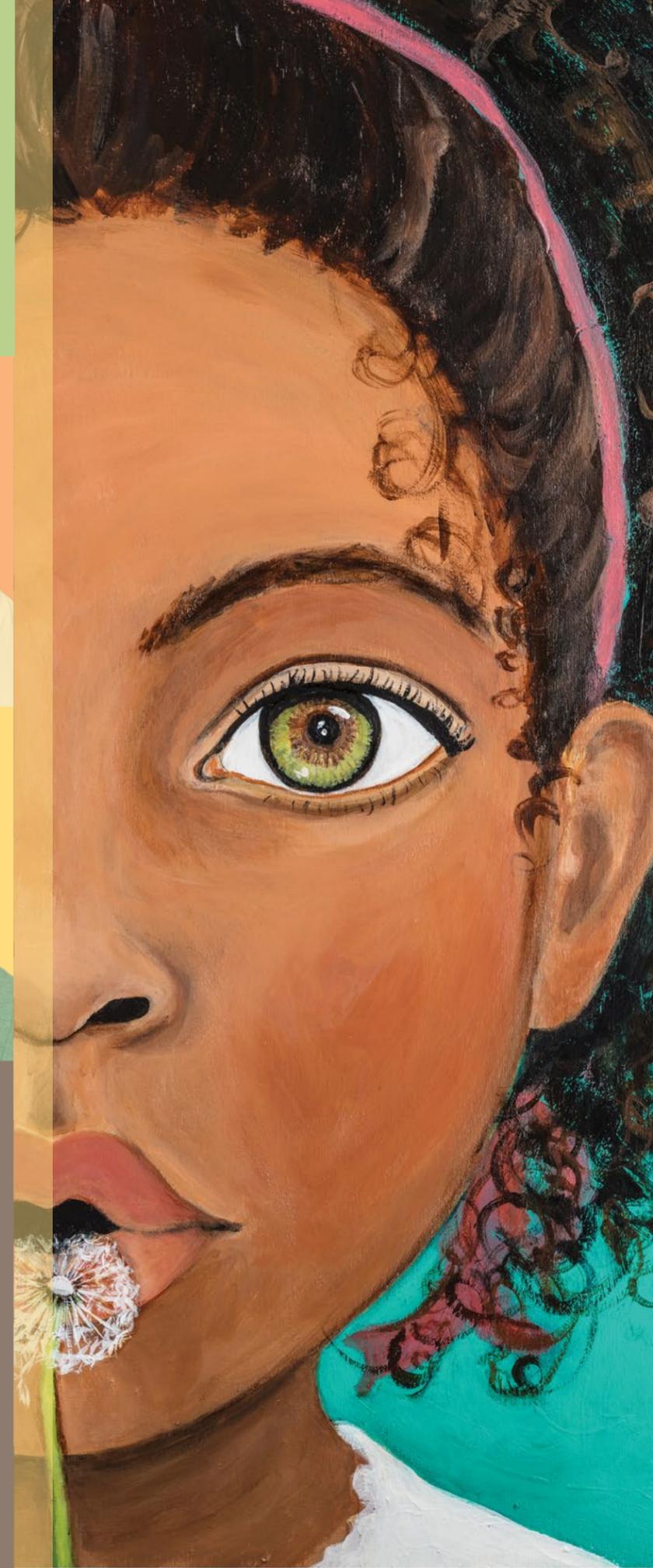
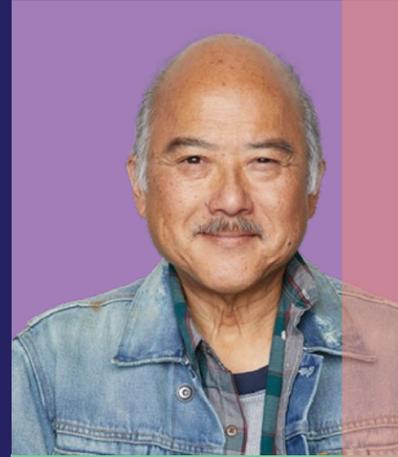




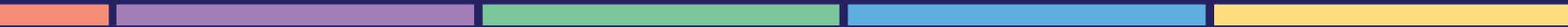
National Institutes of Health

All of Us
RESEARCH PROGRAM



National Institutes of Health
All of Us Research Program
Division of Engagement and Outreach

Annual Report | 2023



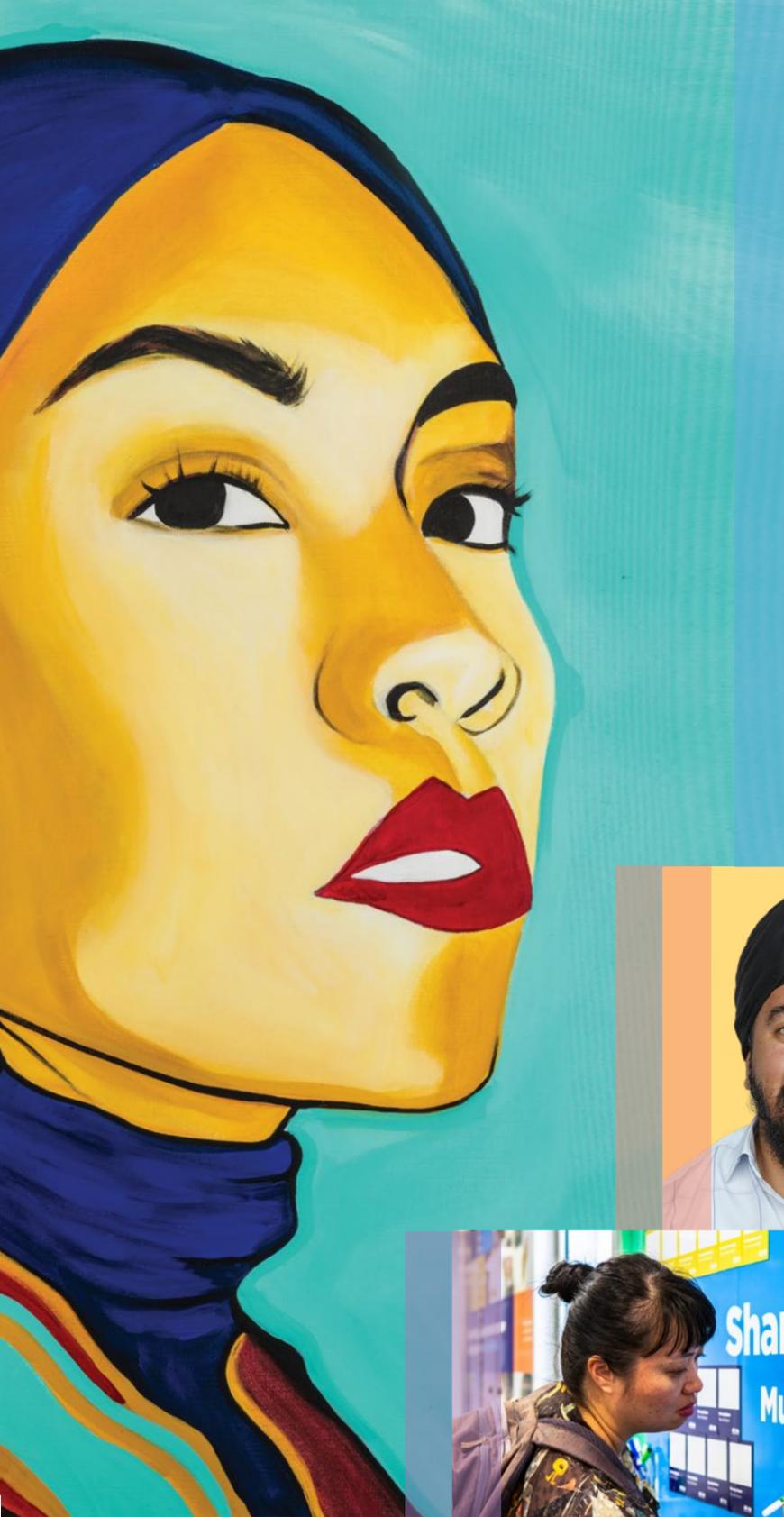


Table of Contents

3	Introduction From Leadership	16	Community Partners
7	Progress Toward <i>All of Us</i> Five-Year Goals	25	Tribal Engagement
9	Who We Are: <i>All of Us</i> Engagement	28	Researcher Engagement and Outreach
10	New Engagement Branches	30	Division of Engagement and Outreach Accomplishments
12	What We Do: Strategic Priorities	32	A Look at the Future
13	Synergizing Perspectives: Insights for Effective Engagement	33	Acknowledgments
14	Engagement by the Numbers		



Introduction From Leadership

Welcome to the 2023 Annual Report of the Division of Engagement and Outreach (DEO). This year, we take great pride in showcasing our extensive efforts in community, researcher, and Tribal engagement. Through innovative programs and collaborative initiatives, we have strengthened relationships, fostered inclusivity, and advanced the collective pursuit of knowledge mobilization.



ONE-ON-ONE CONVERSATION

Transforming Lives Through Precision Medicine: A Year of Groundbreaking Engagement

In a one-on-one conversation, NIH *All of Us* Research Program's Chief Executive Officer Josh Denny, M.D., M.S., and Chief Engagement Officer Karriem Watson, D.H.Sc., M.S., M.P.H., delve into the transformative impact of the *All of Us* Research Program, spotlighting key initiatives from the DEO and the program's commitment to community-led research.

