

**All
of Us**
RESEARCH PROGRAM



| 2022

Division of
Engagement &
Outreach

Annual Report





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Introduction *from* Leadership

Letter from Chief Executive Officer



The *All of Us* Research Program has valued engagement since before the launch of the program. Indeed, engagement was a core element of the [Final Report](#) created by the Precision Medicine Initiative Working Group of the Advisory Committee to the Director, of which I was a member and co-author. This foundational report laid out the vision and outlined recommendations that have become core values of the *All of Us* Research Program, including the following:

- » Participants are partners.
- » Earning trust through transparency.
- » Enrolling participants who reflect the diversity of the United States.

Fulfilling these core values requires a variety of tailored engagement strategies that allow the program to reach all communities across the country.

All of Us has always been guided by these core values, especially when new opportunities or challenges arise. The COVID-19 pandemic required the program to rethink its engagement strategies and expand its digital engagement efforts to maintain active involvement among current participants and engage new contributors. Through the perseverance and creativity of our program staff and partners, *All of Us* was able to continue to engage participants and grow the cohort during the pandemic. Even as skepticism around science and government waxed and waned throughout the pandemic, our program has worked hard to build and maintain trust with our members.

The program has recently expanded its engagement efforts to target diverse researchers to access and use the program data for discovery. The launch of the Researcher Workbench and the continual release of new, diverse data types have created an opportunity for a variety of scientific questions to be answered. Researchers from diverse backgrounds and career stages will bring their unique perspectives to the Researcher Workbench, which can increase our understanding of health and disease and promote health equity. In the future, we want to engage our participants by communicating these scientific discoveries with them to demonstrate how their contributions to the program are leading to better health outcomes for all populations.

I want to thank Dr. Karriem Watson, our chief engagement officer, and our numerous community and program partners across the consortium for supporting the program's efforts to engage participants and researchers. Your continued dedication and innovation will help the program achieve its vision of having a diverse cohort of participants and researchers who are actively engaged and continually contribute to the growth of the program. I am proudly celebrating the accomplishments of 2022 and look forward to our continued efforts in the years to come.

Respectfully,

Joshua C. Denny, MD, MS

Chief Executive Officer, *All of Us* Research Program
National Institutes of Health

Letter from Chief Engagement Officer



I want to first thank ALL of You for your ongoing support of *All of Us*. I came to the *All of Us* Research Program in September 2021. It has been my pleasure to lead a team of committed and passionate engagement partners and lead an amazing team of engagement specialists within the Division of Engagement and Outreach (DEO). Since its inception, *All of Us*, has been committed to shifting the paradigm of research and intentionally including community partners in innovative ways to advance research and to engage populations historically underrepresented in biomedical research.

In this engagement report, we will provide an overview of the mission and vision of community outreach and engagement of the *All of Us* Research Program. We will highlight priority areas of engagement, describe our engagement ecosystem and discuss some of the progress of our national engagement partners.

I also want to take this opportunity to thank my colleagues and the leadership of the *All of Us* Research Program. The leadership of the *All of Us* Research program is committed to community and participant engagement and it is my honor and privilege to work alongside the multiple divisions across the program to ensure that we meet our mission and vision.

Karriem S. Watson, D.H.Sc., M.S., M.P.H.

Chief Engagement Officer, *All of Us*
Research Program
National Institutes of Health

All of Us Five-Year Goals

1



Enrollment and Retention

Enroll 1 million participants who reflect the diversity of the US, cover the lifespan, and have shared all baseline elements. Of these, at least 500,000 participate in ongoing data donation opportunities.

2



Collection and Curation of Data and Specimens

Expand data available for 1 million participants, to include surveys, health data streams, a whole genome sequence, environmental data, and physical measures.

3



Ancillary Studies

Launch ancillary studies program as a core and scalable capability that expands the cohort and delivers new phenotypic, lifestyle, environmental, and biologic data.

4



Researcher Access and Impact

Establish a diverse global community of at least 10,000 researchers productively using *All of Us* data.

5



Participant Return of Value

Incorporate participant return of value into data collections and assess its impact, including return of information to participants on genomics, electronic health record, and other health-related information.

All of Us Engagement

What is Engagement?

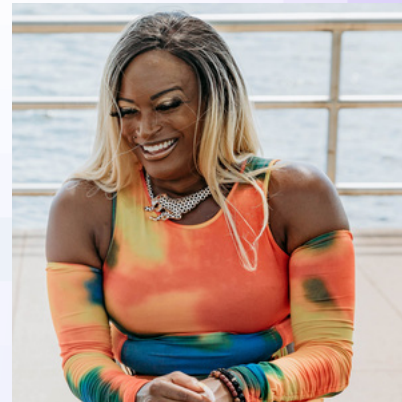
Outreach to stakeholders and grassroots community and researcher engagement is foundational to the *All of Us* Research Program. To that end, we are building a national network of partners that will help initiate and facilitate the four essential and unique components of an active participant community: outreach, engagement, recruitment, and retention.

Outreach: unidirectional interaction, such as providing materials and information to an audience.

Engagement: a broad range of relationship-building bidirectional interactions, including information sharing, consultation, collaboration in decision making, and empowered action between the program, people, awardees, and other partners.

Recruitment: facilitating enrollment in the program.

Retention: ongoing activities with participants after enrollment.



Strategic Core Priorities

The *All of Us* Division of Engagement and Outreach (DEO), in partnership with other divisions and partners, will initiate and maintain strategic and personalized engagement to increase visibility and support the *All of Us* Research Program's mission, core values, and five core goals through the following division-level objectives, ensuring equity and inclusion throughout. The DEO will:



Build Relationships

Continually engage with internal and external partners to build, grow, and maintain trusted relationships through capacity-building.



Advance Engagement Science & Application

Lead internal and external evaluations of outreach and engagement activities and disseminate research findings.



Engage to Retain

Be a champion for all Engagement Ecosystem partners, elevating equity, inclusion, and fostering collaboration as the program increases participants' overall engagement, enrollment, and sustained satisfactory participation in the program.



Engage to Equip Researchers

Build and maintain an inclusive, diverse, and growing researcher ecosystem.



