All of Us Research Program Fireside Chat Series

Session 2: Enrolling Participants

September 23, 2020
7:00 PM – 8:00 PM
www.NHMAmd.org

Welcome

Elena Rios, MD, MSPH, FACP
President & CEO
National Hispanic Medical Association
Washington, DC

- Encourage your patients to enroll and inform others about the clinical trials for COVID-19 Vaccines

  ◦ www.CoronaVirusPreventionNetwork.org

  ◦ www.COVIDVACCINESTUDY1.com

What is the *All of Us* Research Program?

The *All of Us* Research Program is a historic, longitudinal effort to **gather data from one million or more people** living in the United State to create a diverse health database that represents us all.

By taking into account individual differences in **life circumstances, socioeconomics, environment, and biology**, researchers may 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 the value for participants?

Contributing to All of Us makes it possible for your community to be represented in medical research.

Your data could be used in studies that may lead to new understanding and new treatments.

A chance to **learn about your own health**, including personalized risk factors or exposures.

A chance to **learn about additional research opportunities** that may interest you.

Why Participate

Minorities make up

38%

of the US population.

Minority populations to rise to over

57%

of overall population.

Minority enrollment in clinical trials

<10%

African American population = 13.4% of US population

- 6.7% of NIH clinical trial participants nationwide
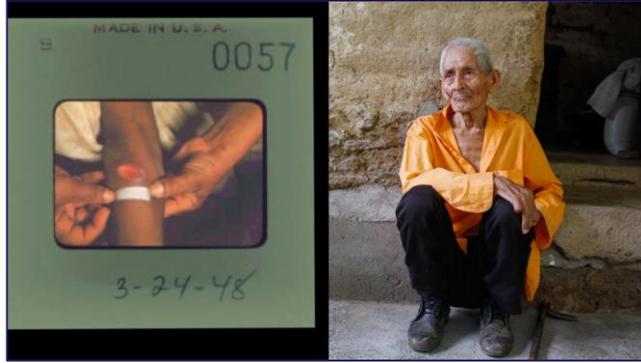 - 1.6% of FDA novel drugs

Hispanic population = 18.5% of US population

- 3.1% of NIH clinical trial participants nationwide
  - 2.7% of FDA novel drugs

Asian American, Native Hawaiian, & Pacific Islander population = 6.1% of US population

- .1% of NIH clinical trial participants nationwide
  - > 1% o FDA novel drugs

Disenfranchisement and Historical Abuses

Enrollment: National

- ⊙ **> 356,000** participants enrolled

- ⊙ **> 271,000** participants completed initial steps

- ⊙ **80%** of current participants self-identify as belonging to one or more population that has been historically underrepresented in biomedical research

- ⊙ Nearly **400 active enrollment clinics** open across the US
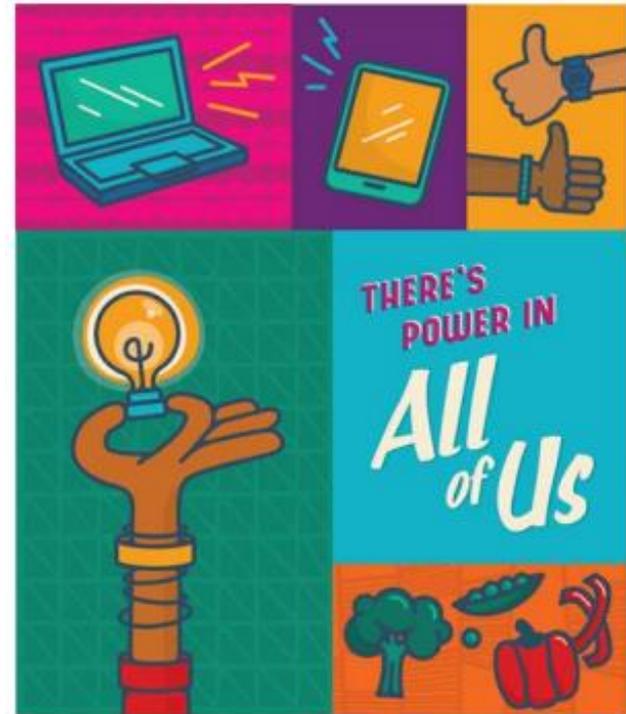
Approach to Privacy and Security

- ◉ 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.

All of Us and COVID-19

The *All of Us* Research Program has initiated three new scientific activities to help us better understand COVID-19 and inform current and future pandemic responses.

- ◉ Antibody Testing
- ◉ COVID-19 Participant Experience (COPE) Survey
- ◉ Electronic Health Record (EHR) Integration

Genetic Return of Results: What information will *All of Us* share with you?

We expect to share information about:

Your ancestry (where your family comes from)	**Your traits, such as why you might love or hate cilantro**	**Whether you may have an increased risk of developing a particular health condition**	**How your body might react to certain medications**	**Other health-related information**

We plan to use many different methods to check your DNA for information. You may get some DNA results sooner than others.

It will take some time to get your DNA results. Some participants may not get their DNA information for a few years.

