



***Affirm***  
Organizational Development  
and Training

MULTICULTURAL  
**DEMENTIA CAMPAIGN**  
PROJECT

**Community and Cultural Connections Inc.**

# **2019 Multicultural Dementia Campaign Project**

## **Community Consultation Report**

# Community and Cultural Connections Inc. Multicultural Dementia Campaign Project

## Community Consultation Report

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The community consultations and writing this report was undertaken by:

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## Executive Summary

An annual Multicultural Dementia Forum/Expo has been held in Inner West Sydney to inform the community about dementia.

In 2018 Community Cultural Connections Inc. (CCCI) in collaboration with the Inner West Sector Support Development and Training Officer, Inner West Council, and the Sydney Local Health District received funds from the Dementia Friendly Communities Program of Dementia Australia to facilitate a Dementia Campaign for culturally and linguistically diverse communities in Inner West Sydney. The main aim of the Multicultural Dementia Campaign was to determine the best way to provide information on dementia to five targeted cultural and language communities in the Inner West. The five communities are Chinese, Greek, Italian, Korean, and Vietnamese.

Consultations were undertaken with each community in the relevant community language with interpreting undertaken by either professional interpreters or bilingual staff.

A total of one hundred people from the five targeted communities participated in face-to-face group consultations, and one carer completed the consultation Interview Questions via email. A total of eighteen staff were consulted or participated in consultations.

The project was undertaken between December 2018 and September 2019.

The findings show that each of the five communities consulted want information about dementia.

Information needs to be provided through a variety of methods and in both the relevant community language and English. A forum/expo as has been held in the past is one method for providing information. As General Practitioners (GPs) are often the first contact for people who have concerns about their health or that of a family member, and as some of the people consulted stated that GPs short consultation times makes it difficult to speak to their doctors about dementia, information at doctors' surgeries as well as information that supports people to raise their concerns and request support from doctors is required.

Information needs to be provided through existing groups run by culturally specific organisations and programs and use existing community communication channels. Information needs to target older people, their sons and daughters, and carers.

Many people obtain information about dementia and relevant services and supports through word of mouth and discussion with their friends. Therefore, the provision of information by 'peers' may be a useful way of providing information.

There is fear of dementia and for some a stigma associated with it. Information needs to highlight ways to prevent or delay dementia, minimise its impact, the possibility for quality of life for a person living with and people caring for a person with dementia, ways to respond appropriately to a person with dementia, and support available. Stigma tends to isolate people with dementia especially if they have changed behaviour. Support for people with dementia, carers and family members, including social support and information on how to relate and respond to a person with dementia is important for reducing isolation and creating awareness to reduce stigma.

The following are general recommendations for a Multicultural Dementia Campaign in Inner West Sydney which relate to all of the five communities. These are followed by preferences for information and specifically for a forum/expo for each of the five-target cultural and language communities.

## **Recommendations**

### ***Recommendation 1***

That information about dementia target people at different stages of the dementia 'journey' including prior to acquiring dementia, being concerned about signs of dementia, and living with or caring for a person who has dementia.

### ***Recommendation 2***

That the Dementia Campaign adopts a variety of methods using both one way information and two way discussions, to provide information about dementia, including through doctors, a community language dementia specialist, existing groups and services, forum/expo/seminar, community language media, personalised mail outs and/or letter box drop, and through general community places.

### ***Recommendation 3***

That the Dementia Campaign provide information in both community languages and English and use the communication channels identified by each community.

### ***Recommendation 4***

That the Dementia Campaign provide through its messages, information channels and language, target both older people and their sons and daughters or younger family members.

***Recommendation 5***

That formats for providing information also include information from peers, such as talks by or videos of people with dementia and carers.

***Recommendation 6***

That messages about dementia highlight the possibility for quality of life for a person living with and people caring for a person with dementia.

***Recommendation 7***

That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project advocate for the investigation of a universal system for providing information on dementia to all older people.

***Recommendation 8***

That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project advocate for the availability of a dementia helpline for the five target communities.

***Recommendation 9***

That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project investigate a broader community dementia campaign which includes the provision of information through schools.

***Recommendation 10***

That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project develop an action plan for the ongoing provision of information to each of the five target communities.

## Information for each of the Five Cultural and Language Communities

### Community from a Chinese Cultural and Language Background

How to Provide Information about Dementia	A Forum/Expo on Dementia
<ul style="list-style-type: none"> <li>• GPs</li> <li>• Existing groups including carers groups (to support word of mouth dissemination)</li> <li>• Day Care Centre or other services used by people with dementia</li> <li>• Chinese language and local newspapers</li> <li>• TV ads</li> <li>• Brochures</li> <li>• Internet, including the 1688 website</li> <li>• Information hotline for carers in Chinese languages.</li> </ul>	<ul style="list-style-type: none"> <li>• A forum/expo that is specifically dementia focused and in Chinese languages.</li> </ul>

