

# *All of Us* Includes Disability

An Introduction to the *All of Us*  
Research Program



National Institutes  
of Health

Webinar presented for AUCD

February 6, 2019



# American Association on Health and Disability

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- Reduce Health Disparities
- Advocate for Community Inclusion
- Promote Full Accessibility
- Integrate Disability into Public Health Agenda
- Advance Knowledge Translation & Disability Research



**AAHD Mission: To promote health and wellness for people with disabilities**

**All of Us**  
RESEARCH PROGRAM

**The future  
of health  
begins  
with you**



# What is the NIH *All of Us* Research Program?

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The *All of Us* Research Program is a historic, longitudinal effort to **gather data from one million or more people** living in the United States to **accelerate research and improve health**. By taking into account individual differences in **lifestyle, socioeconomics, environment, and biology**, researchers will uncover paths toward delivering **precision medicine – or individualized prevention, treatment, and care – for all of us**.



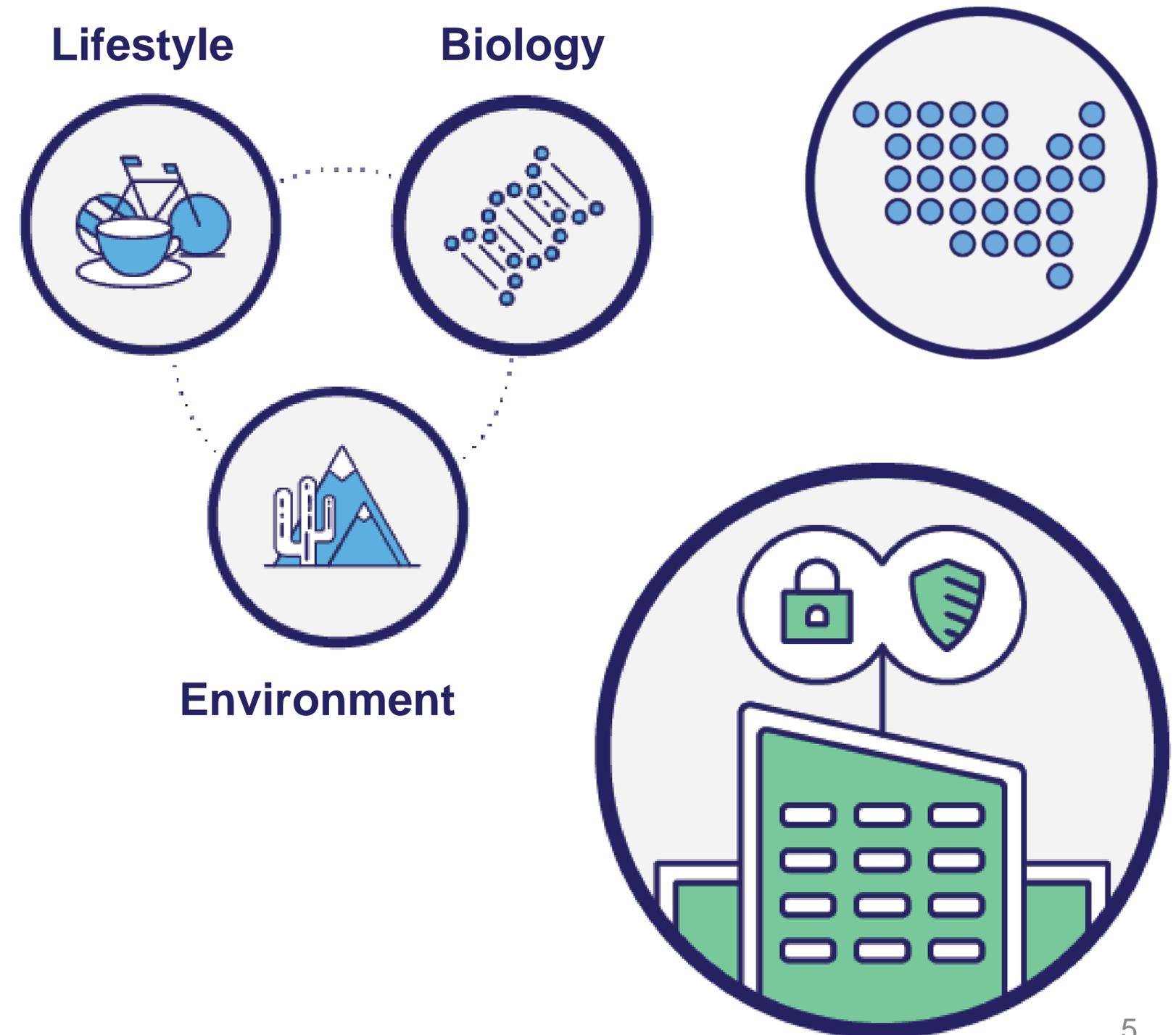
***“All of Us is among the most ambitious research efforts that our nation has undertaken!”***

***NIH Director Francis Collins, M.D., Ph.D.***

# What is precision medicine?

**Precision medicine** is an emerging approach for disease treatment and prevention that takes into account individual variability in lifestyle, socioeconomics, environment, and biology.

It is a radical shift in how each of us can receive the best care possible based on our unique makeup.