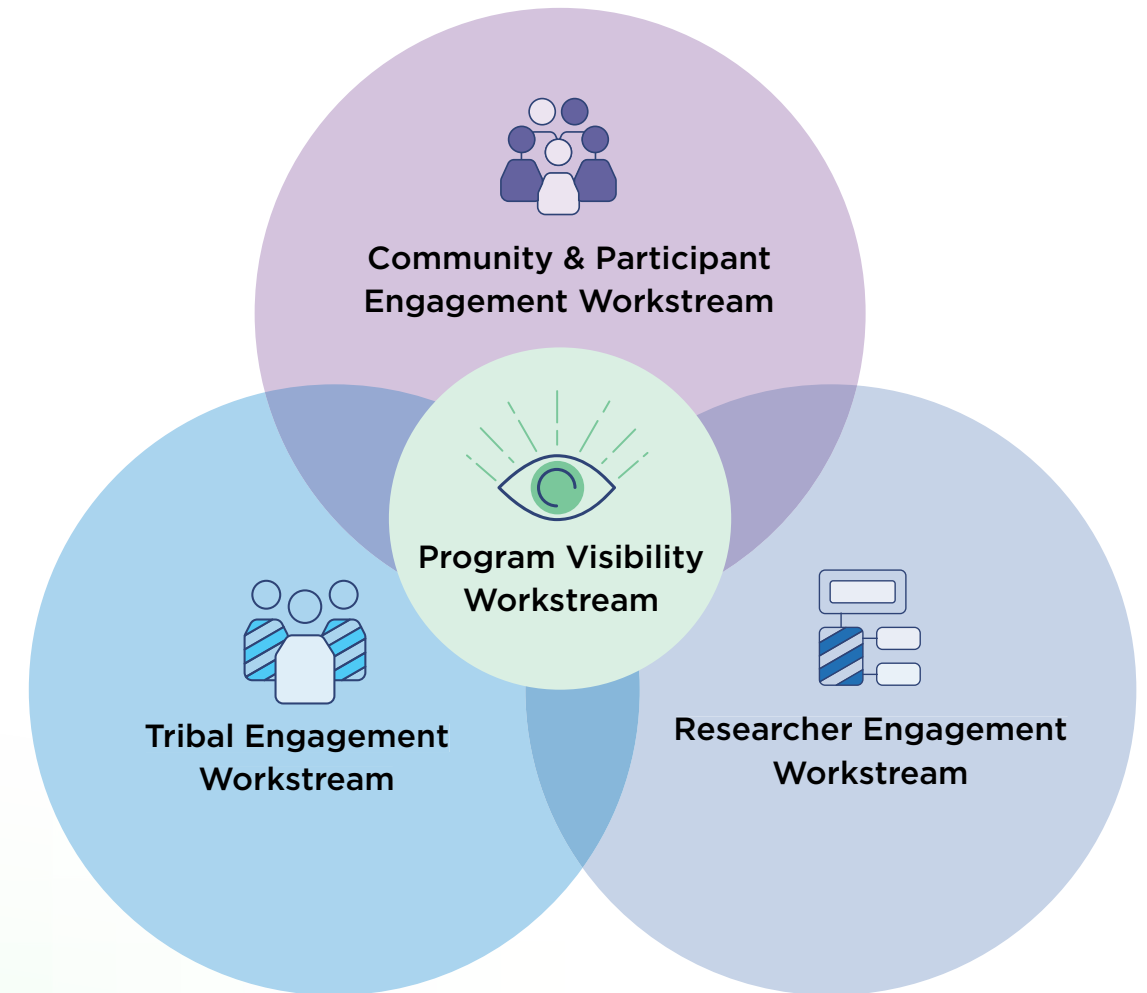
Create a Return of Value Cycle

Promote a virtuous cycle of meaningful return of value to participants, to researchers, and to the public by ensuring participant and community voices are incorporated into all stages to enable equitable scientific discovery.

Engagement Workstreams

The DEO is grouped into four branches:

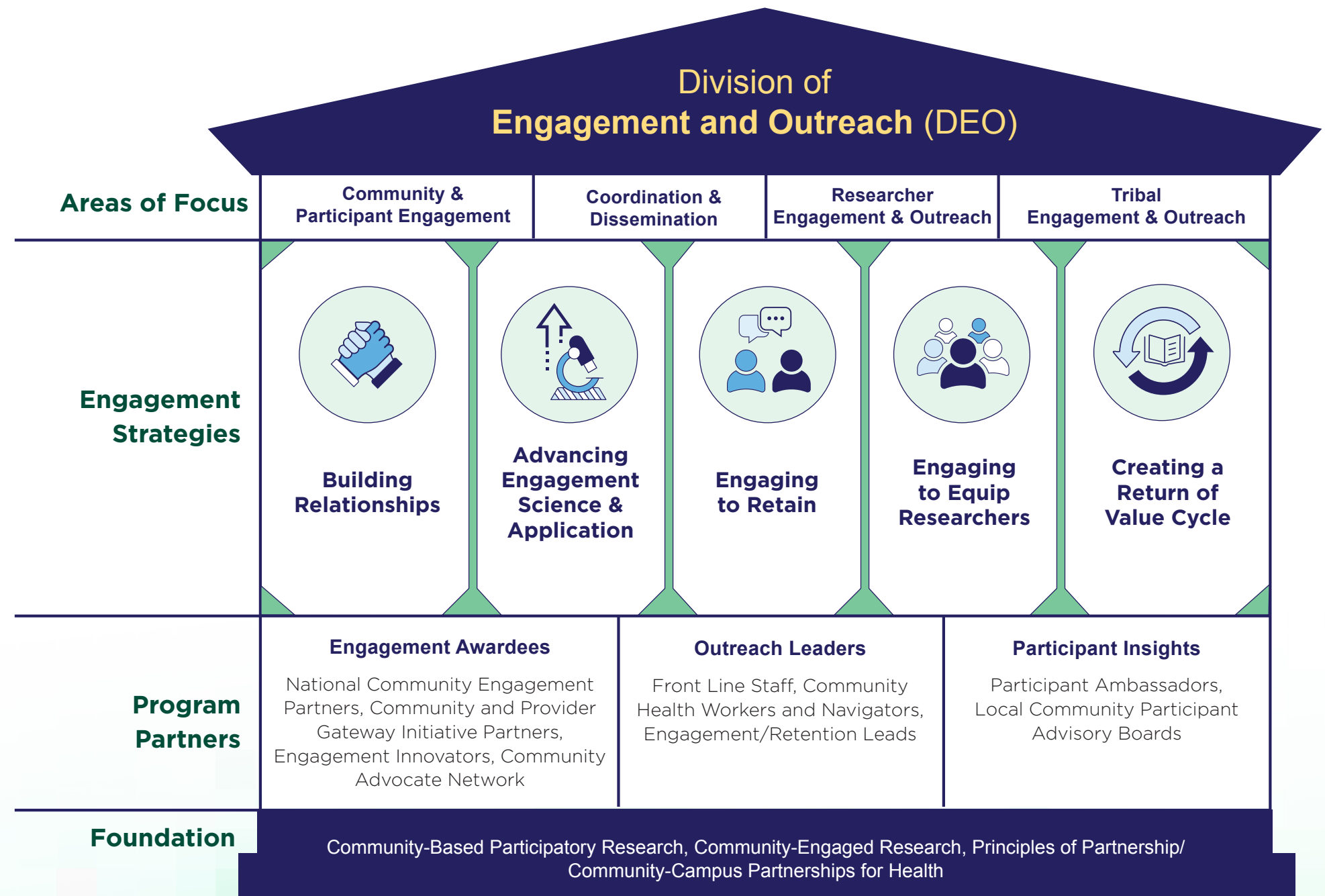
- » **The Community and Participant Engagement:** focuses on building deep invested relationships with communities and participants.
- » **The Researcher Engagement and Outreach Workstream:** builds trust with researchers and organizations across all career stages.
- » **The Tribal Engagement Workstream:** partners and engages with Tribal Nations and Indigenous communities. Tribal Engagement works to establish trust and support the development of resources and capacity necessary for Tribes to actively participate in and benefit from health research. The team aims to advance responsible and community-led participation in the program, enabling Indigenous communities to lead the way to improve health outcomes.
- » **The Program Visibility Workstream:** Works with each workstream to identify and coordinate key opportunities and events for the Chief Engagement Officer, Researcher Engagement and Tribal Engagement teams, and Community Partners.



Together we engage, communicate, and interact with partners, participants, researchers, and their communities.

Engagement Ecosystem

This image shows the various components of the program's engagement ecosystem. Between DEO's four main areas of focus with an emphasis of incorporating the five engagement strategies this enables the program to have wide reach through its national partners and deep connections to communities through various partners, outreach leaders and participant insights. Our partners often work collaboratively to reach specific populations with tailored strategies and assets. They work with us in developing strategies and assets to meet their communities' needs. The foundation of engagement is where the principles of engagement are based: trust, bi-directional relationships, and dialogue between science and research and communities.





Engagement by the Numbers

The DEO conducted 148 visibility opportunities to advance program goals and leverage partnership opportunities. This resulted in the first Notice of Special Interest (NOSI), funded by the National Institute on Minority Health and Health Disparities (NIMHD), for the *All of Us* Research Program. This recognition will allow the program to engage researchers from underrepresented groups to use the *All of Us* Researcher Workbench.

DEO Events

TARGETED AUDIENCE



TOTAL EVENTS

148

Community Engagement Partner Events



Digital or Hybrid Events

NCEP 176
CPGI 501

Subtotal 677



Non-Digital Events

392
572

964

TOTAL EVENTS

1,641



Digital or Hybrid Attendees

NCEP 46,959
CPGI 53,330

Subtotal 100,289



Non-Digital Attendees

306,723
280,956

587,679

TOTAL ATTENDEES

687,968

Engagement Meetings

15

INSTITUTES AND CENTERS (ICS) MEETINGS

Purpose: Build relationships with researchers within NIH ICs to help raise program awareness, learn how to better support intramural researchers, and discuss similar interests and synergies.

5

RESEARCHER STAKEHOLDERS MEETINGS

Purpose: Provide both social connection and opportunities to provide information about the *All of Us* Workbench and how to get access to use the data.

6

ADDITIONAL ENGAGEMENT MEETINGS

Purpose: Build capability with federal and non-federal organizations interested in how *All of Us* engages participant and community organizations.



Participant Partners

The *All of Us* Research Program was established based on a set of core values that includes engaging participants as partners. Currently, there are **45 participant representatives:**

- » **10 participant partners** on the Steering Committee, the Executive Committee, and the Advisory Panel; and,
- » **35 Participant Ambassadors** who help to support the program’s design, implementation, and governance by serving on committees, boards, and task forces.

Vanderbilt University Medical Center

Engagement with these participant partners is administered by the *All of Us* Engagement Core, led by Consuelo H. Wilkins, M.D., M.S.C.I., Senior Vice President and Senior Associate Dean for Health Equity and Inclusive Excellence at Vanderbilt University Medical Center in Nashville, Tennessee. The Engagement Core is composed of national leaders in medicine, engagement, and ethics and—in collaboration with NIH—serves a vital role in ensuring that the *All of Us* Research Program elevates participants’ voices throughout the program.





Community Partners

All of Us National Community Engagement Partners (NCEP) and Community and Provider Gateway Initiative (CPGI)

The national, state, and local engagement partners are building a national network of trusted leaders by raising awareness about the program among African Americans, Asian Americans, Native Hawaiians and Pacific Islanders, Hispanics and Latinos, LGBTQ communities, disability communities, and rural and older adults in an effort to complement and enhance the program's existing outreach and recruitment efforts. These awardees also engage researchers to use the *All of Us* data resources to advance precision medicine and motivate diverse communities to join *All of Us*.

Engagement Partner Key:

C Community Engagement Partner

R Researcher Engagement Partner

To date, the program has

14 national engagement and engagement innovator partners

with more than

115 additional community partners.