### Community from a Greek Cultural and Language Background

How to Provide Information about Dementia	A Forum/Expo on Dementia
<ul style="list-style-type: none"> <li>• GPs</li> <li>• Pharmacies</li> <li>• Speakers on dementia at existing groups (to support word of mouth dissemination)</li> <li>• Seminars</li> <li>• Greek language radio including SBS, 2MM, and 1683</li> <li>• Greek language newspapers</li> <li>• Through a national universal program like the bowel cancer screening program</li> <li>• Disseminate existing multilingual videos developed by Dementia Australia</li> <li>• Distributed to people on the Next of Kin Register maintained by the local police station</li> <li>• Information needs to be in plain language Greek and in English.</li> </ul>	<ul style="list-style-type: none"> <li>• Existing services such as Greek Day Care assist people to participate in a forum/expo</li> <li>• A forum/expo needs to be well advertised on SBS and other Greek language radio</li> <li>• Food needs to be provided.</li> </ul>

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**Community from an Italian Cultural and Language Background**

<b>How to Provide Information about Dementia</b>	<b>A Forum/Expo on Dementia</b>
<ul style="list-style-type: none"> <li>• Through Co.As.It</li> <li>• GPs</li> <li>• Media such as RAI TV including the Medicina 33 program</li> <li>• Italian community language radio</li> <li>• Existing services such as Dementia Cafes, Aged Care Assessment Team (ACAT), hospitals</li> <li>• Brochures at general community places, such as chemists and supermarkets</li> <li>• Written information posted or via letter box drop in Italian and in English</li> <li>• Through the <i>My Health Record</i>, or the establishment of a register similar to the Bowel Screen.</li> </ul>	<ul style="list-style-type: none"> <li>• A forum/expo held either by Area Health or Co.As.It.</li> </ul>

**Community from a Korean Cultural and Language Background**

<b>How to Provide Information about Dementia</b>	<b>A Forum/Expo on Dementia</b>
<ul style="list-style-type: none"> <li>• Information kit or flyers in local areas where people go everyday such as pharmacies, senior centres, libraries, Korean shops, and churches</li> <li>• Korean language hotline</li> <li>• Korean language online platform</li> <li>• Korean magazines</li> <li>• Korean language fridge magnet with information and contact numbers</li> <li>• Existing services such as Australian Korean Welfare Association (AKWA)</li> <li>• GPs</li> <li>• Through a dementia specialist located with a GP or a dementia centre.</li> </ul>	<ul style="list-style-type: none"> <li>• A forum/expo seminar in Korean similar to the one on diabetes held at the Lithuanian Club in Strathfield.</li> <li>• A forum/expo seminar in Korean in Croydon Park (AKWA's head office)</li> <li>• A forum/expo needs to include Korean language 'handouts' and the availability of an individual private consultation using a dementia (screening) 'checklist'.</li> </ul>

**Community from a Vietnamese Cultural and Language Background**

<b>How to Provide Information about Dementia</b>	<b>A Forum/Expo on Dementia</b>
<ul style="list-style-type: none"><li>• Vietnamese language newspaper</li><li>• Vietnamese language radio including SBS and 2VNR</li><li>• Through existing groups and community organisations such as the Vietnamese Seniors Association</li><li>• Through community meetings and gatherings</li><li>• Flyers/brochures in Vietnamese and English mailed to people's homes</li><li>• Libraries and online (to support word of mouth dissemination).</li></ul>	<ul style="list-style-type: none"><li>• A forum/expo needs to be both in Vietnamese and English</li><li>• A forum/expo needs to include opportunities for discussion and to receive answers</li><li>• Transport needs to be provided for people who needed.</li></ul>

## 1. Introduction

An annual Multicultural Dementia Forum/Expo has been held in Inner West Sydney to inform the community about dementia.

In 2018 Community Cultural Connections Inc. (CCCi) in collaboration with the Inner West Sector Support Development and Training Officer, Inner West Council, and the Sydney Local Health District received funds from the Dementia Friendly Communities Program of Dementia Australia to facilitate a Dementia Campaign for culturally and linguistically diverse communities in Inner West Sydney.

The project was undertaken between December 2018 and September 2019.

As part of the development of the methodology for the Campaign, relevant data and literature was referred to and consultation held with five targeted cultural and language communities: Chinese, Greek, Italian, Korean, and Vietnamese. The Chinese, Greek, Italian and Vietnamese communities were selected as they among the most common languages spoken in the Inner West. Korean, which is the sixth most common language, was selected as only limited direct consultation on dementia has been undertaken with the Korean speaking community previously.

This report by independent consultant Grace Leotta outlines a summary of key demographic data and literature, findings of consultations with each of the five targeted cultural and language communities, and recommendations for a future Dementia Campaign.

## 2. Methodology

### 2.1 Approach

The project has involved reference to community profiles and existing literature in the form of literature summaries which informed the consultation and the final methodology for the Campaign, and community consultations with community groups and some staff from each of the five targeted communities.

