

# CASE STUDY HIGHLIGHTS:

## *All of Us* Research Program

How a large, unprecedented national study ensured over 80% enrollment of historically underrepresented participants.

The All of Us Research Program, launched nationally in May 2018, serves as a repository that is collecting data from a diverse and representative U.S. population and across a variety of health conditions. These participants will be followed prospectively over their lifetimes.

The mission of *All of Us* is to enable and accelerate health research and medical breakthroughs, with one of its strategic priorities being the recruitment of a diverse group of participants.






**The Program is inclusive of:**

- Race
- Ethnicity
- Sex
- Gender
- Sexual orientation
- Rural and urban settings
- Insured and uninsured

## APPROACH

### FEASIBILITY ASSESSMENT, COMMUNITY ENGAGEMENT, and MARKETING

The *All of Us* Research Program engaged in a variety of activities to understand public perception of this study and to anticipate and overcome barriers to participation. Activities performed prior to recruitment included:

-  Conducted a pilot study, focus groups, surveys, and listening sessions with the public (focusing especially on underserved groups) about their hopes, ideas, and concerns of such a study.
-  Held workshops, webinars, and a 37-week national tour to invite community members to join the cohort. Events were assisted by volunteers that offered other interactive sessions: CPR trainings, face painting and balloon art for children, photo booth, live music, and art.
-  Produced brochures and documents as free material to help community members explain and disseminate information about the program. These brochures were customized based on specific communities.
-  Created marketing strategies, documents, and pictures intentionally representing diverse populations and promoted inclusion.
-  Developed short videos including information about the program, its benefits, and the importance of diverse participation.

## ENSURING DIVERSE ENROLLMENT

Inclusion of diverse participation was further encouraged by clarifying eligibility to enroll:

- No health insurance required
- Joining the program, and any appointments or activities that were part of the study, were free of costs
- Participation was independent of one's nationality or health status
- Spanish speaking advisors were provided, with plans to add persons able to speak additional languages
- No computer, tablet, or smartphone devices were required to join

### BUILDING TRUST

*All of Us* utilized community advocacy groups and participant advisory boards at participating health care organizations.

These community resources provided reports on participant feedback to help the researchers understand what was successful and what continued to be a challenge.

## RESULTS

As of March 2021, the program had over 374,000 participants enrolled and an additional 274,000 people who have registered and initiated the enrollment process. A 2019 review of the All of Us Research Program indicated that more than 80% of participants in the All of Us Research Program are from groups that have been historically underrepresented in biomedical research and data repositories or clinical trial data to date.

The program provides access to deidentified and encrypted data to researchers, and continues to successfully engage people and provide them with information about participation.

The program also has an online data browser and snapshot summary that provides regularly updated statistics on enrollment numbers and associated demographic data. Data are available for free at <https://www.researchallofus.org/data-tools>.

## CONCLUSION

The *All of Us* Research Program invested considerable time and resources to understand and ensure diverse recruitment. To be successful, the *All of Us* Research Program understood that it would need to add value to all of its stakeholders: participants, health care providers, researchers, and communities.

Recruitment into the study is estimated to continue into 2024 with a weekly recruitment rate of 3,000+ participants. As participants will be followed over decades to come, the *All of Us* Research Program will help researchers better understand health and disease of un-derrepresented populations.

**For citations and more information on this case, please see the [MRCT Center toolkit](#).**