

# Dementia research must include CALD Australians

FECCA has called for more funding to be provided for dementia research, so that the experiences of culturally and linguistically diverse (CALD) Australians are not excluded from research and clinical trials.

The call comes after an article was published in the Medical Journal of Australia yesterday suggesting that Australian dementia research is not sufficiently inclusive of Australians from CALD backgrounds and that, as a consequence, they may be receiving inequitable or inappropriate dementia care.

The article by academics from Sydney University and the National Ageing Research Institute (NARI) found that 42 of the 94 registered active dementia clinical trials in Australia excluded patients not fluent in English. CALD Australians were also excluded from epidemiological research on dementia. The authors found that of 16 studies identified, all collected data exclusively in English, and six excluded participants who were not fluent in English.

NARI is working with the NHMRC National Institute for Dementia Research (NNIDR) to develop a roadmap to help identify research priorities for older CALD people living with dementia and facilitate collaboration between researchers and CALD communities.

FECCA is a member of the reference group for this project and advised on initial community consultations related to the study.

FECCA chairperson Mary Patetsos said that leaving CALD Australians out of clinical trials and other research means that care may not be properly tailored to their requirements in the future.

“We have known for a long time that CALD Australians don’t have equitable access to aged care or dementia services for a whole range of reasons,” Ms Patetsos said.

“This is deeply concerning, especially given that one in three older Australians are from a CALD background.

“The evidence is many CALD people who may have had good English language proficiency, lose this with dementia and revert to their original language. For research and clinical trials not to include the perspectives of CALD Australians who may have lost their ability to speak English is unacceptable.

“A loss of English language proficiency leads to increased isolation and compounds some of the challenges associated with dementia. Funding should be made available, as part of dementia research and clinical trials, to provide interpreters so that CALD Australians can participate.

“This issue is not restricted to the field of dementia. CALD Australians are routinely excluded from a range of social, epidemiological and medical research, the results of which often purport to be representative of the Australian population as a whole or inform service planning.

“FECCA calls on research funding bodies such as the Australian Research Council or the National Health and Medical Research Council to ensure that applicants can demonstrate, where appropriate, how their proposed research will be inclusive of CALD Australians.”

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