In 2022, with the combined support from our partners, the DEO team was able to engage over **870,000 individuals.**



Asian Health Coalition C R

The Asian Health Coalition (AHC) strives to improve the health and wellness of primarily Asians and Pacific Islanders, African and other immigrant communities through advocacy, technical assistance, education, and research. Collaborating with 45 different ethnic community-based organizations across the nation to support the development of culturally and linguistically appropriate health programs and initiatives.

Key Accomplishments:

- » Reached 158,544 AANHPIs across the nation through 391 virtual and in-person events conducted by the 22 AANHPI Engagement and Recruitment Core (ARC) partners that have presence in over 40 states.
- » Launched the Community Scientist Initiative that invited 6 community-based researchers from AANHPI communities nationwide to work with 3 academic researchers through the AoURP Researcher Workbench on research projects that speak to the real needs of the AANHPI community. From this, 4 organizations have completed DURA's and 8 are in the process of obtaining their DURA.
- » Published two manuscripts through the AoURP on the *Progress in Community Health Partnerships: Research, Education, and Action* and the *Journal of Transcultural Nursing*, and presented.



National Baptist Convention USA C

The National Baptist Convention USA (NBCUSA) works closely with African American communities, with a national reach of close to 31,000 churches with 7.5 million members in all 50 states.

Key Accomplishments:

- » Reached more than 10,000 individuals through activities including national and regional meetings, mental and maternal health initiatives, and internal publications.
- » Increased digital presence through social media campaigns and virtual webinars.
- » Trained more than 100 health ambassadors as part of NBCUSA's Health Ambassador program.



National Alliance for Hispanic Health C R

The National Alliance for Hispanic Health is the nation's foremost science-based source of information and trusted non-partisan advocate in the U.S. for Hispanics/Latinos.

Key Accomplishments:

- » Collaborated with the Mobile Engagement Asset to coordinate events, which have resulted in 1,757 quality conversations, 211 accounts created, 121 full enrollments, and 14 salivary kits.
- » Established a community of researchers, training 47 Strengthen Ciencia AoU Ambassadors, who have reached 2,981 researchers through in-person, digital, and social media outreach.
- » Developed a trusted channel of return of information to participants on genomics and EHR working to raise awareness among providers. In December, our partner, the American Nurses Foundation delivered *All of Us* Genomics program information to 1,373 healthcare providers in their network.



American Association on Health and Disability

The American Association on Health and Disability (AAHD) is dedicated to ensuring health equity and inclusion for persons with disabilities through policy, research, and dissemination of information.

Key Accomplishments:

- » Conducted nationwide outreach and awareness campaigns reaching total of 840,450 individuals across AAHD and AAHD partners.
- » Provided program initiatives input as a subject matter expert for disability community on: ancillary study accessibility, disability definition and metrics, and the Researcher Workbench Demographic Survey.
- » Digital outreach and engagement efforts were all on digital platforms due to COVID-19 reaching 500,000 individuals, and an additional 100,000 using 20-30 organizations.



FiftyForward

FiftyForward is the leading resource for adults 50+ in Middle Tennessee who seek to live longer, more fulfilling lives. Our mission is to support, champion, and enhance life for those 50 and older.

Key Accomplishments:

- » Hosted/participated in a total of 152 engagement events, reaching 198,919 potential program participants virtually and engaging in-person with 4,121 potential participants.
- » Hosted successful week-long *All of Us* Journey/MEA visit at one of our FiftyForward centers in Nashville, TN leading to 93 engagements and 41 account creations.
- » Supported a cadre of 17 engaged and enthusiastic older adult Peer Ambassadors ranging in age from 61 to 88 years old. FiftyForward Peer Ambassador, Vera Coleman, received recognition as Nashville Older Adult Direct Service volunteer of the year through Hands On Nashville's prestigious Mary Catherine Strobel Awards for her volunteer work with the *All of Us* Research Program.



Delta Research Educational Foundation

The Delta Research Educational Foundation (DREF) is a nonprofit that supports scholastic achievement, public service programs, and research initiatives focused on African American women.

Key Accomplishments:

- » Collaborated with community partners and health provider organizations (HPOs)/direct volunteers to host two events each month in markets across 22 cities, with a total of more than 119 events with 8,791 attendees.
- » Conducted pilot virtual pop-up clinics in collaboration with HPOs to provide information about the program and a tutorial on navigating the *All of Us* website, as well as to assist in setting up participant accounts and scheduling clinic visits.
- » Outreach to 8 historically black colleges and universities (HBCUs) to conduct R.A.P (Research Accelerates Possibilities) sessions to educate and encourage participation with the *All of Us* Research Program and signing on to the Researcher Workbench. Led to 5 HBCUs obtaining a DURA.



Baylor College of Medicine R

Baylor College of Medicine (BCM) supports new and innovative opportunities to encourage researchers from minority communities to access and utilize the *All of Us* dataset. The *All of Us* Evenings with Genetics Research Program hosted by BCM engages underrepresented early career researchers with the *All of Us* Research Hub.

Key Accomplishments:

- » The Underrepresented Biomedical Researcher Faculty Summit was the most impactful outreach event by an Engagement Partner thus far in terms of the number of newly registered researchers 34, new DURAs signed 6, and number of workspaces created as a result of one event.
- » Conducted two *All of Us* Evenings with Genetics Campus Seminars, on a campus that represents a Hispanic Serving Institution and a Historically Black College and University with a total of 154 attendees.
- » Presented the *All of Us* Research Program to a total of 648 individuals through campus, department, and Office of Research presentations.



Network of the National Library of Medicine C

The Network of the National Library of Medicine provides equal access to biomedical information to enable individuals to make informed decisions about their health.

Key Accomplishments:

- » Partnered with 161 libraries and community-based organizations to host 16 virtual health programs, reaching a total of 2,044 live event attendees and 3,713 post-event viewers. 73% of respondents reported they would go to other *All of Us* events and 46% reported they would talk to their family or friends about *All of Us*.
- » Funded 27 community awards, reaching a total of 4,509 individuals for a total award amount of \$505,072.
- » Partnered with 20 *All of Us* consortium partners that represent individuals underserved in biomedical research communities reaching a total of 1,248 live event attendees and 3,915 post-event viewers.



