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.
Minorities make up **38%** of the US population.

Minority populations to rise to over **57%** of overall population.

Minority enrollment in clinical trials **<10%**

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**Why Participate**

* 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% of 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
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)

HPO Network
(Health Care Provider Organizations)

All of Us, Wisconsin
University of Arizona
University of Pittsburgh

RMCs
California Precision Medicine Consortium
Illinois Precision Medicine Consortium
New England Precision Medicine Consortium
Trans-American Consortium for the Health Care Systems Research Network
New York City Precision Medicine Consortium
Southern All of Us Network
SouthEast Enrollment Center

All of Us, Wisconsin

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New York City Precision Medicine Consortium
Southern All of Us Network
SouthEast Enrollment Center

All of Us, Wisconsin

Platform Development
Scripps Research Translational Institute

Genomics Infrastructure
Baylor College of Medicine
UT Health San Antonio

Biobank

Communication & Engagement
WONDROS

VA Medical Centers
U.S. Department of Veterans Affairs

FQHCs (Federally Qualified Health Centers)
Cherokee Nation Health Services
Comcare of Oklahoma

UX

Genomics Infrastructure
Baylor College of Medicine
UT Health San Antonio

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U.S. Department of Veterans Affairs

FQHCs (Federally Qualified Health Centers)
Cherokee Nation Health Services
Comcare of Oklahoma

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