



Australian Government

NHMRC National Institute for Dementia Research

CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) DEMENTIA RESEARCH ACTION PLAN

Full report

Accelerating research. Enhancing collaboration. Creating change.



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NHMRC National Institute for Dementia Research

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EXECUTIVE SUMMARY

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 Action Plan is founded on the Roadmap's principle of recognising and responding to Australia's cultural and linguistic diversity. Culturally and linguistically diverse (CALD) Australians make up a sizeable portion of the population and, by extension, the population of people currently living with dementia, or who will be living with dementia in the coming decades.

However, CALD Australians are diagnosed with dementia later than non-CALD Australians and awareness of dementia is low in some CALD communities. Understanding cultural differences in approaches to dementia, the role of ethnicity or migration experience in disease risk, and attitudes towards care are important elements of Australia's research program to address the challenges that dementia presents for Australia's ageing population.

This Action Plan has been developed and driven by the 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 arrived at through an extensive consultation process including: two stakeholder workshops, 19 national CALD community consultations, a national survey and, finally, a modified Delphi process. Through this process, 21 priority research and translation needs have been identified; Box 1 details the top five.

Box 1

- **Identify effective ways to promote dementia risk reduction behaviours in CALD communities**
- **Increase the development and uptake of evidence-based, culture-fair tools for dementia screening and diagnosis in primary and acute care settings**
- **Inform ways to improve timely help-seeking for dementia in CALD communities**
- **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**
- **Inform effective ways to train frontline health and care staff on how culture influences dementia, including through continuous professional development.**

Guiding principles are outlined in the Action Plan for all dementia researchers to support increased CALD inclusion in dementia research. Implementation of the guiding principles will be actively supported by NNIDR and NARI through the development of research sector tools, such as guidance and recommendations to include CALD Australians in dementia research.

This Action Plan is essential reading for policymakers, funders, researchers and research leaders. What success looks like and how it could be measured are described in this report. Implementation of the guiding principles and priorities outlined should help guide research investment strategies and enhance commitment to using research to reduce dementia disparities and increase health and care equity among CALD and non-CALD Australians.

CONTEXT

The NHMRC National Institute for Dementia Research (NNIDR) is a major element of the Australian Government's \$200 million initiative to boost dementia research and was established in 2015 to target, coordinate and translate the strategic expansion of dementia research.

NNIDR's vision is to support high quality, high impact research and translation initiatives that produce genuine, positive short and long term outcomes for people living with dementia, their families, carers and the broader community. Its activities and funding recommendations are guided by the Strategic Roadmap for Dementia Research and Translation (Strategic Roadmap).

The Strategic Roadmap was adopted in July 2016 and revised in 2019. A key principle underpinning implementation of the 2019 Strategic Roadmap is the recognition of Australia's cultural and linguistic diversity and the importance of responding to this diversity. The Department of Health Aged Care Diversity Framework states that everyone in Australia has the right to access quality, inclusive and culturally safe aged care services that cater to their individual needs and respect their background and life experiences (Department of Health, 2017). This Action Plan addresses the need for research that builds the evidence base for services that effectively respond to a culturally and linguistically diverse Australian population.

NNIDR partnered with the National Ageing Research Institute (NARI) and key stakeholders to establish a Steering Group (at Appendix A) to consider ways forward in identifying and addressing culturally and linguistically diverse CALD Australians' dementia research needs. The cross-sectoral Steering Group formed to advance this work has led to comprehensive national consultations – the findings from which underpin the CALD Dementia Research Action Plan (see page 7).

BACKGROUND

Australia's population includes people who were born overseas, have a parent born overseas and/or speak a variety of languages other than English – these communities are referred to as CALD (Australian Bureau of Statistics, 2017). According to the Australian Bureau of Statistics, the category CALD excludes individuals born in the United Kingdom (UK), United States (US), Canada, South Africa, and New Zealand. People who are classified as CALD in Australia are also known as minority ethnic groups in other parts of the world such as the UK and US.

In 2016, 28 per cent of the Australian population was overseas-born and an additional 21 per cent had at least one overseas-born parent (Australian Bureau of Statistics, 2017). One in three people aged over 65 is a CALD person (Australian Bureau of Statistics, 2017). With an estimated 447,115 Australians living with dementia in 2019 and this number projected to increase to 1,076,129 by 2058 (Dementia Australia, 2018), CALD people make up a sizeable portion of Australians currently living with, or projected to be living with, dementia in the coming decades.

Despite CALD Australians making up almost a third of the population, they are often excluded from Australian dementia research, and information on ethnicity, language, and country of birth is not routinely collected or reported (Low et al., 2019). For example, a search of the Australian New Zealand Clinical Trials Registry (ANZCTR) found that 42 of 94 current dementia clinical trials in Australia actively excluded those not fluent in English (Low et al., 2019). Similarly, data from 16 Australian dementia epidemiology studies were collected only in English and six of these studies excluded participants not fluent in English (Low et al., 2019). Potential consequences of this under-representation are:

- Non-representative samples in cohort and clinical trial studies, resulting in inaccurate effect sizes on which clinical, policy and economic decisions are based.
- Less data means less consideration of the needs of CALD people with dementia and their families in the formulation of information and services.
- Poorer access to and fewer appropriate health and social services for CALD people with dementia.
- Less effective implementation of research evidence into practice for CALD communities.

CALD AUSTRALIANS AND DEMENTIA

Differences in culture and ethnicity are known to be reflected in dementia risk as well as attitudes and behaviour towards prevention and care (Brijnath, 2014). Different migration trajectories, years lived in Australia, proficiency in English, and socioeconomic status are all important factors that shape attitudes to dementia, its prevention, management, and care (Boughtwood et al., 2011a, Boughtwood et al., 2011b, Boughtwood et al., 2012, Shanley et al., 2012, Australian Bureau of Statistics, 2017).

There is diversity within diversity and older CALD people include post-war migrants from Europe who have been established in Australia for three generations as well as more recent arrivals from Africa and the Middle East, skilled migrants from Asia, and family-reunion migrants. Within these groups, ethnic and religious differences can also play a role in attitudes to dementia. While CALD people from Italy, Germany and China currently make up the largest numbers of Australians over the age of 65, the Indian and Chinese communities are the fastest growing CALD groups in contemporary Australia (Australian Institute of Health & Welfare, 2018). Similar to the general Australian population, the demographics of people living with dementia is constantly evolving. It is crucial for research to keep up with the dementia prevention and care needs of these diverse populations.

The actual prevalence of dementia in CALD Australians is not known. International research suggests that rates of dementia vary depending on ethnicity, migration trajectories, and social factors (Chen and Zissimopoulos, 2018). For example, South Asian migrants in Canada have higher levels of glucose intolerance, hyperinsulinaemia, hypertension and hyperlipidaemia and increased central obesity than Caucasians (Martin et al., 2018), and these cardiovascular risk factors are known to increase the risk of dementia (Livingston et al., 2017). Conversely, some CALD groups might be more likely to practise lifestyles that include known protective factors for dementia such as the consumption of a Mediterranean-style diet (Livingston et al., 2017). Australian data suggest that mild cognitive impairment is three times 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 people (Low et al., 2012).

