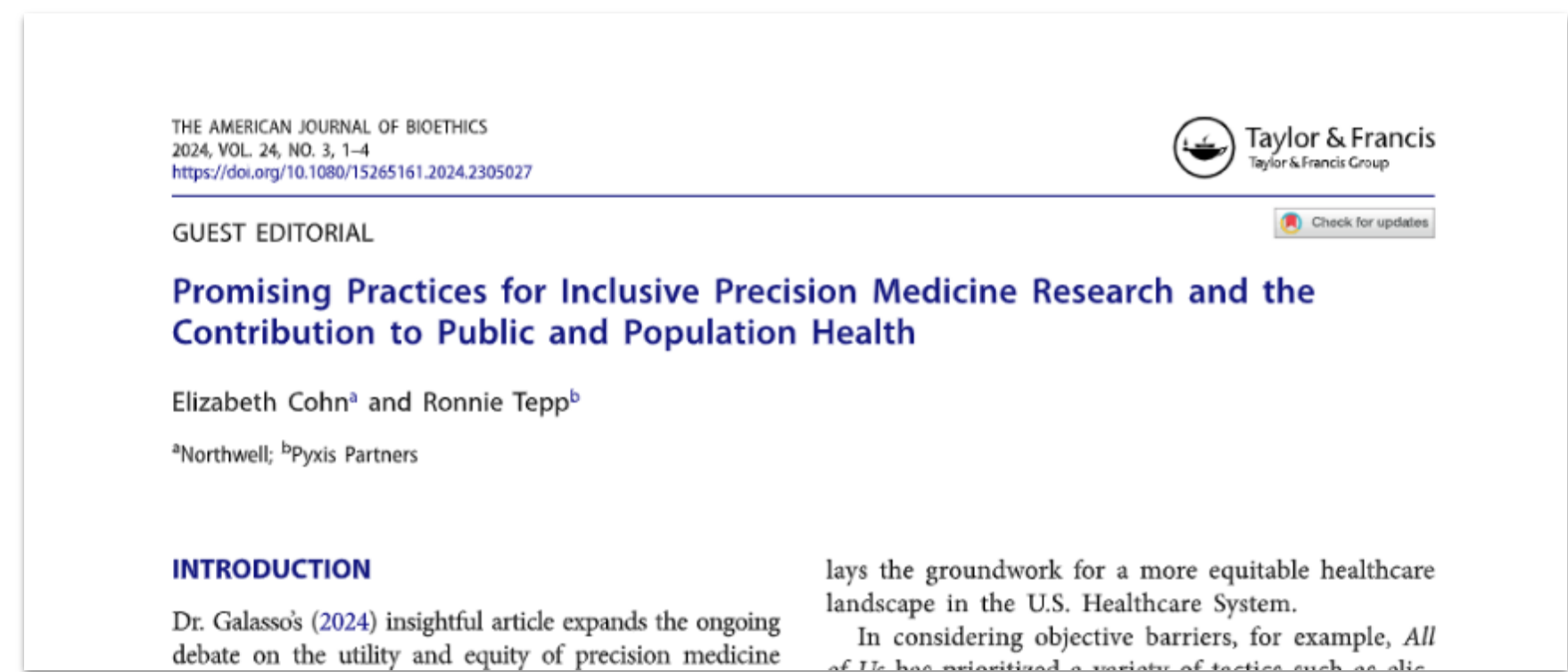


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How Does *All of Us* Define and Categorize Community Engagement