Stanford PRIDEnet C R

PRIDEnet, based out of Stanford University, catalyzes LGBTQIA+ health research by connecting community members with ways to participate in research and creating opportunities for community input to inform all stages of the research process.

Key Accomplishments:

- » Grew online communities via *All of Us* LGBTQ+ (@AllofUsLGBTQ) social media channels with a total of 37K followers, 1.6M impressions, and 18K visits to the *All of Us* LGBTQ+ page (<https://www.joinallofus.org/lgbt>).
- » Engaged a total of 9K+ potential participants, researchers, and providers through LGBTQ+ online and in-person events, contributing to 301 new *All of Us* accounts created and 90 completed consents.
- » Galvanized a total of 32 LGBTQ+ health organizations through PRIDEnet's Community Partner Consortium and Participant Advisory Committee, which provided crucial input on engagement strategies and amplified *All of Us* messages.



Research Triangle Institute (RTI)*

RTI is creating a library of digital engagements for use by consortium partners, with a focus on creating materials related to health care provider engagement and on reducing disparities.

Key Accomplishments:

- » Completed and disseminated a Disparities Landscape Analysis and Exploratory Research Report related to RTI's focus on reducing disparities.
- » Completed and disseminated a Health Care Provider Engagement Landscape Analysis and Exploratory Research Report that guided two sets of workshops focused on activity concept development.
- » With Community Campus Partnerships of Health (CCPH), created the *All of Us* Researcher Academy Institutional Champion Award and held an inaugural outreach webinar about the award in June 2022.



University of Utah*

The University of Utah creates and evaluates experiential learning engagements for the program focused on genetics and general science-related topics for community, multicultural, and provider engagement.

Key Accomplishments:

- » Held quarterly Engagement Incubator meetings to co-create engagements.
- » Held six meetings with the local Validator's Group, which provided feedback on pharmacogenetics communications materials and engagements related to genetics and pharmacogenetics.
- » Held a Summer Institute with high school teachers focused on investigating the *All of Us* Data Browser.



PYXIS PARTNERS

Pyxis Partners and CPGI Network

As a national engagement awardee, Pyxis Partners works with community partners to increase awareness and understanding of the *All of Us* Research Program.

Pyxis also launched and manages the Community Provider Gateway Initiative (CPGI), a network of diverse organizations that raise awareness and promote the *All of Us* Research Program.

Key Accomplishments:

- » Supported 115 CPGI organizations (52 partners and 63 subawardees) across 18 Target Markets in their efforts to raise awareness and educate their communities about *All of Us*.
- » CPGI Partners conducted 1,375 activities that reached 756,416 attendees and resulted in 1,205,720 engagements.
- » CPGI Partners generated and shared 219 prospects with enrollment partners during the November and December Surge Weeks.

* **Engagement Innovators:** The program's two Engagement Innovator awardees, University of Utah and Research Triangle Institute (RTI), design strategies and tactics geared toward raising awareness and reaching into UBR communities.

All of Us CPGI Network

A network of diverse organizations, managed by Pyxis Partners, that raises awareness and promotes the All of Us Research Program.





Hunter College C N

Hunter College, in collaboration with the Physician Affiliate Group of New York (PAGNY) engages community-based organizations, researchers, and health care providers from diverse backgrounds through the Interdisciplinary Guided Network for Investigation, Translation, and Equity program.

Key Accomplishments:

- » Conducted two Data Sandbox workshops to promote use of the dataset with over 53 participants, including nurse clinicians, researchers, community-based organizations, and participant advisory board members.
- » Developed a yearlong Research Fellowship Program to help three fellows become super-users of the *All of Us* Research Hub and Workbench and act as local resources for interested researchers.
- » Launched the PAGNY campaign to increase knowledge of the AoU dataset and browser capabilities. Connected with over 79 researchers and physicians from the NYC Health + Hospital system.

N New National Community Engagement Partners



University of Florida C N

University of Florida leads the Clinical and Translational Science Awards (CTSA)/Partners for the Advancement of Community Engaged Research (PACER) Community Network (CPCN).

Key Accomplishments:

- » Established a core network of CTSAAs, augmented by the national PACER membership, that will focus to increase the number of registered researchers using the *All of Us* Researcher Workbench to analyze the program's dataset.
- » Launched a National Community Advisory Board to support and champion local *All of Us* activities.
- » Partnered with over 20 current and future researchers to provide feedback on improving how to access and use the workbench and how to disseminate *All of Us* program information and generate value for local community partners.



Partners
building
relationships



Deepening relationships with communities
and engaging program participants.



Tribal Engagement

Members of the Tribal Engagement team serve as contacts for *All of Us* leadership and partners who are interested in working with American Indian and Alaska Native (AI/AN) Tribes and organizations: intertribal organizations, urban/non-reservation-based AI/AN groups, Tribal colleges and universities, and AI/AN-serving institutions.

The team's work centers on partnering with Tribal Nations, promoting collaborative Tribal relations, and providing guidance to partners on culturally appropriate AI/AN Tribal engagement and outreach. The team leads partnerships and the development of training and resources for researchers that focus on responsible use of AI/AN data and avoiding stigmatizing research. The team works to promote Tribally-guided research and community-based participatory research approaches with Tribal Nations.

Focus Areas for 2023

- » Strengthening Communication with Tribal Nations and Indigenous communities
- » Engaging and Equipping Researchers to Work with AI/AN Data
- » Working in Partnership with Tribal Nations, and Indigenous individuals and communities

Committed to collaborating with Tribal Nations about the inclusion of AI/AN populations.

Background and Milestones

All of Us respects Tribal sovereignty and appreciates the guidance from Tribal leaders to ensure our work is rooted in full recognition of the sensitivity around data access, use, and protection. We are committed to collaborating with Tribal Nations about the inclusion of AI/AN populations in this research program.