Research has consistently shown that CALD people have poorer knowledge of dementia and negative attitudes and feelings (i.e. stigma) about dementia (Berisic and Nesvadba, 2008, Low et al., 2010). Dementia may initially be thought of as a normal part of ageing, associated with 'madness' (Brijnath, 2014), or seen as fate or a punishment from God (Abojabel and Werner, 2019) because of past conduct, and it is often perceived as a shameful condition (St. John, 2004). Ignorance and misconceptions lead to denial or minimising of symptoms, resulting in delayed diagnosis (Lee et al., 2011, Sagbakken et al., 2018). It may also lead to social isolation of the person with dementia (beyondblue, 2009).

Research shows that CALD people with dementia present later for diagnosis and have a preference for family care and community care over residential care (Low et al., 2011, Brijnath, 2012, Shanley et al., 2012). Reported reasons include cultural attitudes about care responsibilities resting exclusively with families (Lee et al., 2011), lack of knowledge about services, difficulty accessing services (language, health system literacy), and lack of culturally appropriate services (Xiao et al., 2013, Kenning et al., 2017). However, with increased migration, urbanisation, participation of women in the workforce, and smaller houses, there is reduced capacity in families to exclusively care for family members with cognitive impairment and dementia, and reduced availability of extended family support for family carers (Sagbakken et al., 2018).

There are also differences in the expression of symptoms of dementia in CALD people, and these differences can impact on their management and care. People with dementia may lose their language skills, reverting to communication in their primary language, so communication in English may progressively become a challenge for non-native English speakers with dementia (Tipping and Whiteside, 2015). People with dementia rely increasingly on the physical and social environment as their short-term memory declines, and may be less well supported or comfortable in residential care environments that are culturally and linguistically unfamiliar, resulting in feelings of isolation and loneliness, and more behavioural expressions of needs (Runci et al., 2014).

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 risks (Livingston et al., 2017). Australian research is making

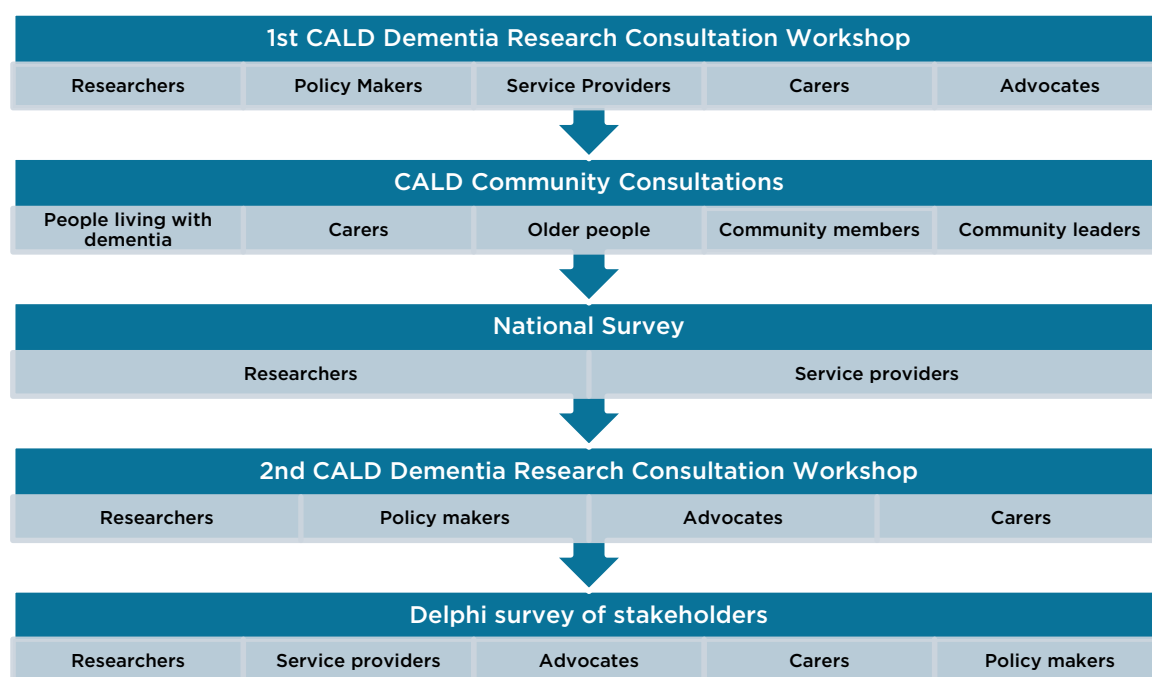
important contributions to risk reduction and early detection strategies (NNIDR, 2018). There is some information on dementia risk factor levels in CALD Australians, but almost no information on differential risks by ethnicity. Communities' acceptance of the premise of prevention and early intervention may also affect uptake of risk reduction strategies (Berisic and Nesvadba, 2008).

This lack of representation of CALD people in dementia research potentially translates into less than optimal care for the estimated one-third of Australians living with dementia, as clinical and service decisions are based on evidence that does not reflect their needs. Research and policy development have important roles to play in addressing this inequity (Haralambous et al., 2014). Just as policy and practical strategies were able to improve the representation of women who were historically excluded from clinical trials (Liu and DiPietro Mager, 2016), this Action Plan will be a step towards addressing the current absences in consideration of cultural diversity in dementia research (Low et al., 2019).

ACTION PLAN DEVELOPMENT

The CALD Dementia Research Action Plan identifies research and research translation priorities and gaps in dementia for CALD communities. The process for identifying the research priorities involved five steps:

1. **A Steering Group** of experts in the CALD, dementia research, and dementia health and care sectors to advise on the development of the Action Plan (See Appendix A).
2. **The 1st CALD Dementia Research Consultation Workshop** (20 November 2018, Melbourne) with attendance from 37 researchers, clinicians, and community representatives involved with dementia and CALD communities to identify key research and translation priorities (See Appendix B).
3. **Nineteen national community consultations** (February-May 2019) with 340 CALD community members to identify dementia-related issues facing CALD communities (See Appendix C).
4. **An online survey** (April-May 2019) involving 102 service providers, clinicians and researchers to confirm the relevance of emerging priorities for the research, health and aged care sectors (See Appendix D).
5. **The 2nd CALD Dementia Research Consultation Workshop** (12 June, Hobart) with 25 experts in dementia and CALD health and care to finalise the draft Action Plan (Appendix E).
6. **A Delphi survey of stakeholders** invited to the two stakeholder workshops to rank 21 CALD dementia research priorities (Appendix F).





