



National Hispanic Medical Association

# *All of Us* Research Program Fireside Chat Series

## Session 4: Research & the *All of Us* Research Program

February 25, 2021  
7:00 PM – 8:00 PM  
[www.NHMAmd.org](http://www.NHMAmd.org)

# Welcome

**Ricardo Correa, MD, EdD, FACP, FACE, FACMQ**

*Director, Endocrinology, Diabetes, & Metabolism*

University of Arizona College of Medicine - Phoenix VAMC

Phoenix Allies Community Health Clinic

## Housekeeping

- Presentations to be followed by Q and A discussion
- Type questions in chat box
- Microphones will be muted
- Recording available next week at [www.NHMAmd.org](http://www.NHMAmd.org)



National Hispanic Medical Association

## SESSION 4: Research

Thursday, February 25, 2021 | 7:00 PM - 8:00 PM Eastern Time

# All of Us Research Program FIRESIDE CHAT SERIES

### PANELISTS



**Courtney Wallin, PhD**

*Outreach Lead*

All of Us NIH Division of Engagement



**Melissa A. Simon, MD, MPH**

*Professor and Vice-Chair of Research, Department of Obgyn  
Director, Center for Health Equity Transformation  
Northwestern University Feinberg School of Medicine*

### MODERATOR



**Ricardo Correa, MD, EdD, FACP, FACE, FACMQ**

*Director, Endocrinology, Diabetes, & Metabolism  
University of Arizona College of Medicine  
Phoenix VAMC  
Phoenix Allies Community Health Clinic*



**Adrienne Roman, PhD**

*Research Support and Outreach Project Manager  
All of Us Data and Research Center*



**Paula Lozano, PhD**

*Community-Based Research Professional  
University of Chicago Medicine*

**For more information & to register:** <https://bit.ly/NHMAFiresideChats>

# Research Hub: Sharing the Value of our Dataset

**All of Us**  
RESEARCH PROGRAM



National Institutes  
of Health

February 25, 2021

Adrienne Roman, Ph.D. - *All of Us* Data & Research Center

Courtney Wallin, Ph.D. – *All of Us* NIH Division of Engagement

## Overview

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- Share brief overview of the *All of Us* program
- Walk through components of *All of Us* Research Hub
- Initiate a discussion

# Thank you to our *All of Us* Community and Provider Partner Network



# Thank you to *All of Us* Consortium Partners

## The Participant Center



## Communications & Engagement



## HPO Network

(Health Care Provider Organizations)

### RMCs

California Precision Medicine Consortium (CAPMC)



Illinois Precision Medicine Consortium



All of Us Wisconsin



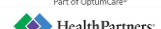
All of Us New England



All of Us Pennsylvania



Trans America Consortium



University of Arizona and Banner Health



New York City Consortium



FQHCs (Federally Qualified Health Centers)



All of Us SouthEast Enrollment Center



VA Medical Centers



## Participant Technology Systems Center (PTSC)



## Biobank



## Data & Research Center (DRC)



## Genomics Partners





# The *All of Us* Research Program: An Innovative Research Effort

- **Diversity at the scale of 1 million people or more**
- **Focus on participants as partners**
- **Longitudinal design, ability to recontact**
- **Multiple data types:** EHR, surveys, baseline physical measurements, biospecimens, genomics
- **National, open resource for all:** broadly accessible to all researchers with open-source software & tools
- **Security and privacy safeguards** for all participant data





# All of Us Mission

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## Nurture relationships

with one million or more participant partners, from all walks of life, for decades