# Examples of Precision Medicine

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Right treatment for the right person --



Prescription  
Eyeglasses



Insulin Pump



Blood  
Transfusions



Hearing Aid

# The Cost of Imprecise Medicine

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## Patients

- Health care is often targeted to the average patient, not the individual
- Health problems can take years to unravel, with significant trial and error



## Providers

- Not enough research to draw on for clinical evidence, especially in diverse populations
- Medical records scattered in different places
- Not enough time for analysis one patient at a time



## Researchers

- Enormous time and cost spent building IT systems vs. doing research
- Siloed data resources and funding opportunities
- Challenges acquiring large sample sizes
- Slow translation of data into knowledge

# Potential activities Asked of Participants



## Enroll, Consent and Authorize EHR

- Recruiting 18+ years old initially; plan to include children in 2019
- Online, interactive consent
- Includes authorization to share Electronic Health Record (EHR) data



## Answering Surveys

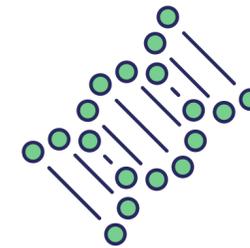
- Three initial surveys: The Basics, Overall Health, & Personal Habits
- Additional surveys will be released on an ongoing basis.



## Physical Measurements\*

- Blood pressure
- BMI
- Heart rate
- Height
- Hip circumference
- Waist circumference
- Weight

*\*Based on diverse sampling and capacity*



## Provide Biosamples\*

- Blood (or saliva, if blood draw is unsuccessful)
- Urine specimen
- Biosamples will be stored at the program's biobank

*\*Based on diverse sampling and capacity*



## Wearables and Digital Apps

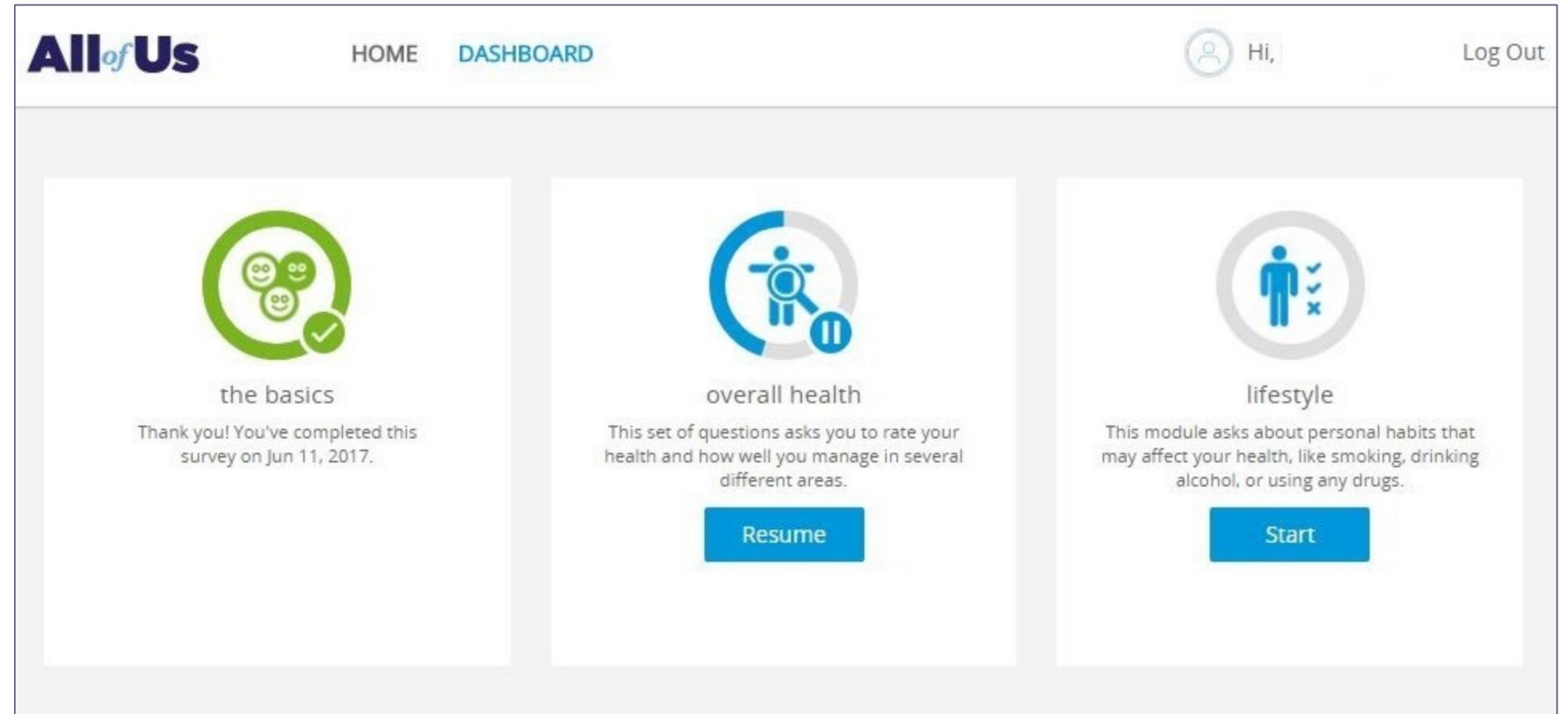
- Share data from wearable fitness devices, starting with FitBit
- Share data about mood & cardio-respiratory fitness through integrated apps
- More integrations to come

*Coming soon*

# Current Survey Modules

## Enrollment Surveys

1. The Basics
2. Overall Health
3. Lifestyle
4. Personal Health History
5. Family History
6. Health Care Access and Utilization