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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}. However, families are experiencing reduced capacity, and reduced extended family support, to exclusively care for family members with cognitive impairment and dementia¹⁰. 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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21 CALD DEMENTIA RESEARCH AND TRANSLATION NEEDS

The Action Plan consultation process identified and prioritised 21 research topics needed to further the objectives of reducing dementia disparities, and increasing health and care equity among CALD and non-CALD Australians. The full list, ranked by stakeholders and including the top five priorities described above, is research to:

1. Increase the uptake of evidence-based, culture-fair tools for dementia screening and diagnosis in primary and acute care settings.
2. Inform the development or adaptation of validated dementia assessment tools for CALD persons presenting with symptoms of dementia, including content of the tools and procedures for administration.
3. 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.
4. Inform effective ways to improve timely help-seeking for dementia in CALD communities.
5. Inform effective ways to train frontline health and care staff on how culture influences dementia, including through continuous professional development.
6. Inform effective ways to promote risk reduction behaviours in CALD communities.
7. Contribute to developing timely pathways to and from diagnosis for CALD persons with dementia.
8. Inform effective ways to improve dementia literacy in CALD communities.
9. Develop and implement evidence-based interventions in primary and acute care settings to reduce the stigma of a dementia diagnosis and facilitate referral to CALD-appropriate services for CALD persons with dementia.
10. Inform understanding of the prevalence of dementia in CALD communities.
11. Inform understanding of the factors that influence treatment adherence for CALD people living with dementia, including research into the cultural acceptability of de-prescribing medications, as well as the prescribing of non-pharmacological interventions (e.g. social interaction, exercise).
12. Develop evidence-based culturally-appropriate measures to assess the wellbeing and quality of life of CALD people living with dementia and their carers.
13. Inform understanding of differences in symptom presentation among CALD persons with dementia versus non-CALD persons with dementia.
14. Investigate differences in communicating dementia diagnosis and prognosis and optimal ways to deliver this information across different ethnic groups.
15. Inform effective ways to decrease stigma in CALD communities in relation to dementia, and service use.
16. Improve understanding of the vulnerabilities of CALD carers (especially women) and interventions on how to improve/sustain their health and wellbeing.
17. Inform understanding of perceptions of dementia risk in CALD communities.
18. Investigate differences in communicating dementia treatments among CALD persons with dementia versus non-CALD persons with dementia and ways to optimise decision-making for treatments across different ethnic groups.
19. Develop technological innovations to improve health and social care for CALD people living with dementia.
20. Contribute to understanding differences in biological indicators of disease presence between ethnic groups.
21. Inform understanding of the use of cholinesterase inhibitors and other medications for dementia among CALD persons with dementia.

APPENDIX A: CALD DEMENTIA RESEARCH ACTION PLAN STEERING GROUP

In October 2018, NNIDR and NARI convened a Steering Group to provide guidance and advice on the development of the CALD Dementia Research Action Plan. Project sponsors from each organisation were Ms Janice Besch, Director NNIDR and Professor Briony Dow, Director NARI. The Steering Group met at least monthly via video/teleconference until the finalisation of the Action Plan in July 2019.

The Steering Group was co-chaired by:

- Associate Professor Bianca Brijnath, NARI
- Stephanie Ellis, NNIDR

Steering Group members included:

- Dr Samantha Croy, NNIDR Project Officer
- Betty Haralambous, NARI
- Associate Professor Lee-Fay Low, University of Sydney
- Associate Professor Dina LoGiudice, University of Melbourne/Royal Melbourne Hospital
- Danijela Hlis, Consumer representative and Dementia Australia advocate
- Sukhwinder Rakhra, Consumer representative
- Rachana Kankipati, Department of Health
- Marissa Otuszewski, Department of Health
- Tina Karanastasis AM, Ethnic Link Services
- Daniel Coase, Federation of Ethnic Communities Council of Australia (FECCA)
- Mary Ann Geronimo, FECCA
- Lauren Clarke, Dementia Australia Research Foundation
- Dr Penelope Moore, Department of Health (until June 2019)
- Cristina Giusti, Dementia Australia (until March 2019)
- Dr Emma Campbell, FECCA (until November 2018)

Terms of Reference

The Steering Group was tasked to:

- Provide input into project directions and methods
- Highlight the priorities of each member's organisation or community for CALD dementia research
- Provide input and feedback on a background document for the project to set the context for and inform community and sector consultations
- Review drafts of the Action Plan and provide feedback
- Provide guidance on attendees for a CALD Dementia Research Consultation Workshop in November 2018 and a Forum in 2019
- Determine which agencies or organisations can provide the relevant information for the development of the action plan
- Assist with community and relevant sector (aged care, dementia research) consultations
- Assist with planning and attend (where possible) Consultation Workshops
- Communicate and promote the Project among each member's network.

Priorities Identified by Steering Group Prior to Consultations

Prior to consultations the Steering Group identified the following high priority areas about how to include CALD Australians in dementia research:

Areas of importance	
Dementia awareness	• Improve dementia literacy among CALD people living with dementia, their families, and communities. • Improve literacy about Australia's health and aged care systems among CALD people living with dementia, their families, and communities. • Develop innovative methods of communication with CALD people with dementia.
Risk reduction and prevention	• Generate updated and reliable epidemiological information on dementia in CALD Australians, including on risk factors and estimates of dementia incidence and prevalence in CALD communities.
Diagnosis	• Improve CALD community equity and access to dementia assessment and diagnosis. • Develop and adapt appropriate dementia screening, assessment, and diagnostic tools for CALD people. • Understand the diagnosis trajectory of older CALD people living with dementia and that of their families, to pinpoint where barriers to diagnosis occur. • Understand the role of family in facilitating diagnosis; how these techniques might differ from mainstream understandings of patient-centred care; and develop strategies to integrate what might appear to be contrary approaches. • Investigate the role of technology in facilitating access to interpreter services, including for assessments and activities of daily living.
Treatment	• Research that is clinically relevant and driven by communities.
Care	• Understand the care trajectory of older CALD people living with dementia and that of their families, to pinpoint where barriers to help-seeking and care occur. • Understand the role of family in facilitating care; how these techniques might differ from mainstream understandings of patient-centred care; and develop strategies to integrate what might appear to be contrary approaches. • Develop methods to skill new and emerging migrant communities, an increasing component of Australia's aged care multicultural workforce, who are increasingly caring for an ageing multicultural Australian population.

Cross-cutting	• Improve CALD literacy and awareness of CALD issues among (dementia) researchers and funding bodies. • Facilitate collaboration across CALD dementia research: across and between researchers, consumers and the aged care / service provision sector. • Generate updated and reliable data on the unmet needs and services for CALD people with dementia. • Improve understanding of the experience of dementia by CALD people • CALD inclusion and involvement in national and significant dementia initiatives.
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The broad areas of awareness, risk reduction and prevention, diagnosis, treatment and care formed the basis of the group work at the first consultation workshop where participants were invited to join a group that matched their area of expertise. Each group included a Steering Group member who was able to guide the discussion to focus on identifying the gaps in research and research translation specifically.

APPENDIX B: 1ST STAKEHOLDER CONSULTATION WORKSHOP

The one-day consultation workshop held in Melbourne on 20 November 2018 brought together 37 researchers, health professionals, CALD consumers and advocates, and ethno-specific and generalist aged care providers. Participants shared information on the work they were doing and what they had learned about the challenge of dementia for CALD communities.

