



# NIH *All of Us* Research Program Advancing Genomic Research through Community Engagement

**Minnkyong Lee, PhD (she/her)**

Deputy Chief Engagement Officer, *All of Us* Research Program

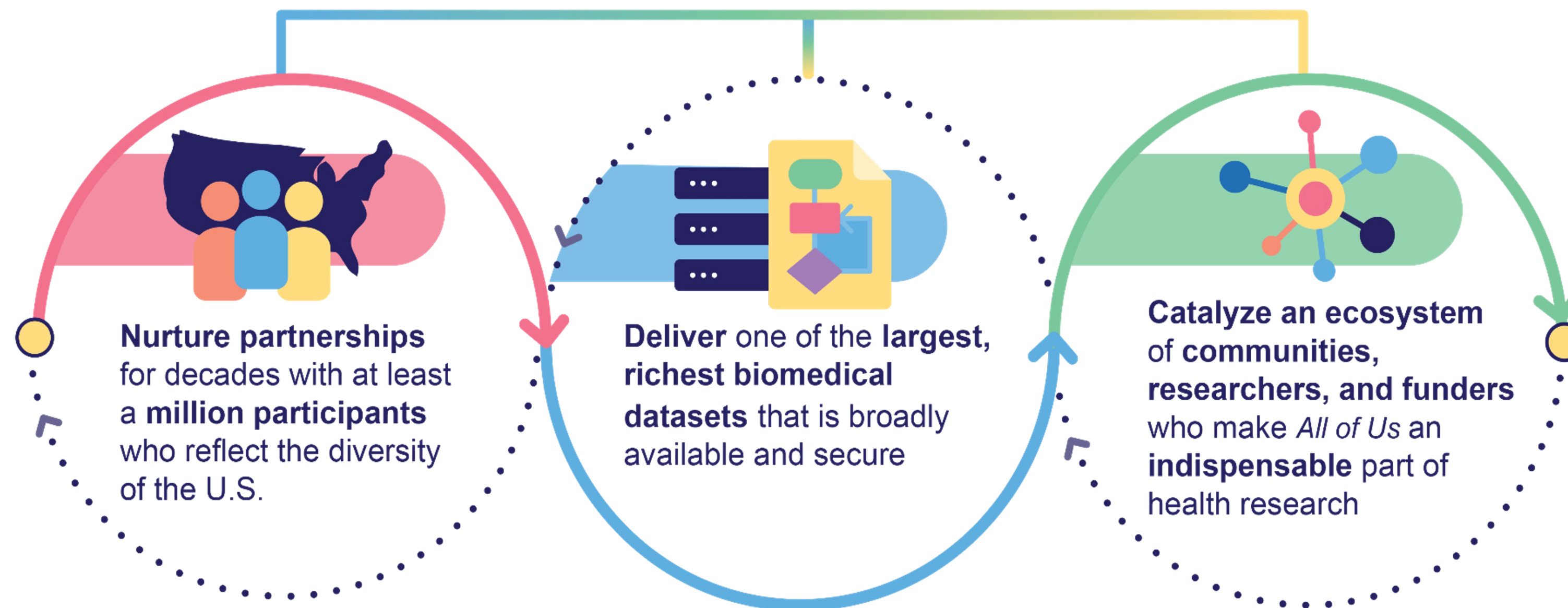
November 8, 2023