## *All of Us Values*

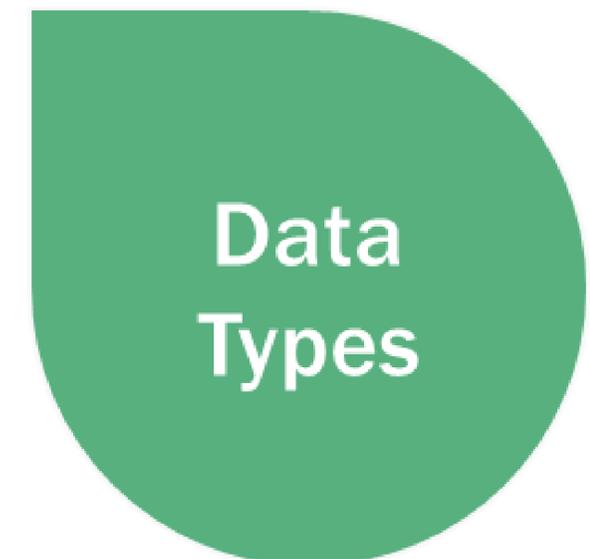
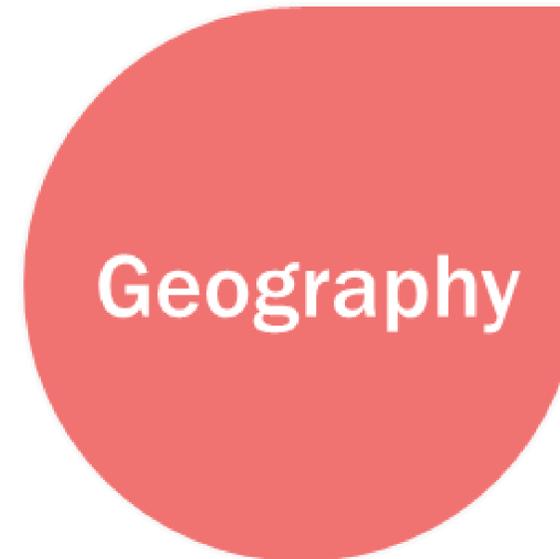
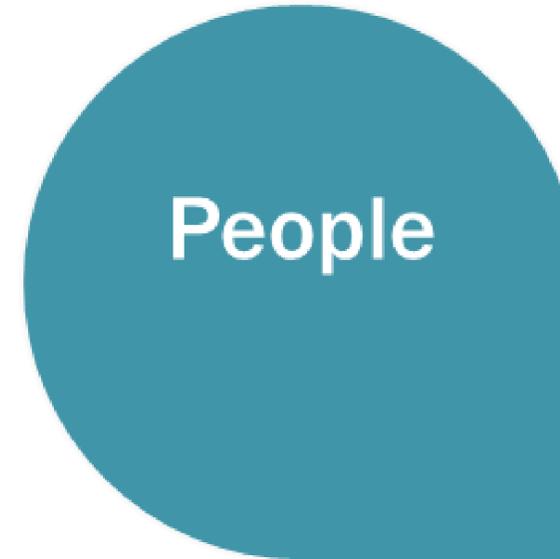
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- Participation in the *All of Us* Research Program will be **open** to interested individuals
- The program will reflect the rich **diversity** of America
- Participants will be **partners** in the program
- Trust will be earned through robust **engagement** and full **transparency**
- Participants will have **access** to information and data about themselves
- Data from the program will be broadly **accessible** to **empower research**
- The program will adhere to the PMI **Privacy** and **Trust** Principles and the PMI **Data Security** Policy Principles and Framework
- The program will be a catalyst for **innovative research** programs and policies

**NOTHING ABOUT US,  
WITHOUT US!**

# A Transformational Approach to Diversity

Reflecting the country's rich diversity to produce meaningful health outcomes for communities historically underrepresented in biomedical research.



# A Transformational Approach to Participation

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Participants in the *All of Us* Research Program will be true partners—not patients, not subjects—in the research process. Involved in every step of program development:

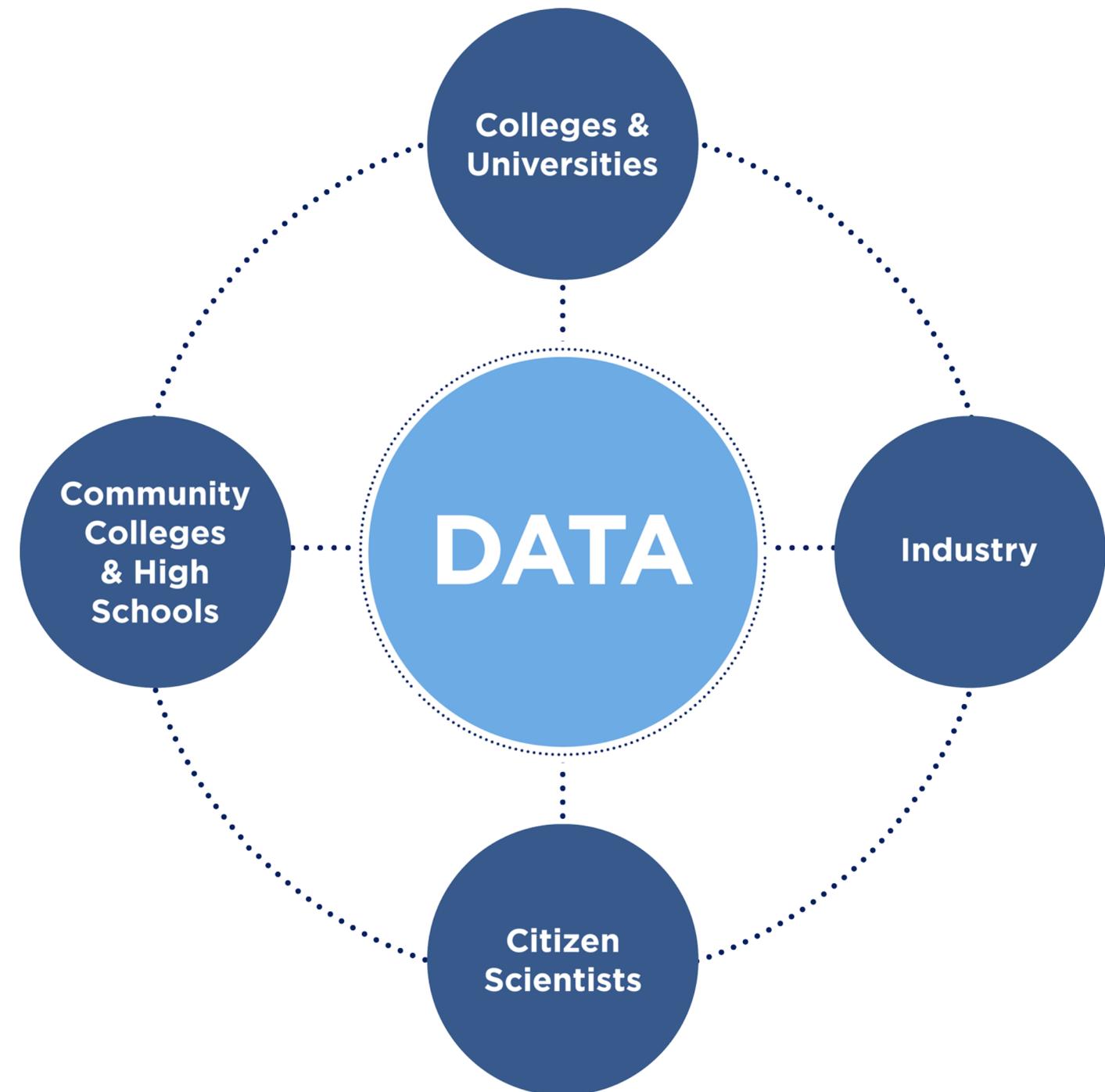
- What data we collect
- What lab analyses we do
- What research is conducted
- How data gets returned