Morning session

The NNIDR and NARI project team set the scene for the workshop by providing an overview of the CALD Dementia Research Action Plan project and explained how the Action Plan would fit under the NNIDR's Strategic Roadmap for Dementia Research and Translation. This was followed by presentations by ethno-specific and generalist service providers, advocates, and a consumer representative who spoke about the challenges that CALD communities face with dementia, highlighting key issues for research translation. Presentations by researchers addressed the low representation of CALD people in dementia research, challenges associated with undertaking dementia research with CALD communities, and the importance of including CALD people in dementia research.

This session was followed by a whole-group discussion about the steps that need to be taken to include CALD communities in dementia research, and the research translation needed to improve dementia outcomes in CALD communities. Participants discussed the extent to which new diagnostic tools need to be developed or if those used internationally could be adapted for use in an Australian context; whether CALD communities should be considered as a whole or as disaggregated specific communities facing common challenges; how to encourage researchers' engagement with CALD communities; and the inclusion of CALD communities in research given the added costs and time commitments needed for such research.

The main messages from the day's discussions were:

- There is a need for research on specific ethnic communities as well as research that includes multiple CALD communities.
- There is a need for researchers to draw on relevant international work to help inform the development of validated methods that might facilitate the inclusion of CALD communities in dementia research as well as to develop their own culturally-appropriate and validated measures in the absence of other measures.
- There is a need for a framework reflecting best practice when it comes to researcher engagement with CALD communities.
- There is a need to advocate to ethics committees, funders, researchers, and politicians for the inclusion of CALD communities in dementia research.

Afternoon session

After lunch, workshop participants broke out into five groups around the themes identified by the Steering Group: (1) dementia awareness, (2) risk reduction and prevention, (3) dementia diagnosis, (4) treatment and (5) care. Participants were invited to join the groups where they felt they had expertise in order to contribute to developing a shortlist of CALD dementia research and research translation priorities.

Participants initially spent time working alone to identify their research and research translation priorities. Then, in their group, they discussed their individual contributions, and collectively identified their key priorities. For each priority that the groups shortlisted, they reflected on:

- What success would look like if this priority was successfully addressed
- Risks and barriers to success
- The steps and resources needed for success.

These priorities, measures of success, barriers to achieving success, and resources needed were then presented to all participants.

All participants were then given three weighted votes and asked to vote on their top three priorities in order of importance – i.e., green = most important; yellow = second most important; red = third most important. After the votes were cast, they were tallied based on their weighted scores. A green vote (most important priority) was three points; a yellow vote was two points; and a red vote was one point.

Table B.1 describes the priorities identified at the workshop.

Priorities identified	Number of votes (scores)			Total scores
	Green	Yellow	Red	
Dementia Awareness				
Understanding low dementia literacy in CALD communities	0 (0)	0 (0)	0 (0)	0
Understanding low levels of CALD engagement in dementia research	0 (0)	0 (0)	0 (0)	0
Understanding what CALD inclusive dementia-friendly communities would look like	3 (9)	0 (0)	2 (2)	11
Ways of improving GP and other health practitioner engagement with dementia research	2 (6)	0 (0)	1 (1)	7
Risk reduction and prevention				
Understanding of dementia risk (biological, sociocultural, environmental and generational) in CALD communities	4 (12)	2 (4)	0 (0)	16
How to do effective health promotion	0 (0)	0 (0)	0 (0)	0
Diagnosis				
Developing appropriate diagnostic tools (both cognitive and functional) to assess for dementia and cognitive decline in CALD patients	1 (3)	2 (4)	7 (7)	14
Data and Funding	2 (6)	2 (4)	1 (1)	11
Education	1 (3)	1 (2)	1 (1)	6
Treatment				
Co-ordination with international research	1 (3)	1 (2)	0 (0)	5
Development of both pharmacological and non-pharmacological CALD-appropriate treatments	0 (0)	0 (0)	0 (0)	0
Care				
Lack of awareness among researchers and aged and healthcare services of the different needs, preferences, and expectations around dementia care and care trajectories in CALD communities	3 (9)	3 (6)	2 (2)	17
Training needs and support and translation into practice for the workforce caring for people living with dementia	2 (6)	0 (0)	5 (5)	11

Based on the total scores, the top three priorities in order of importance were:

1. Lack of awareness among researchers and aged and healthcare services of the different needs, preferences, and expectations around dementia care and care trajectories in CALD communities (17 points; 3 green, 3 yellow, 2 red).
2. Understanding of dementia risk (biological, sociocultural, environmental and generational) in CALD communities (16 points; 4 green, 2 yellow, 0 red).
3. Developing appropriate diagnostic tools (both cognitive and functional) to assess for dementia and cognitive decline in CALD patients (14 points; 1 green, 2 yellow, 7 red).

APPENDIX C: COMMUNITY CONSULTATIONS

Community Selection Rationale/Method

To gain perspectives on the range of CALD experiences with dementia, diverse CALD communities across Australia were consulted by the NNIDR and NARI team. These 19 consultations included communities with the largest proportions of people over the age of 65, the fastest growing migrant communities, and communities with the highest number of recent refugee and humanitarian arrivals.

A total of 340 people were consulted in Perth, Adelaide, Melbourne, Canberra, Sydney, and Brisbane. These consultations included carers, older community members, general community members, community leaders, and people living with dementia. All consultations were conducted with support from a bicultural worker, or interpreter, in the respective community languages apart from the consultations with the Italian, Spanish, German, and Dutch communities, which were conducted exclusively in English.

Summary table of community consultations conducted for CALD dementia research action plan

	Community	Location	Number	Participant overview
1	Arabic-speaking	Perth	24	Mixed gender group including young people, middle-aged, and older people. Group included carers and family members of people with dementia; and a participant suspected by other group members to have dementia.
2	Syrian and Iraqi Consultation 1	Sydney	52	Mixed gender group including middle-aged, and older recently-settled refugees.
3	Syrian and Iraqi Consultation 2	Sydney	20	Mixed gender group of middle-aged and older recently-settled refugees.
4	Italian	Melbourne	21	Mixed gender group of older people, including carers and participant suspected by other group members to have dementia.
5	Chinese (Mandarin)	Perth	11	Mixed gender group of middle-aged and older carers, including one person with dementia attending with their carer.
6	Chinese (Cantonese)	Sydney	13	Mixed gender group of middle-aged and older carers.
7	Greek	Melbourne	24	Mixed gender group of older people, including carers as well as people with dementia.
8	Indian (Hindi)	Melbourne	27	Mixed gender group of older people.
9	Spanish-speaking	Sydney	16	Mixed gender group of middle-aged and older carers.

10	Vietnamese (newly settled)	Sydney	22	All female group of mixed ages.
11	Mon (Burma)	Canberra	5	Mixed gender group of older people.
12	Karen (Burma)	Canberra	5	Mixed gender group of all ages including younger, middle-aged, and older people.
13	German	Adelaide	10	Mixed gender group of older people, including carers and people living with dementia.
14	Nepali (Bhutanese)	Adelaide	14	Mixed gender group of all ages, including carers of older family members.
15	Indian (Punjabi)	Brisbane	16	Mixed gender group of majority older people and small numbers of middle-aged and younger people.
16	Burmese-speaking, mixed ethnicities	Brisbane	22	Mixed gender group of majority older people and some younger and middle-age people, including a carer and people with dementia.
17	Mixed group refugee community leaders	Brisbane	10	Mixed gender group of younger and middle-aged refugee health advisors representing Iraq, Syria, Myanmar, Eritrea, Kenya, Liberia, Afghanistan, Burundi.
18	Filipino	Melbourne	24	Mixed gender older people.
19	Dutch	Melbourne	4	Mixed gender older people and middle-age care co-ordinators.