The consultation sought to answer the following questions:

*What are the issues regarding dementia and responses to it in the five target communities? Such as cultural attitudes to dementia, awareness/understanding of dementia and the care needs associated with these, awareness of existing supports and pathways.*

*How do people obtain information about dementia now?*

*What information and support do they need about dementia, which is useful, informative, and in what formats? What specific information/formats works well for each cultural group?*

*How is it best to provide that information? That is, what channels and messages.*

*How useful is a forum/expo in providing information, or in creating a platform for people to engage?*

*If a forum/expo is a useful way to provide information:*

*What kind of forum/expo would people like to have? What does it look like?*

*What should the forum/expo include?*

*What services does each targeted group already have available to it, and what else might be needed?*

### 2.2 Method

The community consultations, which were undertaken between February and April 2019, were in the form of focus groups comprising primarily of members of existing community groups run by culturally and linguistically specific organisations. Due to the varying nature of the existing community groups and their composition, the sample for each cultural and language community varied from well and active older people, people with dementia, and carers.

Members of a carer support group provided by CASS Group participated in the focus group for the Chinese cultural and language background community, in which a total of twelve people participated. The majority of them are carers of spouses/partners or children of people with dementia. Three CASS Group bilingual staff attended the group and acted as interpreters. A carer participated by completing a survey.

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Eleven people participated in a group for the Greek cultural and language background community. Staff from GWC Community Services, Marrickville Community Health Centre, and Newtown Neighbourhood Centre participated in consultations and/or acted as interpreters. A separate consultation was held with four staff members who work with older people from a Greek cultural background.

Twelve people, members of Co.As.It's Active Ageing Program participated in the focus group for people with an Italian cultural and language background. A Co.As.It. staff member acted as interpreter and two of the Active Ageing Program staff participated in the consultations. A separate consultation was held with six Co.As.It staff members who work with older people.

Twenty-two people including members of CCCi's Vietnamese Seniors Social Support Group and the Vietnamese Seniors Association attended a group consultation for people with a Vietnamese cultural and language background. This was followed with follow-up informal discussions with an individual, pair and small group.

At total of forty-two people participated in consultation with the Korean community. This included twenty people who attended the Australian Korean Welfare Association (AKWA) Centre Based Day Care and twenty-two who participated in a consultation organised by CASS. Two staff members were also interviewed.

### **Limitations and Areas for Further Exploration**

The difference in the composition of the focus groups across the five target communities makes direct comparison in findings from each of the communities difficult.

The semi-structured nature of the focus groups along with the size of the group, and the length of time available for consultation, as well as the varying levels of participation in consultation by staff resulted in different levels of information on each of the key project questions.

As consultations were through existing groups, this project has not consulted with community members who are not connected to groups in their cultural and language community. The information and support needs of people not connected to an existing group is an area for further exploration.

Due to limited opportunity for one-to-one discussion, in most instances carers spoke for the person with dementia. Follow-up interviews and direct, brief interviews with individuals with dementia with the assistance of a carer and/or trusted staff member may be useful to hear the stories, perspectives and needs of people with dementia.

Some focus groups included sons and daughters who are carers of people with dementia, some of whom accompanied their parents and some who came on their own. It is acknowledged that the information and support needs of people with dementia, their spouse/partner and their children vary. This also is an area for further exploration.

### 3. Demographic Data and Literature Review

#### 3.1 Demographics

The Sydney Inner West region area is highly culturally diverse with over 59% of the people 65 years and over from a culturally and linguistically diverse background (CALD). The overall population of people from CALD backgrounds is about 42%. About a quarter of the overall CALD population identifies as not speaking English well or not at all proficient in English. Across the region the most commonly spoken languages are Italian, Arabic, Cantonese, Greek, Mandarin and Korean. The variation in languages spoken in each of the Local Government Areas (LGAs) in the region is outlined in Table 2.

**Table 1: Inner West Sydney Population Aged 65 Years and Over**

	<b>Burwood LGA</b>	<b>Canada Bay LGA</b>	<b>Canterbury Bankstown LGA</b>	<b>Inner West LGA</b>	<b>Strathfield LGA</b>	<b>Total</b>
<b>Overall Population</b>	38425	92382	361551	192030	42331	726719
<b>Population 65+</b>	5424	13197	49130	23026	4808	95585
<b>CALD overall</b>	22017	37415	159082	65674	23832	308020
<b>CALD 65+</b>	3672	6854	31130	12005	3226	56887

Source: Ethnic Community Service Co-operative (ECSC) Inner West Multicultural Access Project (MAPS) Report, 2018

**Table 2: Inner West Sydney Population Aged 65 Years and Over, Five Most Common Languages Spoken**

<b>Burwood LGA</b>	<b>Canada Bay LGA</b>	<b>Canterbury Bankstown LGA</b>	<b>Inner West LGA</b>	<b>Strathfield LGA</b>
Italian 749	Italian 2500	Greek 5940	Greek 2340	Cantonese 451
Cantonese 534	Greek 552	Arabic 5377	Italian 2045	Tamil 344
Mandarin 369	Cantonese 480	Italian 2591	Cantonese 725	Italian 292
Greek 354	Mandarin 352	Cantonese 2195	Portuguese 616	Mandarin 276
Arabic 240	Arabic 2000	Vietnamese 2014	Arabic 599	Korean 249

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Source: ABS 2016 Census

At the time of the development of the Dementia Action Sydney Plan for Inner West in 2013 the estimated number of people under 65 years living with dementia was expected to increase from 295 in 2009 to 301 in 2012 and 327 people by 2018 (NSW Government Health Sydney Local Health District, 2013).