# A Transformational Approach to **Data Access**

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- Data sharing will be a priority to both researchers and participants
- Participants will have access to study information and data about themselves
- Data collection will start small and will grow over time
- Privacy and security will adhere to the highest standards
- NIH will invest to level the playing field so diverse researchers can play



# What is the promise for participants?

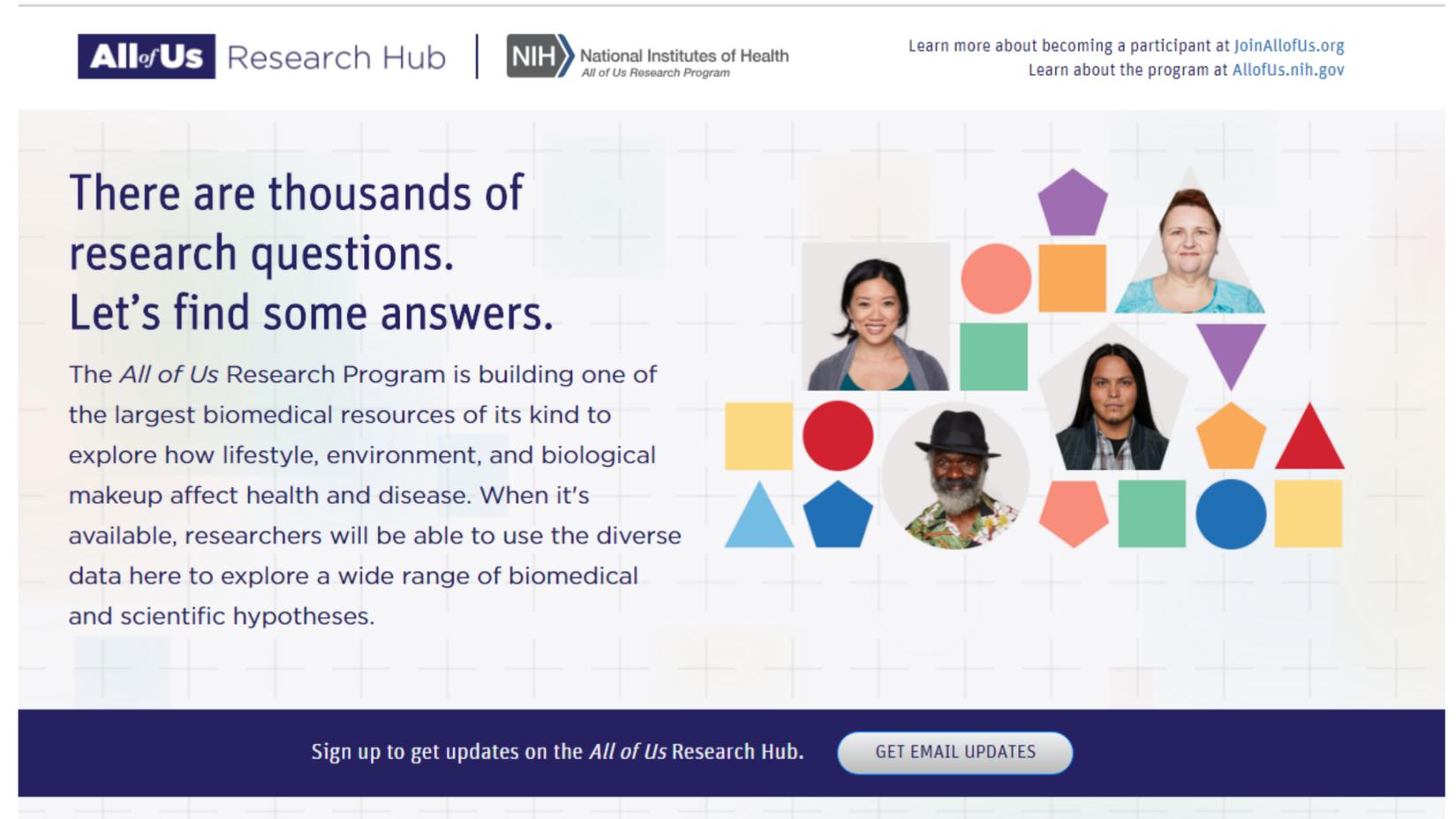
- An opportunity to help **fight disease** and improve the health of future generations.
- An opportunity to **ensure that your community is included** in the studies that lead to new understanding and new treatments.
- The choice to **meet others like you**, perhaps even joining some of them to propose & do research.



