

# Redesign of Dementia Consumer Support Consultation Paper

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**15 November, 2017**

Australian Government  
Department of Health  
[dementia@health.gov.au](mailto:dementia@health.gov.au)

Federation of Ethnic Communities' Councils of Australia

FECCA House, Unit 1, 4 Phipps Close, Deakin ACT 2600 • PO Box 344, Curtin ACT 2605

 02 6282 5755  [admin@fecca.org.au](mailto:admin@fecca.org.au)  [www.fecca.org.au](http://www.fecca.org.au)  @iFECCA

ABN 23 684 792 947

## ABOUT FECCA

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The Federation of Ethnic Communities' Councils of Australia (FECCA) is the national peak body representing Australia's culturally and linguistically diverse (CALD) communities and their organisations. FECCA provides advocacy, develops policy and promotes issues on behalf of its constituency to Government and the broader community. FECCA supports multiculturalism, community harmony, social justice and the rejection of all forms of discrimination and racism so as to build a productive and culturally rich Australian society. FECCA's policies are developed around the concepts of empowerment and inclusion and are formulated with the common good of all Australians in mind.

FECCA has had a longstanding presence in policy and systemic advocacy on ageing and aged care issues for CALD Australians. FECCA is the leading stakeholder in CALD ageing and aged care policy, and has been a significant contributor to a range of collaborations, including the National Aged Care Alliance, and partnerships with other peak bodies, to achieve the inclusion and empowerment of older CALD Australians, their carers, and CALD people who work in the aged care industry.<sup>1</sup> FECCA undertook the consultations to inform the National Ageing and Aged Care Strategy for People from CALD backgrounds<sup>2</sup> and was a member of its implementation committee. Currently, FECCA is represented on the Aged Care Sector Committee Diversity Sub-Group where it is working collaboratively with the Department of Health in developing and implementing the Diversity Framework.

FECCA gives consent for this submission to be published in whole or in part

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<sup>1</sup> FECCA's 2020 Vision for Older CALD Australians, 2015, <http://fecca.org.au/wp-content/uploads/2015/11/FECCA2020Vision.pdf>

<sup>2</sup> Commonwealth of Australia, *National Ageing and Aged Care Strategy for People from CALD backgrounds*, 2015

## FECCA CONTACTS

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**Aleksandra Zivkovic**, Policy and Project Officer

Federation of Ethnic Communities' Councils of Australia

Unit 1, 4 Phipps Close,

Deakin ACT 2600

(02) 6282 5755

[aleksandra@fecca.org.au](mailto:aleksandra@fecca.org.au)

[www.fecca.org.au](http://www.fecca.org.au)

**Cristina Giusti**, Senior Policy and Project Officer, Ageing and Disability

Federation of Ethnic Communities' Councils of Australia

Unit 1, 4 Phipps Close,

Deakin ACT 2600

(02) 6282 5755

[cristina@fecca.org.au](mailto:cristina@fecca.org.au)

[www.fecca.org.au](http://www.fecca.org.au)

# Input to Redesign of Dementia Consumer Support Consultation Paper

## Background

FECCA is one of the leading stakeholders in CALD ageing and aged care policy. Our available data on older people from CALD backgrounds in general highlights that many older CALD Australians have higher levels of disadvantage and other risk factors than older Non-CALD Australians and that these factors may affect their ageing experience in Australia. The life course of migrants from CALD backgrounds, including migration circumstances, and the extent to which cultural traditions are maintained, play a role in health and wellbeing for older people from CALD backgrounds. Language and cultural issues emerge as a common source of difficulty. The literature identifies that older people of refugee backgrounds are particularly vulnerable to physical and mental health issues due mostly to their migration experiences and reasons for migrating. The identified research relating to older people from CALD backgrounds with dementia suggests that a poor understanding of dementia and a cultural stigma relating to dementia can lead to denial of the condition and/or delayed diagnosis for some older people .