## 3.2 Literature Review

In 2018 CCCi undertook a review of available literature, which was provided by Sandra Loyola-Sandoval, Ageing and Disability Officer, the City of Canterbury-Bankstown, and Anne Tunks, Dementia Advisor at Sydney Local Health District. Jacqueline Jasmot Prasad, a social work student from Western Sydney University, undertaking placement with CCCi, documented this as a summary of the literature.

The following is a summary of the findings from the literature highlighting those with implications for the type of and methods for providing information to the five target communities for this project.

There has been limited Australian research focusing on dementia within culturally and linguistically communities, with much of the research being conducted in North America and focused predominantly on Asian, Hispanic/Latino and African American populations (Boughtwood, et al, 2011a).

Better understanding of dementia and availability of support available is an essential first step in managing dementia well. The delay in the diagnosis and referral of people of CALD backgrounds makes the access to timely, relevant and accessible information about dementia and available support crucial (Alzheimer's Australia NSW, 2010).

People from CALD communities make up a significant and increasing proportion of the population living with dementia and CALD communities often lack information about dementia and related services (Boughtwood et al, 2011b Source: Access Economics 2006, and Berisic and Nesvadba 2008). Carers particularly experience difficulty in accessing relevant information.

Explaining dementia to CALD communities, as well as delays in diagnosis and referral of CALD community members, was affected by a range of factors including language barriers and challenges with translation, and differences in the perceptions of dementia by particular communities. Many CALD service providers have spoken of the inappropriate translation of key terms in official literature, such as using a term which translates as 'one who is mad' (Alzheimer's Australia NSW, 2010).

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Boughtwood et al's research (Boughtwood et al, 2011b) shows that problems with literacy is an issue for all CALD communities included in the research. Existing Information for CALD communities tends to be very basic and overly generalised.

In some communities, dementia was consistently seen as "*a normal part of the ageing process*" and as a result people with dementia and their carers were less likely to seek information, advice, diagnosis or support services for this condition (ADHC 2008).

CALD communities tend to respond well to a doctor (Boughtwood et al, 2011b). Doctors were perceived in a very positive light as "*professional*" and "*trust worthy*" and were regularly accessed in relation to information and advice about dementia (ADHC 2008).

Family carers perceived doctors as needing to better promote information about dementia either via resources placed in their waiting rooms, putting audio visual material on surgery televisions and/or communicating directly with carers. Health professionals stated that is important to presenting a diagnosis of, or information about, dementia in a non-confronting way.

Information needs to be specific to the type of dementia, the individual characteristics of the person living with dementia, stage of dementia and tailored to specific family circumstances. More language-specific information is required.

Family carers suggest that as part of getting information, they would like to get emotional support for themselves. Specific areas of information they required included ways to deal with the specific behaviours of their relative, how to care for the person living with dementia at home without hurting themselves physically, and ways they could support their relative emotionally. The relationship of the carer to the person with dementia needs to be explicitly recognised and supported (Alzheimer's Australia NSW, 2010).

Multicultural workers and bilingual GPs stated that useful forums for disseminating of information are radio and television, as some elderly CALD people were illiterate in their own language as well as English.

Most participants in research undertaken by Alzheimer's Australia NSW (Alzheimer's Australia NSW, 2010), especially carers, said they had heard and read information about a variety of issues relating to dementia through community newspapers and language specific radio programs. Younger carers accessed Alzheimer's Australia information over the phone and online however this did not appear to be widespread (ADHC 2008).

Bilingual/bicultural workers play a vital role in educating, supporting and caring for individuals and families within their CALD communities who are affected by dementia (Boughtwood et al, 2011c).

Although many people are unaware of the range of services available, and how these can assist, information sessions and meeting for carers are regularly cancelled in the Inner West, and carers' groups in other locations sometimes struggle to get members.

This may be due to lack of transport and respite, and to people's level of 'discomfort' in attending such meetings (Alzheimer's Australia NSW, 2010).

Specific dementia related research is only available for three of the five target communities for this project, namely Chinese, Italian, and Vietnamese. The following summarises findings with key implications for the provision of information to each of the three communities.

### ***Chinese***

Research shows that the person living with dementia was getting medical attention for another illness when dementia was discovered. Also, clear entrance points for accessing services about dementia were the Australian Chinese Community Association (ACCA). Carers suggested their friends were a good source of information and support (Boughtwood et al, 2010).

Compared to other cultural and language groups, people with a Chinese cultural background tended to have a more developed understanding of a range of service options both Chinese specific and mainstream one (Boughtwood et al, 2011a).

Carers stated that they found it easiest to absorb the information when this was provided in person, but that it was difficult to attend sessions when they were unable to bring the person living with dementia (Boughtwood et al, 2010).

There was acceptance of dementia in the community, as it was seen as a natural part of the ageing process hidden (Alzheimer's Australia, 2010 Source: Alzheimer's Australia 2007a; CIRCA 2008: 32). Older people from a Chinese background do discuss dementia with close friends, possibly before discussing it with their children (Boughtwood et al, 2011a).