2017

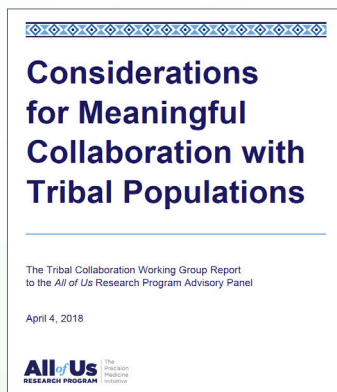
December 2017

All of Us Research Program Advisory Panel establishes Tribal Collaboration Working Group (TCWG)

2018

August 2018

TCWG releases “Considerations for Meaningful Collaboration with Tribal Populations” report



2019

May–November 2019

All of Us hosts listening sessions and Tribal Consultation meetings across the country

2020

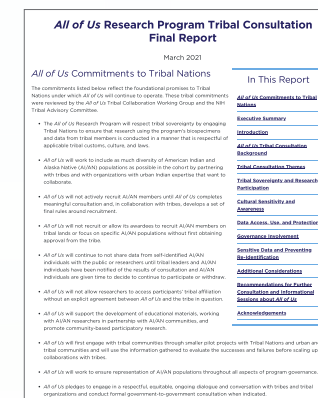
May 2020

Rapid-response Tribal Consultation convened to discuss the COVID-19 serology study

2021

March 2021

All of Us releases Tribal Consultation Final Report



2022

May 2022

Research Opportunity Announcement released by *All of Us* with an area of interest specific to engaging with Tribal Nations and Urban AI/AN Populations

DEO Accomplishments

In 2022, DEO onboarded new partners, supported AoU programmatic goals, expanded scope of current awardees to continue engagement work, collaborated with *All of Us* divisions, served as shared resource, a key contributor of increasing DURAs, and provided Tribal Engagement Community practice.

Researcher Engagement Accomplishments

In 2022, the DEO focused on three core strategies of researcher engagement: awareness and access, bridging communities, and capacity building and collaboration.

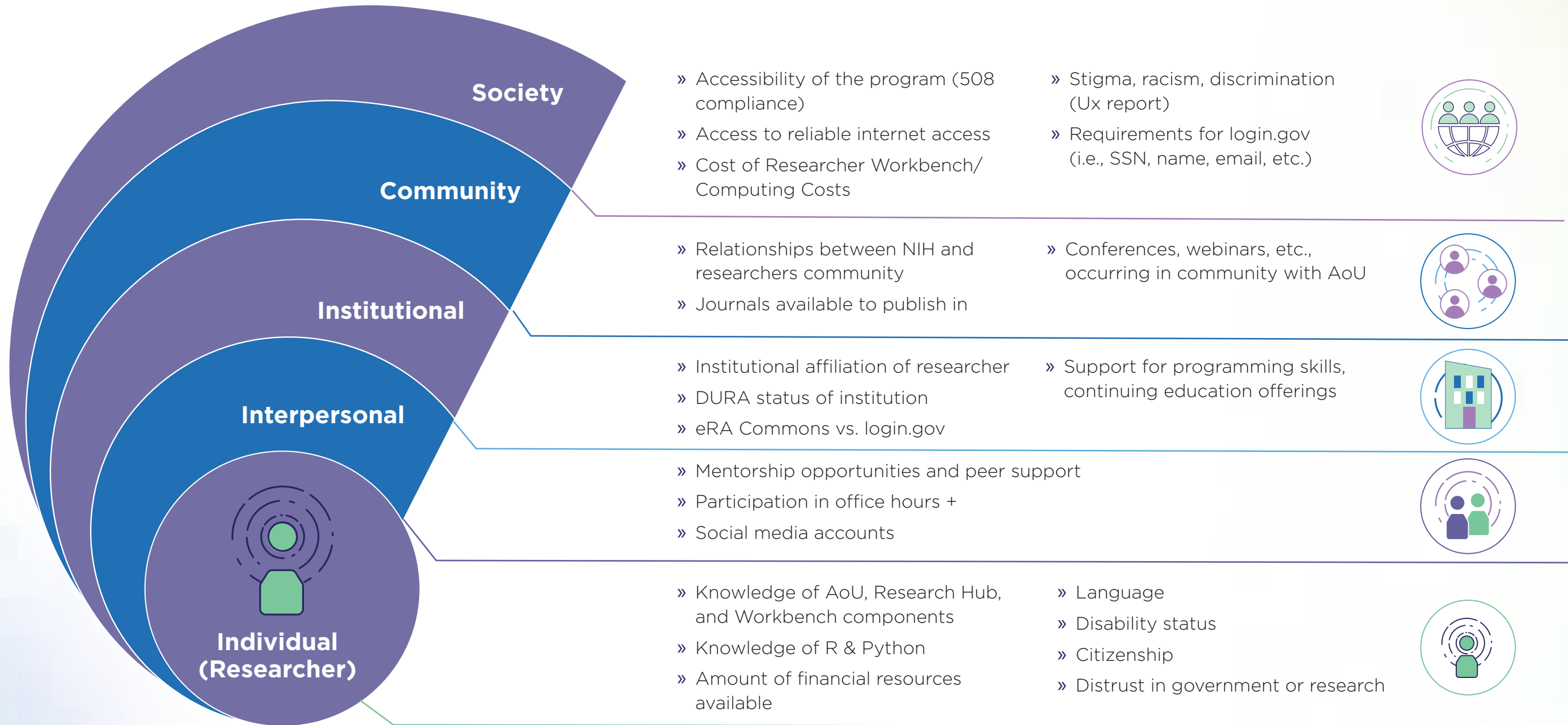
***All of Us* Researchers Convention**

The DEO supports partner organizations in implementing these strategies through the *All of Us* Researchers Convention reaching more than **660 individuals**, and through the creation of **two funding opportunities** in 2022 to expand the Engagement Ecosystem and encourage use of the *All of Us* Researcher Workbench.