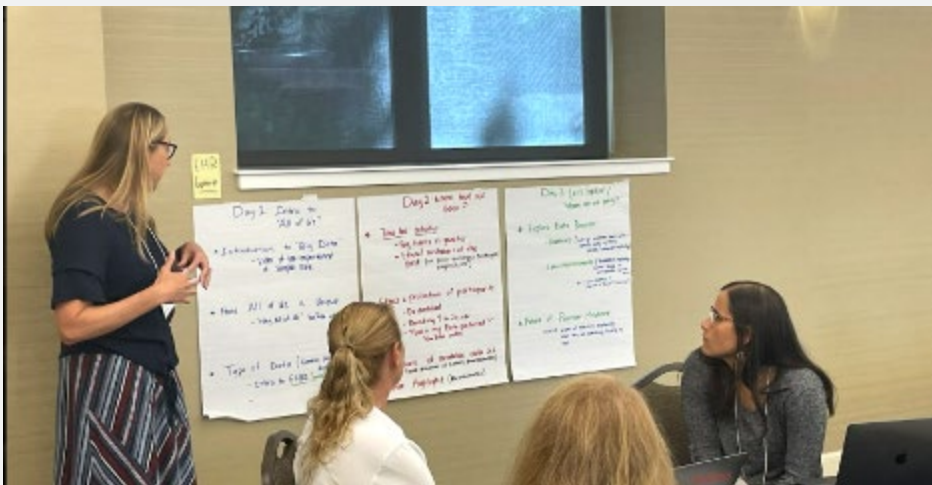
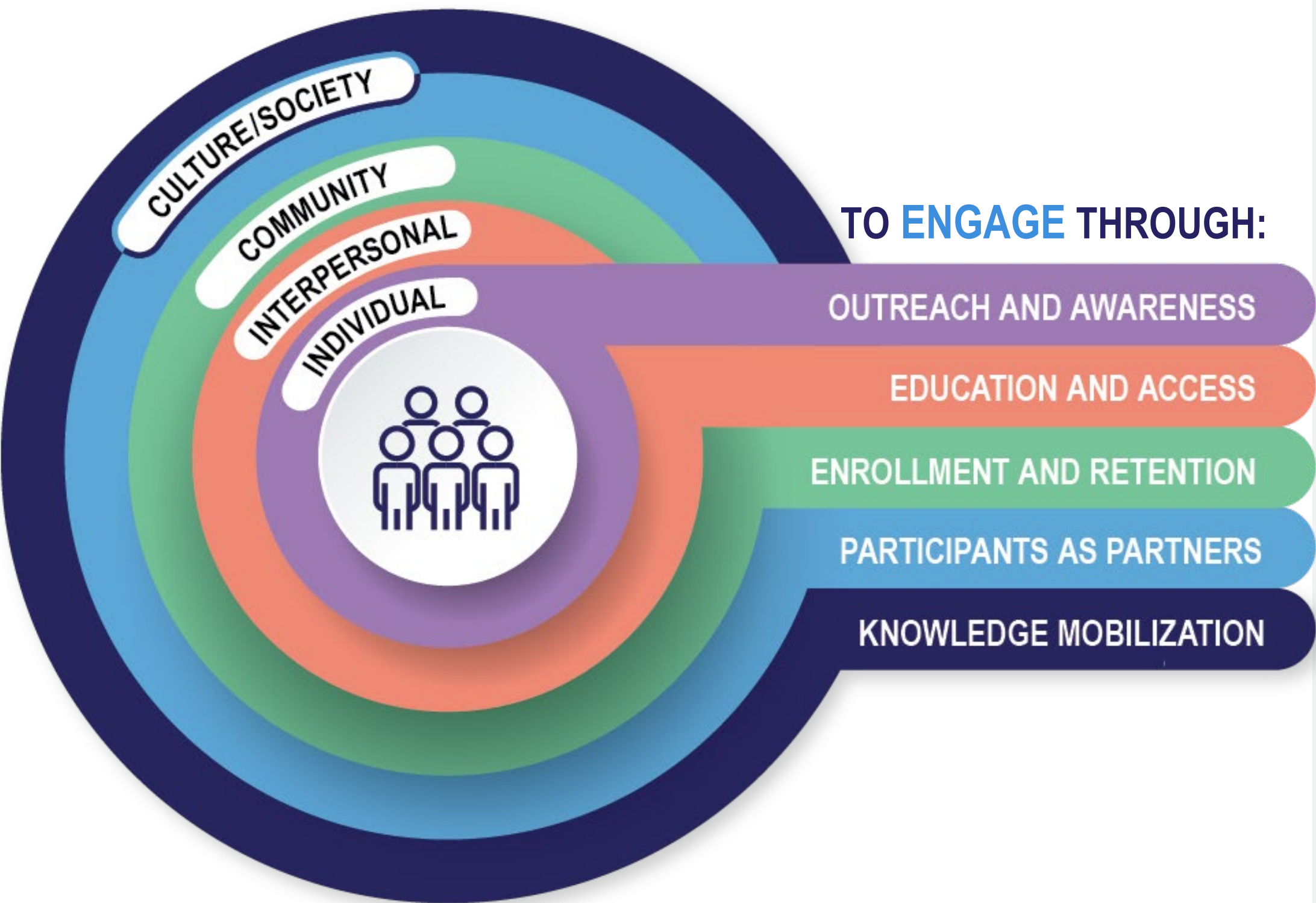