Culturally sensitive assessment tools should be utilised when assessing people from CALD backgrounds. Additionally, older people from CALD backgrounds are often excluded from dementia research due to language barriers, leading to gaps in the evidence base.<sup>3</sup>

According to the latest census data (2016) around 17% of Australians over the age of 80 speak little to no English. This is important information that needs to be taken into consideration when planning any future dementia policy. Loss of any acquired (secondary language) is one of the most common features of dementia. In bilingual individuals, regression to a primary language may be associated with development of cognitive impairment and an increased risk for development of dementia.<sup>4</sup>

People with dementia who speak a language other than English at home are expected to increase 3.4 fold to around 120,000 (113,000 and 124,000 in the low and high cases respectively) in 2050. Of the estimated new cases of dementia occurring in 2009, approximately 61,000 speak English at home while 9,000 speak a language other than English. The new cases of people who speak English at home are expected to increase 5.8-fold to 350,000 (329,000 and 372,000 in the low and high cases respectively) by 2050, while

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<sup>3</sup> <http://fecca.org.au/wp-content/uploads/2015/06/Review-of-Australian-Research-on-Older-People-from-Culturally-and-Linguistically-Diverse-Backgrounds-March-20151.pdf>

<sup>4</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4335728/>

new CALD dementia cases is expected to increase 4.0-fold to around 35,000 (33,000 and 37,000 in the low and high cases respectively).<sup>5</sup> These figures bare significant relevance for formulation of dementia policies.

People from CALD backgrounds face numerous barriers when it comes to accessing services. These include difficulties with language and a lack of knowledge of service systems. The lack of culturally and linguistically appropriate services and culturally appropriate assessment is a major impediment to the accurate and timely diagnosis and treatment for dementia. Brain changes associated with dementia present unique challenges to current and past experiences. Such changes not only have a significant impact on family relationships but also cause difficulties for service provision. Furthermore, there seems to be a lack of understanding of dementia by many people in some CALD communities.<sup>6</sup>

FECCA believes that all these issues need to be taken into consideration when planning any future dementia consumer support policy.

## **Discussion Questions**

### **4.1 Information Questions**

#### **4.1.1 Question one**

**Given the existence of an information line for several years and the continued ongoing low dementia literacy rates, are there additional supports that the information line and website can better leverage to increase dementia literacy in the community?**

#### **Response:**

When considering this question, the FECCA stance is that overall literacy of Australian and CALD communities needs to be taken into consideration. There are many CALD communities whose migration history is one in which lower educated and lower skilled migrants were encouraged to come to Australia to provide a manual workforce for post-war development. For many of these migrants, English language proficiency was low. Many migrants were not able to access English language classes in this era due to a lack of resourcing. Many of these post-war migrants are now a significant cohort of Australia's ageing population.

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<sup>5</sup> Keeping dementia front of mind: incidence and prevalence 2009-2050 - August 2009 Final report by Access Economics Pty Limited for Alzheimer's Australia

<sup>6</sup> <https://www.dementia.org.au/sites/default/files/20101201-Nat-CALD-Perceptions-of-dementia-in-ethnic-communities-Oct08.pdf>

It has been evidenced that hotline or telephone based information systems are not a successful medium of communication with CALD communities, particularly older cohorts. The recent *My Aged Care CALD Accessibility Project*<sup>7</sup> states that reliance on CALD older people being able to hear and understand what is being said and then communicate back in the English language were the key issues identified. With CALD consumers living with dementia, retaining the information obtained is another big issue. Consistent data from various research conducted show that CALD communities prefer to rely on translated brochures, information sessions to community groups, orientation sessions at services and community media for obtaining relevant information<sup>8</sup>.

Another significant issue is limited digital literacy. While digital literacy skills can vary, older CALD migrants are generally unlikely to have received training in the use of many new technologies. Initiatives such as the one currently implemented by the E-Safety Commissioner and funded by DSS (<https://beconnected.esafety.gov.au/mod/page/view.php?id=909#>) need to ensure consistent involvement of CALD community members.

Thirdly, in terms of raising awareness on the overall dementia issue, there are tools available that could be utilised for this purpose. There is evidence that older internet users engage strongly with traditional media, particularly broadcast television—almost all older internet users (99 per cent) watched free-to-air television in the last seven days to June 2015. This compared to 91 per cent of all adult internet users. Older Australians were also much more likely to read a newspaper (75 per cent) when compared to all adults (51 per cent). Radio listening was equally popular with both groups (around 88 per cent).<sup>9</sup>

Reliance of CALD communities on traditional media might be even higher than that of the general Australian population. Older CALD communities rely on SBS, primarily radio, on receiving information relevant to their lives in Australia. One way of improving the awareness could be through promoting websites where relevant dementia information is available on SBS. SBS radio, and indeed the TV, could be an appropriate tool for reaching the CALD communities and improving their awareness. Also, CALD communities' print media would serve as a prominent tool to promote relevant websites where information is available in CALD languages.

