



Australian Government

NHMRC National Institute for Dementia Research

CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) DEMENTIA RESEARCH ACTION PLAN

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VISION

The improved health and wellbeing of Australians from Culturally and Linguistically Diverse (CALD) backgrounds at risk of developing or living with dementia, together with their carers, families, and communities.

This vision will be achieved through high quality, strengths-based research that values and facilitates partnerships; addresses disparities in prevention, diagnosis, treatment and care; improves timely dementia diagnosis and, informs the provision of culturally-appropriate care and support.

Purpose

The NHMRC National Institute for Dementia Research (NNIDR) 2019 Strategic Roadmap for Dementia Research and Translation provides a guide for research and translation aimed at improving the lives of people living with dementia, their families, and carers. This CALD Dementia Research Action Plan is founded on the Roadmap's principle of recognising and responding to Australia's cultural and linguistic diversity. This Action Plan has been developed and driven by NNIDR and the National Ageing Research Institute (NARI), and guided by a Steering Group comprising consumers, advocates, policy makers, and researchers. The priorities presented in this plan have been determined through an extensive consultation process, including: two stakeholder workshops, 19 national CALD community consultations, a national survey, and finally, a survey of key stakeholders to rank the final research priorities for future funding. The Action Plan is essential reading for policymakers, funders, researchers and research leaders. Implementation of the priorities outlined will help to guide research investment strategies as well as enhance commitment to using research that reduces dementia disparities, and increases health and care equity among CALD and non-CALD Australians.

The challenge

CALD Australians make up approximately one-third of Australia's population¹, and by extension, the population of people currently living with dementia, or who will be living with dementia in the coming decades. Current Australian dementia research does not reflect this diversity as people from CALD backgrounds are frequently underrepresented in dementia research and relevant data on ethnicity is not routinely gathered or reported². Yet disparities in health and care outcomes between CALD and the general population are documented; for example in specialist referral rates, medication use and participation in clinical trials^{2,3}.

CALD Australians are diagnosed with dementia later than non-CALD Australians and awareness of dementia is low in some CALD communities. Many people from CALD backgrounds experience difficulty finding culturally-relevant aged care services³. Understanding cultural differences in approaches to dementia, the role of ethnicity or migration experience in disease risk, and attitudes towards care are therefore important elements of Australia's research program to address the challenges that dementia presents for all of Australia's ageing population.

Guiding principles for CALD-inclusive dementia research

1. Research should include co-design and partnership approaches that involve CALD communities and other stakeholders over the life-span of the study.
2. Research should collect, analyse, and report on CALD variables in experimental and epidemiological studies.
3. Innovations in Australia's approach to dementia should be accessible to all Australians, regardless of culture or language.
4. Researchers should work to develop and support partnerships between the health sector, care providers, training organisations, ageing and ethnic peak-bodies, and CALD communities to ensure rapid translation of evidence into practice.

Research priorities

Priority A: Identify effective ways to promote dementia risk reduction behaviours in CALD communities

Dementia prevention is an international priority. There is now strong evidence that the risk of dementia can be reduced at a population-level by tackling modifiable risks⁴. There is some information on dementia risk factor levels in CALD Australians, but almost no information on differential risks by ethnicity. Communities' acceptance of the premise of prevention and early intervention may also affect uptake of risk reduction strategies.

Priority B: Increase the development and uptake of evidence-based, culture-fair tools for dementia screening and diagnosis in primary and acute care settings

The actual prevalence of dementia in CALD Australians is not known. Australian data suggest that mild cognitive impairment is higher in CALD people, but it is not known whether this is a real difference or an artefact of education and language, as well as cultural biases in cognitive tests, or indeed inadequate neuropsychological test norms for older CALD people⁶.

Priority C: Inform ways to improve timely help-seeking for dementia in CALD communities

Research has consistently shown that CALD people have poorer knowledge of dementia, negative attitudes and feelings (i.e. stigma) about dementia, and present later for diagnosis^{5,7}. Information on effective ways to improve timely help seeking, from diagnosis to care, in communities is needed to improve health and wellbeing outcomes and contribute to greater efficiency in the Australian health system. Research into effective ways to improve dementia literacy and reduce stigma across CALD communities will underpin this work.