This is a long-term relationship and the value to participants (and researchers) will grow over time.

# What is the promise for researchers?

- The opportunity to **save time and resources** and **accelerate your research breakthroughs**.
- The ability to easily **share workspaces and analyses** with research partners and reviewers.
- The chance to learn from the program's pilots and experiments and **leverage innovations** for other studies and cohorts.



The screenshot shows the top section of the All of Us Research Hub website. At the top left is the 'All of Us Research Hub' logo, followed by the NIH logo and 'National Institutes of Health All of Us Research Program'. On the right, there are two links: 'Learn more about becoming a participant at [JoinAllofus.org](https://www.joinallofus.org)' and 'Learn about the program at [Allofus.nih.gov](https://www.allofus.nih.gov)'. The main banner features a grid of colorful geometric shapes (squares, circles, triangles, pentagons) and several circular portraits of diverse individuals. The text on the banner reads: 'There are thousands of research questions. Let's find some answers. The All of Us Research Program is building one of the largest biomedical resources of its kind to explore how lifestyle, environment, and biological makeup affect health and disease. When it's available, researchers will be able to use the diverse data here to explore a wide range of biomedical and scientific hypotheses.' At the bottom of the banner is a dark blue bar with the text 'Sign up to get updates on the All of Us Research Hub.' and a button labeled 'GET EMAIL UPDATES'.

<https://www.researchallofus.org/>

As with most studies, we are collecting, evaluating, and curating initial datasets.

# Approach to Privacy and Security

- Guided by privacy, trust, and data security principles developed by experts with input from the public.
- Data warehouse is built with the most advanced security available.
- Experts have done and will continue to do rigorous security testing.
- Data is encrypted and direct identifiers are removed.
- Researchers must agree to a code of conduct before accessing the data.
- Participants' preferences will be respected.
- Protected by a Certificate of Confidentiality.
- Committed to transparency in the event of a data breach.



**Safeguarding your identity and data to the best of anyone's abilities is our most important responsibility.**

# Program Building Blocks & Enrolling in *All of Us*

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# The *All of Us* Research Program Consortium

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## DATA AND RESEARCH CENTER

Big data capture, cleaning, curation, & sharing in secure environment

*Vanderbilt, Verily, Broad Institute*

## BIOBANK

Repository for processing, storing, and sharing biosamples (35+M vials)

*Mayo Clinic*

## PARTICIPANT TECHNOLOGY SYSTEMS CENTER

Web and phone-based platforms for participants

*Vibrent Health*

## PARTICIPANT CENTER / DV NETWORK

Direct volunteer participant enrollment, digital engagement innovation, and consumer health technologies

*Scripps Research Institute  
(with multiple partners)*

## HEALTHCARE PROVIDER ORGS NETWORK

HPOs with clinical & scientific expertise, enrollment & retention of participants

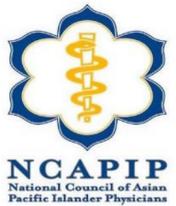
*30+ regional medical centers, FQHCs, VA, and future awards to grow network*

## COMMUNICATIONS & COMMUNITY NETWORK

Communications, marketing, and design expertise; engagement coordination and community partners network

*Wondros, HCM, 29 community partner organizations, and future awards to grow network*