The communities consulted included:

- Those familiar with the Australian health care system and who have well-established ethno-specific support services;
- More recently established communities whose members are less familiar with available supports for people living with dementia and their families;
- Those who have been exposed to war, trauma, and conflict.

Together, these consultations provide a picture of the range of CALD community experiences with dementia resulting from factors such as culture and migration trajectories.

KEY THEMES

Recognising the early stages of dementia

There were varying levels of awareness of dementia in the different communities. In some consultations (e.g. Italian), community members noted that dementia had become so common with the communities' ageing population that even younger people were aware of it. In others, such as the Mon, Karen, Nepali and Vietnamese groups, dementia was not usually encountered and there was little awareness of it.

In many cases, community members described symptoms of dementia but said that these were not considered to be problems that required medical attention. Many saw the symptoms of dementia, even

in its later stages, as part of the natural processes of ageing that was the responsibility of the family to manage. Community members from Middle-Eastern, African, and Asian backgrounds reported that family members compensated for difficulties an older CALD person might have with everyday tasks, and that this meant that dementia was not seen to be a problem until it was much further advanced. Consistent with the literature on CALD Australians' dementia diagnosis, many communities provided accounts of family members' diagnoses happening after a major accident or serious illness that required hospitalization. In other instances, help was finally sought when the person with dementia's safety was at stake.

There was a marked difference in health-seeking behaviour among the different communities. In established European communities such as the Italian, Greek, and German communities and among those that had high levels of English proficiency (e.g. the Filipino community), General Practitioners (GPs) were regularly consulted for health concerns, including problems with memory. In other communities, especially those from refugee backgrounds (e.g. those from African countries, Syrian, Iraqi, and Bhutanese Nepali refugees), there was a general reluctance to seek medical attention, sometimes relating to perceived language barriers or a reluctance to seek help for what were considered issues of mental illness.

A consistent theme was the challenge of recognising early symptoms associated with dementia. While carers had a good idea of the difference between normal ageing and dementia, other community members sought greater clarity about what exactly were dementia signs and symptoms. Many community members described experiences of difficulty in gaining a dementia diagnosis as it was common for people to present to GPs expressing concerns about dementia and to be told that the problems they or their family members were experiencing were normal parts of ageing.

CALD community perspectives on dementia risk and immunity

While there was a marked variation between communities in terms of dementia awareness and knowledge of risk reduction strategies, isolation was identified as a major issue of concern for communities and was the most frequently and consistently cited risk factor. Different communities compared the situation of older people in their countries of origin to the experience of ageing in Australia. Older people in their countries of origin were perceived to be less isolated, able to gather in public spaces, and were surrounded by people they could talk to. In contrast, life in Australia was painted as potentially being a more isolating experience for the older person with the absence of public physical spaces, and language barriers. Ethno-specific aged care facilities where older people, people experiencing dementia, carers, and family members could gather and receive services in-language were seen as important to addressing social isolation.

Not being able to communicate in one's own language was seen as isolating and of concern in established European communities (e.g. Italian and German) who had high levels of English proficiency and who considered their needs in most other areas to be similar to the needs of the general Australian population. Since a person with dementia often loses their ability to communicate in languages other than their first language, having services staffed by bilingual care workers was considered to be important for addressing the needs of a multicultural ageing population.

The focus on isolation as a risk factor led some communities to consider themselves to be vulnerable to dementia due to disruptions to social networks and systems of support resulting from migration (e.g. Karen, Spanish, Indian, Syrian and Iraqi). On the other hand, the focus on isolation as a risk factor also led other communities (e.g. Indian) who prided themselves on their family-orientedness and communitarianism to see themselves as being immune to dementia, which some considered to be a particularly Western problem resulting from weak familial structures and the perceived lower status of older people in Australian society.

Special issues for CALD Australians of refugee background

Consultations with refugee communities indicated that the impact of torture and trauma is a critical concern for many Australians from a refugee background. Many of the communities consulted (including non-refugee groups) saw dementia to be a result of hardship, and fear of the impact of such experiences was especially pronounced for people of refugee background. In consultations with recently settled Iraqi and Syrian refugees, some community members indicated that they thought that dementia was an inevitability based on their experiences of war and conflict. Community members expressed concerns about the impacts of physical head injuries, as well as the psychological traumas associated with experiences of war. A consultation with a refugee health advisory group reiterated these concerns and raised the problem of the difficulty of distinguishing the symptoms of dementia from those of Post-Traumatic Stress Disorder (PTSD), a common condition suffered by people who have experienced torture and trauma.

Stigma

The stigma of dementia was especially pronounced in Indian and Middle-Eastern community consultations where dementia is considered to be a mental illness, which is itself heavily stigmatised. Other groups, such as the Burmese communities, noted that 'dementia' was often translated as 'mad' or 'crazy'. In Arabic-speaking communities, dementia is considered to be something that is shameful that the family should keep to themselves. The stigma of dementia was so strong that when community members expressed their own fears of getting dementia, they did so in relation to the shame that it would bring on their children and how this would affect a child's marriage prospects. In many Asian communities (e.g. Nepali, Vietnamese, Indian), dementia was seen to result from discord within the family or family members' neglect of the older person.

There was also stigma in many communities around the use of residential aged care facilities. Some noted the loss of standing a community member would face if it was known that their parents were in residential aged care. Carers in Chinese, Spanish, and Filipino consultations spoke of their guilt at their parents going into nursing homes. Some families sought support from counsellors to manage these feelings of guilt. In consultations with emerging communities (e.g. Vietnamese, Indian, Karen), participants acknowledged that it was considered unacceptable in their communities for a parent to go to a nursing home, but understood the different conditions of life in Australia where children needed to work and families did not have the support of large extended families that they did in their countries of origin. Community members consulted overall had a more favourable attitude towards services that catered to their specific needs, such as those around language, food, spirituality and cultural mores.

Priorities identified through the consultations:

1. Improve dementia literacy in CALD communities and thereby timely diagnosis and help-seeking.
2. Decrease stigma in CALD communities in relation to dementia, and service use.
3. Understand perceptions of dementia risk and efficacy of risk reduction in CALD communities; and how to address perceptions to promote adoption of risk reduction behaviours.
4. Understand how to adapt multimodal interventions to reduce dementia risk in CALD communities, including the use of co-design methodologies.
5. Understand the levels and strength of association of risk factors associated with being of CALD background (e.g. being of a particular ethnicity, being bilingual or multilingual, being a refugee).
6. Develop innovative research partnerships with CALD communities and aged care services to co-design, test and implement culturally-specific models of dementia care.
7. Build health and care systems literacy in CALD communities to enhance their understanding and capacity to navigate the health and aged care system through dementia workshops and training.

