

Including ethnic and cultural diversity in dementia research

Australian dementia research needs increased representation of people from culturally and linguistically diverse backgrounds

Evidence-based practice and policy must be based on the best available evidence, which should be representative of the population.¹ However, the current body of dementia research does not reflect the ethnic and cultural diversity of the Australian population. Hence, people from culturally and linguistically diverse (CALD) backgrounds may receive inequitable dementia care as there is less evidence to help optimise clinical and service decisions.

There are established differences related to ethnicity and culture in dementia prevalence and incidence, presentation, understanding of dementia, help-seeking and service use.^{2,3} Evidence is also emerging about differences in neuroimaging and blood biomarkers that may have an impact on diagnosis.² While there are no established differential responses to dementia medications by ethnicity, they are possible, given that 20% of new Food and Drug Administration pharmaceutical approvals in the United States had known racial or ethnic differences in effects.⁴

Culture can underpin differences in health outcomes,⁵ alongside biological differences by ethnicity. For example, diet and health literacy may have lifelong impacts on brain health.^{6,7} Communities' acceptance of the premise of prevention and early intervention (versus fatalism and therapeutic nihilism) can also affect uptake of risk-reduction strategies.⁸

The sparse data we identified relating to the ethnic diversity of participants in Australian dementia research suggest that CALD people are under-represented. We searched the Scopus database and of the 15 published dementia clinical trials published between 2016 and 2018, two studies reported that 33.3% and 31.6% of participants were from non-Australian backgrounds,^{9,10} and three studies reported that 7.1%, 12.5% and 57.0% of participants spoke English as a second language.^{11–13} The remaining ten studies did not report ethnicity-related data. We also searched the Australian New Zealand Clinical Trials Registry and ClinicalTrials.gov and found that 42 of the 94 currently registered active dementia clinical trials in Australia (44.7%) excluded patients not fluent in English. A systematic review of 96 international randomised controlled clinical trials to improve cognition related to dementia (total of 37 278 participants) found that of the 39 trials (39.4%) reporting ethnicity, pooled data showed that only 11.4% (95% CI, 7.5–15.9%) of participants were non-Caucasian.¹⁴

Epidemiological research is also critical to informing service planning and risk factor identification. We searched for dementia-related Australian cohort studies using Scopus, and from the lists of cohorts presented on the website of the Dementia Centre for Research



Collaboration¹⁵ and by the Australian Institute of Health and Welfare.¹⁶ The 16 studies identified collected data exclusively in English, and six excluded participants who were not fluent in English. From the nine studies that reported country of birth, our pooled calculation is that 27.2% of participants were born outside Australia; lower than the 37% of people aged 65 years and over who were born outside Australia, as reported in the 2016 census.¹⁷ Country of birth data do not allow distinction between people born in English-speaking and non-English speaking countries. About 0.6% of people with dementia in Australia have symptoms that start before the age of 65 years,¹⁸ so we included people aged 65 years and over as a comparison group.

Australian dementia research is contributing to international research gains in early detection and lifestyle-related risk reduction.¹⁹ Major initiatives include the Australian Imaging, Biomarkers and Lifestyle (AIBL) prospective risk identification study with over 1000 participants,²⁰ the Maintain Your Brain online dementia risk-reduction trial with a target of 8500 participants,²¹ and the Australian Dementia Network (ADNeT) dementia registry and memory clinic network.²² Given that one in three older people in this country are from a CALD background,¹⁷ it is important that these initiatives focus on achieving ethnic or cultural diversity in their samples, and support the participation of people with low English proficiency. At the very least, data collected on CALD variables, such as country of birth, years lived in Australia, proficiency in English and language spoken at home, must be considered in the analyses and subsequent publications.

There are several Australian projects underway exemplifying how to undertake research with CALD communities. Examples include:

- the Moving Pictures study (<https://movingpictures.org.au>), which seeks to increase dementia awareness through films and comics that document the lived

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experience of carers across Australia who speak Hindi, Tamil, Arabic, Mandarin and Cantonese;

- the potential of using technologies such as Skype or Zoom to facilitate timely interpreter-mediated cognitive assessments and dementia diagnosis in older CALD patients;²³ and
- the codesign of mobile phone applications to enable everyday conversations about care delivery between hospital and home case workers and CALD people with dementia and their families.²⁴

Notably, the NHMRC National Institute of Dementia Research (NNIDR), in partnership with the National Ageing Research Institute, is developing an action plan for dementia research focused on CALD communities.²⁵

This action plan will outline research priorities and gaps in dementia research for these communities to facilitate collaboration across CALD dementia research and between researchers and CALD communities.

Women were historically excluded from clinical trials, and policy and practical strategies have successfully improved their representation and, equally importantly, sex-specific analysis of data.²⁶ Ethnic and cultural diversity in research has been similarly neglected. The disparities and inequities described in relation to dementia research apply across the rest of medical research.²⁷

We believe that across all Australian dementia research, overall CALD participation should be around 30%, proportional to the total CALD population in Australia of people aged 65 years and over.¹⁷ However, we are not advocating targets for CALD participation in dementia research in specific studies; rather, we want researchers to consider cultural and linguistic diversity based on their research project — that is, the research aims, the characteristics of the population within the recruitment catchment, financial and time constraints, and generalisability.

There are several ways studies could be more inclusive of CALD participants. For example, a study of a public health campaign to increase timeliness of diagnosis of dementia in localities that have high proportions of older CALD groups could maximise the reach of the campaign through culturally targeted messages and materials. Studies could also recruit sufficient numbers of CALD participants to allow subgroup comparisons of response to the campaign. Furthermore, a qualitative study on the experiences of people with dementia in residential aged care may not support participation of non-English speakers, but may have a purposeful sampling strategy that includes cultural diversity in English speakers, which would add minimally to study cost through recruitment of this more diverse sample.

We propose the following strategies that may increase CALD participation in research:

- recognising diversity as a priority — grant funders should require applicants to address how they will support the inclusion of CALD populations or at least justify their exclusion;
- funding the additional costs of translation or interpreters;
- leveraging existing datasets to study ethnic and cultural differences in dementia; and
- support from academic publications in encouraging reporting of variables relating to ethnicity or culture, and ethnicity-specific analysis, where appropriate.

The US Food and Drug Administration has published recommendations for measurement and reporting of race and ethnicity²⁸ that are also applicable in Australia. Other strategies include the development of methodologies to enable and facilitate CALD participation; for example, culture-fair tests that are not biased by culture and language,²⁹ “recruitmentology” (the study of recruitment of diverse samples), or a matchmaking service to encourage researchers to build relationships with CALD communities who want to be more involved in research.³⁰ We also need to increase the awareness and skills of researchers in including people from CALD backgrounds in research. For instance, we need to promote information about ways of defining the target CALD groups, such as using country of birth, ancestry, language spoken at home, or identification with a culture. Finally, we might be able to increase uptake of research opportunities by CALD participants through ensuring that research questions are relevant to them, increasing awareness of dementia, and ensuring accessibility of materials, such as cultural relevance, language and level of literacy. Through such strategies, Australian dementia research, and Australian medical research more broadly, can more accurately reflect the ethnic and cultural diversity of the Australian population.

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