

# FACTSHEET

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alzimpact.org

## ENACT Act

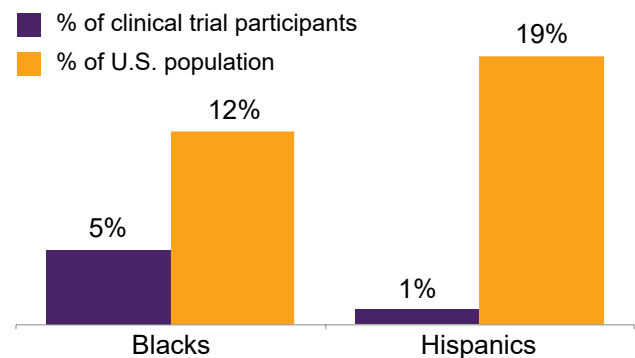
### How much diversity is there in Alzheimer's clinical trials?

- While studies indicate that Blacks are about twice as likely and Hispanics are about one and a half times as likely as Whites to develop Alzheimer's, they are significantly underrepresented in trials.
- One report estimated that across all clinical drug trials (not just Alzheimer's), Blacks and Hispanics represented just 5% and 1% of participants, respectively.
- Evidence suggests that this trend is similar in Alzheimer's research. A 2016 analysis of 10 biomarker studies found only two had adequate Black representation. And a 2023 meta-analysis found that the typical Alzheimer's neuroimaging study underrepresented all ethnorracial groups.
- The underrepresentation of different racial and ethnic groups in clinical trials limits knowledge on how a treatment, diagnostic, or prevention strategy may affect certain populations.

### What are some of the barriers to increasing representation in research?

- Among underrepresented communities there is a significant lack of trust in the research community. According to a 2021 survey, nearly two-thirds of Blacks and more than a third of Asian, Hispanic, and Native Americans believe medical research is biased against people of color.
- Additionally, access to clinical trials by diverse communities is often limited. For example, clinical trial sites are often not near their neighborhoods, which can add a financial burden to participation.

### Underrepresentation in Clinical Trials



### How does the Equity in Neuroscience and Alzheimer's Clinical Trials Act (ENACT) address the issue?

- In December 2022, Congress passed and the President signed into law legislation that included key provisions of the ENACT Act. Specifically, the law directs the National Institute on Aging (NIA), once Congress provides funding, to:
  - Expand community engagement, outreach, and the number of Alzheimer's clinical trials in areas with high concentrations of underserved populations.
  - Improve the diversity of clinical trial staff.
  - Utilize technology, such as remote patient monitoring, to promote trial design flexibility.
- The Act also requested an NIA assessment of the data and metrics used in planning, recruiting, and retaining clinical trial participants from underrepresented communities, as well as how such information affects grant-making decisions.