

SUBMISSION TO THE ROYAL COMMISSION

Questions about you

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Do you live in a remote, rural or regional area? : I do not live in a remote, rural or regional area

Previous submission:

This submission is on behalf of : Other

Name of service provider or other person : The National Ageing Research Institute (NARI)

About your submission

Which of the Royal Commission's terms of reference is your submission about?: Challenges and how to best deliver aged care services to people living with dementia; Challenges and how to ensure aged care services are person-centred (including by allowing people to exercise choice, control and independence of care and improving engagement with family and carers); Challenges and how to best deliver aged care services in a sustainable way (including through innovative models of care, use of technology and investment in the aged care workforce and infrastructure)

What, if any, specific concern/s does your submission relate to? Discrimination of any kind; Loneliness, disengagement, disconnection and/or boredom

What type of aged care services does your submission address? Care in an aged care home (nursing home); Services of any kind to a person living with dementia; Other

Other service addressed : Aged care for culturally diverse older people.

Your Submission

What would you like to tell the Royal Commission?

The need for evidence-based approaches to address the aged care needs and vulnerabilities of culturally and linguistically diverse Australians

Who we are

The National Ageing Research Institute (NARI) is an independent research institute focused on translational research in ageing. A key focus of NARI's work is research with culturally and linguistically diverse (CALD) older people, conducted in partnership with communities, health professionals, and service providers.

Summary of submission

NARI advocates that a strong evidence-base is required to respond to the needs of older CALD Australians and to address the particular challenges that they face in the Australian aged care system. Research to develop this evidence-base must consider the diversity of CALD Australians, their different vulnerabilities, and innovative models must be co-designed with CALD communities to deliver effective and cultural sensitive services.

Our submission to strengthen evidence-informed service delivery focus on:

1. Addressing language barriers;
2. Delivering sustainable, culturally appropriate models of care;
3. Increasing awareness of dementia and care options in CALD communities;
4. Leveraging the multicultural aged care workforce;
5. Generating robust national data on which policy decisions can be made.

CALD older people, Aged Care, and the need for research

Australia is one of the most multicultural countries on earth, surpassing the United States, Canada and the United Kingdom in the proportion of people born overseas [1]. One in three older Australians was born overseas, predominantly in non-English speaking countries [2]. Therefore to achieve equity in service provision, people from CALD backgrounds must be included in the planning and provision of aged care services. This imperative is included in policy documents such as the Commonwealth Department of Health's Aged Care Diversity Framework, which states that it is a right of all Australians, regardless of background or life experience, to be able to access good, inclusive care [3]. Further, the Department's guide for age care providers around the care of older CALD people stresses the importance that this care be culturally appropriate [4].

What is culturally appropriate depends on culturally-derived beliefs and attitudes that are embedded in the communities, migration experiences, and health literacy levels including an understanding of how the health and care system works [5]. While post-war European migrants currently make up a large portion of the CALD Australians aged over 65, this will change over the coming years with Indian and Chinese communities being the fastest growing CALD populations [2], and with more

recent arrivals from African countries and the Middle East.

Key areas where research can contribute to improving the quality of aged care to CALD older people and their families

1. Overcoming language barriers

In some CALD communities, such as the Mandarin, Vietnamese, Greek, Maltese, and Spanish-speaking groups, language can be a major barrier to older people accessing services [6]. Difficulties in translation and interpretation contributes to delayed diagnoses of conditions and delayed uptake of services [7]. Almost 2 in 10 older Australians speak a language other than English at home, and 1 in 20 speak English poorly or not at all [2]. Aged Care Assessment Teams (ACAT) rely on interpreting services when assessing non-English proficient clients [8], yet interpreting services in Australia are subject to supply and demand imbalances, inconsistent quality of services, and lack of availability in regional areas [9, 10].

Lack of proficiency in English and an inability to communicate with care staff can be especially problematic for CALD people with dementia in aged care facilities. Even people living with dementia who have acquired English fluency may progressively lose their ability to communicate in non-primary languages [11, 12]. Thus, while there may be high levels of English proficiency in some CALD communities such as the German- or Dutch-speaking communities, language barriers may still be present for the older CALD person with dementia in aged care. Being unable to communicate can result in social isolation, depression, and a greater prominence of the behavioural symptoms of dementia [13], which can leave an older CALD person with dementia vulnerable to an increased risk of experiencing abuse.

Recent NARI work has explored solutions to these problems through the use of video-interpreting and translation apps in care environments. Our findings suggest that these solutions can go some way towards mitigating the barrier and added vulnerability of low English proficiency [14]. Research into ways to effectively and feasibly roll out the use of technological solutions such as video-interpreting and translation apps is needed. There also needs to be specialised training for interpreters who work with older people accessing the aged care system, and especially people whose communication abilities are affected by dementia. Innovative solutions, designed with CALD people and service providers, can lessen the challenge of limited English proficiency.