Engaging Communities from the Start

Reflecting on the program's inception, Dr. Denny emphasizes the vital role of community engagement. From the early stages, the program sought input from diverse voices, recognizing the importance of involving communities in shaping biomedical research.

“

Josh Denny (JD): Community engagement was foundational. We wanted to hear directly from the communities we serve, ensuring their values and needs are at the core of our mission.”

Karriem Watson (KW): “We're now seeing the progress ... and it's amazing to be able to see it. I think about where the program started and what we heard in those original 77 community engagement studios, where we talked to community members about how they felt about research, what the importance of research meant to them, and the importance of data.”

From Promise to Progress: Precision Medicine in Action

The conversation transitions from the promise of precision medicine to tangible progress. Dr. Denny showcases advancements in treating diseases such as cystic fibrosis, heart disease, and various cancers, exemplifying the program's commitment to turning medical promises into reality.

“

JD: I feel like, personally and professionally with engagement and the importance of participant voices, we come as participants and bring our own experiences.”

JD: Part of the reason why I’m a physician is I grew up with a narrative in my family of my father having four siblings who died at a very early age from cystic fibrosis. Cystic fibrosis is a really great example for the power of precision medicine and science to make a difference. Cystic fibrosis treatments have evolved significantly. We’ve gone from single-digit survival rates to multidrug therapies, turning it into a chronic illness.

Community Voices at the Forefront

Dr. Watson highlights the bidirectional nature of community engagement, citing the importance of ongoing dialogue and action. The program’s growth to 18 National Community Engagement Partners underscores its commitment to addressing historical mistrust and building relationships with underrepresented populations.

“

KW: Our approach is bidirectional. We listen to communities, act on their feedback, and forge partnerships that ensure our program is responsive to their values and priorities.”

KW: Bringing together descendants of Henrietta Lacks and participants from the United States Public Health Service Untreated Syphilis Study at Tuskegee, in Alabama, showcased the program’s commitment to building trust and fostering dialogue.



Tribal Engagement: Respecting Tribal Sovereignty

The leaders discuss the rewarding experience of engaging with Tribal Nations and American Indian and Alaska Native (AI/AN) populations. Dr. Watson emphasizes the importance of partnerships and Tribal consultations to ensure that the program aligns with the values and priorities of Tribal Nations.

KW: One of the things that we do at *All of Us* is thinking about how we can continue to build trustworthy relationships, to create spaces and places for us to address historical misgivings and have some of those tough conversations ...Tribal engagement has been so rewarding, and really an opportunity for us to do a lot of listening again.

Pediatric Engagement: Shaping the Future

Looking ahead, Dr. Denny outlines the program’s commitment to pediatric engagement. With a focus on thoughtful enrollment and return of value tailored to different age groups, the program aims to include participants from birth through their entire life course.

JD: We’re excited to enroll our youngest participants and learn from parents and guardians about how best to serve them. I’m really looking forward to beginning enrollment ... More of a pilot and beta testing phase in 2024, with the earliest age ranges, and then expanding as we develop other protocols for older children.

“

JD: Engaging children from an early age ensures the program evolves with them.”

Building Trust and Fostering Progress

The conversation concludes with an emphasis on trust as the cornerstone of the program’s success. Dr. Denny commends the DEO ecosystem for leading engagement efforts, underscoring the collaborative journey toward advancing precision medicine for the benefit of all participants and communities.

As the DEO annual report unfolds, it celebrates the *All of Us* Research Program’s unwavering dedication to transforming lives, bridging gaps in health care, and pioneering a future where precision medicine is accessible to all of us.



[Watch the full conversation between Drs. Denny and Watson](#)

A Note From Our Deputy Chief Engagement Officer

We are proud to introduce the deputy chief engagement officer, who will play a pivotal role in driving our engagement efforts and ensuring that we continue to uphold the values of inclusivity, transparency, and meaningful collaboration in all our endeavors.



“With transparency at heart, I aim to work closely with our division and partners, ensuring that lines of communication remain open and effective, and ultimately strengthening the bonds within our division and fostering collaboration between branches and the diverse partners within our engagement ecosystem.”

Dear Engagement Community:

It was another exciting year for the *All of Us* Research Program! In 2023, we reached a program milestone of enrolling more than 750,000 participants and continued to expand our engagement ecosystem with the addition of three partners dedicated to Tribal engagement. We now have 18 National Community Engagement Partners and more than 100 partners and subawardees in our ecosystem.

On a personal note, after serving on the DEO for six years and having the privilege to work directly with many of you, I had the honor of taking on a new role as deputy chief engagement officer.

In this role, I will continue to serve as a strong advocate for our division and our ecosystem of engagement partners. In collaboration with our team and other division members, I am dedicated to improving efficiency and communication, reducing redundancy, and increasing visibility around our activities. The newly implemented monthly reports will serve as a mechanism for raising awareness of our progress. These efforts will help fortify our infrastructure, which has served as a foundation for all of our achievements thus far.

As I look forward to 2024, I am confident that we will continue to make a meaningful impact in improving health care for all with our collective efforts and our shared commitment to advancing precision medicine and research.

Minnkyong Lee, Ph.D.

Deputy Chief Engagement Officer, Division of Engagement and Outreach



Pediatric Engagement Roadmap

The DEO developed and implemented the Pediatric Engagement Roadmap, which outlines short-, medium-, and long-term goals, activities, and strategies for pediatric engagement. It includes best practices for achieving equity in pediatric enrollment, incorporating a variety of perspectives in the design and implementation and fostering a sense of ownership and partnership.



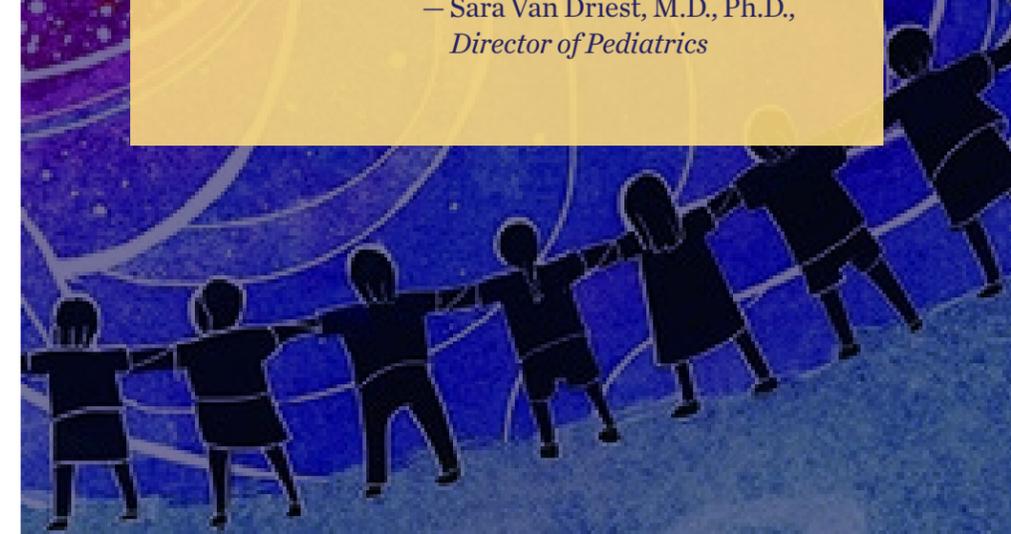
In collaboration with Dr. Sara Van Driest, director of pediatrics, and the Division of Cohort Development, the DEO hosted three community engagement studios in Nashville and Chicago and a series of listening sessions that brought together participants, prospective participants, and community members who are parents or guardians, as well as pediatricians interested in engaging and enrolling children in the program.



“We know that kids grow and thrive in the context of their families. Engaging with families now, as outlined in the Pediatric Engagement Roadmap, is crucially important to achieve our long-term goal of transforming the future of pediatric health research for the benefit of all children.”



— Sara Van Driest, M.D., Ph.D.,
Director of Pediatrics



“Our efforts of engaging diverse communities in the journey of research participation are led by building trusted partnerships and aligning our work with community priorities.”



— Erica Zumba, M.B.A., M.P.H.,
Community and Participant Engagement
Branch Director

Progress Toward *All of Us* Five-Year Goals

1 Enrollment and Retention

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

In 2023, the DEO expanded the community engagement partner network to support engagement efforts by onboarding new partners and supporting local grassroots organizations in rural areas through new awards with the Community and Provider Gateway Initiative (CPGI) network. Additionally, **three of our national partners are now supporting enrollment and retention efforts.**

2 Collection and Curation of Data and Specimens

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

The Interdisciplinary Guided Network for Investigation, Translation and Equity (IGNITE) project, led by the Feinstein Institutes for Medical Research at Northwell Health, conducted **six community health convenings across the United States**. These Data Roadmap events provided an opportunity for community members to share their thoughts on the *All of Us* Research Program’s Scientific Roadmap for future planned data and tools available to researchers.

3 Ancillary Studies

Launch ancillary studies as a core and scalable capability, expanding the cohort and delivering phenotypic, lifestyle, environmental, and biologic data.

The DEO provided guidance for ancillary studies, and the DEO framework for ancillary studies has helped create the foundation for the *Handbook for Developing All of Us Ancillary Studies*. One of the key features that the DEO and the Division of Medical and Scientific Research (DMSR) have incorporated is the **establishment of the Community and Participant Advisors for Ancillary Studies (CAPAAS)**. This board is composed of 10 community and participant representatives who provide input and feedback on the creation of an ethical and respectful ancillary research program that is relevant and responsive to the needs and priorities of the *All of Us* community and participants.