## Deliver the largest, richest biomedical dataset ever

that is easy, safe, and free to access



## Our Mission

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



## Catalyze the robust ecosystem

of researchers and funders hungry to use and support it



## Build and maintain a strong *All of Us* Team

capable of achieving the program's mission

## Engaging Researchers

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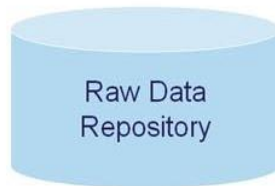
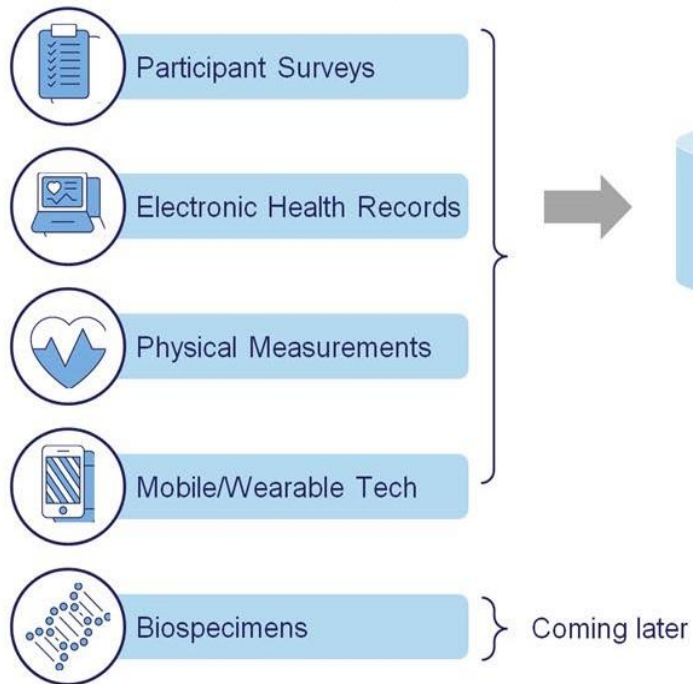
- *All of Us* is committed to engaging diverse investigators to explore and interrogate our dataset.
  - Creating a demographically diverse researcher cohort will promote responsible and ethical use of our data, generate outcomes that return greatest value to our participant communities, and accelerate research impact.
  - Encouraging students and early stage investigators will bring fresh, creative perspectives to the platform and lead to innovative research outcomes.
  - Ensuring access for researchers from various institution/organization types will establish a truly equitable resource for all.

Research Hub

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# All of Us Research Data Pipeline

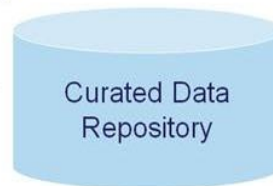
## Data Collection from Consented Research Participants



## Data Curation

Data  
Harmonization  
Privacy  
Methodology  
QA/CC

The text 'Data Curation' is positioned above a right-facing arrow. Below the arrow, the processes of 'Data Harmonization', 'Privacy', 'Methodology', and 'QA/CC' are listed.



# All of Us Research Hub

All of Us Research Hub | NIH National Institutes of Health  
All of Us Research Program

ABOUT DATA & TOOLS DISCOVER FAQ Q APPLY

RESEARCHER LOGIN

## Welcome to the All of Us Research Hub

The All of Us Research Program, part of the National Institutes of Health, is building one of the largest biomedical data resources of its kind. The All of Us Research Hub stores health data from a diverse group of participants from across the United States.

Approved researchers can access All of Us data and tools to conduct studies to help improve our understanding of health.

APPLY FOR ACCESS

Scroll Down



EXPLORE THE NEW COVID-19 PARTICIPANT EXPERIENCE SURVEY



EXPLORE NEW DATA AVAILABLE IN THE DATA BROWSER

## Data Snapshots

Data Snapshots showcase the scale and diversity of the All of Us Research Program participant cohort. The snapshots provide participant demographics, geographic distribution, and more. We update the snapshots daily.



367,000+

Participants



233,000+

Electronic Health Records



279,000+

Biosamples Received

Follow along! Go to  
[www.researchallofus.org](http://www.researchallofus.org)

All of Us  
DATA & RESEARCH CENTER

# Research Hub Components

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## PUBLIC



**Data Browser**



**Data Snapshots**



**Survey Explorer**



**Help Desk**

*Launched May 2019*



Data Passport Model

## RESTRICTED

Researcher Workbench



**Data Dictionary**



**Concept Set Selector**



**Cohort Builder**



**Notebooks**



**Help Desk**

*Beta Launch: May 2020*

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[APPLY FOR ACCESS](#)

▼  
Scroll Down



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Biosamples Received

## Research Hub

Data and Tools

Data Snapshots

Data Browser

Research

Projects

Directory

Apply Page



## Data and Tools

The *All of Us* Research Hub includes powerful data and analysis tools to help researchers with their work. As the program grows, more data types and tools will be available for researchers.