# Community and Provider Partner Network



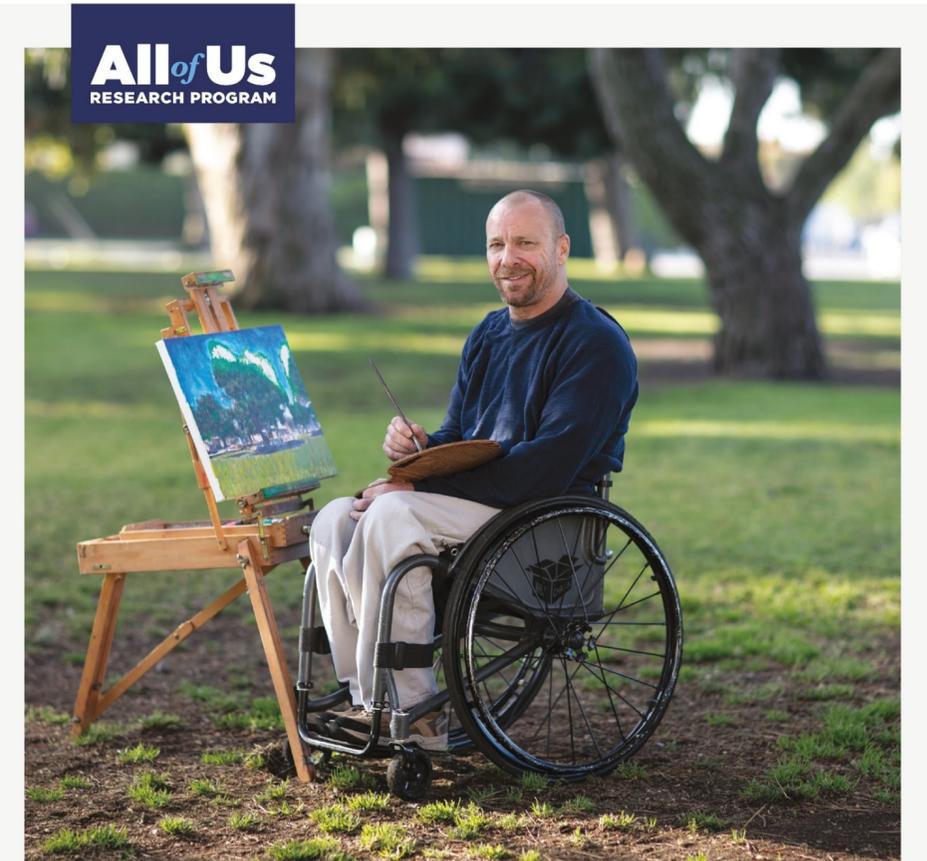
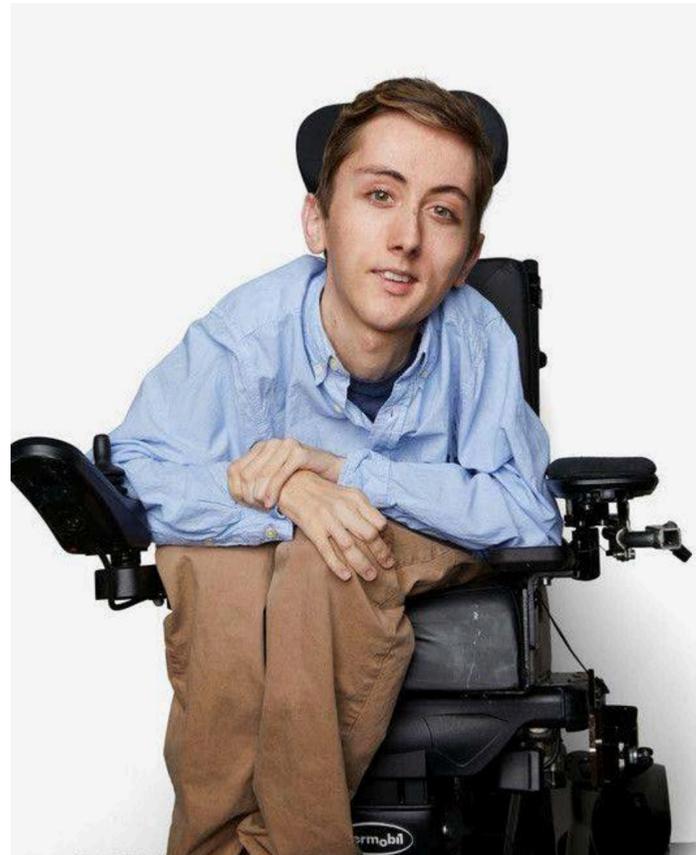
## AAHD Role

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- Identify and fund 4 trusted intermediaries
- Develop a disability-focused rationale for involvement in *All of Us*
- Review *All of Us* program materials and messages to ensure appropriateness for persons with disabilities
- Conduct national education and outreach on *All of Us* to the disability community



# All of Us Materials



**Be one in a million**

Join the All of Us Research Program

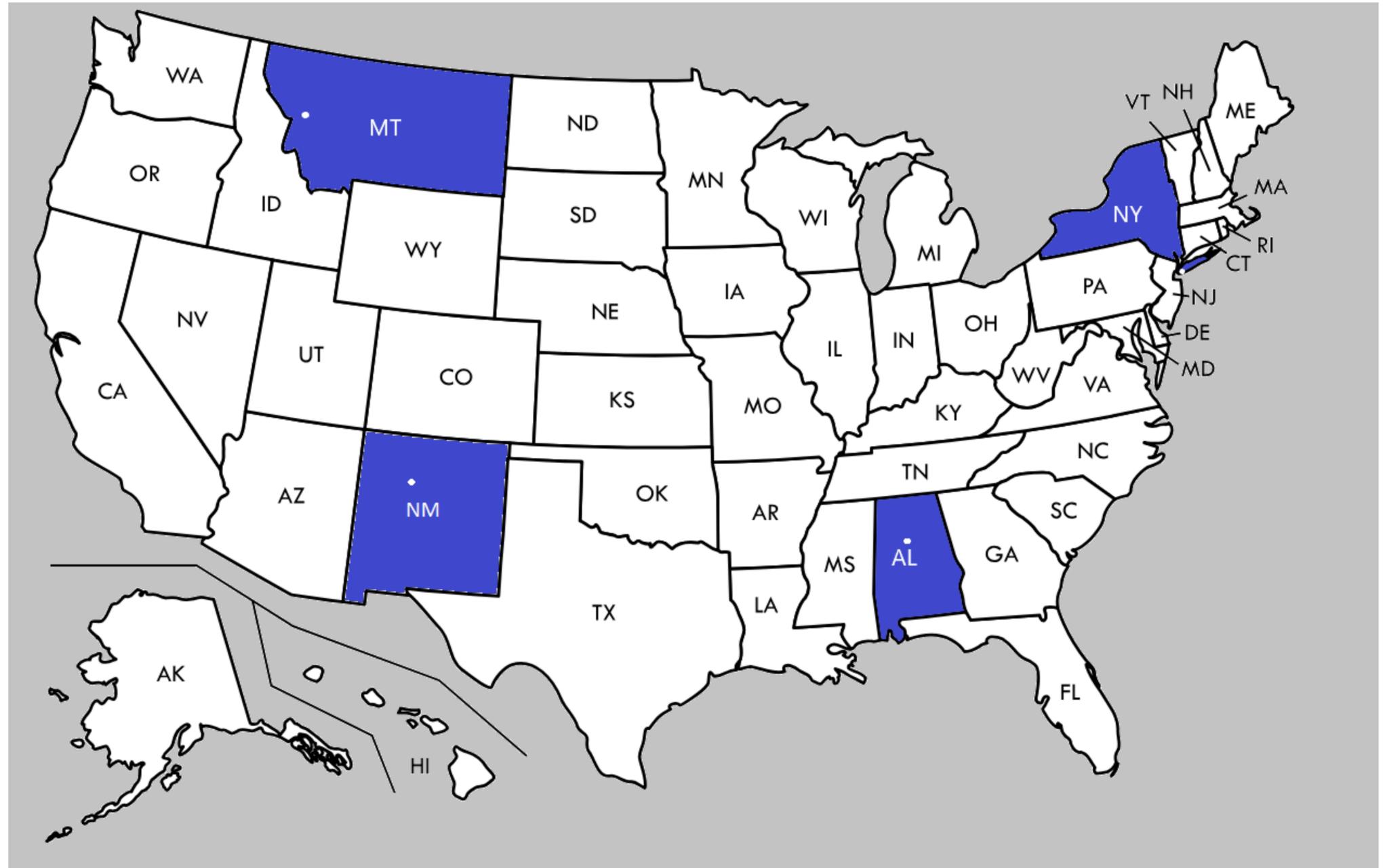
**JoinAllOfUs.org**  
**(844) 842-2855**