4 Researcher Access and Impact

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

To expand the engagement of researchers and faculty from minority-serving institutions (MSI), the DEO onboarded a Hispanic-serving institution (HSI) engagement partner. Collectively, **29% of the engagement partners' researcher-focused events attendees registered for the Research Workbench**. Additionally, two institutional engagement working groups were established—one focused on HSIs and one around historically Black colleges and universities (HBCUs).

5 Participant Return of Value

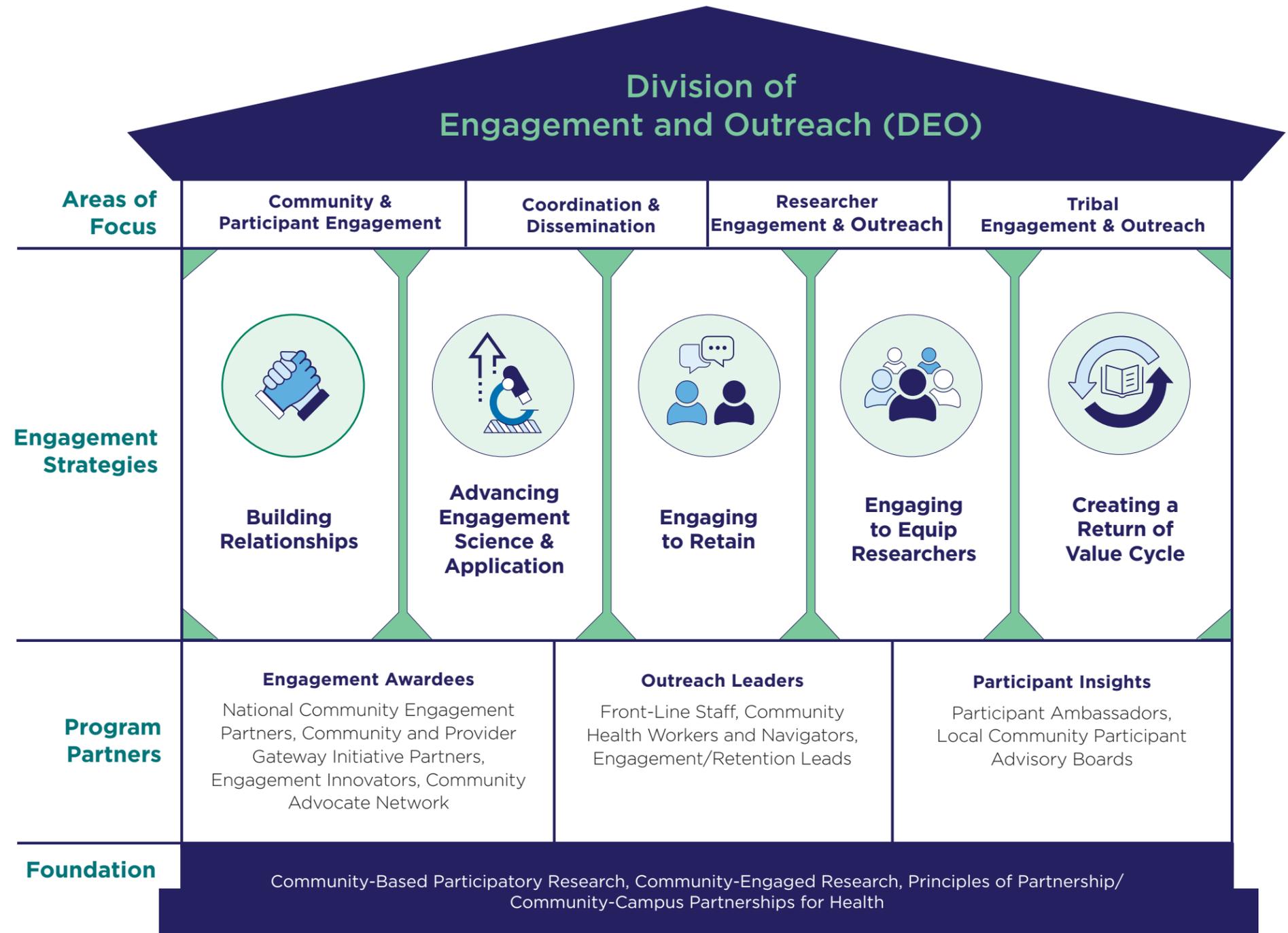
Incorporate participant return of value into data collections and assess its impact, including return of information to participants on genomics and electronic health records.

Leading Goal 5, Dr. Watson identified existing gaps in current goal language and developed a plan to be responsive to the community beyond the return of results. Additionally, working with Pyxis Partners as logistical coordinators, **the DEO held two community convenings** to better inform objectives around return of value.

Who We Are: *All of Us* Engagement

Community engagement, as defined by the *All of Us* Research Program, is relationship-building through bidirectional interactions, including information sharing, consultation, collaboration in decision-making, and empowered action among the program, people, awardees, and other partners. The DEO seeks to build trust, foster meaningful relationships, and ensure that the perspectives and needs of the community are central to the program's initiatives.

The DEO provides strategic direction for engagement with stakeholders, implements and evaluates ongoing engagement efforts to refine the program's approach and identify new needs, and ensures the engagement ecosystem's expertise in community engagement is considered when improving user experiences with the program's resources.



New Engagement Branches

To enhance our capacity and responsiveness, the DEO has undergone a restructuring and is now organized into specialized branches.



Coordination and Dissemination Branch

Yong Crosby, M.B.A., *Director*

The Coordination and Dissemination Branch is responsible for orchestrating seamless DEO operations and strategically supporting the growth of the engagement ecosystem. Through a combination of operational oversight, workforce development, relationship building, and program visibility support, the Coordination and Dissemination branch works with other branches, divisions, and consortium partners to effectively support the program's objectives. There are four teams under this branch:

- » Project Management and Operations Team
- » Workforce Development and Human Resources Team
- » Relationship Management Team
- » Dissemination and Visibility Team



Community and Participant Engagement Branch

Erica Zumba, M.B.A., M.P.H., *Director*

The Community and Participant Engagement Branch is responsible for building and maintaining trusted relationships with the program's engagement ecosystem. This branch focuses on activities that will increase outreach, awareness, education, and access for diverse communities to be a part of the research process. The branch also focuses on activities that engage to enroll and retain participants to the program, while ensuring that participants in the program are partners. Finally, this branch develops opportunities to share the workbench data, engage communities in precision medicine research, and create a cycle of return of value. There are four teams under this branch:

- » Community Engagement and Outreach Team
- » Pediatric Engagement Team
- » Enrollment by Community Partners Team
- » Participant Engagement Team

The DEO is grouped into four branches:

- » Coordination and Dissemination Branch
- » Community and Participant Engagement Branch
- » Researcher Engagement and Outreach Branch
- » Tribal Engagement and Outreach Branch



Researcher Engagement and Outreach Branch

Rubin Baskir, Ph.D., *Director*

The Researcher Engagement and Outreach Branch builds bidirectional relationships with researchers across all career stages, institution types, and demographics to develop an inclusive, diverse, and growing researcher community that uses the *All of Us* dataset to advance genomic and health equity research. There are three teams under the branch:

- » Outreach and Partnership Development Team
- » Capacity Building, Education, and Training Team
- » Evaluation, Outcomes, and Impact Team