Engagement Awardees



Cohn, E., & Tepp, R. (2024). Promising Practices for Inclusive Precision Medicine Research and the Contribution to Public and Population Health. *The American Journal of Bioethics*, 24(3), 1–4. <https://doi.org/10.1080/15265161.2024.2305027>

How Does *All of Us* Operationalize the Framework



Outreach and Awareness

The National Baptist Convention, USA, Incorporated, supports health and wellness activities for its more than 31,000 churches. In 2023, they reached nearly **20,000 community members** through a variety of digital and in-person events.

Education and Access

The University of Utah Summer Institute (July 18–20, 2023) provided tailored education opportunities and improved access for **17 high school life science teachers** from 13 states across the country

Enrollment and Retention

The National Alliance for Hispanic Health developed a facilitated enrollment model and piloted implementation in five sites, resulting in **385 accounts created in 2023**.

Participants as Partners

Today, the program includes **35 Participant Ambassadors** and **10 Participant Partners** who serve on the Steering Committee, the Executive Committee, and the Advisory Panel.

Knowledge Mobilization

IGNITE through **Northwell Health** conducted **Data Sandbox workshops** with more than 53 participants in 2022 and launched its Spanish version in 2023.

(Data from CY 2022- 2023)

Effective Engagement Is Demonstrated by Doing Something Different and Creating Measurable Change: The Story of Macon County

Macon County Community Convening Tuskegee, Alabama - February 9-10, 2023

Attendees: 300 | Total YouTube Views: 1,633

- Addressed historical trauma by discussing the *U.S. Public Health Service Study of Untreated Syphilis in the African American Male* and the story of Henrietta Lacks
- Invited **local organizations in Macon County to plan, co-develop, and further partnerships**
- **Convened over 300 community members** to discuss importance of participation, the value that community wants to see in the study, and how future collaborations can develop



Collaborating Partners



Effective Engagement Is Demonstrated by Doing Something Different and Creating Measurable Change: The Story of Macon County *(cont.)*



Breaking Chains – Redefining the Untreated Syphilis Study

Macon County Health Care Authority, Inc., CPGI Partner
Bethel Life Center, Tuskegee, AL; May 16, 2024

Attendees: 87

UAB Mobile Unit Enrollments: 10

Coinciding with the 27th anniversary of President Clinton's national apology, the *Breaking Chains* symposium delved into the historical context and lasting implications of the *U.S. Public Health Service Study of Untreated Syphilis in the African American Male* on Macon County and this nation.

Engagement Partners



Enrollment Partners



Founded and Organized by



Sessions Included:

- Remarks by Dr. Charlotte Morris, ninth president of Tuskegee University, and descendants of the *U.S. Public Health Service Study of Untreated Syphilis in the African American Male* participants
- Educational session on genetics by Dr. Altovise T. Ewing, genomic health equity scientist.
- Panel discussing the federal apology and the effects of the study in research ethics, moderated by Dr. Steven Sodeke



Get Connected to *All of Us*

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joinallofus.org/engagement