### ***Italian***

Research shows that there is limited knowledge of dementia within the community. People in the Italian community reported that dementia is often not talked about and can be hidden (Alzheimer's Australia, 2010 Source: Alzheimer's Australia 2007a; CIRCA 2008: 32) as people are reluctant to discuss dementia outside the family due to fears of being judged by other community members (Boughtwood et al, 2011a).

Italian consumers were aware of services provided by Italian specific organisations such as Co.As.It. but had low awareness of mainstream services (Boughtwood et al, 2011a), with clear entrance points for accessing services about dementia being Co.As.It (ADHC, 2008)

## **Vietnamese**

Like the Chinese community, there was acceptance of dementia in the community, as it was seen as a natural part of the ageing process (Alzheimer's Australia, 2010 Source: Alzheimer's Australia 2007a; CIRCA 2008: 32).

For people with a Vietnamese background, the family's Vietnamese-speaking General Practitioner (GP) was the single most important information point regarding dementia services (ADHC, 2008). People depend on Vietnamese speaking doctors for all dementia related needs, as they had low awareness of service options (Alzheimer's Australia, 2010).

## 4. Consultation Findings

The following outlines consultation findings for each of the five cultural and language groups. The findings are categorised as responses to the following questions:

*When people first had concerns about dementia where did they go?*

*What do people want to know about dementia?*

*How is dementia seen in the community and what impact does that have?*

*How is it best to provide information about dementia?*

*What support do people with or supporting a person/people with dementia need?*

Due to the focus group size, composition, priorities of the members, and input of staff, not all the above questions were equally discussed with each of the target communities.

### 4.1 Community from a Chinese Cultural and Language Background

#### ***When people first had concerns about dementia where did they go?***

Some people struggled with caring for a family member for several years before they found out about dementia. They didn't know what it was or where to go for help. Some received information at the hospital or at the Day Care Centre.

Several people found about dementia through doctors, a family member, *My Aged Care*, and the social services to which they were referred.

One person stated that she did not know what dementia was until she went to Burwood Library where she gained knowledge about dementia. She then went to a workshop and information sessions.

***"I didn't know where to get help."***

Community member

#### ***What do people want to know about dementia?***

When people first found out that they or their family member has dementia they wanted to know what dementia was and if there was treatment for dementia such as therapy or exercise to slow dementia down. Staff also stated that people are keen to know how to prevent dementia.

As well as information about dementia people want to know about support for carers.

### ***How is it best to provide information about dementia?***

As GPs are often the first contact for people with concerns about their health, GPs are an important source of information about dementia and supports and services available.

Generally word of mouth and existing groups are an important source of information. The carers' support group has been a source of information and advice, as well as emotional support.

The best ways for providing information about dementia are the Day Care Centre or other services used by people with dementia, both Chinese language and local newspapers, TV ads, brochures, and the internet, including the 1688 website.

One person who has attended general ageing expos said that they were useful, but most of the talks were not dementia focused. Dementia focused expos in Chinese are useful.

It was stated that an information hotline for carers is required.

### ***What support do people with or supporting a person/people with dementia people need?***

Activities provided through Day Care Centres are important as a source of support for the person with dementia and the carer. Interaction provided through Dementia Day Care was helpful for a person with dementia as well as the carer, as it gave her a break from caring and an opportunity to do other tasks.

A couple of carers stated that physical activity and going out to a park were helpful for the person with dementia. One stating that physical activity was more helpful than medication.

Carers spoke of their need to socialise more and communicate with each other, and for a "place to distress" and that support groups are helpful for carers.

Several carers stated that they need emergency assistance, particularly temporary respite.

One person stated that a counselling and accessing six free counselling sessions was "extremely useful" and encouraged others to seek counselling.

***"Treatment is holistic – social interaction, exercise, nutrition."***

Community member

One person stated that young people need to know about dementia so they can offer appropriate support.

## **4.2 Community from a Greek Cultural and Language Background**

### ***When people first had concerns about dementia where did they go?***

People with a family member with dementia went to their local GP, or were referred to a hospital including Royal Prince Alfred (RPA) or the Aged Care Assessment Team (ACAT).

Staff stated that they identify signs in some of the people who attend Day Care programs. They then proceed to tell carers and recommend they consult a doctor. The non-threatening environment provided by the programs is important in communicating with carers about signs of dementia and the need to seek support.

### ***How is dementia seen in the community and what impact does that have?***

Some of the community members consulted stated that there is now less stigma about dementia “as everyone knows someone” with dementia. They did however, speak of a person with dementia losing friends, and of the need to educate children and young people at school that dementia is part of life, and to respect older people.

Staff stated that dementia is stigmatised and because of this people “put up with it as long as they can” before seeking help. Challenging behaviour is particularly embarrassing and causes shame. Housebound women with dementia whose husbands will not let them go out are particularly isolated. In turn male carers struggle with caring, including with household duties such as cooking and cleaning. People do not want to impose on their children, as “they’re busy”.

Many older people with Greek backgrounds were impacted by World War II and the Greek Civil War and experienced trauma as children. In Australia they worked hard and raised a family and now do not want to lose their independence or be vulnerable. Staff also stated that the current generation older people who were the first in their family to migrate to Australia, have not grown up with elderly parents. Therefore, they are unfamiliar with the ageing process and the support required.