Tribal Engagement and Outreach Branch

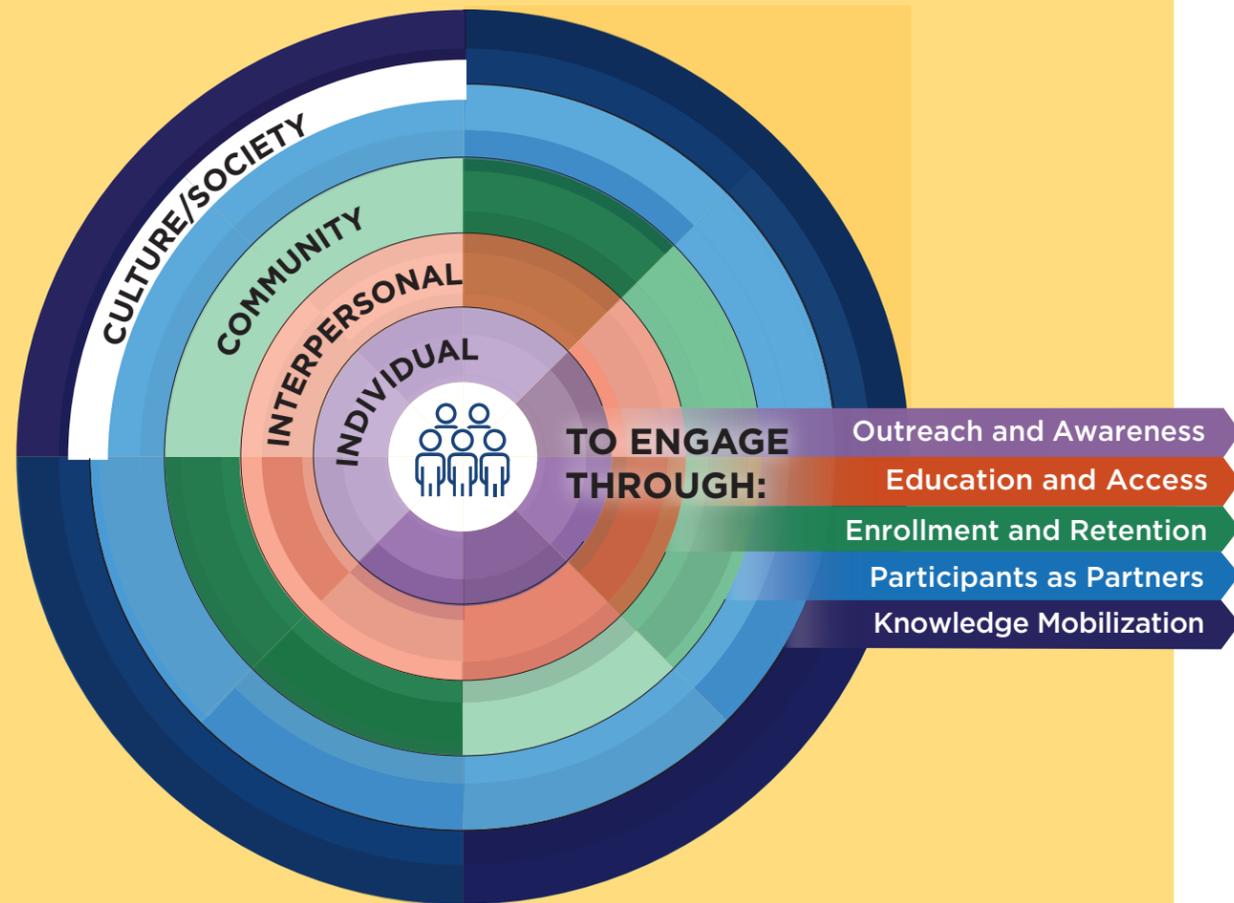
Michael Hahn, *Director*

The Tribal Engagement and Outreach Branch 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 on improving health outcomes. There are four teams under the branch:

- » Program Alignment and Project Management Team
- » Communications and Initiative Development Team
- » Tribal Relations and Partnership Development Team
- » Native Hawaiian and Pacific Islander Engagement Team



What We Do: Strategic Priorities



This year, we are also thrilled to highlight the successful rollout of our Community and Participant Engagement Framework, alongside our Researcher Engagement Framework; both have played pivotal roles in amplifying the impact of the DEO, fortifying our connections with the engagement ecosystem at every level.

The Community and Participant Engagement Framework is operationalized by the following approaches:



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, the information, and the ability to make an informed decision to participate and advocate for research participation.



Enrollment and Retention

Activities with the intent to enroll and retain fully informed potential participants and communities in the program.



Participants as Partners

A full integration of engaged participants to elevate their voices, expertise, and experience as collaborators 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 that the data are being used by individuals from groups that are underrepresented in biomedical research.

Synergizing Perspectives: Insights for Effective Engagement



VANDERBILT
UNIVERSITY
MEDICAL
CENTER

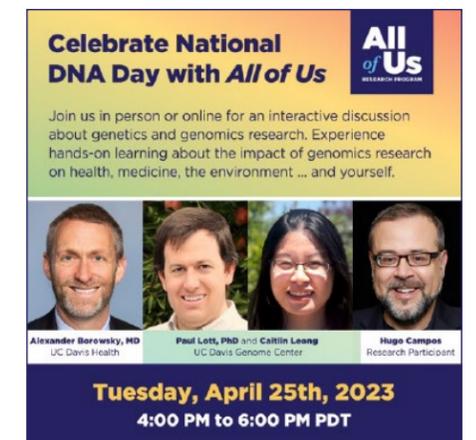
As a national community engagement partner, Vanderbilt University Medical Center is leading the national program to integrate participants and advocates into the oversight of the *All of Us* Research Program. This work is led by Dr. Consuelo Wilkins and her team, with an expanded scope of work to support pediatrics by identifying four pediatric champions as new participant partners and integrating at least one participant partner across four *All of Us* Research Program divisions.

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. [Meet the participant partners.](#)

Highlights of the participant partners' contributions include the following:

» At the October 26, 2023, **Consortium Meeting (Face-to-Face or *All of Us* Research Program Scientific Meeting), two participant partners and six Participant Ambassadors led a breakout session**, “Ask Me Anything: A Participant-Led Conversation About *All of Us*.” Panelists included Christina B. Andrews, Cynthia Arnsdorff, Randee Bloom, Daniel G. Garza, David Storm, Vanessa Uzoh, and Christine Von Raesfeld.

- » **In press in BMJ Open:** “Integrating Participants as Partners in Research Governance and Operations: An Approach from the *All of Us* Research Program Engagement Core,” by Catherine Hammack-Aviran, Alecia Malin Fair, Melinda Aldrich, Jennifer Richmond, Selena McCoy Carpenter, Karriem S. Watson, Elizabeth G. Cohn, and Consuelo Hopkins Wilkins.
- » Michelle Anderson (Participant Ambassador, 2020–2022) was the subject of a **YouTube video** and ***USA TODAY* article**.
- » On April 25, 2023, Hugo Campos (Participant Ambassador) was one of the panelists at the National DNA Day event with *All of Us* California and the Sacramento Public Library.



Daniel G. Garza (he/him/él) has been a patient leader for more than 20 years. He speaks publicly about HIV, anal cancer, and mental health. Daniel shares his story on social media through several campaigns, including Positively Fearless; volunteers for organizations such as Radiant Health Centers; and works with NMAC as a language justice consultant and a facilitator training new advocates. Daniel is a published author. His *Grumpy Bunny and the Colors Game* is a guided meditation book for children.

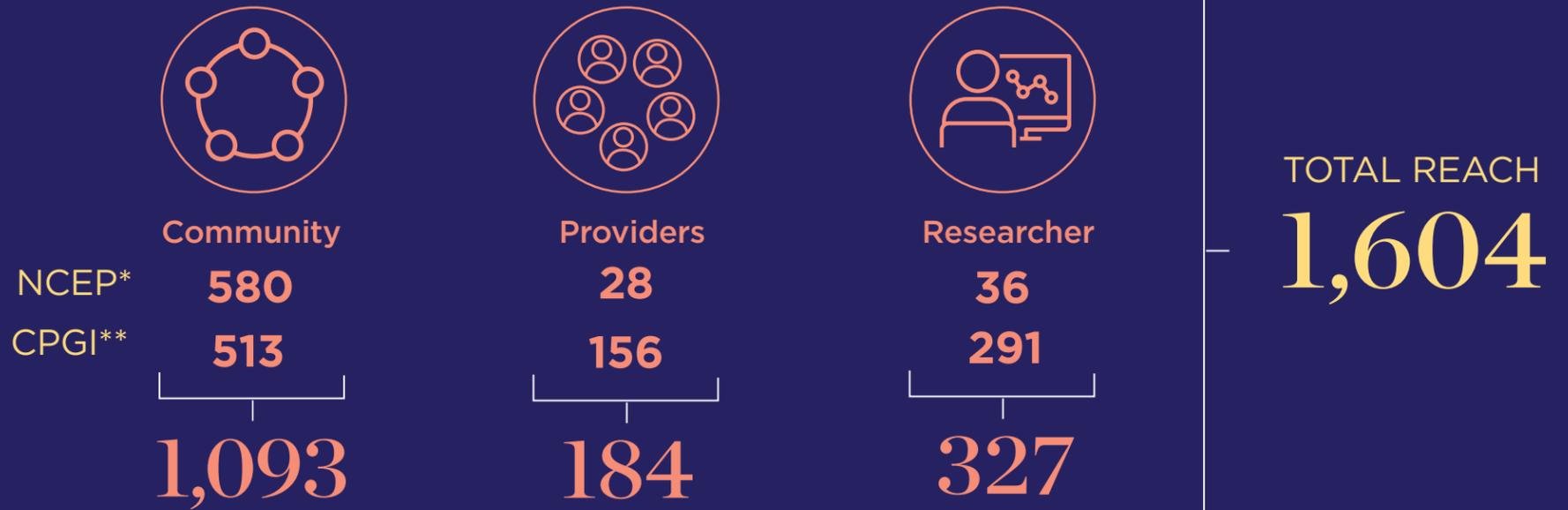
Engagement by the Numbers

The DEO conducted

93 VISIBILITY OPPORTUNITIES

to advance program goals and leverage partnerships opportunities.

Targeted Audiences



COUNT CRITERIA:

“Community”

- “Participant” as the Audience Type

“Providers”

- “Provider event with/without CME Credit” in the Activity Attributes
- “Health Care Providers” as one of the Target Demographics

“Researchers”

- “Researcher” as the Audience Type
- “Researchers” as one of the Target Demographics

* National Community Engagement Partners (NCEP)

** Community and Provider Gateway Initiative (CPGI)

50

RESEARCHER PRESENTATIONS

Community Engagement Partner Events



Digital or Hybrid Attendees

NCEP **34,373**

CPGI **7,675**

Subtotal **42,048**



Nondigital Attendees

383,952

187,040

570,992

TOTAL ATTENDEES
613,040



Digital or Hybrid Events

NCEP **47**

CPGI **158**

Subtotal **205**



Nondigital Events

560

475

1,035

TOTAL EVENTS
1,240

Engagement Meetings

24

INSTITUTE AND CENTER (IC) MEETINGS

15

RESEARCHER PARTNER MEETINGS

29

ADDITIONAL ENGAGEMENT MEETINGS



Community Partners

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

The invaluable contributions of our National Community Engagement Partners have significantly enhanced our collaborative efforts. In the following pages, we will delve into our partners' remarkable progress toward our engagement goals. We also extend a heartfelt welcome to the latest additions to our continuously expanding engagement ecosystem.