### Release Timeline

[← PREVIOUS](#)[NEXT →](#)

### COVID-19 Participant Experience (COPE) Survey

Launched December 2020



### DATA BROWSER



The Data Browser provides interactive views of the publicly available *All of Us* Research Program aggregate-level participant data, including EHR domains, survey responses, and physical measurements.

[OPEN THE DATA BROWSER](#)

### DATA SNAPSHOTS



The snapshots include data visualizations showing the participant cohort size and attributes, including how many participants are from groups underrepresented in biomedical research.

[GO TO DATA SNAPSHOTS](#)

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## Data Snapshots

These aggregated, public-facing data snapshots provide an overview of *All of Us* Research Program participant characteristics and the types of data that we collect from participants.

Note: There are many stages of the *All of Us* participant journey. More than 453,000 people have registered with the program by creating online accounts at [JoinAllOfUs.org](https://JoinAllOfUs.org), beginning the enrollment process. The snapshots below highlight participants in the *All of Us* Research Program.

*The following numbers are approximated to protect participants' privacy. Numbers reflect data collected through February 8, 2021.*

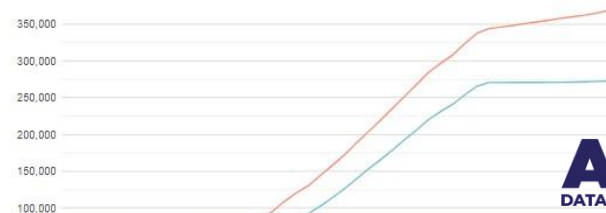
### Participants at a Glance



### Enrollment Numbers

This graph represents participants who have consented to join the program and those who have completed all initial steps of the program. The initial steps are consenting, agreeing to share electronic health records, completing the first three surveys, providing physical measurements, and donating at least one biospecimen to be stored at the biobank.

*The following numbers are approximated to protect participants' privacy. Numbers are updated as of February 8, 2021.*



Research Hub

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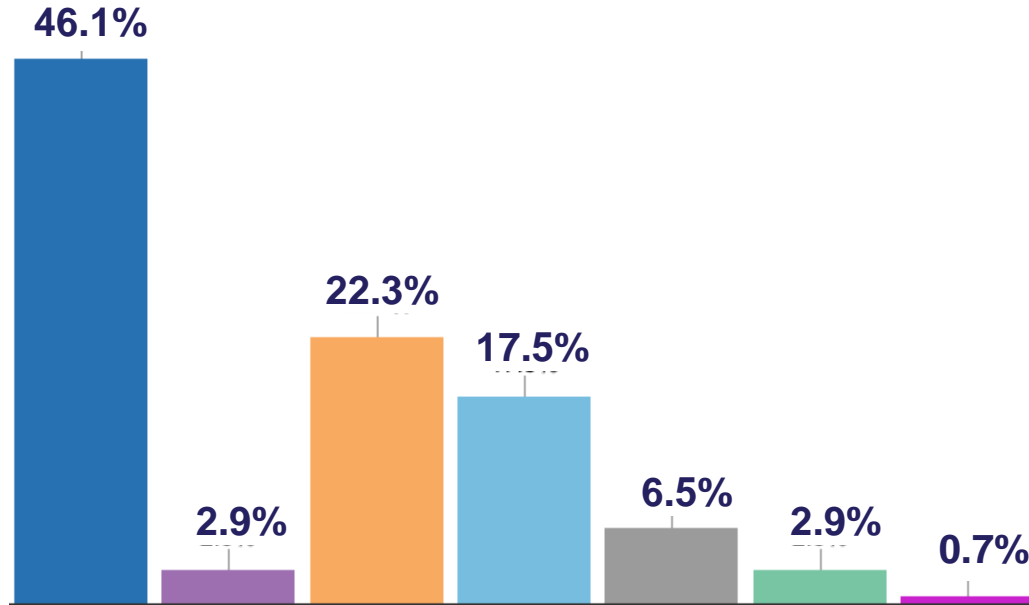
# Selected Data

## Snapshots

(Updated 2/23/2021)

