

FACTSHEET

MAY 2021

alzimpact.org

ENACT Act

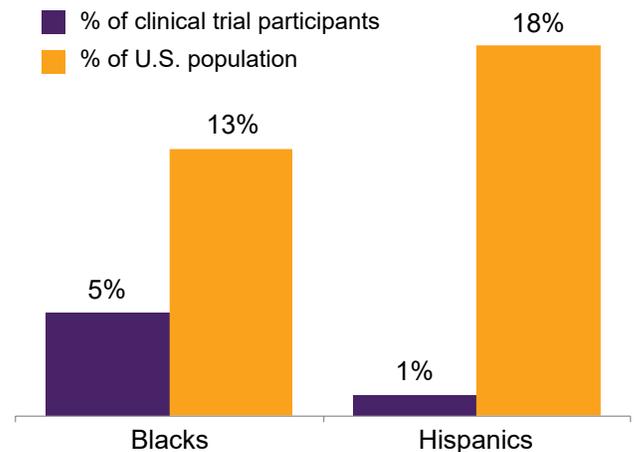
Alzheimer's disease disproportionately affects Black and Hispanic older Americans.

- Although Whites make up the majority of the over 6 million people in the United States with Alzheimer's, research shows that Blacks and Hispanics are at higher risk.
- Blacks are about two times more likely than Whites to have Alzheimer's and other dementias.
- Hispanics are about one and one-half times more likely than Whites to have Alzheimer's and other dementias.

However, Alzheimer's research to date has not included sufficient numbers of Blacks and Hispanics.

- In 2018, across all clinical drug trials (not just Alzheimer's), Blacks represented only 5% of trial participants and Hispanics represented only 1%, despite representing 13% and 18% of the population, respectively.
- The best available evidence suggests that this trend is similar in Alzheimer's research. A study from 2016 found that among 10 recent Alzheimer's biomarker studies, only 2 of them had recruited adequate numbers of Blacks.
- The underrepresentation of racial and ethnic minorities in clinical trials limits knowledge of how a treatment or diagnostic may affect these populations.

Underrepresentation of Blacks and Hispanics in Clinical Trials



Additionally, changing demographics and risk factor profiles necessitate recruitment of more Asian and Native Americans into Alzheimer's clinical trials.

- By 2050 Asian Americans are projected to comprise nearly 8% of those aged 65 and older. However, over the last two decades, less than 1% of the National Institutes of Health's (NIH) total budget has gone to research projects focused on Asian Americans.
- Native Americans have high rates of chronic conditions, including conditions that are suspected risk factors for Alzheimer's, such as obesity, diabetes, and hypertension. Despite this, available data suggest that participation of Native Americans in clinical trials is very low.

Including more individuals from traditionally underrepresented populations in Alzheimer's clinical trials will require establishing trust and lowering the burden of participation.

- According to a recent survey, nearly two-thirds of Blacks believe that medical research is biased against people of color. This belief is also held by more than a third of Asian Americans, Hispanics, and Native Americans.
- Additionally, there can be significant barriers for underrepresented populations to access clinical trials. For example, individuals from diverse communities often must travel long distances to research sites, which can result in a substantial financial cost to the participants.

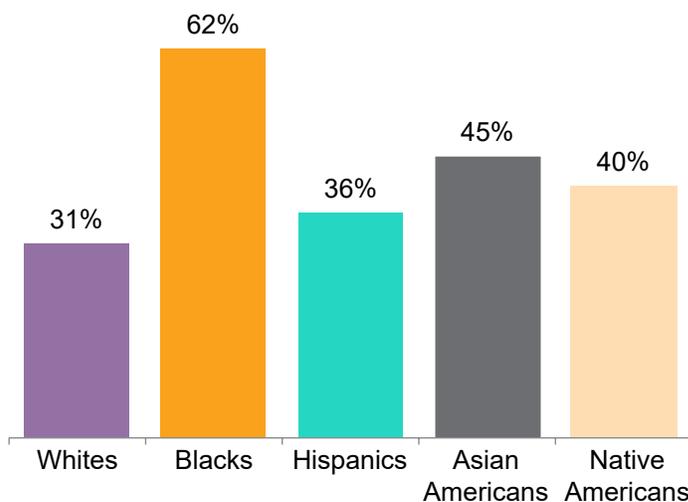
Current NIA Efforts

The National Institute on Aging (NIA) has established centers across the country that offer local resources, support, and opportunities to participate in research on Alzheimer's and other dementias. NIA currently funds 31 Alzheimer's Disease Research Centers (ADRCs) at major medical institutions across the United States and four Exploratory ADRCs that are designed to expand and diversify research and educational opportunities to new areas of the country, populations, areas of science, and approaches to research.

There are also eight Alzheimer's disease-focused Resource Centers for Minority Aging Research (RCMARs). These Centers focus on enhancing the diversity of the aging research workforce through the mentoring of promising scientists from underrepresented groups.

For more information on ADRCs, visit: nia.nih.gov/research/adc.

Percentage of Adults Who Believe Research is Biased Against People of Color



The Equity in Neuroscience and Alzheimer's Clinical Trials (ENACT) Act (S. 1548 / H.R. 3085) seeks to increase representation in Alzheimer's clinical trials among traditionally underrepresented groups. The bill would:

- Provide funding for the NIA to build trust among underrepresented populations by expanding education and outreach and increasing the diversity of clinical trial staff.
- Reduce the burden associated with participating in clinical trials by:
 - Funding new Alzheimer's Disease Research Centers (ADRCs) and increasing the number of Alzheimer's clinical trials in areas with high concentrations of underrepresented populations.
 - Requiring grant recipients to use community-based engagement strategies in their outreach to underrepresented populations.