» **Vanderbilt University Medical Center (VUMC)**

Engagement Core (Participants as Partners):

Consuelo Wilkins, M.D., M.S.C.I., *Principal Investigator*

» **American Association on Health and Disability (AAHD)**

Pediatric Engagement:

Charles Drum, Ph.D., J.D., M.P.A., *Principal Investigator*

» **University of Arizona**

Researcher Engagement:

Jason Karnes, Pharm.D., Ph.D., BCPS, FAHA,
Principal Investigator

In 2023, with the combined support from our partners, the **DEO team engaged more than**

613,130 INDIVIDUALS

To date, the division has

18 NATIONAL ENGAGEMENT PARTNERS

with more than

106 ADDITIONAL COMMUNITY AND PROVIDER PARTNERS





The 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:

- » Formed the **AAHD Disability Consortium, a partnership of 24 national and local disability organizations** that reached approximately 600,000 individuals across AAHD and the Disability Consortium.
- » Conducted listening sessions with members of the disability community and the Disability Consortium that resulted in the creation of an Endorsement and Inclusion Statement highlighting the importance of disability community engagement, accessibility best practices, and research for disability health equity in the *All of Us* Research Program.
- » In partnership with consortium member Vanderbilt University, sponsored **two researcher engagement webinars for more than 50 disability and health researchers**.



All of Us Evenings with Genetics Research Program at Baylor College of Medicine

The *All of Us Evenings with Genetics* Research Program engages researchers from diverse backgrounds to use NIH's *All of Us* data resources to advance precision medicine.

Key Accomplishments:

- » Held information sessions with **11 HSIs and HBCUs**.
- » **Hosted the annual Biomedical Researcher Faculty Summit for 35 early-stage investigators**.
- » Hosted the Researcher Workbench Support Office Hours with a total of 71 participants, resulting in 16 new Researcher Workbench accounts.
- » Hosted a training on Python and the Researcher Workbench, with a total of 23 attendees.



Delta Research and Educational Foundation

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

Key Accomplishments:

- » **Engaged 23,264 individuals from African American communities in 20 cities and 8 HBCUs.**
- » Engaged 560 researchers through DREF's National Research Working Group, which consists of 28 researchers who are members of Delta Sigma Theta Sorority, Inc. The group helped 10 institutions obtain data use and registration agreements (DURAs) and promoted the *All of Us* Research Hub and Researcher Workbench through lunch-and-learn sessions and DREF's second national symposium.
- » Leveraged DREF's partnerships with Delta Sigma Theta Sorority, Inc., and 20 national and faith-based organizations to engage more than 25,000 African Americans at conferences held across the country and encourage participation in the *All of Us* Research Program.



Asian Health Coalition

The Asian Health Coalition works with Asian American, Native Hawaiian, and Pacific Islander (AANHPI)–serving organizations across the nation to create culturally appropriate, cost-effective, and scalable education and outreach for AANHPIs within the *All of Us* Research Program.

Key Accomplishments:

- » Partnered with **23 AANHPI Engagement & Recruitment Core partners** to engage and educate AANHPIs **in more than 40 states** across the country.
- » Used various ethnic media platforms to reach 769,611 AANHPIs through 13,718 promotional activities.
- » Partnered with the *All of Us* team to launch the pre-enrollment for the AANHPI Project—which aims to **culturally and linguistically adapt *All of Us* pre-enrollment screens into five approved Asian languages**—and selected five pilot sites for the first stage of this project.



National Alliance for Hispanic Health

The Alliance is the United States' foremost science-based source of information and trusted nonpartisan advocate for Hispanic populations.

Key Accomplishments:

- » Supported a **network of 41 promotores in 15 community-based organizations to reach 91,771 potential participants.**
- » Developed a facilitated enrollment model and piloted implementation in five sites, resulting in **385 accounts created** in underserved communities.
- » Supported the *All of Us* Journey tour, resulting in **51,460 accounts created.**
- » Implemented a Research Ambassadors Program that led to **815 Researcher Workbench registrations.**
- » **Awarded research grants to 48 researchers** to advance understanding of cervical cancer in Latinas.
- » Partnered with Color to **train 326 consortium members** in genetic health-related return of results.
- » Conducted a digital media campaign in partnership with Univision, resulting in **11.2 million impressions.**



IGNITE Program

Northwell Health, in collaboration with Hunter College, Physician Affiliate Group of New York, Columbia University, and Pyxis Partners, engages community-based organizations, researchers, and health care providers from diverse backgrounds through the IGNITE program.

Key Accomplishments:

- » Funded **two community-based organizations** that provide **services to Hispanic/Latinx New Yorkers.**
- » **Launched a Spanish version of the successful Data Sandbox model**, a novel application of the program Public Data Browser to communities.
- » Launched the 12-session *All of Us* Friday Morning Coffee Series, a curriculum on the Researcher Workbench, with more than 160 registered attendees.
- » Launched the first national *All of Us* Community Health Convening series focused on the Scientific Roadmap.



RTI International

RTI International conducts community, health care provider, and researcher engagement to develop bidirectional relationships between these groups and the *All of Us* Research Program.

Key Accomplishments:

- » Partnered with PRIDENet at Stanford Medicine to support engagement and pilot enrollment.
- » Developed **two free continuing education courses about *All of Us*** and the return of genetic research results through a Web-based app that enables accessible, accredited learning opportunities for health care providers.
- » Designed and implemented the *All of Us* Researcher Academy, with funding to research teams at **13 HBCUs**. With Community-Campus Partnerships for Health, conducted three webinars/road tours attended by more than **600 people from 40 HBCUs**. To support the next generation of research leaders, offered an internship-mentorship program, held faculty scholar convenings, and distributed three newsletters to 440 subscribers.



University of Utah

The Utah team collaborates with consortium, community, and teacher representatives to co-create engagements and lessons designed to inform participants and potential participants and engage high-school students who want to use the Research Hub.

Key Accomplishments:

- » Held a **three-day *All of Us* Research Hub Summer Institute** with 17 high school teachers from 13 states across the country.
- » Developed content and engagement opportunities for use by consortium members in engagement, recruitment, and retention of participants: seven videos with collateral materials and **11 hands-on engagements with accompanying video micro-workshops**.



National Baptist Convention, USA, Inc.

The National Baptist Convention, USA, Inc., through its H.O.P.E. Health Ministry, supports health and wellness activities for its more than 31,000 churches.

Key Accomplishments:

- » Provided **outreach and education to nearly 20,000 people**, based upon meeting counts, sign-in sheets, and virtual sessions.
- » Trained more than 200 certified health ambassadors with *All of Us*-infused components; based upon regional reports, these new health ambassadors participated in *All of Us*-related activities to actively engage about 6,500 members.





FiftyForward

FiftyForward is the leading resource for adults 50 and up 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 and participated in a total of 130 engagement events, **reaching 165,946 potential program participants virtually** and more than **5,000 in person**.
- » In conjunction with the *All of Us* engagement team, planned and facilitated a special Walk with a Doc event for Older Americans Month (May 2023).
- » Collaborated with multiple *All of Us* consortium partners and local partners representing communities underserved in biomedical research. Highlights included partnering with the Network of the National Library of Medicine (NNLM) for a screening of “The Human Trial” at the historic Belcourt Theatre in Nashville and with the NNLM and the National Alliance for Hispanic Health for the virtual Caregiving Today event and hosting the Mobile Engagement Asset’s three-week Nashville-area visit.



PRIDENet

PRIDENet (Stanford Medicine) 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:

- » Engaged more than **11,000 potential participants**, researchers, and providers through production of LGBTQIA+ events and making connections in clinics and at conferences, contributing to **324 new *All of Us* accounts created** and **85 completed consents**.
- » Grew online communities, adding 897 new followers across @AllofUsLGBTQIA social media channels (for a total of 20,197 followers), 979,861 social media impressions, and 31,000 visits to the [All of Us LGBTQIA+ page](#).
- » Produced the PRIDENet Researcher Basecamp to enable 17 early-career academic and community-based researchers to learn the foundations of conducting sexual and gender minority research with *All of Us* data, resulting in 20 new Researcher Workbench registrations, five new data use and registration agreements, and one new Controlled Tier rider.

“From the beginning, one of the program’s core values has been participants as partners. Partnering with and integrating participants into the program has not only led to the success of our program but has ignited a culture shift in the way research is done. I believe that it is our participants’ voices, perspectives, and experiences that truly make *All of Us* feel like everyone is included. Because without participants, *All of Us* does not exist.”



— Angelica Johnson, M.S.W.,
Program Officer, Community and Participant
Engagement Branch



University of Florida

The 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:

- » Eight CPCN sites presented on the *All of Us* Research Program at **19 major local events and national conferences**, registering **160 researchers**, who created **288 workspaces**.
- » Provided technical registration and/or data analysis support for 59 individual researchers with 16 abstracts/papers in progress.



The Network of the National Library of Medicine

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

Key Accomplishments:

- » Funded or hosted **95 engagement activities**, in collaboration with **25 public libraries and community organizations** and 15 unique *All of Us* consortium partners, reaching more than 3,600 community members in 38 states; Washington, D.C.; and Puerto Rico.
- » All NNLM *All of Us* Program Center (NAPC) events reached areas with at least one category of populations underrepresented in biomedical research.
- » All NAPC activities directed traffic to joinallofus.org, with more than **3,000 potential participants** accessing the site, **51 registrations**, and **34 completed primary consents**.