### Race & Ethnicity

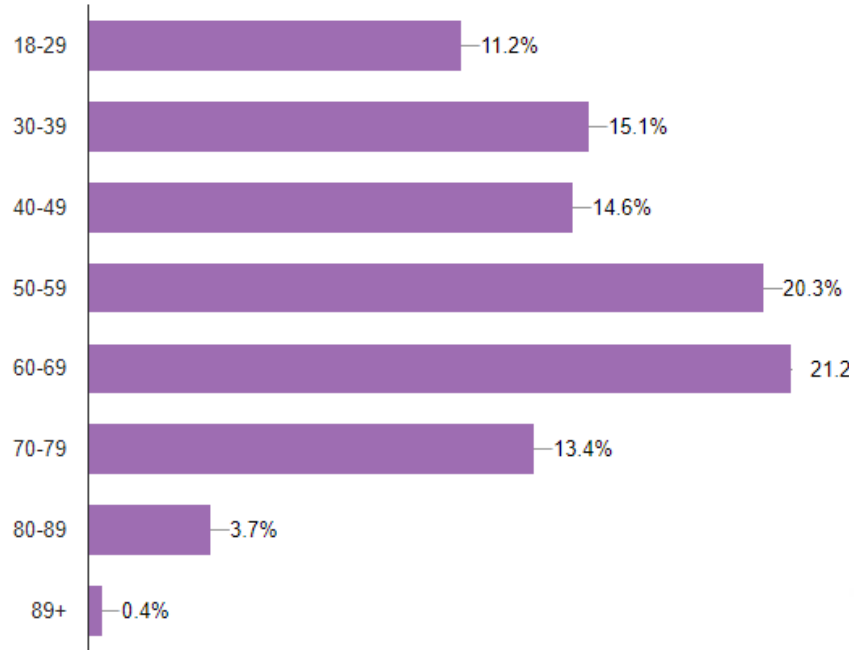
White Asian Black, African American or African Hispanic Latino or Spanish More than one race/ethnicity Other Prefer not to say



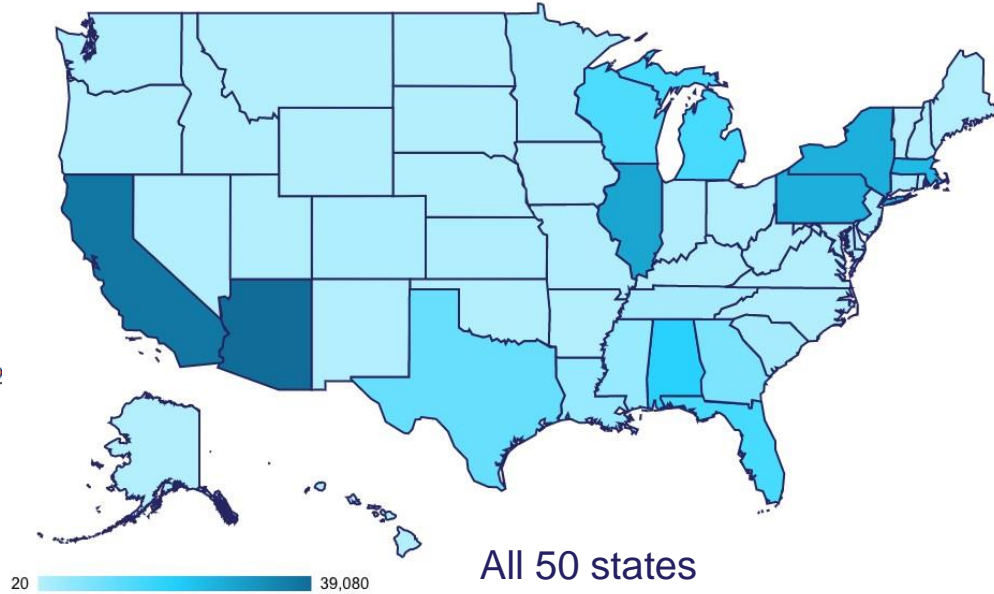
# Selected Data Snapshots

(Updated 2/23/2021)

## Age



## Geography



All 50 states  
Bilingual enrollment  
Interactive mobile exhibits

## Search Across Data Types

Keyword Search

includes 316,760 participants and is current as of 10/1/2020.



FAQs



Introductory  
Videos



User Guide

## Research Domains:

### Conditions

14,770

medical concepts

2,000 participants in this domain

View Top Conditions

### Drug Exposures

27,311

medical concepts

174,660 participants in this domain

View Top Drug Exposures

### Labs & Measurements

13,631

medical concepts

182,000 participants in this domain

View Top Labs & Measurements

### Procedures

27,702

medical concepts

182,000 participants in this domain

View Top Procedures

## Survey Questions:

### Life Basics

18

questions available

316,760 participants in this domain

This survey includes participant demographic information.