APPENDIX D: RESEARCH AND HEALTH AND AGED CARE SECTORS SURVEY

An online survey to complement community consultations was opened for submissions from 8 April to 29 May 2019. The survey was distributed to the NNIDR Membership and Steering Group member contact lists, with input invited from the following (individuals or organisations):

- Aged/dementia care and service providers
- Clinicians / allied health workers
- Dementia researchers
- Interested members of the public, including CALD people living with dementia, their carers and families.

The survey asked seven (closed and open-ended) questions about the priorities for dementia research and translation, the inclusion of CALD Australians in research activities, and tailored strategies for them in service provision. It also sought information on respondent demographics.

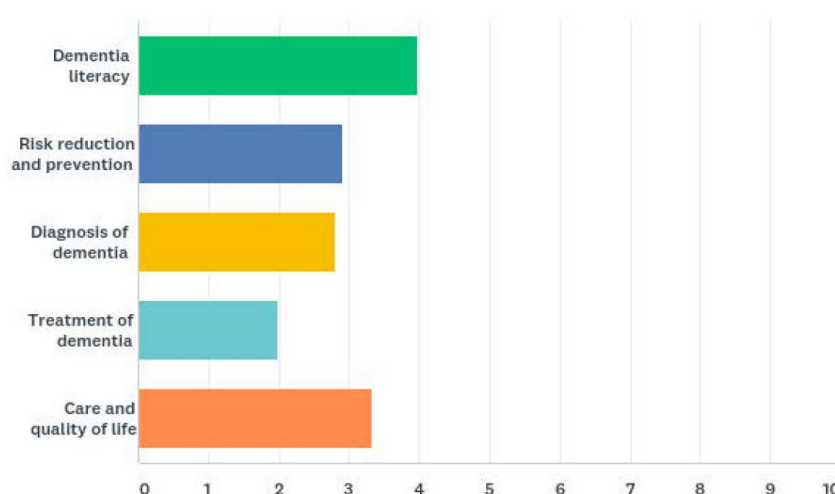
Results

A total of 102 responses were received, primarily from researchers (54%, n=55), clinicians and allied health professionals (21%, n=21), aged/health care workers (21%, n=21), and CALD community organisation members and/or ethno-specific care providers (11%, n=11). Twenty-one respondents (21%) identified as carers or family members of a person with dementia.

Respondents were primarily female (83%, n=85), and born in Australia (n=58), but were from highly diverse cultural backgrounds with 43 different countries of birth and 49 different ethnic/cultural backgrounds recorded.

Priority Areas for the Action Plan

Survey respondents were asked to rank the five priority areas identified by the Steering Group in order of importance to their work. Awareness and knowledge of dementia for CALD communities was clearly the highest priority (with 50% [n= 51] respondents ranking it first, and 22% [n=22] ranking it second), followed by dementia care and quality of life (26% [n=27] ranking it first and 22% [n=22] ranking it second).



Respondents were then asked to vote for their five most important outcomes for CALD dementia research. Eleven outcomes, based on discussions at the first Consultation Workshop, were provided

for voting, with respondents also able to add their own suggestions. Respondents converged on three key outcomes as the most important goals for dementia research and translation, namely

- 1) Increased CALD community knowledge of dementia and awareness of dementia services (73%).
- 2) Increased awareness and training for GPs, health professionals and service provision staff about the unique issues CALD communities experience in relation to dementia (70%).
- 3) Development of CALD-relevant models of care (e.g. ethno-specific, support for care at home, community support system (65%).

The first and third outcome priorities resonated with feedback received during the community consultations. The second and third priority outcomes align with the priorities identified during the first consultation workshop. The outcomes of increased researcher knowledge about how to include CALD communities in research and a greater understanding of CALD-specific care needs in formal care settings, and how to meet them, both received votes from 48% of respondents.

Challenges for CALD and dementia

When asked about the most significant challenges in providing dementia care to CALD people, respondents focused on:

- Language and communication problems between CALD people with dementia and care workers or health professionals. A number of responses discussed the topic of people with dementia reverting to their first language, low numbers of bilingual care workers, and the unwillingness, or lack of confidence, of care and service providers to use interpreters.
- Low awareness of cultural needs and preferences in the health and aged care sectors. A large number of responses highlighted this issue, which was seen to result in isolation and loneliness through a loss of connection to cultural origins, and/or an unwillingness by families to seek help.
- Lack of accurate, validated diagnostic tools for CALD people was identified as a major concern by clinicians and researchers, as was low use of the RUDAS tool (the Rowland Universal Dementia Assessment Scale, designed to minimise cultural and language biases in assessments) by General Practitioners. This was resulting in reduced misdiagnosis, or late diagnosis.
- Lack of appropriate CALD support resources, where the need for CALD specific staffing was highlighted. A number of respondents were of the view that Australia's health and aged care system itself was a barrier for CALD people with dementia in accessing appropriate care.
- Different understandings of dementia, and how to care for someone with dementia. This issue was seen as resulting in poor identification of dementia and awareness of risk factors; late presentation and low levels of help-seeking or engagement with services - often due to dementia stigma in some CALD communities and cultural norms around the importance of home and family care.

What is needed to improve care and quality of life outcomes?

Respondents were asked their views on what information was needed to improve care and quality of life outcomes for CALD people with dementia. Responses coalesced around the following themes:

- Improved epidemiological data on CALD and dementia to support service planning and resourcing for CALD-appropriate services.
- Improved understanding of the cultural norms that may influence access to healthcare systems, uptake of care services, and co-development of culturally-appropriate solutions to meet specific

care and support needs. Both of these points were seen as essential to respond to the mistrust of, or unwillingness to engage with, health and care systems and services.

- Effective care interventions, including to support language loss and cultural disconnection, and CALD-relevant risk reduction programs.

Current patterns of inclusion of CALD in research and services

When researchers (n=70) were asked how often they included CALD participants in research, 26% replied 'always', and 30% responded 'usually'. Almost half (44%, n=31) indicated they only sometimes or rarely included CALD participants.

The barriers that participants cited included time, cost (e.g. for interpreters and translating materials), researchers not considering diversity or CALD in recruitment, difficulty reaching community networks and gaining community member trust, and stigma of dementia in the community.

When service providers (n=41) were asked if they had a strategy or policy for including and accommodating CALD people in service provision, 58% (24) indicated they did, with a further 27% (11) indicating their organisation had made some attempt to include or accommodate CALD people. However, only three survey responses were received from respondents who indicated they worked for mainstream aged care providers.

The barriers that participants identified in responding to CALD-specific needs and preferences were: language and communication barriers; poor access to interpreters; a lack of information and assessment tools in different languages; and staff not understanding or being trained in specific CALD needs and preferences.

Several respondents noted their workplace had a diversity coordinator and/or diversity committee officer, and several others noted the importance of engaging with the Partners in Culturally Appropriate Care (PICAC) program and multicultural community organisations as a source of support for service providers.

Summary remarks

"The reality is that many services available to CALD communities are mainstream and not at all user-friendly or even helpful to people from CALD who have very particular requirements regarding health care services.... The one-size-fits-all system is not working in Australia, evidenced by the reluctance of many CALD groups failing to access primary healthcare services to prevent and remedy health issues until the situation is dire and any help sought is often too late.... Focusing on family-friendly person-centred services will help to reverse this trend."