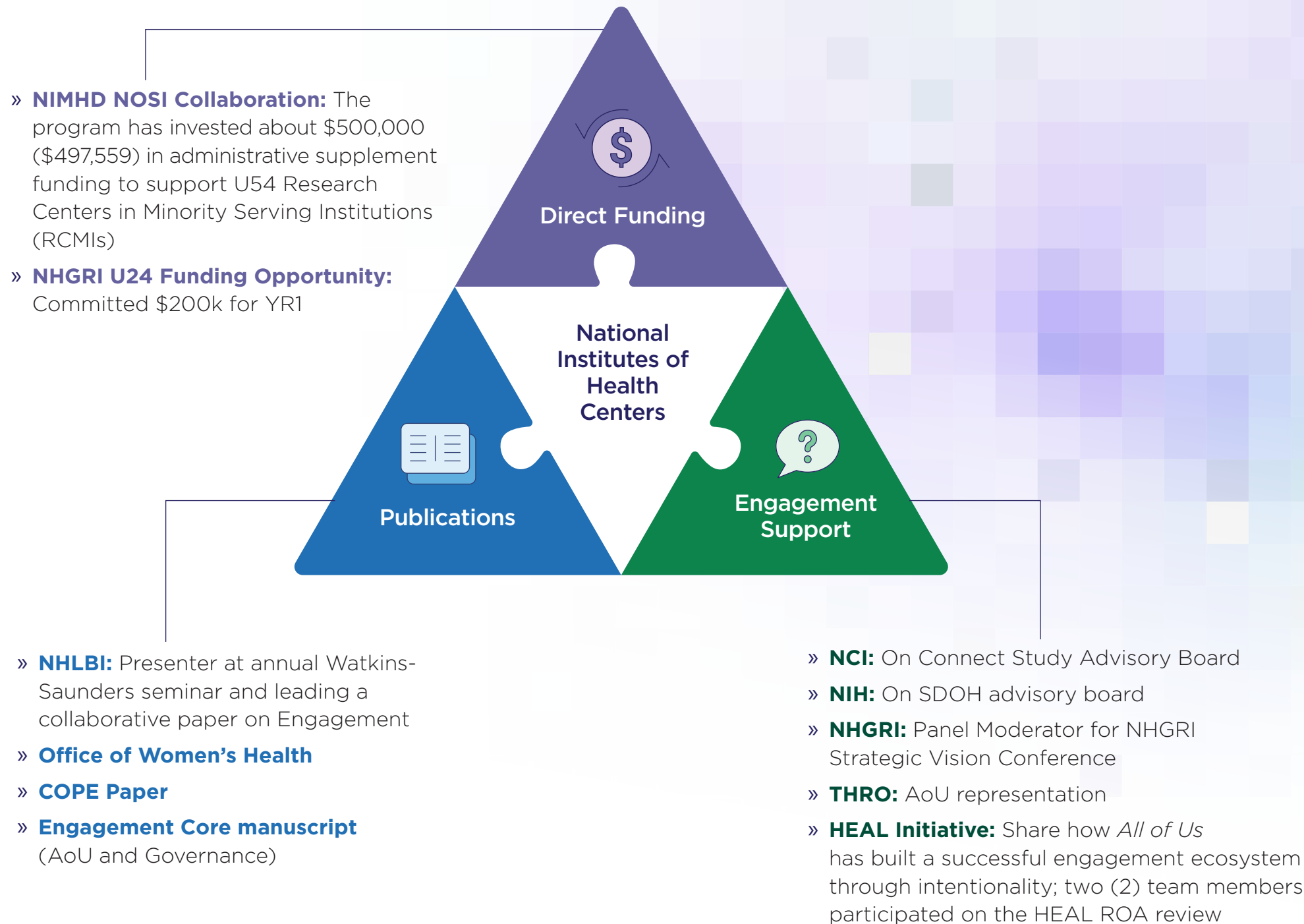
Social-Ecological Model of Researcher Engagement

The below framework examines the isolated, yet interconnected, societal factors that can positively or negatively affect a researcher’s likelihood and ability to access or utilize the data available in the *All of Us* Research Hub. We make it a priority to ensure that we identify potential barriers and solutions across these various levels to ensure equitable access for all.



Visibility and Outreach Accomplishments

Engagement with Institutes and Centers



NIMHD NOSI Collaboration

This NOSI invites applications for administrative supplements to NIMHD Research Centers in Minority Institutions (RCMI) U54 awards of \$500,000 to support pilot research projects led by postdoctoral fellows, junior faculty, or other early-stage investigators who use the *All of Us* Research Program dataset. NIMHD is particularly interested in health equity studies that explore the role of social determinants in health outcomes or clinical care for populations that experience health disparities.

Community and Participant Engagement Accomplishments

In 2022, the DEO's Community and Participant Engagement focused on three core strategies: building relationships, recruiting to retain, and creating a return of value cycle by working together with partners and participants as partners.

Pediatric Community Engagement Studios

The DEO lead listening sessions to support program efforts for pediatric enrollment. The team conducted Community Engagement Studios in Nashville and Chicago and a listening session with *All of Us* Participant Ambassadors on pediatric enrollment. These sessions, held in Q2 2022, presented an opportunity for feedback from current participants and community members on pediatric enrollment in *All of Us*. The team was particularly interested in the perspectives of those who care for children under 18.

Participant Ambassador Expansion

All of Us has expanded the Participant Ambassadors and participants in governance, as well as the staff to manage cohort operations to ensure more participant voices are meaningfully engaged and represented on all levels within the consortium. The nomination process now includes nominations from NCEPs.

Tribal Engagement Accomplishments

- » Assembled a Community of Practice group consisting of partners across the program who are interested in working with AI/AN populations and have experience with Tribal engagement. The goals of this group are to share knowledge and experiences working with AI/AN Tribes and urban Indian populations and organizations and collaborate.
- » Co-authored the program's first research opportunity announcement (ROA) with an area of interest focused on AI/AN communities titled "Engage with Tribal Nations and Urban and Non-Tribal Land Based AI/AN Populations." This funding opportunity will build on the Tribal consultation held in 2019 and devotes funding directly to resource development and community-driven priorities for Tribal communities.
- » Provided specific guidance and protocol development for participant-facing components of the program, including guidelines in the Nutrition for Precision Health ancillary study and resources for the Mobile Engagement Asset specifically for Tribal engagement.



Across all Workstreams

Research Opportunity Announcement (ROA)

Developed and published the first *All of Us* ROA to fund organizations that can help *All of Us* build its cohort of volunteers who reflect the rich diversity of the United States, including engaging with Tribal Nations and urban and non-Tribal land-based AI/AN populations.

