

Barriers to recruitment and retention of participants dementia clinical trials identified

July 30 2021



Credit: CC0 Public Domain

Research presented today (Thursday 29 July) at the 2021 Alzheimer's Association International Conference (AAIC) in Colorado, shows that more must be done to tackle the barriers to recruitment and retention of participants for clinical trials from traditionally underserved communities.

One study, which involved a survey of 406 people living in Wisconsin in the US, showed that Black, Latino and American Indian potential clinical trial participants are significantly more likely to volunteer if asked by a person of the same race, and are more impacted than [white people](#) by the potential disruption of work and family responsibilities and availability of transportation and childcare that taking part in a clinical trial may entail.

In separate research carried out by the National Institute on Aging (NIA), part of the US National Institutes of Health, a key barrier identified in the exclusion criteria set for [clinical trials](#). Commonly used Alzheimer's clinical trial exclusion criteria, such as psychological disorders and [cardiovascular disease](#), have the potential to disproportionately affect African Americans and Hispanics/Latinos, which may play a role in their reduced enrolment in research.

This supports evidence from the Alzheimer's Research UK's Clinical Trial Report "Translating Science into breakthroughs: the future of late-stage [dementia](#) clinical trials in the UK," which was published in May of this year and showed that there is much work to do to ensure that UK dementia clinical trials tackle racial barriers to inclusion.

The NIA has today launched a new online tool, Outreach Pro, to help researchers and clinicians increase awareness and participation in clinical trials on Alzheimer's disease and other dementias, especially among traditionally underrepresented communities.

Speaking about the research, David Thomas, Head of Policy at Alzheimer's Research UK, said:

"This research adds to our understanding of the barriers we must overcome to make sure that dementia clinical trials include people from all backgrounds and communities. This research focuses on the US, and further investigation to understand how these challenges may be reflected in the UK research landscape will be important for informing necessary policy changes here.

"It has long been recognized as an urgent problem that people from ethnic minority groups are severely underrepresented in clinical research, which can raise questions about the safety and effectiveness of treatments across different patient populations. While age is the biggest risk factor for dementia, the condition affects people from all walks of life.

"The reasons for underrepresentation in research are complex, but common themes include lack of access to healthcare services, which are often the gateway to participation in research, historical distrust amongst certain communities and the relationships between risk factors for poor health and deprivation.

"This study adds to our own analysis of Alzheimer's in the UK, which showed that problems around lack of access to transport or having to work longer/or less convenient hours with little to no holiday, can have a key impact on a person's capacity to participate in a clinical trial that could last months or years.

"This is why we urgently need a UK government Dementia Strategy that engages with communities and makes more diverse and inclusive participation in dementia research a top priority.

"Everybody diagnosed with a form of dementia should have a chance to discover, get involved and participate in dementia research. Right now, only a small number of people eligible to take part in dementia clinical [trials](#) actually do so—just 2% of those diagnosed with dementia are part of the UK registry for dementia research Join Dementia Research (JDR)."

More information: Translating Science into breakthroughs: the future of late-stage dementia clinical trials in the UK.

www.alzheimersresearchuk.org/al-trials-in-the-uk/

Provided by Alzheimer's Research UK

Citation: Barriers to recruitment and retention of participants dementia clinical trials identified (2021, July 30) retrieved 25 April 2024 from <https://medicalxpress.com/news/2021-07-barriers-retention-dementia-clinical-trials.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.