Engagement and Retention

The Engagement and Retention Leads Group consists of more than 50 principal investigator-designated representatives from the diverse enrollment awards who are responsible for engagement and retention efforts such as building partnerships, creating trust with communities, conducting outreach, and strategizing methods to retain participants.

Key Accomplishments:

- » Leads supported two community convenings with more than **350 community and consortium members in Tuskegee, Alabama, and San Diego, California**. The events focused on the importance of research participation for all and provided information on the program return of value.
- » A work group of eight leads co-developed metrics to measure the impact of engagement and retention efforts.
- » A work group of five leads prepared a development guide that included engagement and retention best practices, resources, and future recommendations on engagement and retention efforts.



Pyxis Partners

Pyxis Partners is a national engagement partner and manages a network of more than 100 national and local organizations that reach and engage diverse communities to educate them about research, break down barriers, and move them toward participation in the *All of Us* Research Program. The Pyxis team also works with the DEO to develop and implement programming focused on expanding the pipeline of diverse researchers and creating opportunities and support for those researchers to access and use the *All of Us* dataset.



Key Accomplishments:

- » Supported more than 100 partners with engagement and communications counselors (52 partners and 54 subawardees).
- » Accepted **61 scholars and 32 mentors into the Research Scholars Program** (RSP) and supported them through the eight-month program.
- » Partnered with the National Library of Medicine and the University of Pittsburgh to bring the Racial Equity Consciousness Institute, a series of conversations and learning modules focused on racial equity consciousness, to the RSP cohort.
- » Partnered with the DEO and leaders in Macon County, Alabama, to create a community convening to discuss **participation in research, the community's history as it relates to research**, and opportunities to move forward together to ensure representation.

Community and Provider Gateway Initiative (CPGI) Partner Network

The CPGI Network consists of community and health care provider partners that work to bring awareness of the *All of Us* Research Program to their communities. These partners collaborate with other local program partners and serve as trusted voices to build trust with the program and move community members along their personal engagement journey toward participation and retention.

Key Accomplishments:

- » More than 100 partners (52 partners and 54 subawardees) **conducted 813 activities and reached 167,392 potential participants** and researchers, generating **63,492 engagements across 30 states**.
- » CPGI partners in New Orleans, Detroit, and New York **connected 774 prospective participants with local enrollment partners** through the use of partner-specific landing pages via the Program Management Toolkit.
- » **Twenty partners completed 126 researcher-facing activities**, reaching more than **7,000 researchers**. Partners engaged with eight HBCUs and 42 HSIs to increase the number of diverse researchers registered and using the *All of Us* Researcher Workbench. Four partners secured DURAs, and four contributed to six institutions securing DURAs.

[All of Us CPGI Network Organizations on next page.](#)

All of Us CPGI Network

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





CONNECTION
 collaboration
 diversity
 active
 participant
 vital
 TRANSPARENCY
 ENGAGE
 motivation
 community
 interactive
 PARTNERSHIP
 involvement
 enthusiasm
 trustworthiness
 passion
 responsive
 CONNECTION
 understanding
 relationship
 helpful
 interactions
 commitment
 nurture
 OPPORTUNITIES
 communication

Tribal Engagement

The program's Tribal engagement is driven by partnership with Tribal Nations and feedback from Indigenous leaders and communities. The focus areas for 2023 were to strengthen communication, engage and equip researchers to work with AI/AN data, assess Tribal community readiness to participate in the program, and co-develop an outreach campaign to increase interest in health research from an Indigenous lens.

To support the program in these efforts, three new awards were made to:



University of Arizona

Project: Developing Partnerships to Advance Precision Medicine with AI/AN Tribal Nations

Teshia G. Arambula Solomon, Ph.D., M.S., *Principal Investigator*



American Indian Science and Engineering Society (AISES)

Project: We Are All Scientists

Kathy DeerInWater, Ph.D., *Principal Investigator*



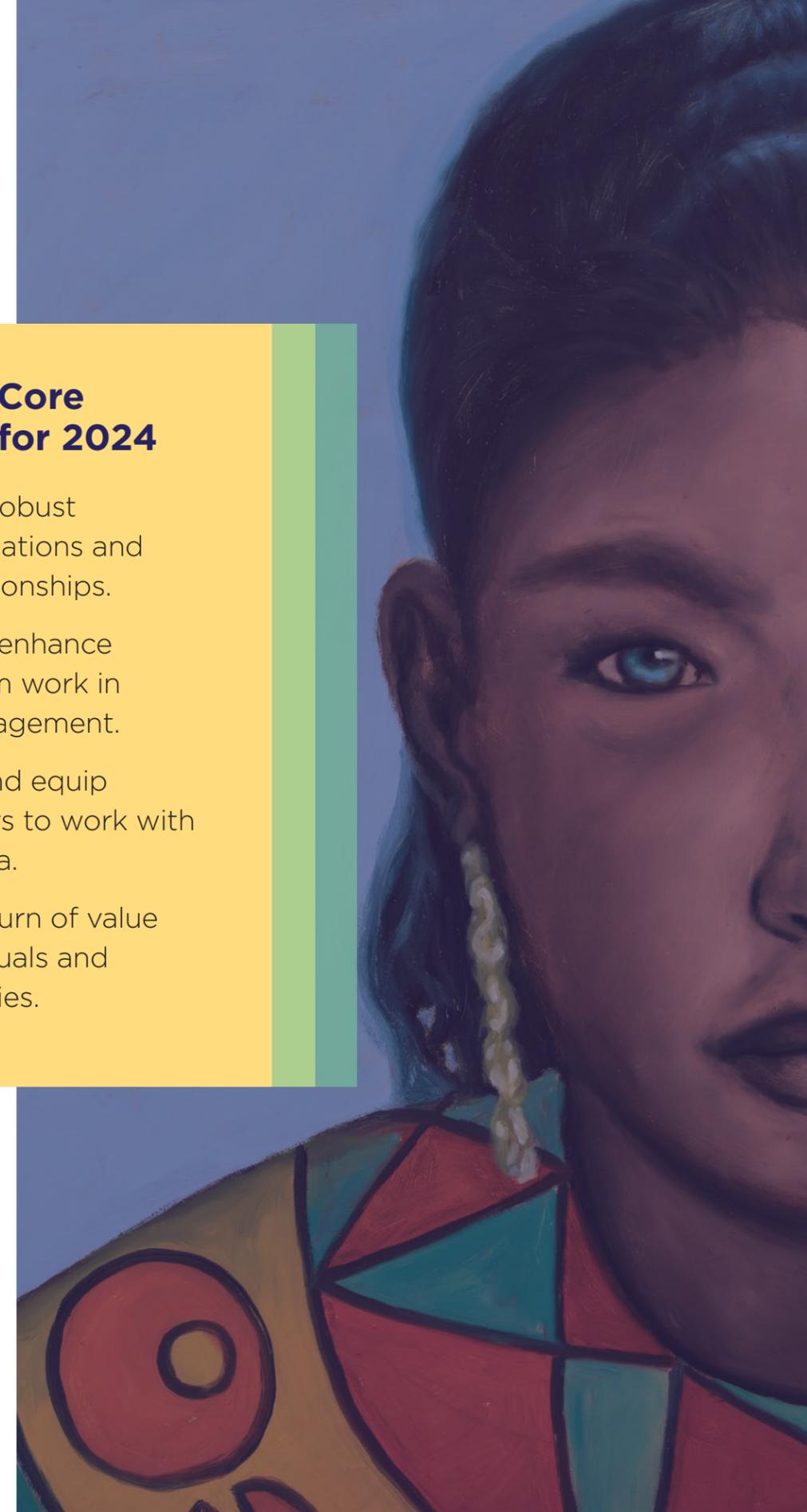
Marshfield Clinic Research Institute

Project: Engage Tribal Nations and Urban and Non-Tribal Land Based AI/AN Populations in Wisconsin

Scott Hebring, Ph.D., *Principal Investigator*
Dorothy Farrar Edwards, Ph.D., *Co-Investigator*
Zeno Franco, Ph.D., *Co-Principal Investigator*

Strategic Core Priorities for 2024

1. Establish robust communications and build relationships.
2. Align and enhance consortium work in Tribal engagement.
3. Engage and equip researchers to work with AI/AN data.
4. Ensure return of value for individuals and communities.



The program has onboarded two new team members with expertise in Tribal engagement.

Molita Yazzie, M.A.H.S., M.Sc.,

who is Dine’ from the Western Navajo Agency in northern Arizona, is a senior analyst for AI/AN Indigenous engagement. She supports the *All of Us* Research Program by building relationships with Tribes by first seeking to understand their needs and concerns, providing genetic research education, and implementing strategies related to AI/AN partnerships and interested party engagement to lend to the program’s mission.



Vicky Murray, M.A., an AI/AN

senior analyst for AI/AN Indigenous engagement from the Tribal Engagement and Outreach Branch, recognizes the sensitivity and care that this work requires—particularly in relation to incorporating Tribal sovereignty: “As a team we each bring different subject matter expertise in working within Indian Country, and we play to those strengths.”



Key Highlights

May 2023

The program convened the *All of Us* Indigenous Research Working Group (IRWG), which is made up of five AI/AN researchers from across all career stages, institution types, and demographic areas.