### ***What do people want to know about dementia?***

People want to know how to prevent dementia for example, through quality food and natural medicines.

***“You need information before you get sick.”***

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Administered by Community and Cultural Connections Inc, Inner West Area Sector Support Development Officer, Inner West Council,  
and Sydney Local Health District

People with a loved one with dementia want to know how to talk about dementia with family, relatives, and friends, and how to respond and interact appropriately with people with dementia. A carer stated that she found information provided by a specialist to speak softly to the person with dementia particularly useful.

Staff identified that information about benefits such as Carer Allowance and Home Care Packages is also required.

As some people who are waiting for Home Care Packages want to know why there is a long waiting list for example for two years and over, for services in the home.

People thinking about the future stated that they require an explanation of bond rules for residential aged care.

### ***How is it best to provide information about dementia?***

People who participated in consultations identified several ways for communicating about dementia. These included: GPs, pharmacies, through existing groups such as speakers attending groups, seminars, Greek language radio including SBS, 2MM, and 1683, and Greek language newspapers.

It was stated that information needs use simple spoken Greek rather than medical or academic Greek. Information needs to be provided in Greek and in English for the children and family members of older people.

Word of mouth including through existing groups is an important channel for information provision.

While GPs are a critical source of information, if the GP does not communicate in the person's language and/or does not have enough time with their patient, signs of dementia will not be identified. A focus on supporting GPs to provide timely information is important. GPs also need to keep more information such as pamphlets in their waiting rooms. These need to be accompanied with a sign inviting people to take a pamphlet.

Staff also stated that mailing information that is personalised in Greek and in English using simple language is also useful. Information in English is necessary for the children of older people.

Information needs to be both localised for example, through a local resource providing information on local services, and universal. A national universal program like the bowel cancer screening test is a useful way of ensuring everyone receives information about

dementia. Multilingual videos developed by Dementia Australia are a useful source of information but there needs to be more emphasis on disseminating them.

Information distributed to people on the Next of Kin Register maintained by the local police station maybe a way to reach people not connected to community groups or services.

Some people who participated in the focus group stated that the church is not a useful avenue for providing information as “they will say put the person in a nursing home”.

Staff stated that a forum/expo is a useful way of providing information and raising awareness of dementia and support and services available, and that in fact they took about 100 people who participate in their Day Care programs to the previous one. The forum/expo needs to be well advertised on SBS and other Greek language radio. As food attracts people to events, food needs to be provided.

***“People who participate in groups are more informed.”***

Staff member

### ***What support do people with or supporting a person/people with dementia need?***

Groups and the company they provide are viewed as helpful. The Dementia Café and similar services are required. The Dementia Café provides a safe place for the person with dementia and a break for carers.

As well as support for the person with dementia, support is also required for family members. This may be in the form information such as what to expect, as dementia progresses for example, a parent may not recognise their son or daughter, and a support group for emotional support. A carer stated that she and her family have never been offered emotional or psychological support.

Generally, the availability and cost of support means that carers without adequate support “self-sacrifice” to support their family member. The long waiting list for support in the home is a barrier to accessing support.

Most family members are trying to keep the person with dementia at home. The high cost of residential aged care is seen as exorbitant especially for people on limited income. Some people who participated in the consultation expressed anger at the high cost of residential aged care both of the bond that can be \$300,000 - \$400,000, and daily or weekly payments for those without a bond. People are concerned about having to sell their home so they can have a bond or using most of their Age Pension on weekly payments. Staff confirmed that

people are reluctant to use their assets for their care, as they want to leave their assets to their children.

Residential care is often outside of the area and requires carers and family members to travel long distances to visit. Spouses/partners of people in residential care spoke about catching two buses to visit which they do on a regular basis.

Staff stated that people in residential aged care with dementia have benefited significantly from support provided by Greek speaking volunteers who read and interact with the person sometimes with tools such as a memory box.

### **4.3 Community from an Italian Cultural and Language Background**

#### ***When people first had concerns about dementia where did they go?***

All people consulted stated that they know a person with dementia. This included a husband/partner, mother-in-law, neighbour or friend.

Most people affected by dementia in their family initially received information from a hospital. Some received information from someone else who had dementia or who know a person with dementia. They did not receive any “formal” information about dementia.

Staff stated that often they identify clients in their programs who may have dementia. They identify a person’s loss of ability to undertake daily tasks and of independence and the family’s concern about the person. Staff will provide assistance including referrals. Sometimes Co.As.It. receives a referral when the situation becomes serious and carers find it difficult to manage on their own.

#### ***How is dementia seen in the community and what impact does that have?***

It was stated that the community is “scared” as people do not know much about dementia and at the same time understand it is on the increase.

Staff stated that older people do not want to talk about dementia and often hide and deny their symptoms. There is “a lot of stigma” about dementia which contributes to people not seeking help.

Staff have also identified a difference in responses to dementia from children of older people, with those born in Australia more open to seeking help and talking about dementia, and those born overseas often not seeking help as “they do not want to disappoint their parents”.

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Community members stated that the second generation (their children) are “very busy” and they believe that “mum and dad will live forever”. Therefore, they do not engage with obtaining information unless it’s necessary.