All of Us Consortium

DV Network
(Direct Volunteers)

Walgreens | BlueCross BlueShield | National Blood Collaborative | Urban One | The Behavioural Insights Team | Medscape | careevolution HEALTHCARE TECHNOLOGY

Montage Marketing | PicnicHealth | Bloodworks Northwest | San Diego Blood Bank Foundation | Sync for Science | fitbit | QTC Medical Group, Inc. | Gulf Coast Regional Blood Center *Commit for Life.* | SageBionetworks

New York Blood Center | Quest Diagnostics | patientslikeme | ACHA American College Health Association *advocacy • education • research* | WebMD | DXC.technology

Biobank — MAYO CLINIC

Communication & Engagement — WONDROS | THE UNIVERSITY OF UTAH | PYXISPARTNERS

HPO Network
(Health Care Provider Organizations)

RMCs

California Precision Medicine Consortium

UC San Diego Health | UC DAVIS HEALTH | Keck Medical Center of USC | UC Irvine Health | UC HEALTH | UCSF University of California San Francisco | San Diego Blood Bank *Saving lives today. Improving life tomorrow.* | CS Cedars-Sinai

Illinois Precision Medicine Consortium

Northwestern University | THE UNIVERSITY OF CHICAGO | NorthShore University HealthSystem | RUSH | THE UNIVERSITY OF ILLINOIS AT CHICAGO | UIC

New England Precision Medicine Consortium

PARTNERS HEALTHCARE | MASSACHUSETTS GENERAL HOSPITAL | BRIGHAM HEALTH BRIGHAM AND WOMEN'S HOSPITAL | BU Boston University School of Medicine | BOSTON MEDICAL EXCEPTIONAL CARE. WITHOUT EXCEPTION. | University of Massachusetts UMASS Medical School

Trans-American Consortium for the Health Care Systems Research Network

Henry Ford HEALTH SYSTEM | Essentia Health | BaylorScott&White HEALTH | SPECTRUM HEALTH | Baylor College of Medicine

New York City Precision Medicine Consortium

COLUMBIA UNIVERSITY MEDICAL CENTER | NYC HEALTH+ HOSPITALS | NewYork-Presbyterian | Weill Cornell Medicine
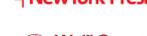
Southern *All of Us* Network

UAB SCHOOL OF MEDICINE *Knowledge that will change your world* | UAB THE UNIVERSITY OF ALABAMA AT BIRMINGHAM *Knowledge that will change your world* | THE UNIVERSITY OF MISSISSIPPI MEDICAL CENTER | UAB MEDICINE UAB HOSPITAL | Tulane University | TUSKEGEE UNIVERSITY | Cooper Green Mercy HEALTH SERVICES | HUNTSVILLE HOSPITAL | University of Alabama Medical Center | USA UNIVERSITY OF SOUTH ALABAMA HEALTH SYSTEM | LSU Health NEW ORLEANS

SouthEast Enrollment Center

U Health | UNIVERSITY OF MIAMI MILLER SCHOOL OF MEDICINE | EMORY UNIVERSITY | MOREHOUSE SCHOOL OF MEDICINE | OneFlorida Clinical Research Consortium

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All of Us, Wisconsin

Marshfield Clinic | CLEMENT J. ZABLOCKI MEDICAL CENTER | University of Wisconsin SCHOOL OF MEDICINE AND PUBLIC HEALTH | MEDICAL COLLEGE OF WISCONSIN | BloodCenter of WISCONSIN PART OF VERSITI

University of Arizona

THE UNIVERSITY OF ARIZONA | Banner Health

University of Pittsburgh

University of Pittsburgh

FQHCs (Federally Qualified Health Centers)

Cherokee HEALTH SYSTEMS | Community Health Center, Inc. | JACKSON-HINDS COMPREHENSIVE HEALTH CENTER | Eau Claire Cooperative Health Centers | San Ysidro Health | HRHCare COMMUNITY HEALTH

VA Medical Centers

VA | U.S. Department of Veterans Affairs

Platform Development

Scripps Research Translational Institute | Sage BIONETWORKS | VANDERBILT UNIVERSITY | WONDROS

vibrent | BROAD INSTITUTE | verily

Genomics Infrastructure

Baylor College of Medicine | JOHNS HOPKINS MEDICINE | UTHealth The University of Texas Health Science Center at Houston | BROAD INSTITUTE

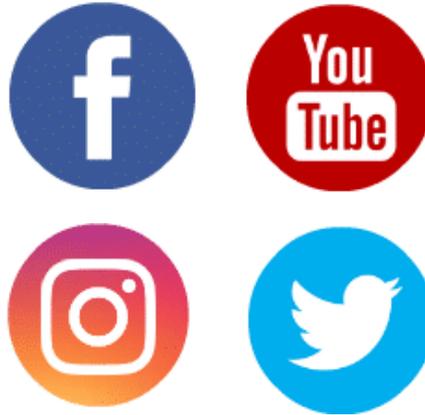color | PARTNERS HEALTHCARE | UNIVERSITY of WASHINGTON

All of Us Community and Provider Partner Network *(as of September 2020)*

Learn More

JoinAllofUs.org
ResearchAllofUs.org

@AllofUsResearch
#JoinAllofUs

AllofUs.nih.gov

All of Us Research Program
Fireside Chat Series
Session 2: Enrolling Participants

Panelists:

José Ramón Fernández-Peña, MD, MPA
President-Elect, American Public Health Association
Director, Health Professions Advising Northwestern University

Edgar Gil Rico, MBA
Senior Director for Innovation and Program Development National Alliance for Hispanic Health

Bert Johansson, MD, PhD
Treasurer
NHMA Board of Directors

Heather Kitzman, PhD
Director of Research
Baylor Scott and White Health and Wellness Center

Moderator:
Elena Rios, MD, MSPH, FACP
President & CEO
NHMA

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NHMA
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