"...I believe that the CALD Action Plan needs to prioritise working with [...] CALD communities to build trust and co-design community development interventions that will enable increased health literacy within these communities, while also empowering CALD community members to speak up about the types of services that are important for them, and which they would engage in."

"There is a need for more research which includes and is specific to CALD Australians. Greater inclusion of CALD Australians in research will only help to substantiate the needs of CALD Australians and the culturally-appropriate factors that impact on care and quality of life outcomes for these populations."

Survey Recommendations for the Action Plan

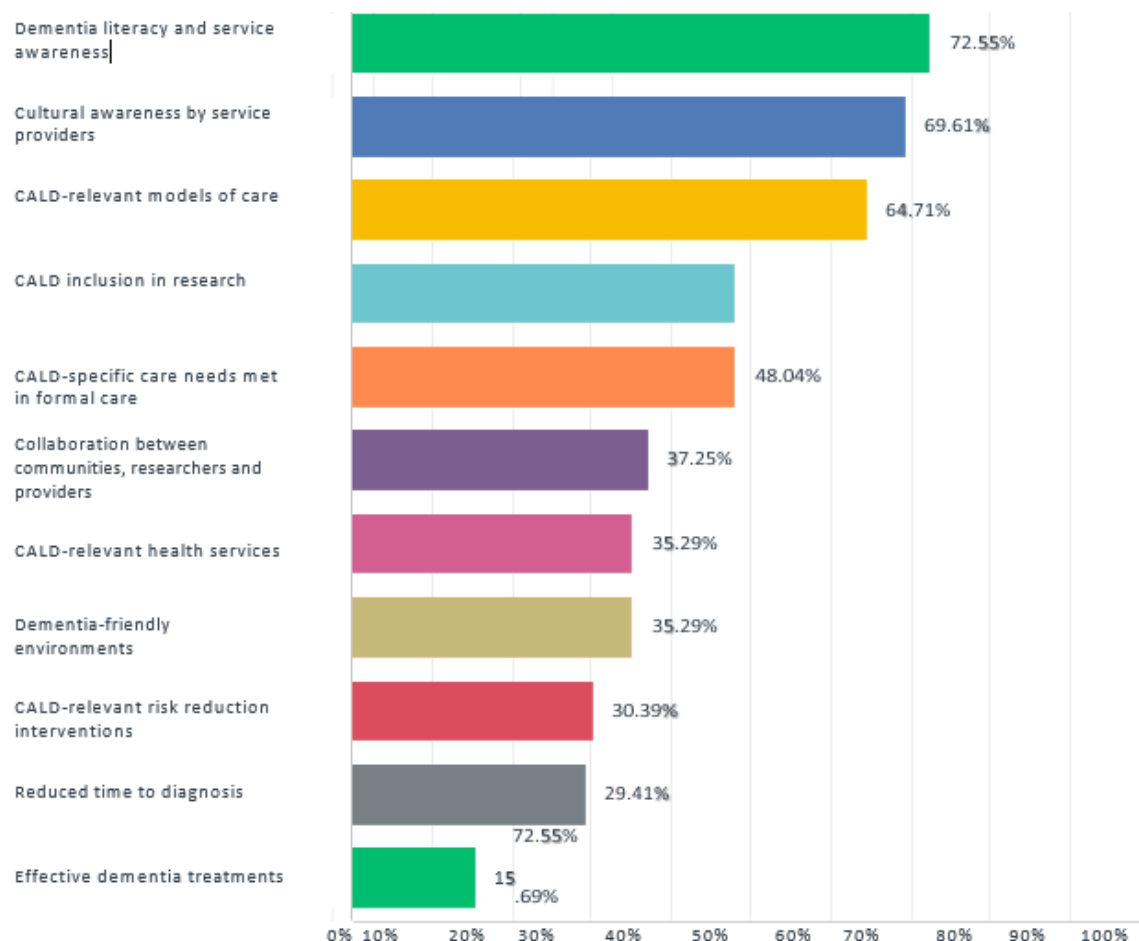
The majority of respondents identified the following strategies as essential:

- Cultural competency awareness and training for health care professionals, and health and aged/care workforce
 - More trained bicultural or bilingual staff in aged and home care.

- CALD-specific dementia information, and CALD-appropriate services, models of care, and care pathways that are co-designed with communities. In particular:
 - Dementia education is needed in communities to reduce stigma.
 - Information is needed for caregivers on how to access services.
- Specialised CALD contact or outreach officers to provide a link between communities and services
- Recognition in the research sector on the importance of including CALD perspectives and involvement of CALD participants and communities in all dementia research, including clinical trials, and at all stages. In particular:
 - Extra resources to engage interpreters/translators and/or community support people are needed.
 - Active and tailored recruitment strategies should be recommended.
 - Improved connections with communities should be facilitated.

Q2. What do you think are the most important outcomes for dementia research involving CALD communities?

Please pick your top five (5) priorities for your own research, workplace or community:



ANSWER CHOICES	RESPONSES	No.
Dementia literacy and awareness of services	72.55%	74
Cultural awareness by health and service providers	69.61%	71
CALD-appropriate models of care	64.71%	66
Inclusion in research	48.04%	49
CALD-specific care needs met in formal care settings	48.04%	49
Collaboration between communities, service providers and researchers	37.25%	38
CALD-relevant health services	35.29%	36
Dementia-friendly environments for CALD communities	35.29%	36
CALD-relevant risk reduction strategies and programs	30.39%	31
Reduced time to diagnosis	29.41%	30
Effective dementia treatments	15.69%	16

APPENDIX E: 2ND STAKEHOLDER WORKSHOP

A second stakeholder workshop was held on Wednesday, 12 June 2019, in Hobart. This was a half-day workshop that involved 25 researchers, service providers, advocates and consumers, including representatives from Department of Health, FECCA, and Dementia Training Australia (DTA). The workshop was broken into two parts: a whole-group discussion of the proposed priorities, and small group discussions of the implementation of each of the priorities.

Feedback on Priorities

The NNIDR and NARI project team began by introducing the aims of CALD Dementia Research Action Plan and its alignment with the NNIDR's Strategic Roadmap. The team provided an overview of the outcomes of the first workshop, the community consultations and the survey, and outlined the plan for the finalisation of the action plan. Each of the priorities in the draft action plan was presented and discussed in turn.

The priorities were grouped into six areas that included dementia awareness; risk reduction; screening, assessment and diagnosis; treatment; care; and inclusion in research. Within these broader areas, the priorities were categorised according to funding, policy and translation, and training and education. Attendees were asked to consider the appropriateness of the priority, the clarity of the way the priority was worded, and if they thought there was anything missing. The group discussed the role of the Action Plan and its scope, the relation between research and policy and translation, and how to capture the needs of different groups in the priorities.

The key recommendations the group made were:

- 1) To make clear the research need in the wording of the priorities
- 2) To maintain the policy and translational aspects of the plan
- 3) To consider the role of implementation research before prescribing solutions
- 4) To consider how items may apply across the life course and be relevant pre and post diagnosis of dementia.