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

# Four Partner Sites

- Lakeshore Foundation – Birmingham, AL
- University of Montana Rural Institute – Missoula, MT
- University of New Mexico Center for Development and Disability – Albuquerque, NM
- Center for Independence of the Disabled, NY – New York, NY



# Four Partner Sites – Lakeshore Foundation (Birmingham, AL)

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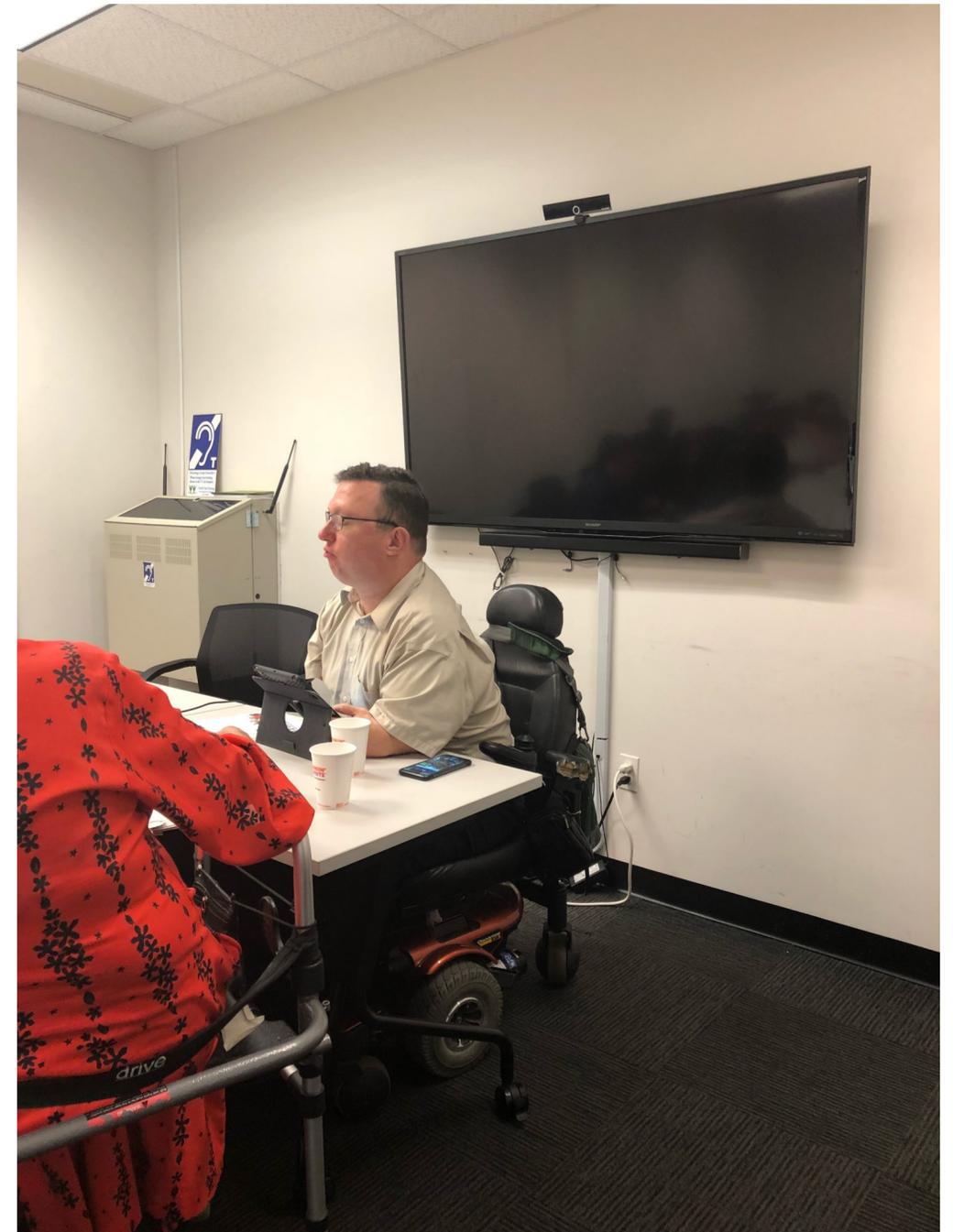
- Hosted vendor booth at launch event in Birmingham
- Hosted the MEA on May 12th
- Working with local disability organizations to promote All of Us
- Conduct webinar for local disability community
- Posting on social media