These funded organizations will help design and implement strategies to raise awareness of the program through community organizations and HPOs, drive increased enrollment of participants, foster regular communication with participants, and engage the research community to use the data being gathered.

Manuscripts and Published Papers

One published paper in 2022, by Chief Engagement Officer and close scientific experts, covers the importance of leveraging existing partnerships, engaging participants beyond recruitment and embracing diverse perspectives, titled *Adapting a conceptual framework to engage diverse stakeholders in genomic/precision medicine research*.

Two manuscripts by two Community Engagement Partners based on their work with the *All of Us* Research Program were published. The first manuscript by the Asian Health Coalition is an

in-depth discussion of a national engagement strategy for recruiting Asian Americans and other minorities into biomedical research, titled *Establishing a National Engagement Strategy for Recruiting Asian Americans and Other Minorities into Biomedical Research*. While the second manuscript is a summary for researchers on gender identity by PRIDENet at Stanford University, titled *Understanding Gender Identity, Sex Assigned at Birth, and Sexual Orientation*. An additional four papers are currently in progress.

Conferences

Five conference abstracts were submitted in 2022 to further engage diverse researchers. At one of the largest conferences this year, the American Public Health Association acknowledged [150 Years of Creating the Healthiest Nation: Leading the Path Toward Equity](#). The DEO gave a presentation, titled “Using Big Data to Advance Precision Health and Address Health Disparities: the *All of Us* Research Program.”



Two manuscripts by two Community Engagement Partners based on their work with the *All of Us* Research Program were published.

A Look at the Future

“Actively Engaged” and Engagement Metrics

In 2022, the DEO proposed definitions for “actively engaged” as a term that can foster a more robust participant experience.

In 2023, “Actively engaged” metrics aim to assess the evidence or participant intention of continuing participation. DEO and the Technology team will collaborate for automated data capture and tracking of these participant engagement metrics.

Expansion of the Research Scholars Program

Goal 4: Researcher and Access Impact. In 2023, DEO will continue to support this goal by offering the annual NIH AoU Research Scholars Program (RSP). RSP is a professional development workshop. RSP eight month program:

- » Champions student researchers from underrepresented communities
- » Fosters a network of peers and mentors, in an effort to increase diversity in the biomedical workforce.
- » Provides training and hands-on experience to students who are conducting a research project using the AOUP workbench.

Scholars will design and display a poster presentation on their findings at the annual MSRS.

Expansion of the *All of Us* Researcher Academy

Goal 4: Researcher and Access Impact. The inaugural Institutional Champion awards for the *All of Us* Researcher Academy included six HBCUs. Plans to expand the Researcher Academy by up to seven additional Institutional Champion awards as well as select an additional cohort of Institutional Champions at HSI is a division goal in 2023.

Community Partners to Begin Enrollment

Supporting Goal 1: Enrollment and Retention. In 2023 three National Community Engagement Partners are to conduct enrollment identified based on their capacity, level of expressed interest, and existing infrastructure:

- » Stanford PRIDENet
- » National Alliance for Hispanic Health (NAHH)
- » The National Library of Medicine (NLM)

Pediatric Engagement

Under the Program’s top 3 priorities for 2023: Pediatrics. DEO aims to leverage partnerships within the existing *All of Us* Engagement Ecosystem and build upon those relationships.

New Ownership of Program Goal 5: Return of Value

To ensure that engagement principles are rooted in the way value is returned to participants and communities, Dr. Watson has joined goal 5 as the new goal owner.

Testimonials

“Connecting directly with LGBTQ+ community members, researchers who are conducting SGM research, and health providers serving LGBTQ+ communities across the country is one of the most rewarding aspects of being a National Community Engagement Partner. We often hear firsthand about the broken trust that LGBTQ+ communities have with research more generally, and being a part of helping to restore trust and share how All of Us is doing things differently is an honor and privilege.”

— PRIDEnet

It’s exciting to work with the *All of Us* Research Program to increase the representation of our communities in health research. We look forward to working with the program to encourage more participation within the AANHPI community through culturally and linguistically appropriate approaches in the coming years.

— Asian Health Coalition

“I have been a caretaker in the past for a family member. I am currently supporting a caregiver. This is such an important work and your providing support is so valuable. Thank you!

— Attendee, “Caregiving Today”
virtual health program, November 2022

FiftyForward is honored to partner with the *All of Us* Research Program to support the program’s commitment to inclusion of underrepresented groups in biomedical research, working to ensure representation of older adults and individuals from rural communities. We applaud the program’s laser focus on engaging a diverse group of participant partners and are excited to see the data being collected and shared with researchers to advance precision medicine for all.

— FiftyForward

“It’s extremely important that people are aware and are getting involved with clinical research because until we have a seat at the table, the medical remedies that are not done on us, will never work for us.”

— Antonio J. Martez, Kappa Alpha Psi Fraternity Inc., Member of the Black Greek Letter Consortium (BGLC)

Summary

In 2022, the *All of Us* Engagement Team and its partners persevered through the continued challenges of the COVID-19 pandemic to engage and enroll diverse participants as partners in the program. Using digital, phone, and in-person activities, they connected with their communities to build relationships. To connect with people across the country around health and precision medicine, *All of Us* partnered with local disability organizations, provided programs and services to older adults, worked with elected officials, and created bilingual health resources to reach a wider audience. The program's Engagement Ecosystem has begun to increase communication and outreach to implement Tribal leaders' recommendations in a culturally sensitive manner.

The engagement work has also expanded to focus on the researchers who will use the program's data to learn more about health and well-being, in hopes of supporting the health of our diverse communities and advancing health equity. Outreach to researchers studying health in underrepresented communities—including AANHPI, Black, Hispanic, and SGM communities—has been an important aspect of the engagement partners' work. By bringing new participants and researchers to the *All of Us* Research Program, the full Engagement Team and its partners—including Participant Ambassadors, Front Line Staff and community advisory boards—make an essential contribution to supporting the program's core values.

Fulfilling our core values requires a variety of tailored engagement strategies that allow the program to reach all communities.



Acknowledgements

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