June 2023

As part of its ongoing efforts to engage and solicit input from Tribal communities, *All of Us* held [four virtual informational and discussion sessions](#) with AI/AN communities. More than 250 attendees from various Tribal governments and Tribal representations came together, making it a diverse and inclusive gathering.

September 2023

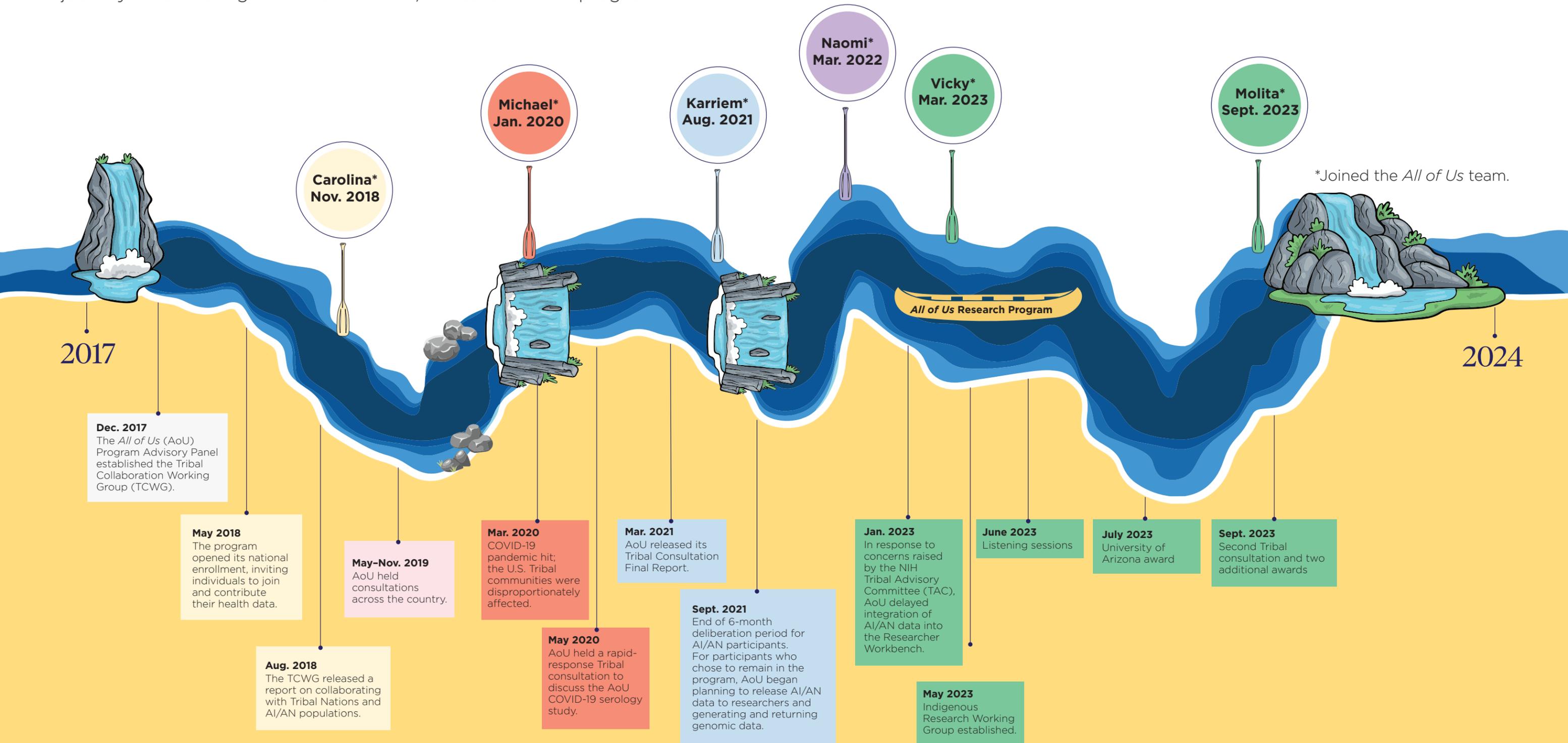
September 12: The program convened the Tribal Collaboration Working Group (TCWG).

September 28: The program hosted the third formal Tribal consultation, focused on the development of engagement efforts important to Tribes.

This past year the program enhanced Tribal engagement efforts and increased our existing AI/AN representation to ensure that we are responsive to the voices of Tribes.

Tribal Engagement River of Life Reflection Timeline

The river of life features key points in time and is a representation of our *All of Us* journey in facilitating the inclusion of AI/AN data into the program.



Researcher Engagement and Outreach

In 2023, the DEO worked with partners to further expand the pathways of researchers engaging with the Researcher Workbench by implementing strategies to build capacity for researchers across all career stages.

Key Highlights

PRIDENet *All of Us* Researcher Basecamp, March 23–24, 2023:

An in-person training course for researchers underrepresented in the biomedical workforce (UBW) to launch LGBTQIA+/sexual and gender minority projects resulting in **five new DURAs, one Controlled Tier driver, 20 new workspaces, and more than 15 newly registered UBW researchers.**



More than
1,200 PEOPLE REGISTERED TO ATTEND

Researchers Convention, March 29–31, 2023:

A virtual event that provided an opportunity for researchers using the *All of Us* dataset to showcase their work. More than 1,200 people registered to attend, and more than 400 attended each day of the convention.

“The Division of Technology and Platform Development is proud to collaborate hand in hand with the DEO—they have been vital in helping us understand the perspectives and motivations of the full diversity of researchers, and they are creating amazing opportunities for early researchers to help advance precision medicine. They are creating the next generation of researchers, and that generation is more diverse than any that has existed before.”



— Chris Lunt, *All of Us* Research Program Chief Technology Officer

Key Highlights, *continued*

Baylor College of Medicine Biomedical Researcher Faculty Summit, May 17-19, 2023:

The second annual in-person training hosted:

34 UBW EARLY-STAGE INVESTIGATORS REPRESENTING 29 INSTITUTIONS (including 5 HBCUs)

7 MULTIDISCIPLINARY RESEARCH TEAMS

University of Utah Summer Institute 2023, July 18-20, 2023:

Seventeen high school life science teachers registered on the Researcher Workbench attended an annual multiday workshop designed to introduce high school teachers to *All of Us* and to engage students in conducting research using the Researcher Workbench.



AIM-AHEAD and RTI Partnership, September 1, 2023-August 30, 2024:

A joint partnership between the **Artificial Intelligence/Machine Learning Consortium to Advance Health Equity and Researcher Diversity (AIM-AHEAD)** and **RTI International** was set up to increase researcher diversity in artificial intelligence/machine learning (AI/ML) by leveraging *All of Us* data and infrastructure.



Capacity Building *All of Us* Researcher Academy Institutional Champions:

AWARDS TOTALING

\$900,000

(with a maximum of \$75,000 per institution for stipends) were made to 12 HBCUs, and the program has now expanded to other higher education institutions.

***All of Us* SEPA Mini-Grants:**

TWO SUPPLEMENTS TOTALING ABOUT

\$98,000

were issued through the University of Utah to existing Science Education Partnership Awards (SEPA) to facilitate high school usage of the Researcher Workbench, reaching approximately 100 high school students.

22% of the new DURAs established have been a result of our partners' efforts.

AT LEAST 8.1% of newly registered researchers are a result of our partners' efforts.

Data from August 22, 2023 to January 22, 2024

Special thanks to the Division of Technology and Platform Team and the Data and Research Center for our close collaboration.

DEO Accomplishments

The DEO held two community convenings as part of the return of value initiatives to bring program awareness and information about opportunities to participate and address health equity and important research questions affecting communities.

African-American Community Convening

[Macon County Health Research Symposium](#)

[Moving Us Forward!](#), Tuskegee, Alabama, February 9-10, 2023: The success of *Moving Us Forward!* can be measured by the trust that the program has built with local community leaders and organizations across Macon County.

Nearly 300 people participated in the conversation, and three local organizations have joined the *All of Us* Research Program as funded partners to continue this important conversation in the community. These organizations are:

- » Macon County Research and Review Board
- » Epsilon Chapter of Nursing Sorority Chi Eta Phi Sorority, Inc.
- » Macon County Health Authority

Hispanic Community Convening

Mes de la Herencia Hispana: All of Us Festival, San Diego, California, October 14, 2023:

In celebration of Hispanic Heritage Month, this convening included discussion forums on how the local Latinx/Chicano community is shaping the future of health research. This event **hosted more than 100 community members** in collaboration with national and local partners and eight tabling organizations.





“When I hear ‘**knowledge mobilization**,’ I think about the lasting impact *All of Us*—including the DEO and our partners’ engagement efforts—will have on society as a whole. Through presentations, publications, curricula development, and the sharing of reproducible findings, the *All of Us* Research Program will leave a lasting impression in the field of health equity research.”