Following this consultation, the project team fine-tuned and restricted the priorities to focus on research. Training and education items were amalgamated with implementation research and translational and policy items that overlapped were streamlined and re-classified as guiding principles.

Implementation of the Action Plan

The second part of the workshop involved workshopping implementation of the plan in smaller groups. Attendees broke into three groups depending on their expertise and interests to discuss the first three priorities, then into different groups for the remaining three priorities. Participants were asked to consider how the plan could be implemented, and how collaborations needed to enact the plan could be formed and supported. Key points that participants raised were:

- The need to incentivise the inclusion of CALD people in dementia research
- The need to support sustained collaboration between researchers working on CALD dementia research
- The need for guidelines about when and how to include CALD people in dementia research and for working with CALD communities
- The need to address methodological issues arising from including diverse groups
- Greater clarity around what the category of 'CALD' included and what variables are important for different kinds of research.

APPENDIX F: DELPHI SURVEY RESULTS

Following a modified Delphi approach, the 21 identified priorities were put to stakeholders, peak bodies and organisations. Invitees to both workshops were sent a link to an online survey where they were asked to rank the priorities from 1 to 21 with '1' being the most important and '21' the least important. Results of the ranking were analysed in Survey Monkey. The items were scored in reverse, with an item ranked '1' getting a score of '21' and so on.

Fifty-six individuals were invited to take part including researchers, service-providers, advocates and carers. Of these, 26 filled out the survey. Sixty-five percent (17) of respondents were researchers, 27% (7) were service providers. Two carers also responded to the invitation. The majority of participants (70%, n=18) in the Delphi survey had more than ten years' experience in their role. Eighty-one percent (21) were female.

Individual Stakeholder Ranking of the Priorities (N=26)

1	Research to increase the uptake of evidence-based, culture-fair tools for dementia screening and diagnosis in primary and acute care settings.	15.04
2	Research to inform effective ways to improve timely help-seeking for dementia in CALD communities.	14.91
3	Research to 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.	14.32
4	Research that informs the development or adaptation of validated dementia assessment tools for CALD persons presenting with symptoms of dementia, including content of the tools and procedures for administration.	14.13
5	Research into effective ways to promote risk reduction behaviours in CALD communities.	13.83
6	Research to inform understanding of differences in symptom presentation among CALD persons with dementia versus non-CALD persons with dementia.	13.3
7	Research that contributes to developing timely pathways to and from diagnosis for CALD persons with dementia.	13.04
8	Research to inform understanding of the prevalence of dementia in CALD communities.	13
9	Research into effective ways to train frontline health and care staff on how culture influences dementia, including through continuous professional development.	12.84
10	Research into the factors that influence treatment adherence for CALD people living with dementia, including research into the cultural acceptability of de-prescribing medications, as well as the prescribing of non-pharmacological interventions (e.g. social interaction, exercise).	12.43
11	Research to inform effective ways to improve dementia literacy in CALD communities.	12.04
12	Research to develop and implement evidence-based interventions in primary and acute care settings to reduce the stigma of a dementia diagnosis and facilitate referral to CALD-appropriate services for CALD persons with dementia.	11.74
13	Research that investigates differences in communicating dementia diagnosis and prognosis and optimal ways to deliver this information across different ethnic groups.	11.5
14	Research into developing evidence-based culturally-appropriate measures to assess the wellbeing and quality of life of CALD people living with dementia and their carers.	11.42
15	Research to inform effective ways to decrease stigma in CALD communities in relation to dementia, and service use.	10.14
16	Research to inform understanding of perceptions of dementia risk in CALD communities.	9.45
17	Research into better understanding the vulnerabilities of CALD carers (especially women) and interventions on how to improve/sustain their health and wellbeing.	9.21
18	Research that investigates differences in communicating dementia treatments among CALD persons with dementia versus non-CALD persons with dementia and ways to optimise decision-making for treatments across different ethnic groups.	7.67

19	Research into technological innovations to improve health and social care for CALD people living with dementia.	7.57
20	Research that contributes to understanding differences in biological indicators of disease presence between ethnic groups.	6.48
21	Research into the use of cholinesterase inhibitors and other medications for dementia among CALD persons with dementia.	4.81

Five peak bodies and organisations were also approached to advise on the ranking of the priorities. We received input from a total of nine organisations (with some peak bodies approaching their member organisations).

Organisation Ranking of the Priorities (N=9)

1	Research to increase the uptake of evidence-based, culture-fair tools for dementia screening and diagnosis in primary and acute care settings.	15.78
2	Research that informs the development or adaptation of validated dementia assessment tools for CALD persons presenting with symptoms of dementia, including content of the tools and procedures for administration.	15.67
3	Research to develop and implement evidence-based interventions in primary and acute care settings to reduce the stigma of a dementia diagnosis and facilitate referral to CALD-appropriate services for CALD persons with dementia.	14.22
4	Research to inform effective ways to improve dementia literacy in CALD communities.	14.11
5	Research into better understanding the vulnerabilities of CALD carers (especially women) and interventions on how to improve/sustain their health and wellbeing.	13.67
6	Research to 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.	13.33
7	Research into effective ways to train frontline health and care staff on how culture influences dementia, including through continuous professional development.	13.13
8	Research to inform effective ways to decrease stigma in CALD communities in relation to dementia, and service use.	12.63
9	Research that investigates differences in communicating dementia treatments among CALD persons with dementia versus non-CALD persons with dementia and ways to optimise decision-making for treatments across different ethnic groups.	12.38
10	Research that contributes to developing timely pathways to and from diagnosis for CALD persons with dementia.	11.89
11	Research into developing evidence-based culturally-appropriate measures to assess the wellbeing and quality of life of CALD people living with dementia and their carers.	11.75
12	Research to inform effective ways to improve timely help-seeking for dementia in CALD communities.	11.11
13	Research that investigates differences in communicating dementia diagnosis and prognosis and optimal ways to deliver this information across different ethnic groups.	10.75
14	Research into effective ways to promote risk reduction behaviours in CALD communities.	9.88
15	Research into the factors that influence treatment adherence for CALD people living with dementia, including research into the cultural acceptability of de-prescribing medications, as well as the prescribing of non-pharmacological interventions (e.g. social interaction, exercise).	9.67
16	Research to inform understanding of perceptions of dementia risk in CALD communities.	9.63
17	Research to inform understanding of the prevalence of dementia in CALD communities.	9.11
18	Research that contributes to understanding differences in biological indicators of disease presence between ethnic groups.	8.22
19	Research to inform understanding of differences in symptom presentation among CALD persons with dementia versus non-CALD persons with dementia.	6.78

20	Research into the use of cholinesterase inhibitors and other medications for dementia among CALD persons with dementia.	6.38
21	Research into technological innovations to improve health and social care for CALD people living with dementia.	6.25

Responses from individuals and organisations were combined, with the organisations' submissions counting as one vote, and the final ranking of the priorities in the Action Plan reflects responses from both individuals and the organisations.

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- Filipino Community Council of Victoria
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