View Complete Survey

### Overall Health

21

questions available

316,760 participants in this domain

Survey includes information about how participants report levels of individual health.

View Complete Survey

### Lifestyle

26

questions available

316,760 participants in this domain

Survey includes information on participant smoking, alcohol, and recreational drug use.

View Complete Survey

### Personal Medical History

465

questions available

89,640 participants in this domain

This survey includes information about past medical history, including medical conditions and approximate age of diagnosis.

View Complete Survey

### Health Care Access & Utilization

17

questions available

316,760 participants in this domain

Survey includes information about a participant's access to and use of health care.

View Complete Survey

### Family Health History

186

questions available

92,080 participants in this domain

Survey includes information about the medical history of a participant's immediate biological family members.

View Complete Survey

### COVID-19 Participant Experience (COPE)

151

questions available

62,920 participants in this domain

Survey includes information about the impact of COVID-19 on participant mental and physical health.

View Complete Survey

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## Research Projects Directory

Information about each research project within the Workbench is available in the Research Projects Directory below. Approved researchers provide their project's research purpose, description, populations of interest, and more. This information helps *All of Us* ensure transparency on the type of research being conducted.

At this time, all listed projects are using data in the Registered Tier. The Registered Tier contains individual-level data from electronic health records, survey answers, physical measurements, and Fitbit. These data have been altered to protect participant privacy.

Note: Researcher Workbench users provide information about their research projects independently. Any views expressed in the Research Projects Directory belong to the relevant users and do not necessarily represent those of the *All of Us* Research Program.

Information in the Research Projects Directory is also cross-posted on [Allofus.nih.gov](https://allofus.nih.gov) in compliance with the 21st Century Cures Act.

There are currently **370 active workspaces**. This information was updated on **1/21/2021**.

**SORT BY TITLE:**    [ABC](#) | [DEF](#) | [GHI](#) | [JKL](#) | [MNO](#) | [PQR](#) | [STU](#) | [VWX](#) | [YZ](#) | [0-9](#)

Access to care and ophthalmology outcomes ▼

PROJECT PURPOSE(S)

- Population Health ...

Acute Respiratory Failure Phenotyping ▼

PROJECT PURPOSE(S)

- Disease Focused Research (Acute Respiratory Failure) ...

ADHD ▼

PROJECT PURPOSE(S)

- Disease Focused Research (attention deficit hyperactivity disorder)

Research Hub

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Data Snapshots

Survey Explorer

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Data and

Tools Data

Snapshots

Survey

Explorer Data

Browser

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## How to Apply



### LEARN MORE ABOUT THE DATA AVAILABLE

Explore what data are currently available with the [Data Browser](#), and view the amount of information available with the [Data Snapshots](#). Then, learn about the [Data Access & Use Policies](#) and our workbench.



### CHECK FOR YOUR INSTITUTION'S AGREEMENT

[Check that your institution has signed the Data Use and Registration Agreement](#). If your institution is not listed, please fill out [the form](#) to initiate the process.



### REGISTER AS A RESEARCHER

Complete your researcher profile, sign the Terms of Service, and agree to the the Privacy Policy. Please note: a Data Use and Registration Agreement must be in place, and you must have an eRA Commons account.



### CONNECT ERA COMMONS

Connect to your eRA Commons account upon applying to the Researcher Workbench.



### COMPLETE ALL OF US RESPONSIBLE CONDUCT OF RESEARCHER TRAINING

Understand more about our privacy safeguards and the ethics surrounding the use of participant data.



### SIGN DATA USER CODE OF CONDUCT

Sign the Data User Code of Conduct.