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<sup>7</sup> Culturally and Linguistically Diverse (CALD) Accessibility Project Report, June 2017. Multicultural Communities Council of Illawarra

<sup>8</sup> [http://refugeehealthnetwork.org.au/wp-content/uploads/Report\\_2016\\_September\\_Victorian-Refugee-Health-Network\\_Talking-About-Health\\_FINAL-WEB2.pdf](http://refugeehealthnetwork.org.au/wp-content/uploads/Report_2016_September_Victorian-Refugee-Health-Network_Talking-About-Health_FINAL-WEB2.pdf); see also Culturally and Linguistically Diverse (CALD) Accessibility Project Report, June 2017. Multicultural Communities Council of Illawarra

<sup>9</sup> <https://www.acma.gov.au/theACMA/engage-blogs/engage-blogs/Research-snapshots/Digital-lives-of-older-Australians>

One such website for raising awareness of dementia amongst CALD communities is the “It’s not a disgrace, it’s dementia” website<sup>10</sup>. A large resource of language specific resources are available and depicts real life stories of dementia experiences in various cultures and how dementia can be dealt with using the supports available.

The website [www.caresearch.com.au](http://www.caresearch.com.au) is also a useful tool for CALD communities and should be further promoted.

Finally, the websites where information on dementia can be found could be made more user-friendly for CALD community members. Although it is commendable that relevant information on dementia is currently available in 40 different languages, reaching the pages with different languages might be a struggle for CALD members, as it requires high levels of English proficiency and understanding of the original content. It could be made easier if on the home page there was a link to lead to specific language information.

#### **4.1.2 Question two**

**Noting the outreach services outlined at 3.4, are there further considerations needed to better support:**

- **consumers with low IT literacy or lack of access to IT infrastructure?**
- **special needs groups, especially with people with low literacy levels, from Culturally and Linguistically Diverse backgrounds or from regional, rural and remote areas to have equity of access to these core information supports services?**

#### **Response:**

An estimated one million adult Australians (six per cent) have never accessed the internet (as at June 2015). Older Australians account for the majority of this group—71 per cent of offline adults fall into the age group of 65 and over. The older the person is, the less likely they are to use the internet. For Australians in the 65 to 69 age range, 11 per cent had never accessed the internet, and this proportion increased to 42 per cent for those aged 80 and over. It is therefore important to note that while the internet is the most frequently used method for contacting government for those aged 64 and under, older Australians are most likely to make contact in person. According to the Digital Transformation Office, the number of those who ‘prefer not to’ or ‘will not use’ digital channels to interact with government was as high as 54 per cent in people aged over 65. People in remote or rural areas were also

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<sup>10</sup> <https://www.dementia.org.au/nsw/its-not-a-disgrace-its-dementia>

less likely to support a digital transformation of government services, which is partly explained by the relative quality of internet access and speeds outside metropolitan areas.<sup>11</sup>

The above figures are additionally amplified when it comes to CALD communities and their limited access to digital technology. Many older CALD migrants operating on a fiscally restrictive pension may be very limited in their capacity to engage with digital technology because of financial constraints. As a consequence, we can see that older CALD migrants may be very easily excluded from digital exchange. FECCA believes that there are strategies that could be employed to improve digital literacy of older CALD Australians. One strategy could be increased funding to assist with basic digital literacy training and digital access. This may include additional funding to local governments and libraries to ensure that adequate free internet is available to those who need it. The current “Be Connected” initiative by the E-Safety Commissioner<sup>12</sup> works to this end and it needs to ensure that there is appropriate involvement by CALD communities. There also needs to be a serious attempt to consider how to migrate CALD clients from their dependence on a ‘human’ interaction (with or without interpreters) to clients that can start on the digital journey, even a limited one.<sup>13</sup>

While pop-up clinics providing dementia education are to be considered a useful and productive initiative, there will be a need to ensure equal participation of all community members in these activities. The organisers should ensure that the relevant announcements of these events reach all the target groups, CALD communities included. Older and ageing migrants are a huge group - 23% of the Australian population aged over 65 years come from a migrant background, and this figure will move rapidly beyond 30% in the next decade. For those older, established communities, this is a significant cohort. It will therefore be crucial when planning and executing these activities that CALD communities are reached.

Finally, we need to ensure that government and other sectors operate in a way that is dementia friendly. Federal and state government agencies will need to address dementia awareness training amongst staff. They need to be skilled to understand and work with dementia people living with dementia.