— Sydney McMaster, CHES, Program Officer,
Researcher Engagement and Outreach Branch

Program Visibility Highlights

American Association for Cancer Research Annual Meeting

Orlando, Florida, April 14–19, 2023

Plenary: 3,000 attendees

National Health IT Collaborative for the Underserved (NHIT®) Health Equity Legislative Summit

Washington, D.C., September 21, 2023

Panel: 70 attendees including U.S. Congress staff



American Public Health Association Annual Meeting and Expo

Atlanta, Georgia, November 12–15, 2023

Over 12 *All of Us* sessions and exhibit space accommodating researcher engagement and enrollment partners: 15,000 attendees

Annual Biomedical Research Conference for Minoritized Scientists

Phoenix, Arizona, November 15–18, 2023

Researcher Workbench demo with the Data and Research Center: 100 attendees

Administrative Supplements

National Cancer Institute (NCI)

Funded institutions:

- » City College of New York—Karen Hubbard, *Principal Investigator (PI)*
- » University of California, Irvine—Sora Tanjasiri, *PI*
- » Temple University—Lin Zhu, *PI*

NCI Center to Reduce Cancer Health Disparities (CRCHD) Partnerships to Advance Cancer Health Equity (PACHE)

P20 and U54 awards to support pilot research projects led by postdoctoral fellows, junior faculty, or other early-stage investigators (ESIs) that use NIH’s *All of Us* Research Program dataset.

AIM-AHEAD Collaboration (Office of Data Science Strategy [ODSS])

Funding Timeline:

September 1, 2023–August 31, 2024

Through the RTI award, *All of Us* is providing support and training for 12 AIM-AHEAD AI/ML trainees to use the *All of Us* dataset.

A Look at the Future

Evaluating Our Impact

In 2023, the DEO conducted a comprehensive retrospective evaluation covering the division's activities from September 2017 to December 2022. Planned activities included:

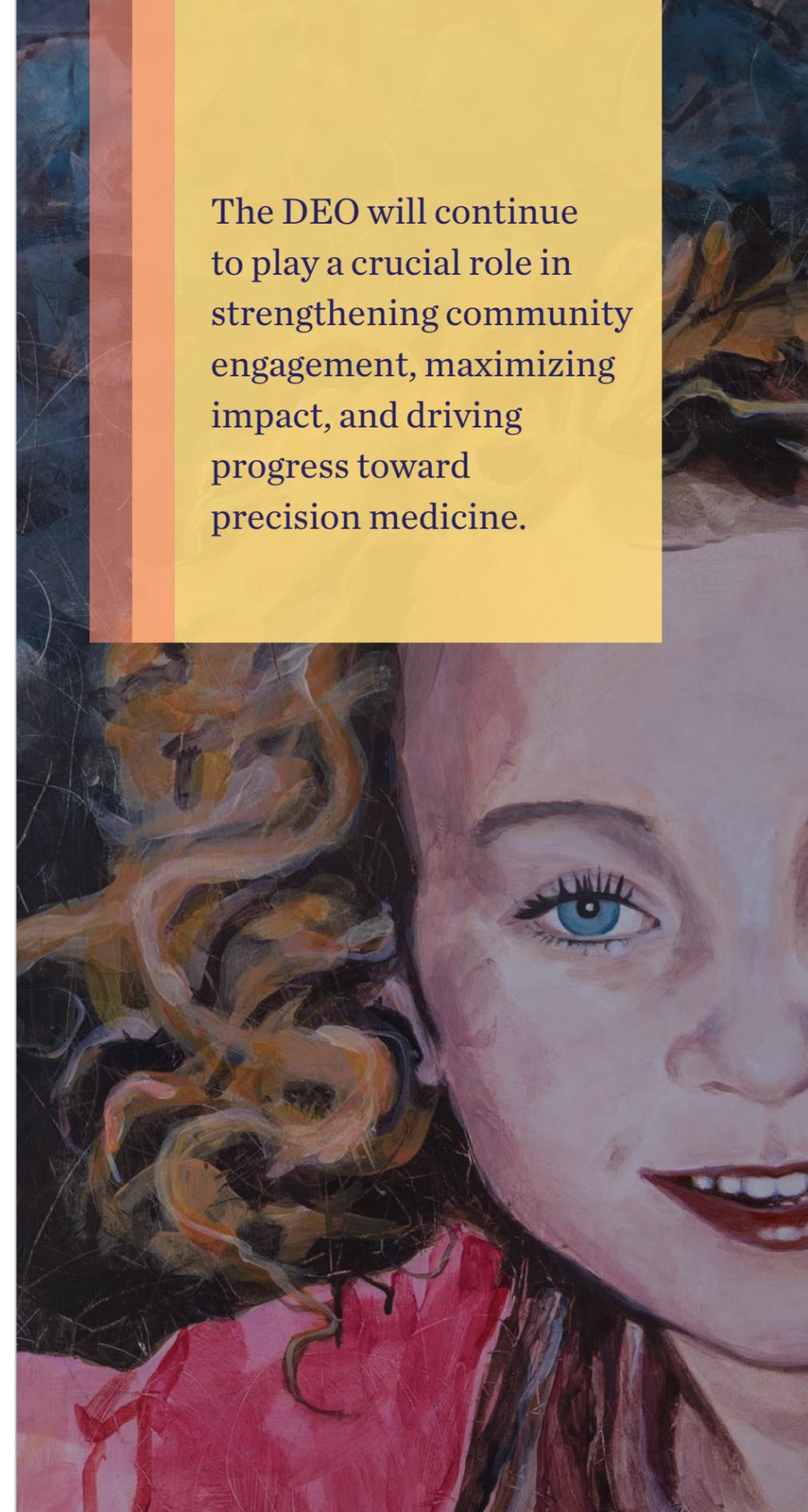
- » Laying the foundation for ongoing impact assessments through retrospective evaluation of community partner engagement.
- » Defining, measuring, documenting, and communicating the impact of the DEO's engagement work on *All of Us* goals and precision medicine advancement.
- » Understanding partner definitions of "return of value" for participants and researchers.
- » Assessing program impact and identifying previously unknown outcomes.

In the next year, the DEO will work on evaluating the impact of various efforts by **funded community engagement partners, using the DEO Community Engagement and Participant Framework's five areas of engagement.**

Expanding Community Engagement and Supporting Program Priorities

- » Expanding community engagement by collaborating with **advocacy groups** related to the top five most-studied health conditions on the *All of Us* Researcher Workbench.
- » Continuing to implement the **Pediatric Engagement Roadmap** and providing guidance on how to operationalize the DEO Community and Participant Engagement Framework to foster trust and transparency that result in effective pediatric enrollment and continuous participation.
- » Supporting the **Participant and Partner Services Center (PPSC) and Center for Linkage and Acquisition of Data (CLAD) launch** to ensure that participant voices are integral throughout the process.
- » Facilitating the return of genomic results to participants who have provided affirmative consent and continue to **lead Goal 5 initiatives.**
- » **Broadening Researcher Workbench access** and providing capacity-building opportunities to enhance MSI capabilities.

The DEO will continue to play a crucial role in strengthening community engagement, maximizing impact, and driving progress toward precision medicine.



Acknowledgments

Extending Our Gratitude

On behalf of the entire DEO, we extend our heartfelt gratitude to the diverse community of more than 800 consortium partners who have been instrumental in our journey. Your unwavering support, dedication, and collaborative spirit have been the driving force behind our achievements.

We also wish to express our sincere appreciation to the leadership team, including the *All of Us* Chief Executive Officer, all the branches and divisions leadership, and the entire *All of Us* team, whose guidance and vision have steered us toward success.

Furthermore, we acknowledge the invaluable contributions from our partners across the National Institutes of Health in their many centers, institutes, and offices. Your support and collaboration have been crucial in advancing our mission to enhance health equity, inclusivity, and research excellence.

To all involved, your insights, expertise, and shared commitment have amplified the impact of our initiatives and brought us closer to our collective goals. As we reflect on the remarkable progress we have made in 2023, we look forward to the continued collaboration and innovation that the future holds.

Together, we are shaping the landscape of health research, and we remain deeply appreciative of your partnership in this transformative journey.



Team at the 2023 DEO retreat in Bethesda, Maryland. Missing the valuable presence of Erica Zumba in the photo and celebrating the new journey our colleagues Amanda Anazco and Kelly Jenkins-Brown have embarked on.

Karriem S. Watson, D.H.Sc., M.S., M.P.H.,
Chief Engagement Officer

Minnkyong Lee, Ph.D., *Deputy Chief Engagement Officer*

Erica Zumba, M.B.A., M.P.H., *Community and Participant Engagement Branch Director*

Michael Hahn, *Tribal Engagement and Outreach Branch Director*

Rubin Baskir, Ph.D., *Researcher Engagement and Outreach Branch Director*

Yong Crosby, M.B.A., *Coordination and Dissemination Branch Director*

Ahmed Elmi, M.P.H., CHES, *Community Engagement and Evaluation Lead*

Angelica Johnson, M.S.W., *Engagement Specialist*

Angely Giambra Zamora, M.S., *Visibility Engagement Specialist*

Anna Mitiku, M.P.H., *Engagement Specialist*

Carolina Cerrone, M.S.P.H., *Health Science Policy Analyst*

Faith Blackburne-Proctor, M.P.A., *Engagement Specialist*

Humberto Marquez Mendez, *Engagement Specialist*

Jessica Lee, *Engagement Specialist*

Krista Forbes, M.P.H., M.Div., *Engagement Specialist*

Molita Yazzie, M.Sc., M.A.H.S., *Senior Analyst for American Indian/Alaska Native Indigenous Engagement*

Naomi Aspaas, RN, *Associate Director of Tribal Engagement and Outreach*

Sheila James, *Engagement Specialist*

Sofia Bouhaouala, M.P.H., *Program Analyst*

Sydney McMaster, CHES, *Engagement Specialist*

Vicky Murray, M.A., *Senior Analyst for American Indian/Alaska Native Indigenous Engagement*