# The *All of Us* Research Program

## Our Mission

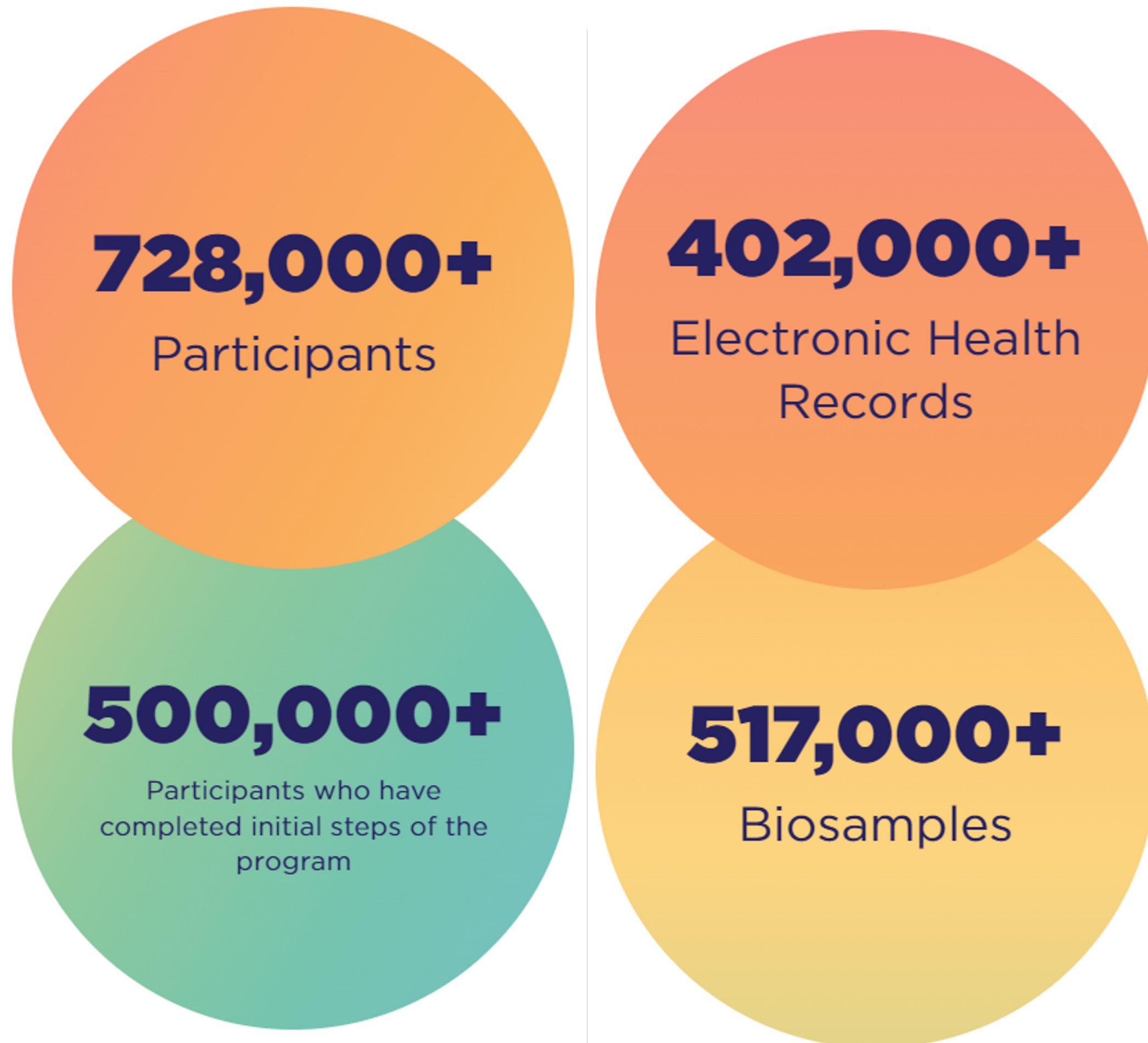
Accelerate health research and medical breakthroughs,  
enabling individualized prevention, treatment, and care for all of us



Made possible by a team that maintains a culture built around the program's core values