2. Delivering sustainable, culturally appropriate models of care

Overall, CALD Australians are under-represented in residential aged care but over-represented in their use of community aged care services [15] and there is a strong preference for family care and community over residential care amongst some CALD groups [5, 16-18]. It is tempting to view this as a positive, as it can suggest older CALD Australians enjoy greater intergenerational support and are less of a strain on public services. However, the cultural responsibilities of family care predominantly fall on women, and can reinforce gender inequalities [19].

Lower uptake of residential care among CALD groups may also reflect barriers to access such as lower levels of literacy about health and aged care services, lower English proficiency, a lack of trust in those services, community stigma associated with formal care, and lack of culturally appropriate options [6, 20-22]. For example, Chinese and Mediterranean seniors were found to have a strong preference for services that supported the care of older people in the home and had a poor understanding of respite services for dementia compared to third generation Australians [18]. Migrants to Australia often have expectations that their adult children will provide care in old age or in the event of a chronic illness. This aligns with other findings that highlight that people from some CALD communities can be unfamiliar with the concept of formal care, which may be at odds with cultural mores about the roles of family care, the importance of ageing and dying in place, and the stigma attached to relinquishing care for relatives to ‘strangers’, particularly in residential services [5, 20, 23, 24]. However, these assumed obligations can conflict with the dominant Western values that have shaped the work commitments, living arrangements, and life-course aspirations of their children [19, 23, 25-27].

NARI researchers recently conducted 19 Australia-wide consultations with CALD communities for the NHMRC National Institute for Dementia Research, about the dementia-related issues facing communities. The consultations indicated that older CALD people from many communities often acknowledge that the nature of life in Australia is different to their countries of origin, and that their traditional expectations about family care may not be possible for their family members who have acculturated to the Australian way of life [28]. Our consultations also suggest that there is a lack of clarity about how care needs can be met in an environment of shifting expectations and lifestyles. There is an urgent need for evidence on what kinds of home-based or institution-based models of care can best support the needs of older CALD people and their carers and how knowledge and access to these models can be improved.

One approach to meeting the care needs of CALD communities has been the provision of ethno-specific aged care services [13]. Ethno-specific aged care is preferred by many CALD people [5] as it provides older people with the benefits of culturally familiar language, food, and activities. However, access to such services varies by location and size of the community. It is not sustainable to have ethno-specific services for all CALD communities across Australia and in light of demographic transitions, some current ethno-specific care services (e.g. Maltese) may no longer be needed in 10 to 20 years. Further research is needed into how the needs of CALD communities who lack access to ethno-specific care can be effectively serviced by the more mainstream aged care providers and how ethno-specific services that will be redundant in 10 to 20 years can transition to caring for other communities or be future-proofed in other ways.

3. Increasing awareness of dementia and care services

NARI is currently undertaking one of the world’s largest projects on dementia care in CALD communities. The *Moving Pictures* study uses film and media resources to raise awareness of dementia and dementia care in 10 languages, thereby reaching some of the largest CALD communities in Australia. These languages are: Mandarin, Cantonese, Vietnamese, Hindi, Tamil, Arabic, Greek, Italian, Spanish, and English. Our approach has been to co-produce the resources with communities in their own languages to ensure they are both culturally sensitive and effective at conveying the message. As part of the project, we interview CALD carers of people living with dementia who describe their experiences of caregiving, and the barriers they face in obtaining a diagnosis and accessing services for their family member with dementia. Consistent with previous research, these barriers included lack of English proficiency, lack of knowledge about dementia and health services, stigma within their communities, cultural obligations about care and caregiving, inconsistent advice from health professionals, and long wait times for services. The purpose of the films is to dispel some of the stigma and anxiety associated with dementia and dementia care, and inform communities about the pathways through which they can access healthcare and support from doctors, MyAgedCare, or other community services.

While some of the barriers mentioned above can be addressed through collaboration with communities, not all can. Other barriers such as lack of digital literacy (which restricts access to the MyAgedCare website), lack of culturally appropriate services, lack of English proficiency, lack of available interpreters with relevant expertise, and a lack of availability of culturally adapted materials need to be addressed on the side of policy and services [29].

These examples show the importance of improving awareness and literacy, but they also show the importance of improving pathways of access between CALD families and care services. Dismissal of dementia symptoms by doctors as ‘normal’ ageing, refusals to refer to specialists, and use of culturally inappropriate assessment tools are consistently noted as barriers to obtaining a timely dementia diagnosis for CALD patients.

4. Leveraging an increasingly multicultural aged care workforce

Some CALD communities are already strongly represented in the aged care workforce; for example, a 2016 survey showed 40% of recent employees in residential aged care facilities were migrants [30], primarily working as personal care attendants (PCAs). Most PCAs are from Indian and Filipino backgrounds, but there is increasing representation from those from Iraq and Sudan [30, 31].