In banking, initiatives where people with dementia and their carer access information on how to more effectively manage their finances is a good model<sup>14</sup>. This service could be made

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<sup>11</sup> <https://www.acma.gov.au/theACMA/engage-blogs/engage-blogs/Research-snapshots/Digital-lives-of-older-Australians>

<sup>12</sup> <https://beconnected.esafety.gov.au/mod/page/view.php?id=909#>

<sup>13</sup> <https://www.godigi.org.au/blog/innovation-it-and-cald-communities>

<sup>14</sup> for example: <https://www.westpac.co.nz/assets/Who-we-are/Dementia/Brochures/Dementia-Managing-Finances.pdf>

additionally accessible to CALD communities if available materials are translated in as many CALD languages as possible.

## **4.2 Awareness Questions**

### **4.2.1 Question three**

**The Australian Government has been providing support for dementia awareness and stigma reduction activities for over a decade. However, less than 30 per cent of those people living with dementia who access Australian Government funded dementia consumer support programs, heard about the supports from a health professional. Noting the proposed awareness activities outlined at 3.3, given the continuing low rates of dementia literacy among health professionals are there other specific supports that would encourage self-management, independence and reablement to ensure people recently diagnosed with dementia connect to the available support services early?**

#### **Response:**

FECCA often receives anecdotal evidence of “head in the sand” approach by medical professionals when it comes to dementia. FECCA is aware of public hospitals’ low awareness of dementia and Residential Aged Care Facilities sending people with dementia to emergency wards when they could be treated at the facility; or their policies dictate that certain conditions or events necessitate presentation to the emergency wards around the country.

The late diagnosis of dementia is to be considered problematic. Medical and health professionals should be guided to ensure that in making a timely diagnosis that families are able to actively prepare for the future.

FECCA believes that Primary Health Networks (PHNs) could serve as a good instrument to utilise in the education of health professionals including General Practitioners (GPs). There are currently 31 PHNs operating throughout Australia.<sup>15</sup> Through our consultations, we have evidence of a variety of PHNs who work with clinicians and the community, engaging meaningfully in the decision making processes. We also understand that PHNs maintain lists of GPs who have capacity in practical language skills to support CALD communities. With their involvement and outreach and knowledge of particular communities, they could provide significant support in educating health professionals on dementia.

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<sup>15</sup> <http://www.health.gov.au/PHN>

FECCA also recommends including dementia awareness into Continual Professional Development (CPD) curricula for professions that are working in health and aged care space. This would enable a streamlined approach to continued awareness raising and improving knowledge of this important health issue.

Additionally, teaming up with the Medical Board of Australia (regulating Australia's medical practitioners) and the Australian Medical Council (The AMC's purpose is to ensure that standards of education, training and assessment of the medical profession promote and protect the health of the Australian community); this process might ensure a streamlined approach and greater reach of targeted campaigns. Also, specialised web sites for medical professionals (such as My Health Record for example) could have special features on dementia and early diagnosing of dementia.

Moreover, considering that dementia in people from non-English speaking backgrounds, often causes them to revert to their primary language, medical specialists targeted by the campaign need to be kept aware of availability of Free Interpretation Services (FIS)<sup>16</sup>.

According to DSS data, in 2016-2017 financial year, only 19% of registered GPs and 32% of registered medical specialists used FIS.<sup>17</sup> In dementia, early diagnosis is key and GPs are an important link in establishing the diagnosis. Diagnostics of dementia could be facilitated by access to free suitable qualified interpreting services by CALD people. It could also assist them to better understand their rights, availability and eligibility for the services in place. Any dementia campaign targeting the medical profession should also include relevant information on availability of FIS.

It is also important to be able to attain as many resources as possible in print in several languages. These materials can be visibly displayed in medical practices and pharmacies. They can also be given by GPs and other professionals targeted by the campaign to patients and family members. A targeted awareness campaign for General Practitioners, Pharmacists, Registered and Enrolled Nurses and Allied Health Professionals is therefore strongly supported by FECCA.

In aged care, better integration with other available support systems such as primary health and community support should be enabled. In that sense, it is important that the government captures information in relation to identifying as a certain population group with special needs as part of their client record<sup>18</sup>.

Stimulating environments will assist people living with dementia to remain living in their own homes for as long as possible. Immediate access to Home Care packages should also be

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<sup>16</sup> <https://www.dss.gov.au/our-responsibilities/settlement-and-multicultural-affairs/programs-policy/settle-in-australia/help-with-english/free-interpreting-service>

<sup>17</sup> Increase of Usage and Uptake of the DSS Free Interpreting Service Project

<sup>18</sup> Legislated review of aged care 2017 by David Tune

enabled – Priority Level 5 Home Care packages – that provide for respite, personal care, clinical care, meal services and social support in the home, as recommended in the Aged Care Legislated Review Report by David Tune. This will be important to enable family members to continue working without fear of leaving their loved ones with dementia at home alone.