# All of Us by the Numbers

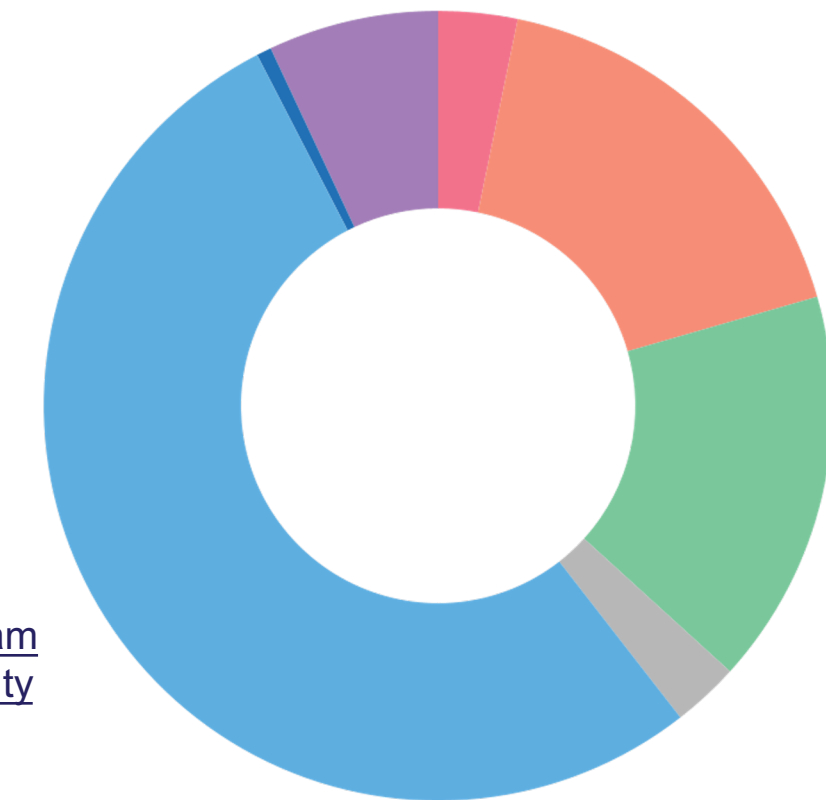
## Participation



Updated October 31, 2023

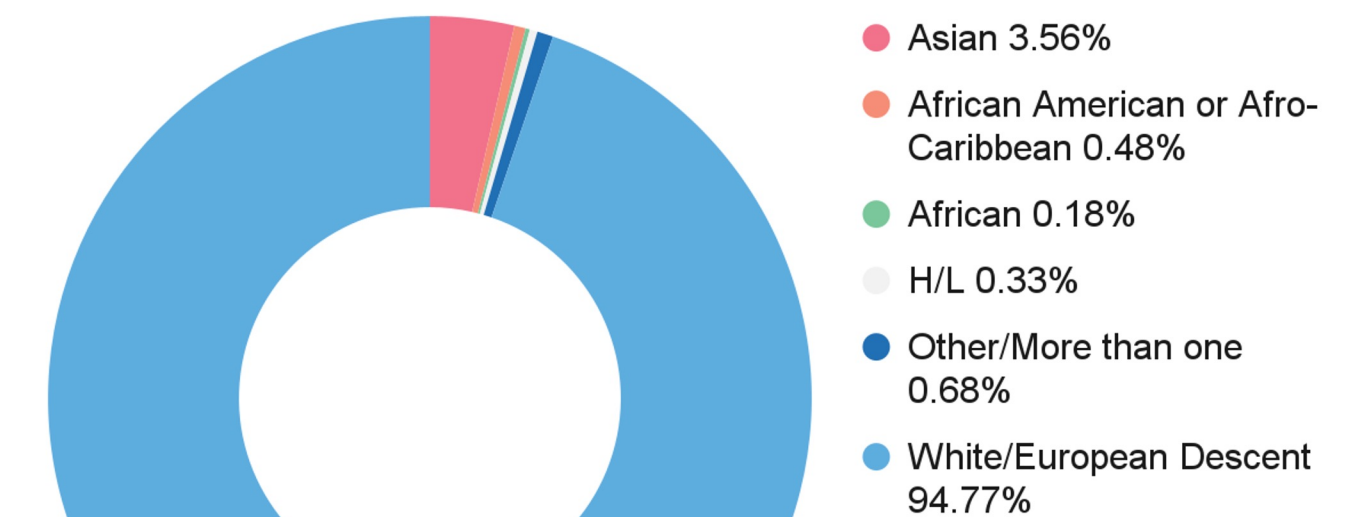
## All of Us Research Program

- Asian 3.2%
- BAA 17.1%
- H/L 16%
- MENA, NHPI, or None fully describe me 2.7%
- White 52.3%
- Prefer not to say 0.60%
- More than one race 6.9%



Source: [All of Us Research Program Data Snapshots, Race and Ethnicity](#)  
(Updated October 30, 2023)

## Other Genomic Studies



Source: [Global Genome Wide Association Studies \(GWAS\)](#)  
(Updated October 10, 2023)