Priority D: Develop, test, and implement culturally-specific models of dementia care that improve access to care and quality of life for CALD persons with dementia and their carers

Existing research has shown that CALD people have a preference for family care and community care over residential care^{8,9,10}. However, families are experiencing reduced capacity, and reduced extended family support, to exclusively care for family members with cognitive impairment and dementia¹¹. Research is needed to inform the development and provision of culturally-appropriate care and support, and culturally-appropriate measures to assess the wellbeing and quality of life of CALD people living with dementia and their carers.

Priority E: Inform effective ways to train frontline clinical health and care staff on how culture influences dementia, including through continuous professional development

The underrepresentation of CALD people in dementia research may translate into less than optimal care for one-third of Australians living with dementia, as clinical and service decisions are based on evidence that do not reflect their needs. Research is required on how to train frontline care staff effectively to build cultural literacy and improve understanding of unique issues CALD communities experience in relation to dementia. Support for translation of these findings into practice is also needed.

What success looks like

Dementia Awareness and Risk Reduction

Research in dementia awareness will contribute to improved dementia literacy in CALD communities and help facilitate timely help-seeking. A greater understanding of dementia in CALD communities will address stigma faced by people with dementia and their families. Research into effective risk reduction for CALD communities will assist with promoting greater adoption of healthy behaviours. These efforts will also enhance health and care systems literacy in CALD communities and capacity to navigate the health and aged care system.

In the short term, this will be measured through description of CALD-targeted activities and audience reach in new dementia awareness and risk reduction campaigns. In the medium to long term, this will be measured through the number of grants and publications in dementia awareness, prevalence and risk that include people and results relating to CALD communities.

Screening, diagnosis, and management

Research into dementia screening and diagnosis will contribute to the development and increased use of culturally-appropriate screening and assessment tools. This will contribute to better diagnostic experiences for CALD people, including increased timeliness and accuracy of diagnosis of dementia.

In the short term, this will be measured through the establishment of new partnerships in service delivery that are well-evidenced, and involve CALD-appropriate practices and interventions (or similar). In the medium to long term, this will be measured through the availability and use of culturally appropriate and valid dementia assessment tools that are suitable for CALD older people.

Care

Care research under the Action Plan will contribute to enhanced care for CALD people living with dementia. Key outcomes also include a more culturally-competent health care, aged care and dementia workforce to enhance satisfaction with aged care staff and other health care staff among CALD people living with dementia and their families. Along with better understanding of, and capacity to respond to, carer wellbeing and support needs, this will promote improved health, care, and psychosocial outcomes for CALD people living with dementia and their carers and families.

In the short to medium term, this will be measured through the development and implementation of culture-fair technology guidelines as part of innovative design cycles.

In the longer term, this will be measured through the development and implementation of evidence-based culturally-appropriate wellbeing and quality of life tools and resources, as well as culturally-informed models of care for CALD people living with dementia and their families and carers.

Representation in research

Greater CALD representation in dementia research will lead to more accurate prevalence estimates and projections of CALD Australians with dementia and increase understanding of differences in biological indicators of disease presence between ethnic groups. Implementation of the Action Plan will drive greater inclusion of CALD communities in dementia research, including increased representativeness of CALD participants in clinical trials, cohort studies, and brain banking initiatives. This will enhance the capacity of the research workforce to undertake research with CALD communities through the development of best-practice guidelines for how to engage with CALD communities in research.

In the short term, this will be measured through evidence of greater inclusion of CALD people as reported in funded and published dementia research, and through description of collaborations and joint activities (e.g. grant or tender submissions, public information events, community consultations) among researchers, ageing and ethnic peak bodies, and CALD communities.

In the medium term, this will be measured through the evaluation of representativeness of CALD participants in clinical trials, cohort studies, and brain-banking initiatives. In the longer term, this will be measured through updated dementia prevalence estimates and projections based on more accurate CALD data.

Next steps

Implementation of the Action Plan will be actively supported by NNIDR and NARI through the development of research sector tools, such as best practice guidelines and recommendations to include CALD Australians in dementia research.

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