

## Expanding Latinx Health Research with the *All of Us* Research Program

The National Institutes of Health’s *All of Us* Research Program aims to address the disparities in health research for underrepresented populations, including Latinx\* communities, by creating the nation’s largest and most diverse health database. The project focuses on precision medicine to improve health care through personalized treatment and prevention strategies rather than a “one-size-fits-all” approach we often see today. Precision medicine research could provide better health outcomes for all backgrounds.

### ABOUT THE *ALL OF US* RESEARCH PROGRAM

The *All of Us* Research Program’s goal is to enroll one million or more people living in the United States to contribute information to this historic health database. The 10-year project is one of the largest programs from the National Institutes of Health (NIH) and involves partnership with hundreds of organizations across the country.

Partner organizations, including UnidosUS, work to educate communities about the importance of health research and enroll people in the *All of Us* Research Program. More than 372,000 people have enrolled in the project since 2018, providing health information by answering surveys, providing physical measurements (like height and weight) and biosamples (like blood, saliva, and urine), and sharing their Electronic Health Records. The project will continue to collect health information and provide available data to researchers. This allows researchers to study how genetic, behavioral, and environmental factors affect health and wellness.



Photo courtesy of *All of Us* Research Program partner Mexican Coalition, Bronx, NY.

\* The terms “Hispanic” and “Latino” are used interchangeably by the U.S. Census Bureau and throughout our materials to refer to persons of Mexican, Puerto Rican, Cuban, Central and South American, Dominican, Spanish, and other Hispanic descent; they may be of any race. Our materials may also refer to this population as “Latinx” to represent the diversity of gender identities and expressions present in the community.

The *All of Us* Research Program is unique both for its size and its emphasis on diversity. It is also unique in that participants in the project are not enrolling in a specific clinical study; rather they are providing their information so that researchers can conduct thousands of studies across a wide variety of health and wellness areas. The benefit of having such a large, centralized database of health information is that researchers can apply to use the *All of Us* database instead of creating new data sets for their studies, which are typically smaller and less diverse. There are more than 2,500 active research projects and 66 publications currently using information from the *All of Us* Research Program health database.

Participants in the *All of Us* Research Program who provide biosamples can also choose to learn about their own health through DNA results. DNA results can include genetic ancestry (where in the world your family comes from), genetic traits (such as why you like or don't like cilantro), and possible risks for certain health conditions or reactions to medications. The project is not health insurance and does not provide medical diagnoses or treatment for health conditions.

### ***What does “underrepresented in health research” mean?***

This phrase refers to populations that currently or historically have not been included in research about health at the same rate as other populations. People of certain races and ethnicities, ages, sexual orientations, geographic locations, and disability statuses have historically been underrepresented. This includes the Hispanic/Latinx population.

### ***What does “precision medicine” mean?***

Precision medicine is health care that is customized based on the patient as a unique individual, considering factors like genetics, environment, lifestyle, and family health history. Precision medicine includes not only treatment but also prevention and wellness. The *All of Us* Research Program health database is aimed at facilitating the advancement of personalized health care.

### ***Disparities in Health Research and Researchers in Hispanic/Latinx Communities***

The Latinx population in the United States currently is and historically has been widely underrepresented in health research, which contributes to a higher rate of negative health outcomes for Latinx communities.

Latinx individuals make up 18% of the population in the United States. However, only 4% of NIH-funded Research Program Grants are focused on Hispanic/Latinx health. Additionally, in a review of NIH grant applications, only 3% of lead researchers who applied for NIH-funded Research Program Grants identified as Hispanic.

The *All of Us* Research Program aims to close these gaps by encouraging health research to identify the unique health care needs of specific populations like the Latinx community, and by encouraging more accessible health research opportunities. The *All of Us* Research Program encourages the participation of all

people living in the United States regardless of immigration status. The program does not ask for citizenship status during enrollment.

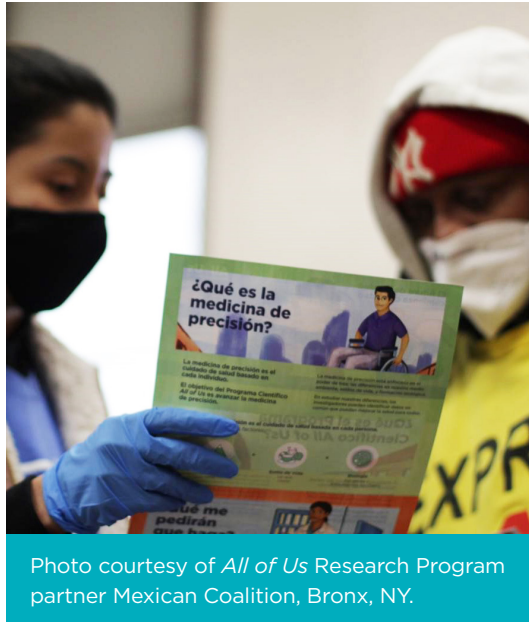


Photo courtesy of All of Us Research Program partner Mexican Coalition, Bronx, NY.

### **Activating Community-Based Organizations with Outreach Best Practices**

Many organizations, including UnidosUS and community-based organizations across the country, are working with the All of Us Research Program to educate and enroll people who have historically not been appropriately represented in health research, like the Latinx community. However, there are many barriers that prevent people in these groups from participating. Some barriers to participation in the Latinx community include language barriers; mistrust in health research due to historical abuse of minorities in medical studies; concerns about the privacy of health information provided to the project; fear relating to the immigration statuses of

participants or their family members; and lack of access to the technology needed to complete surveys or enroll in the program, like internet access or an email address. Many of these barriers were magnified or heightened by the COVID-19 pandemic.

Organizations like UnidosUS are working with Latinx communities to overcome these barriers by engaging community-based organizations to educate the community about the All of Us Research Program. UnidosUS has worked with All of Us since 2017 through direct programming (like events, panels, and social media) and partnerships with affiliate organizations to conduct outreach in their communities.

Two ways that affiliate organizations have been successful at removing barriers to participation include engaging *promotores de salud* (community health workers) and adding education about the All of Us Research Program to existing events.

*Promotores de salud* are trusted members of the local community who share information about the All of Us Research Program through *charlas*, small-group or one-on-one conversations. These intimate conversations are effective because the *promotores de salud* can address the specific concerns of the person or group that less personal, larger events may not address. *Promotores de salud* hold *charlas* at popular Latino grocery stores or shopping malls, consulates for Latin American countries, food pantries, and even in their own homes. *Charlas* are also held virtually over platforms like Zoom.

Organizations are able to meet the community where they are by including All of Us Research Program information at existing events, such as classes on health care, immigration, and English as a second language (ESL) or larger community celebrations.

Affiliate organizations also use their social media platforms such as Facebook, Twitter, and WhatsApp to reach community members.

By using these community engagement tactics, the Latinx community is overcoming barriers to participation and, ultimately, narrowing health research disparities.

## ABOUT THE AUTHOR

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**UnidosUS**, formerly the National Council of La Raza, is the largest Latino civil rights and advocacy organization in the United States. UnidosUS has been a community partner of the *All of Us* Research Program since December 2017, serving in different capacities to ensure Latinos are no longer underrepresented in biomedical research.

## ACKNOWLEDGMENTS

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