# How We Got Here: The Program's *Intentionality* Since Its Inception



# Messenger Matters: The Importance of Community Partners in Engaging Diverse Communities

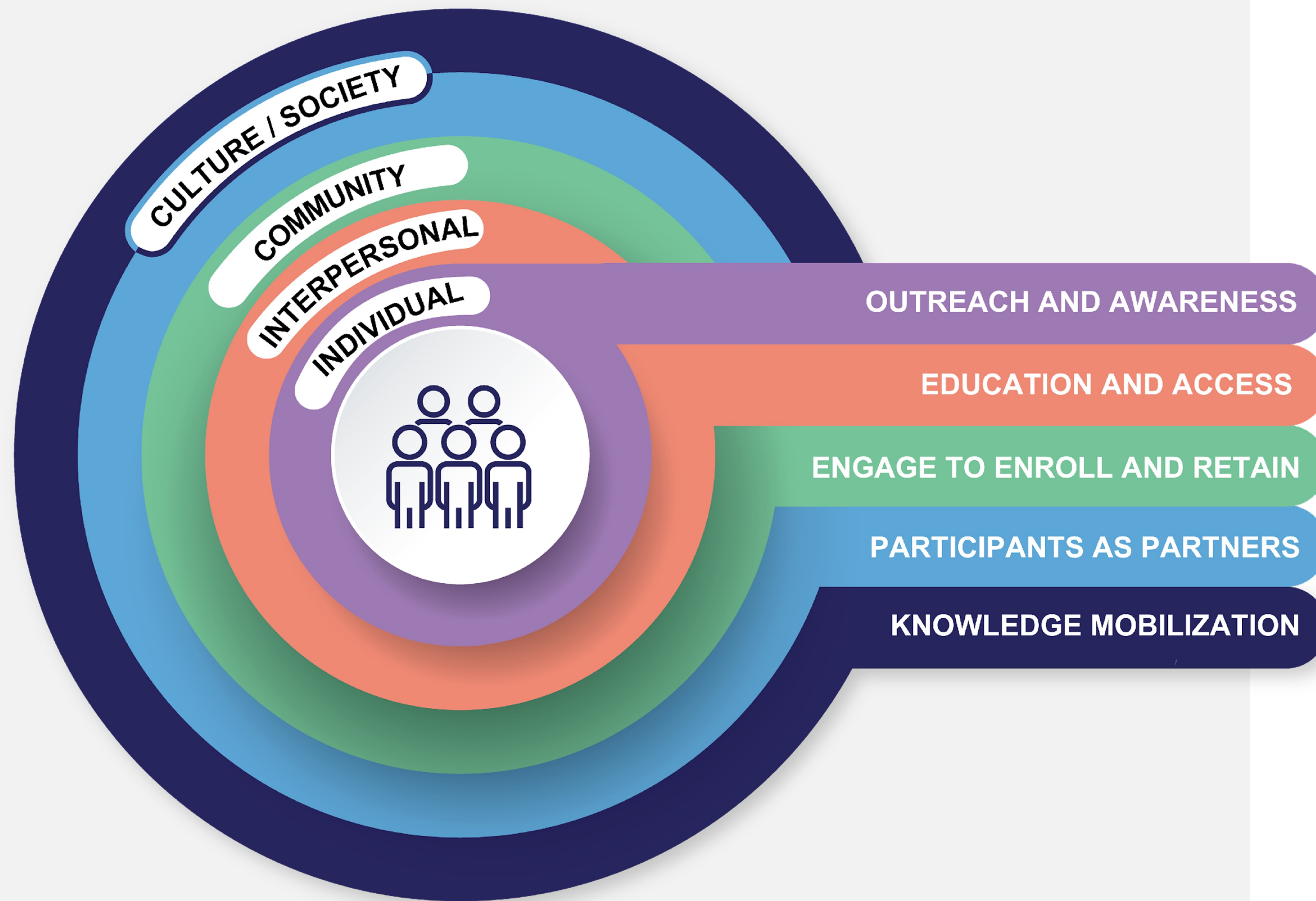


Engaging with participants at an *All of Us* booth at the annual Linda Vista Multicultural Fair



Engaging with attendees at the 2020 National Rural Health Association (NRHA) Policy Institute Conference

# Community and Participant Engagement Framework



## ■ Outreach and Awareness

Interactions focused on fostering trust, such as providing materials and information to an audience to learn about research, precision medicine, and the *All of Us* Research Program.