#### 4.2.2 Question four

**Are there any other groups which should be included in the targeted awareness and stigma reduction campaign and how should they be prioritised?**

**Response:**

CALD communities would benefit greatly with targeted awareness and stigma reduction campaigns. Low health literacy, including understanding local health services and how to navigate the Australian health system, restricts access to health care to CALD communities<sup>19</sup>.

It is important to note that different CALD communities often have different perceptions of dementia. For example, Dementia is considered by many Arabic-speaking people to be a normal part of ageing but associated with mental illness. It is also seen as “God’s will”. There is some reluctance in the Arabic community to admit to the illness and, because of the stigma, may stay away from friends and community and become isolated. The family is also likely to limit visits in fear of mockery or criticism.

In the Macedonian community for example, there is generally little understanding about dementia, however the awareness is being raised through **ethnic organisations**. There is a lack of knowledge of the service system and how to access services and information. Both older and younger generations of Macedonian community believe that dementia is a normal part of ageing.<sup>20</sup> Similar examples could be found for other ethnic communities in Australia.

One way of reducing the stigma in the above communities and in many other CALD communities, could be through reach out to the community organisations providing CALD support, religious and ethnic organisations. Culturally inclusive materials could be distributed to these organisations translated into various languages. Targeted coaching sessions could also be organised for leaders of community ethnic or religious organisations (for example, for

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<sup>19</sup> [http://refugeehealthnetwork.org.au/wp-content/uploads/Report\\_2016\\_September\\_Victorian-Refugee-Health-Network\\_Talking-About-Health\\_FINAL-WEB2.pdf](http://refugeehealthnetwork.org.au/wp-content/uploads/Report_2016_September_Victorian-Refugee-Health-Network_Talking-About-Health_FINAL-WEB2.pdf)

<sup>20</sup> <https://www.dementia.org.au/sites/default/files/20101201-Nat-CALD-Perceptions-of-dementia-in-ethnic-communities-Oct08.pdf>

Muslim communities, it could be the Imams – something similar to what is currently being done in the organ donation space<sup>21</sup> ) whose support should be sought in this process.

Targeted community coaching sessions are another way of assisting in this area, as there is evidence that CALD communities prefer face to face communication rather than written information. The best approach is to work with key community leaders through interpreters in a ‘train-the-trainer’ model so that they can convey messages to their communities<sup>22</sup>

## **4.3 Outreach Questions**

### **4.3.1 Question five**

**Are there other factors to consider in ensuring services are appropriate and accessible to the most vulnerable or marginalised people living with dementia?**

#### **Response:**

There is strong evidence that an early diagnosis assists a person with dementia to continue to live independently in their own home for longer. This helps to avoid early or unnecessary admission to a care setting or hospital, enhancing the quality of life for people with dementia and carers and also providing substantial savings on long-term care costs. Pharmacological and non-pharmacological treatments can be more effective with earlier diagnosis. This is particularly relevant for CALD communities, where often for cultural or other reasons associated with dementia stigma, people prefer to stay at home longer.

Psychological evaluation tests of mental functioning are very important in the diagnosis process. Because some of these tests have been shown to have educational, social and cultural biases, it is important that they are properly adjusted and adapted to the needs of CALD community members. For example, The Psychogeriatric Assessment Scale (PAS) used in Aged Care supplement funding processes is not suitable for all cultures as an assessment tool. A tool such as the Rowland Universal Dementia Assessment Scale (RUDAS) for example, which is a culturally sensitive screening tool, should be utilised for CALD community members. RUDAS is a short cognitive screening instrument designed to minimise the effects of cultural learning and language diversity on the assessment of baseline cognitive performance.<sup>23</sup>

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<sup>21</sup> <http://www.donatelife.gov.au/islamic-faith>

<sup>22</sup> Siggins Miller Evaluation of the Participation Trials for My Health Records

<sup>23</sup> <https://www.dementia.org.au/resources/rudas>

FECCA recommends that the RUDAS is the primary assessment tool to be utilised for accessing any government subsidised dementia support supplement.

