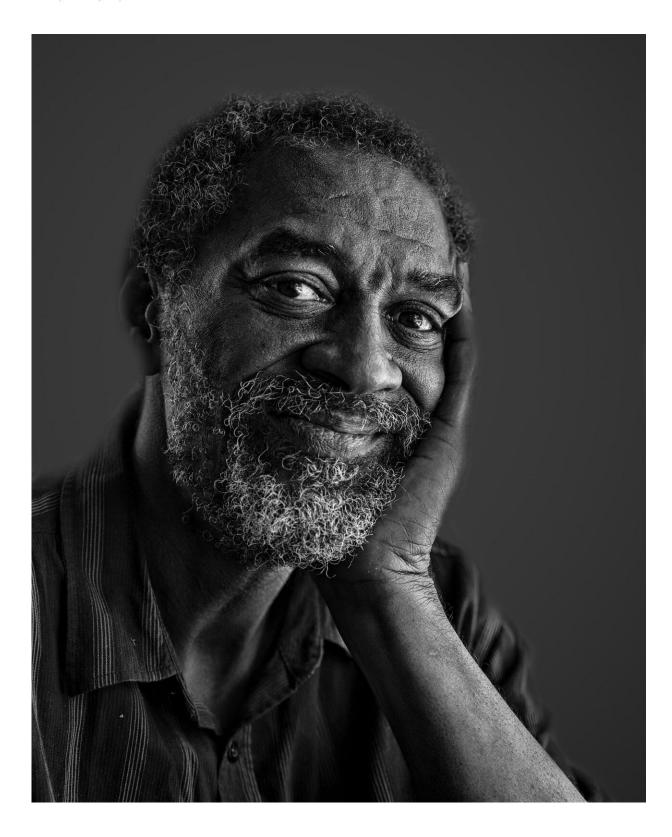


All US racial and ethnic minority groups are underrepresented in Alzheimer's neuroimaging research, study shows

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Alzheimer's disease (AD), which affects an estimated 6.5 million adults in the United States, hits some groups harder than others. Compared to non-Hispanic whites, Hispanic Americans are 1.5 times as likely to develop AD, and African Americans are twice as likely.

But scientists know little about the reasons behind these disparities, because the vast majority of AD research has been done with non-Hispanic white people.

A new study that reviewed 11,871 research articles on AD brain imaging, led by researchers at the Keck School of Medicine of USC, has now revealed the extent of the gap in representation. Overall, approximately 84% to 87% of study participants are non-Hispanic white. (Non-Hispanic white people make up less than 60% of the U.S. population.)

According to the new research, all racial and ethnic minority groups, including Black/African Americans, Hispanic/Latinos, Asian Americans and American Indian/Alaska Natives are underrepresented. The results were just published in *Communications Medicine*.

"As far as we know, this is the most comprehensive review of representation in the Alzheimer's disease neuroimaging literature," said senior author Duke Han, Ph.D., director of neuropsychology in the Department of Family Medicine and a professor of family medicine, neurology, psychology and gerontology at the Keck School of Medicine. "It gives us a good sense of the current state of the literature and what needs to be addressed moving forward."

A gap in representation

From the pool of nearly 12,000 studies on AD and neuroimaging, the research team identified a subset of papers that recruited samples in the



U.S. and met other experimental criteria. In their final analysis, they calculated representation for 719 studies that reported participant race or ethnicity directly ("direct studies") and 1,745 studies that drew from external databases where race or ethnicity was reported ("indirect studies").

The researchers reported the median diversity statistics from the studies they analyzed, meaning those that fell in the middle of the range, to avoid results being skewed by extreme outliers. Among direct studies, 87.4% of median study participants were non-Hispanic white, 7.3% of participants were Black/African American, 3.4% were Hispanic/Latino and 0% were Asian American, Native Hawaiian/Pacific Islander, and American Indian/Alaska Native, multiracial or another race.

Indirect studies derived from larger databases were slightly more diverse, with median representation of 83.7% non-Hispanic white, 11.6% Black/African American, 4.7% Hispanic/Latino, and 1.75% Asian American participants. In all cases, minority groups were underrepresented relative to their share of the U.S. population.

"This is a pretty big deal, especially as we look toward the future, where an increasing proportion of the U.S. will be ethnic minority groups," said Aaron Lim, Ph.D., a postdoctoral fellow in Han's research lab and first author of the study. "If their representation isn't adequately captured, then this disparity in research will grow and grow."

The researchers also found that 94% of indirect studies drew from just 10 shared databases, suggesting that these large, multi-site studies—which collect data from thousands of participants over many years—are driving a sizable chunk of AD research.

"If that's the case, it's incumbent upon those research groups to adequately represent the communities they are recruiting from," Lim



said.

A two-pronged approach

Improving representation in the AD neuroimaging literature will require a two-pronged approach, said Han. First of all, large, multi-site studies need to recruit more diverse samples.

Fortunately, that is already starting to happen, thanks in part to grants from funding agencies (such as the National Institute on Aging) specifically geared toward improving diversity. In 2020, the Alzheimer's Disease Neuroimaging Initiative, one of the largest studies of AD, launched a new effort to recruit underrepresented minority groups. Those changes are even starting to be reflected in the literature: Han, Lim and their colleagues found that representation of Black/African American participants increased from 3.39% between 1994 and 2017 to 8.29% between 2018 and 2022.

Smaller AD studies focused specifically on collecting brain scans of people from ethnic and racial minority groups will also be key. Those can help capture details of participants' lived experience, Lim said, including how systemic inequities such as health care access or socioeconomic status may affect AD risk.

"In the past, some researchers were so focused on recruiting large groups of participants, that it took priority over the importance of representation," said Han. "Now, there's an increasing focus on balancing numbers with representation. This increased emphasis on diversity in neuroimaging is a welcome sight."

More information: Quantification of Race/Ethnicity Representation in Alzheimer's Disease Neuroimaging Research in the USA: A Systematic Review, *Communications Medicine* (2023). DOI:



10.1038/s43856-023-00333-6, www.nature.com/articles/s43856-023-00333-6

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