## ■ Education and Access

Activities that foster education build upon efforts in outreach and awareness to promote the understanding of participation in research. Access is having the resources, information, and the ability to make an informed decision to participate and advocate for research participation.

## ■ Engage to Enroll and Retain

Engagement activities with the intent to recruit and enroll fully informed potential participants and communities in the program.

## ■ Participants as Partners

Full integration of engaged participants to elevate their voices, expertise, and experience as a collaborator to co-design, provide feedback and champion research/the program.

## ■ Knowledge Mobilization

Enhancing who has access to data, research discoveries, or best practices of the program. Ensuring the data is being used by individuals from groups that are underrepresented in biomedical research.

# Best Practices to Engage Communities Historically Underrepresented in Biomedical Research

## Best Practices for LGBTQIA+ Community Engagement & Enrollment



PRIDEnet is a key partner in the cocreation of materials that collect gender identity, sex assigned at birth, and sexual orientation from participants, such as the **Basics Survey**, Standard Appearance Release Forms, etc.

The program makes resources available to researchers to ensure appropriate analyses of these data elements. They highlight the importance of understanding gender identity, sex assigned at birth, and sexual orientation.



The **Basics Survey** disability-related questions were co-developed with AAHD to address critical data missing on **life functions** and improve the program's ability to calculate disability metrics.

The program also created a **Disability Community Toolkit** containing general and community-based best practices for engaging persons with disabilities.

# Culturally Congruent Engagement



## DREF Research Accelerated Possibilities (RAP) Program

- DREF is partnering with **8 HBCUs across the country** to educate and engage students to participate in the *All of Us* Research Program, Research Hub, and Researcher Workbench.



## 22+ Delta Researchers

- The 22+ DREF Research Working Group is comprised of **22 active researchers, 2 student researchers, and 4 network members from the Delta Sigma Theta Sorority, Inc.**
- The group plans Lunch and Learn educational sessions to address heart, maternal, and mental health.
- During each session, DREF presents a speaker who discusses their prospective research aimed at improving health care through research.