## Four Partner Sites – Center for Independence of the Disabled, NY (New York, NY)

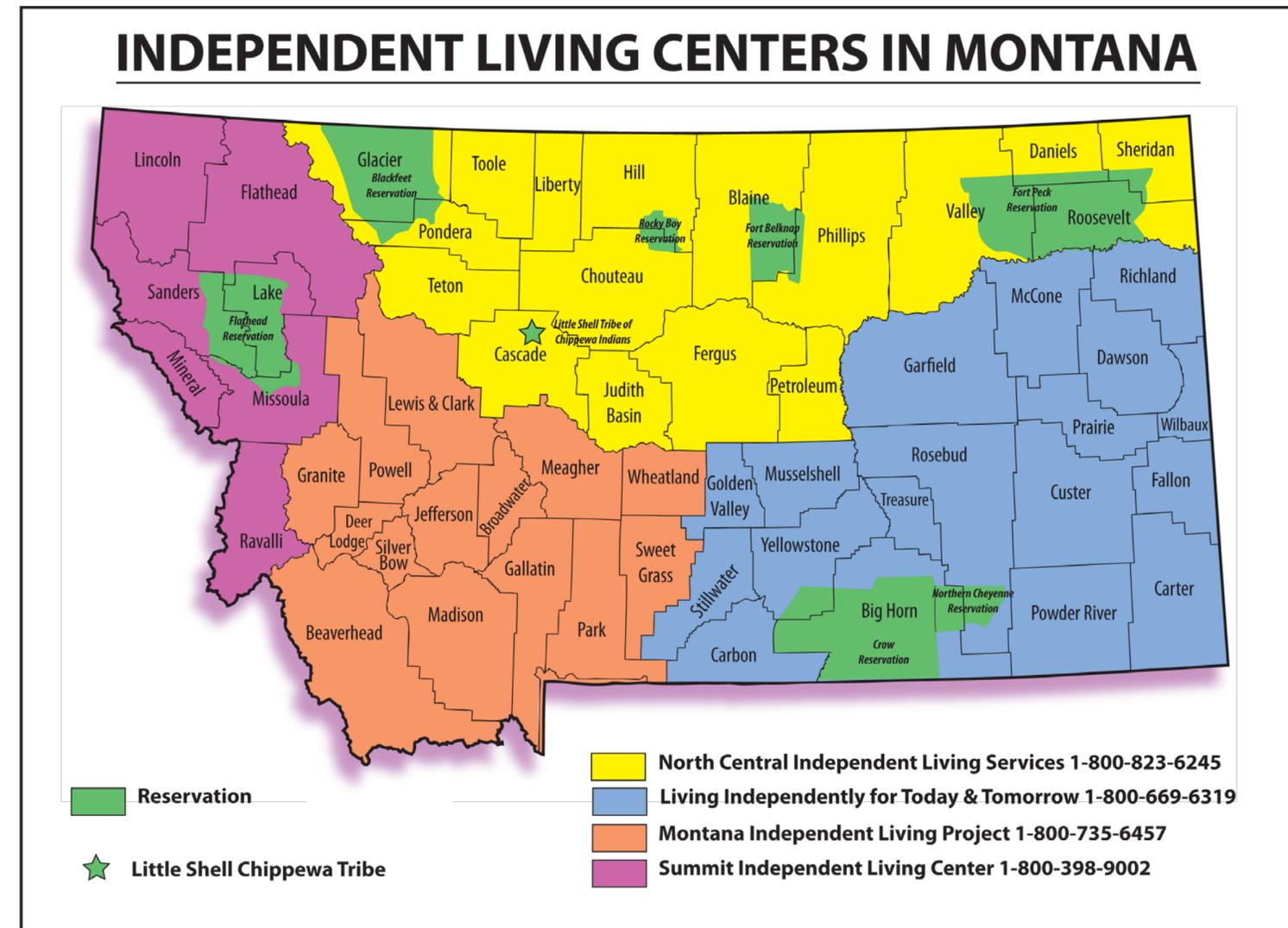
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- Utilize disability press outlets to highlight All of Us
- Highlighted All of Us in community workshop
- Host exhibit booths at local community events
- Promote All of Us at the Disability Pride Parade
- Conduct webinar for local disability community
- Posting on social media



# Four Partner Sites – University of Montana Rural Institute (Missoula, MT)

- Working with local disability organizations to promote All of Us
- Activate an All of Us communications committee
- Host exhibit booths at local community events
- Conduct webinars for local disability community
- Posting on social media



## Four Partner Sites – University of New Mexico Center for Development & Disability

- Host a minimum of six exhibit booths at disability-related conferences
- Place articles in relevant paper and electronic newsletters of various center programs
- Collaborate with the directors or senior staff of several New Mexico disability commissions to explore ways to publicize the program
- Work with the five independent living centers in the state to help publicize the program
- Host the MEA at the end of November/beginning of December



Reports from Montana & New Mexico

# What are UCEDDS Doing for *All of Us*?



National Institutes  
of Health

## The future of health begins with you.

The *All of Us* Research Program has a simple mission. We want to speed up health research breakthroughs. To do this, we're asking one million people to share health information. In the future, researchers can use this to conduct thousands of health studies.

JOIN NOW

▶ WATCH INTRODUCTION



EXPLORE OUR TOUR ACROSS AMERICA ▶



ATTEND LAUNCH EVENTS IN PERSON OR ONLINE ▶



WATCH DIRECTOR ERIC DISHMAN SHARE PROGRAM UPDATES ▶

Have Feedback?

## Learn More

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



**@AllofUsResearch**  
**#JoinAllofUs**  
**#AllOfUsInclusion**

# Questions?

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