***“For the people who fear it (dementia), we must encourage them to talk about it more and offer more information.”***

Community member

### ***What do people want to know about dementia?***

Community members consulted are interested in receiving information about dementia. Most people want to know what dementia is, if there is a cure for dementia and if will they get dementia.

Staff stated that people should be informed about the symptoms of dementia and where to get help.

### ***How is it best to provide information about dementia?***

Staff stated that information is often given when the person is hospitalised, during a community care assessment or when they become involved with a service. Co.As.It. provides information to care recipients and their carers.

People who participated in community consultations and or staff listed the following ways for providing information: the family GP, dementia specific forums or seminars held either by Area Health or Co.As.It, media such as RAI TV including the Medicina 33 program where information regarding different health issues is provided and discussed, Italian community language radio, existing services such as Dementia Cafes, ACAT, as well as general community places, such as chemists and supermarkets. Leaving a brochure on dementia “here and there” “where people go all the time” is a useful way of supporting the community to be aware of dementia and supports available.

Staff stated that GPs play a critical in identifying dementia and linking to services and supports and therefore, need to be aware of supports available.

Written information should be posted or provided as a letter box drop to older people both in Italian and in English. Providing information in writing would assist people to find the necessary information more quickly. Written information sent to the older people in English will reach their children so can become aware and can assist appropriately.

Staff suggested a universal approach for providing information such as through the *My Health Record*, or the establishment of a register similar to the Bowel Screen to remind the

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community to check. It was also suggested that a register of people with dementia would be useful if it was used to regularly send information about dementia to them and their carers.

Staff stated that because of the fear of and stigma related to dementia the message needs to be that “it is not the end of the world” and that it is possible to have dementia and have quality of life. Also, because there is a delay in people seeking support it is important to provide information to “target people around them”.

### ***What support do people with or supporting a person/people with dementia need?***

Community members stated that it is important that support groups become available to people who need to talk about dementia. These groups we should include people who have experienced dementia who can give examples of what they did.

As well as information, dementia specific support groups need to be available for carers and family members, who are identified as experiencing stress.

Support groups are important in providing an opportunity for group members to share information from their experience with each other.

***“(What is needed is) a support group for the family (they are) stuck at home night and day (caring for the person).”***

Community member

Staff stated that most people want to keep their family member at home, so supports to enable them to do this is important to the community.

## **4.4 Community from a Korean Cultural and Language Background**

### ***When people first had concerns about dementia where did they go?***

The majority of people who participated in one of the consultations stated that they know a person with dementia.

When people known to people who were consulted had concerns about dementia many went to a Korean speaking GP. Some went to Hospital Emergency or a professional organisation like the Australian Korean Welfare Association (AKWA), or Dementia Australia. Other sources of information were South Korean television programs, the Korean Newspaper – Hanho Korean Daily, and several magazines including Korean Monthly Business and Community Magazine, Kyomin Journals, Korean Town journals and Mylife and the Weekly Korean Life.

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### ***How is dementia seen in the community and what impact does that have?***

In one of the community consultations it was stated that talking about dementia is OK and that there is no stigma attached to it. In another community consultation it was stated that if a person has dementia, he or she is likely to become isolated. A person with dementia is seen as “crazy”. People therefore try to hide their symptoms. Fear of being identified as having dementia further aggravates the situation. Exclusion and stigma extend to a friend who supports a person with dementia, with community members saying “Why do you want to spend time with a crazy person.”

In this consultation it was stated that there is a need to change attitudes so people can be supportive of a person with dementia.

***“People say they’re (people with dementia) are crazy.”***

Staff member

### ***What do people want to know about dementia?***

People who participated in community consultations stated that they want information on how to prevent dementia for example through medication, diet, exercise and other preventive strategies such as English classes or regular social group, how to delay it, on how to identify or recognise dementia, such as signs or symptoms, and on how to respond to dementia once a person has dementia.

Some stated that while learning a new language is seen a preventive strategy it can actually create more stress.

A checklist in Korean to identify if people have dementia was requested by participants of one of the group consultations. Staff also stated that a ‘check’ similar to that provided by Diabetes Australia and undertaken by a person with a Korean cultural and language background would be useful and provide an entry to support. Staff also that that a fridge magnet with information in Korean and contact numbers would also be useful.

### ***How is it best to provide information about dementia?***

Information needs to be provided through a variety of methods and channels. These include, the availability of an information kit or flyers in local areas where people go everyday such as pharmacies, senior centres, libraries, Korean shops, and churches. A hotline staffed by a knowledgeable Korean speaking person, an Australian based Korean language online platform, Korean magazines, and expos in Korean are useful information channels.

People associated with the Australian Korean Welfare Association (AKWA) nominated it as a useful place for obtaining information.

Staff stated that the provision through a Korean organisation and bilingual worker is important as it removes cultural barriers.

Australian produced Korean language radio is not a useful channel as most people watch or listen to media from Korea.

While GPs are often the first contact it was repeatedly stated that GPs don't have the time to communicate and explain issues. Most GPs spend five to fifteen minutes with a patient which is not enough time for the person to raise or for the doctor to explain issues.