## Asian Health Coalition Language Pilot

- Simplified and Traditional Chinese
- Hindi
- Vietnamese
- Korean



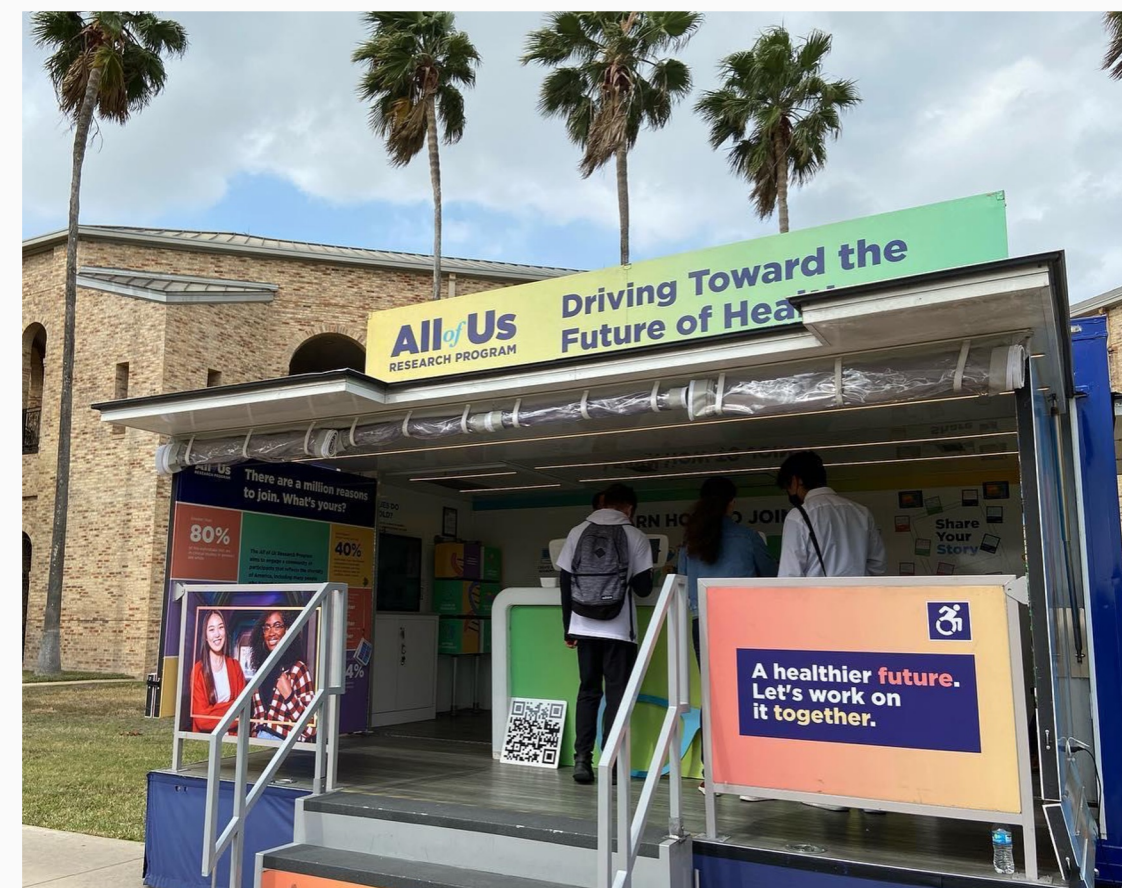


# The Power of Collaboration & Meeting Communities Where They Are

Central *All of Us* Journey, UT School of Public Health, March 6-10, 2023



- The *All of Us* Journey, our Mobile Engagement Asset (MEA), is a traveling mobile exhibit that addresses access issues by going where the community is located.
- UT Health supported media promotion for MEA two-week visit to Brownsville, TX.






327 Quality Conversations  
121 Total Engagements  
150 Accounts Created  
98 PM&B Collections  
1 Media Interview

# The Largest Research Undertaking in Genomics Return: Individual DNA Results

- *All of Us* began returning health-related DNA results to participants less than one year ago (December 2022)
- We are offering health-related DNA results to 5k participants a week
- We still have more work to do to provide an equitable DNA results experience to all eligible participants
- Top 5 genes (HDR): *BRCA2*, *LDLR*, *BRCA1*, *MYBPC3*, *PMS2*

## Next:

- Prioritizing to fulfill our commitment to all eligible participants
- Clear, transparent communications to participants on their status

DNA Results	Participants
 <p>Genetic Ancestry</p> <p>Traits</p>	<p><b>180k+</b> offered choice</p> <p><b>146k+</b> (79%) said “yes”</p> <p><b>144k+</b> viewed results</p>
 <p>Hereditary Disease Risk (HDR)</p>	<p><b>180k+</b> offered choice</p> <p><b>94k+</b> (51%) said “yes”</p> <p><b>69k+</b> viewed results</p>
 <p>Medicine and Your DNA (PGx)</p>	<p><b>180k+</b> offered choice</p> <p><b>90k+</b> (49%) said “yes”</p> <p><b>66k+</b> viewed results</p>