**APPLY NOW**



Welcome to the  
**RESEARCHER WORKBENCH**

A secure platform to analyze *All of Us* data



**Workspaces** +

See all workspaces

⋮ HbA1c Distributions of Type 2 Diabetics

OWNER

Last Changed: 03/26/20, 02:01 PM

⋮ Original - How to Get Started with Registered Tier Data

WRITER

Last Changed: 03/25/20, 09:45 AM

⋮ R2019Q4R3 - How to Get Started with Registered Tier Data

READER

Last Changed: 12/08/20, 01:25 PM

⋮ How to Work with All of Us Survey Data

READER

Last Changed: 01/15/21, 01:39 PM

Recently Accessed Items

	Item type	Name	Workspace name	Last changed	Dataset
⋮	Cohort	T2D_survey_any_hba1c	HbA1c Distributions of Type 2 Diabetics	May 14 2020	All of Us Dataset v3
⋮	Cohort	test	Type 2 diabetes Test with Lou	Apr 28 2020	All of Us Dataset v3
⋮	Notebook	Medication Sequences Code	Medications pathway (sequences) - Phase 1	Apr 27 2020	All of Us Dataset v3
⋮	Notebook	test	Feedback	Apr 23 2020	All of Us Dataset v3
⋮	Notebook	Concept Longitudinality	CDR Characterization	Apr 23 2020	All of Us Dataset v3

Showing 5 most recent items

Quick Tour and Videos



Research Hub



Researcher Workbench

Ex.

Workspace

Ex. Analysis

Support Hub

## Beta Phase of the Researcher Workbench

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Current components:

- Data: physical measurements, survey data, and some EHR data - much more to come (e.g., genomics, digital health technology)
- Tools: Dataset Builder, Cohort Builder (more to come!)
- Help Resources: FAQs, sample notebooks and workspaces, documentation, Help Desk



## Beta Phase of the Researcher Workbench

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- *All of Us* is different from other research programs and launching in beta reflects our program's iterative design.
- Currently, researchers must be capable of working in R or Python to analyze this data at this time. Additional analytical tools will come later.
- Researchers may apply for access to the Workbench if they:
  - Have an eRA Commons account
  - Are affiliated with U.S. institutions that have signed Data Use and Registration Agreement
- We welcome input from researchers during the beta testing phase to help make the Workbench more robust over time.

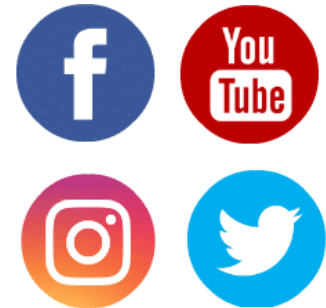
## To Learn More...

- Visit [ResearchAllofus.org](https://www.researchallofus.org) and [JoinAllofus.org](https://www.joinallofus.org)
- Enroll in the Researcher Workbench: <https://www.researchallofus.org/apply/>
- Request a Workbench Demonstration: <https://is.gd/workbenchdemo>
- Questions or interested in follow-up conversations?

Reach out to:

Courtney Wallin, NIH ([Courtney.Wallin@NIH.gov](mailto:Courtney.Wallin@NIH.gov))

Ashley Green, DRC ([Ashley.E.Green@VUMC.org](mailto:Ashley.E.Green@VUMC.org))



**@AllofUsResearch**  
**#JoinAllofus**

# *All of Us* Research Program

## Fireside Chat Series

### Session 4: Research & the *All of Us* Research Program

**Melissa A. Simon, MD, MPH**

*Professor and Vice-Chair of Research*

Department of Obgyn

*Director*

Center for Health Equity Transformation

Northwestern University Feinberg School of Medicine

# *All of Us* Research Program

## Fireside Chat Series

### Session 4: Research & the *All of Us* Research Program

**Paula Lozano, PhD**

*Community-Based Research Professional*

University of Chicago Medicine



National Hispanic Medical Association

*All of Us* Research Program  
**FIRESIDE CHAT SERIES**

**SESSION 1: Precision Medicine**

Thursday, July 30, 2020; 3:00 PM; 4:00 PM Eastern Time

**SESSION 2: Enrolling Participants**

Wednesday, September 23, 2020; 7:00 PM - 8:00 PM Eastern Time

**SESSION 3: Seniors**

Thursday, December 10, 2020; 7:00 PM - 8:00 PM Eastern Time

**SESSION 4: Research**

Thursday, February 25, 2021; 7:00 PM - 8:00 PM Eastern Time

**SESSION 5: Women's Health**

Thursday, May 27, 2021; 7:00 PM - 8:00 PM Eastern Time

**For more information & to register:** <http://bit.ly/NHMAFiresideChats>