To work in aged care, the minimum qualification is a Certificate III in Individual Support (hereafter ‘the Certificate’). Several education initiatives target migrants to complete the Certificate but often charge high fees, and do not provide adequate training for working with people with dementia in residential and community aged care environments. These oversights matter because more than 50% of people in residential aged care have dementia [32] and migrant care workers have limited experiences of dementia care [31]. Moreover, migrant workers face many challenges in aged care around communication difficulties and prejudicial treatment [31].

If we limited our views to this deficit model – which recognises only problems and deficiencies arising from having a CALD aged care workforce and the need for further training to plug these knowledge gaps – then we miss a unique opportunity in Australia: i.e., the opportunity to engage with migrant workers and CALD communities about what good quality care entails.

Such engagement reveals a language of hope. Our work shows that care lexicons across different languages describe multifaceted and nuanced care relationships. Words in Hindi such as *seva* (service); *zimme daaree* (responsibility); and *dhyaan* (attention); vernaculars in Chinese such as *Guān Huái* (closed bosom) or the love and care a mother gives her child, and *Zhào Gù* (to shine and watch over someone); and in Arabic, *hanān* (kindness, compassion, and love) and ‘*ināyat* (to look after an old or sick person). These are languages that enmesh people within their families and communities, and are radically different to Western notions of individually-oriented care [33]. They speak to care practices of empathic imagination, responsibility, witnessing, and solidarity [34] and are vast untapped cultural infrastructures of care.

Equipping aged care workers to approach questions of care predicated on cultural notions of reciprocity, mutual responsibility, and respect is important for two reasons: (1) because many aged care workers are often from the very CALD groups where there is limited understanding of the term dementia but more comprehensive understandings of care. (2) Despite increased ethnic diversity among providers and people with dementia it is difficult to culturally match the two groups. In our work, we have visited Italian care facilities where there are no Italian-speaking staff, mainstream facilities where the all-white residents are cared for by Samoan staff, and Greek facilities where staff had to be recruited from Greece because second-generation Greek-migrants were not interested in working in aged care.

Ethno-specific services have a shelf-life; sustainable care models need to be inclusive and reflect the culturally diverse communities we all live in. Implementing strategies to make work satisfying and meaningful, and improve the quality of care are front and centre for the Commonwealth Aged Care Workforce Strategy Taskforce. Population ageing, and the person-centred nature of the work means it is unlikely that these jobs will be replaced by technology in the near future, thus making employment sustainable. Migrant care workers are likely to grow as a proportion of the aged care workforce; therefore, harnessing the benefits of a multilingual, multicultural aged care workforce to cater to the needs of older people, including CALD people, starts from a position of strength and builds connections between these vulnerable populations.

5. Generating robust national data on which policy decisions can be made.

Despite CALD Australians making up a third of the population [35], they are often excluded from Australian research, and information on ethnicity, language, and country of birth is not routinely collected or reported [36]. 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 [36]. Similarly, data from 16 Australian dementia epidemiology studies were collected only in English and six of these studies excluded participants not fluent in English [36]. Potential consequences of this under-representation are non-representative samples in epidemiology and clinical trial studies resulting in inaccurate effect sizes on which clinical, policy and economic decisions are based, and less effective implementation of research evidence into practice for CALD communities.

Currently, there is no single variable for CALD; rather, variables are multiple and intersecting and researchers and policy-makers frequently report difficulty in identifying which variables to collect and how to bring them together in a robust analysis that accounts for the cultural and pathological heterogeneity often found among CALD study participants. NARI recommends that minimum criteria be established for what constitutes CALD-related data (e.g. country of birth, years lived in Australia, language spoken at home etc.) and that these criteria be followed across all government funded surveys such as those administered by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare.

NARI also recommends that to facilitate the recruitment and participation of older people from multiple CALD groups in national studies, a national platform and registry is needed. We have already built a digital prototype for a culturally and linguistically diverse research engagement network (CALD-REN), which includes more than 1600 CALD organisations segmented by state, ethnicity, organisation type (e.g. health service, community, business, media etc.), and key contacts. CALD-REN is already being used within NARI to recruit for national studies, build relationships with CALD communities across the country, and disseminate information. But this critical national research infrastructure platform is needed to benchmark existing health and social disparities between older CALD people and older Australians and systemically determine whether policy and practice interventions are reducing these disparities.

Conclusion

The Royal Commission provides an opportunity to reflect and act on how Australia has cared for its diverse older populations and how it will do so into the future. To best deliver aged care services to older Australians (of whom CALD people make up a third), robust research into the diverse care needs of CALD Australians is needed. NARI's experience in such research indicates that in order for interventions and delivery to be successful, programmes must be co-designed with communities and service providers. With its diverse, multicultural population, Australia has a unique opportunity to develop innovative models for caring for diverse older people; such models will be relevant to the ageing populations of many advanced economies.

References

See attachment.

Supporting material provided:

References.pdf

Can this submission be made public I agree to my submission being made public under my name