# Program Priorities for 2023: Researcher Access

## Our Researchers



**7,550+**  
Registered  
Researchers



**380+**  
Academic  
Institutions

**97 MSIs**

**40 HBCUs**  
**57 HSIs**



**110+**  
Not-for-Profit  
Organizations

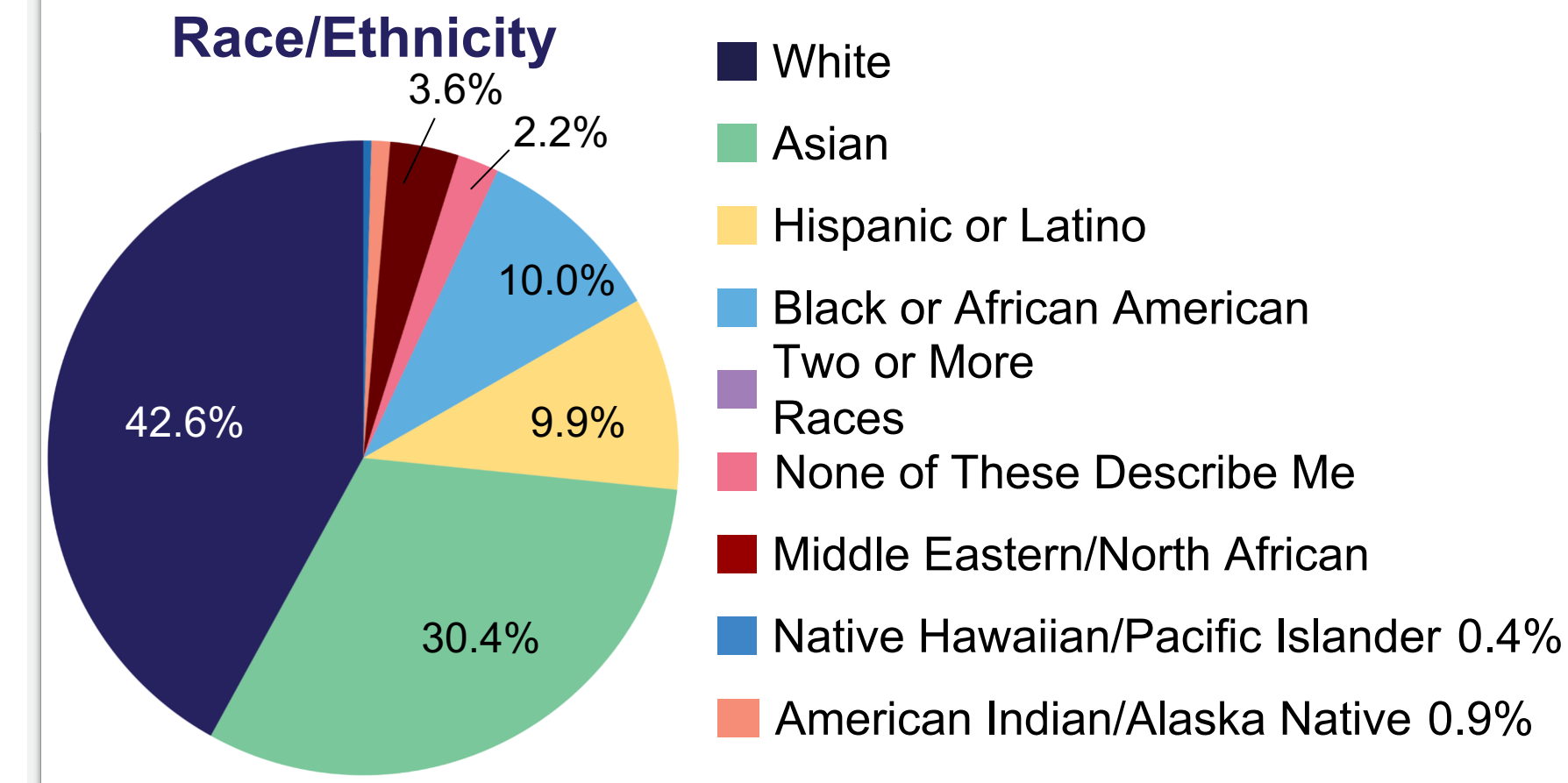


**70+**  
Health Care  
Institutions

*We expect to meet our 2026 Goal of 10,000 Researchers Goal in 2024!*

## A Focus on Diversity

- **96%** of researchers are diverse
- **>75%** are underrepresented in the biomedical workforce (UBW)
- **>30%** are UBW for Race or Ethnicity



# Researcher Engagement Highlights

## PRIDEnet *All of Us* Researcher Basecamp

March 23-24, 2023



## Biomedical Researcher Faculty Summit

May 17–20, 2023



## University of Utah Summer Institute

July 18-20, 2023



In-person training course for researchers who are UBW to launch LGBTQIA+/SGM-related projects in the Workbench, resulting in:

- **5 new DURAs**
- 1 Controlled Tier driver
- 20 new workspaces
- **15+ researcher (UBW) registrations**

A 3-day summit alternating between hour-long speaker presentations, data science training, and networking/research team working sessions.

- **34 scholars** from
- **26 institutions**,  
all of whom created Researcher Workbench accounts

Annual multi-day workshop designed to introduce high school teachers to *All of Us*.

**2023 session goal:** Excite and motivate teachers about engaging students in conducting research using the Workbench.

- **17 high school life science teachers** attending
- All teachers were registered on the Workbench



# Get Connected to *All of Us*

**Minnkyong Lee, PhD (she/her)**  
Deputy Chief Engagement Officer,  
*All of Us* Research Program  
minnkyong.lee@nih.gov



[researchAllofUs.org](https://researchAllofUs.org)