#### **4.3.2 Question six**

**Will this model of redesign services embed improved access to services and outcomes for people living with dementia into the future?**

##### **Response:**

This model of redesign services has the potential of improving access to services and outcomes for people living with dementia. FECCA believes that, in the Information and Awareness segment, special attention should be paid to people from culturally and linguistically diverse backgrounds. It is projected that the prevalence of dementia in CALD populations will increase to 45,651 in 2020 and 119,582 in 2050. Different cultural perceptions of dementia are present in culturally and linguistically diverse communities. In some communities, dementia is a taboo issue which is not openly discussed, resulting in even higher levels of stigma and negative community perceptions. These cultural perceptions impact on individual willingness to access services and decrease the likelihood of accepting support. In addition, individuals and their carers and families from CALD backgrounds often have limited knowledge of services, lower utilisation rates of community services and lower access to respite care. They may also prefer services that provide care and support in the home, for safety as well as cultural reasons, and are less likely to use residential care services. It is therefore important to ensure that all the materials used in the awareness campaign are available in CALD languages. The trusted intermediators need to be made aware of availability of Free Interpretation Services (FIS) for CALD community members.

#### **4.4 Intervention Questions**

##### **4.4.1 Question seven**

**Current early intervention supports only reach around 1 per cent of people recently diagnosed with dementia. The combined emphasis of the Information (3.2) and Awareness (3.3) elements of the dementia consumer supports are expected to reach a substantially higher proportion of the diagnosed population. Are there other elements that should be considered in order to increase the proportion of the diagnosed population who will know about and want access to these services?**

**Response:**

One element that should be taken into consideration is the role of community organisations in raising awareness in their communities on specific issues. They provide valuable services and with additional funding through grants could be a valuable tool for educating CALD communities. As stated in the Multicultural Communities' Council of Illawarra submission, CALD aged care consumers and their representatives look to organisations and individual practitioners whom they have developed trusting and meaningful relationships over a period of time, such as locally-based community aged care services providers and GPs.

Secondly, multicultural community link workers are often the primary service providers assisting families to access health and welfare services and as such, have extensive experience of, and possess in-depth knowledge about, CALD family care-giving for dementia. The persons occupying multicultural worker positions may come from a range of professional and work backgrounds, but essential requirements for these positions include proficiency in the relevant community language, an understanding of the cultural norms of the community, a sound knowledge of the principles of access and equity, an understanding of the Australian healthcare system, and the ability to work effectively with their communities. Due to their close relationship and knowledge of families, multicultural workers can offer an important perspective that is invaluable in informing the provision of carer education and support within CALD communities.<sup>24</sup> They could and should be a valuable medium for educating the diagnosed population and their carers on the access to available services.

FECCA fully supports an expansion of the CALD Link worker program conducted by Dementia Australia in the South Western area of Sydney, ideally this model should be replicated in other areas where there are substantial older CALD population groups. These link workers provide an invaluable support to their respective communities. Presently there are three cultural link workers taking part in this program for the Chinese, Cambodian and Croatian communities. Effective research and feedback mechanisms could be utilised to gauge the need for other culturally specific officers to bridge the information and service conduit gap in relation to accessing dementia specific services.

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[https://www.researchgate.net/profile/Chris\\_Shanley/publication/51753058\\_Culturally\\_and\\_Linguistically\\_Diverse\\_CALD\\_Families\\_Dealing\\_with\\_Dementia\\_An\\_Examination\\_of\\_the\\_Experiences\\_and\\_Perceptions\\_of\\_Multicultural\\_Community\\_Link\\_Workers/links/565240f208ae1ef929756ee5.pdf](https://www.researchgate.net/profile/Chris_Shanley/publication/51753058_Culturally_and_Linguistically_Diverse_CALD_Families_Dealing_with_Dementia_An_Examination_of_the_Experiences_and_Perceptions_of_Multicultural_Community_Link_Workers/links/565240f208ae1ef929756ee5.pdf)

## **4.5 General Questions**

### **4.5.1 Question eight**

**Is the proposed breakdown of funding proportions for each element appropriate?**

**Response:**

The FECCA stance is that the proposed breakdown of funding is generally appropriate. The one potential concern could be with the Outreach – Targeted Supports, where \$2 million per year is envisaged. Considering that this program will be rolled out on the national level and that rural and remote areas of Australia will be targeted with this outreach, additional funds for this specific outcome should be considered.

Finally, FECCA recommends that within each component, a portion of funds be allocated specifically for CALD initiatives considering the great need in this diverse cohort.

FECCA appreciates this opportunity to input into the consultation process on the *Redesign of Dementia Consumer Supports*.