A Korean speaking person who is a dementia specialist to them who can use the checklist to assess and provide time to discuss the results and action to take fulfils a role that GPs are not. It was stated that such a dementia specialist is required in each area located with a GP or a dementia centre.

Face to face information provision and discussion was stated was the best way of providing information.

***“Reading (about dementia) is difficult; talking is better.”***

Community member

A seminar on dementia similar to the one diabetes held at the Lithuanian Club in Strathfield for the Korean community would be useful. A forum/expo in Korean with ‘handouts’ also in Korean and the availability of an individual consultation would be useful. The group associated with AKWA stated that a forum/expo needs to be held in Croydon Park, the location of AKWA’s head office.

Information also needs to target family members and friends of people with dementia. People with parents with dementia need to know how to respond to their parents.

The messages about dementia need to include that its beneficial have a check if people are concerned – “Just in case, check it out” what help to prevent dementia and that it can happen to anyone.

***What support do people with or supporting a person/people with dementia need?***

Social support groups similar to Alcoholics Anonymous were nominated as important for support and education, especially for people who have recently discovered they have dementia. Dementia Day Care and what was referred to as a “dementia playground”, an outdoor space is also important for people with dementia and people who support people with dementia.

Staff stated that respite is important for carers and families who look after people with dementia 24 hours per day.

Access to appropriate home support services is a “big, big issue”. Most of the care staff do not have a Korean background and do not speak Korean. There is a need for bilingual care staff.

## **4.5 Community from a Vietnamese Cultural and Language Background**

### ***How is dementia seen in the community and what impact does that have?***

Some people stated that there is not a stigma associated with dementia. For some there is concern about discussing issues such as memory loss with their GP or persisting in discussing it when they are told “not to worry”.

### ***What do people want to know about dementia?***

When people who have or know someone with dementia first found out that they or their family member has dementia they wanted to know to support the person with dementia and if there are different levels of dementia. One person did not know about dementia.

Now people want to know what dementia is, how stop, prevent or avoid it, such as through exercises, preventative medication, and immunisation.

Some people want to know how they can get more information about what they should do if they have concerns about themselves for example, of some memory loss. Some feel uncertain about discussing their concerns with the doctor and question whether their GP knows enough about diagnosing dementia.

People who care for a person with dementia want to know what you can do to support the person at home, including what to do to reduce the symptoms, and ways to help people who “have completely lost their memory”.

### ***How is it best to provide information about dementia?***

People who participated in the consultation nominated several ways for providing information about dementia. These include the Vietnamese language newspaper, Vietnamese language radio including SBS and 2VNR, through existing groups and community organisations such as the Vietnamese Seniors Association, and through community meetings and gatherings. It was stated that some people need transport to participate in groups and community events.

Flyers/brochures in Vietnamese and English mailed to people's home are also useful as people appreciate personal contact.

As people acquire information through word of mouth, information to the general community such as through libraries and online is also useful.

Of the people who participated in the consultation, three people have been to the Vietnamese Dementia forum/expo and described it as "very good", "useful" and "helpful."

Some stated that a Dementia forum/expo is a useful way to provide information that it needs to be both in Vietnamese and English. A forum/expo needs to include opportunities for discussion.

***"(At the forum/expo) we want answers as well as an opportunity to raise questions."***

Community member

### ***What support do people with or supporting a person/people with dementia need?***

The main support that people want is opportunities to stay well and to foster wellbeing such as, opportunities to exercise, to study and participate activities that "activate the brain" such as practise a language, and to go out and socialise.

Some community members are active in self-help activities such as meditation, exercise, and going out.

***"(What helps) is the opportunity to enjoy; to go out – to be happy."***

Community member

Community members stated that sharing experiences with each other provides both information and support.

Some stated that support for carers is also required.

## 5. Discussion and Conclusion

Each of the five communities consulted want information about dementia.

Many of the people consulted know someone with dementia. Some people found out about dementia when they were in hospital.

Fear of or stigma related to dementia results in people hiding their symptoms and therefore not seeking information or support.

In some communities dementia is seen as part of the ageing process. This may result in both reducing the stigma related to dementia and to people not seeking external assistance.

Information about dementia needs to highlight the range of support available at all stages of a person's dementia and their care.

The type of information required depends on where people are on the dementia 'journey'. People interested or concerned about dementia require accurate information on what dementia is. Active older people requested information on how to prevent or minimise the risk of acquiring dementia including through healthy living such as exercise, diet, study and mental activity, and social interaction.

People with concerns about dementia either for themselves or a spouse/partner require information on where to go if they have concerns about issues such as memory loss.

People living with or caring for a person with dementia require information on treatment and 'rehabilitation' such as medication, positive activities, for example going to the park or interaction through a Dementia Café or day program, and about the type of supports available and how to access them.

Carers for people with dementia requested information about what to expect when a loved one has dementia, such as they may not be able to recognise their family member, how to positively interact with and best support a person with dementia, as well as information about services and supports including emergency respite, and emotional support for carers.

A person's challenging behaviour may result in isolation. Information on responding to challenging behaviour can support the carer, as well the person's circle of family and friends to stay connected to them.

As older people consider options as they age, information and support to navigate the aged care system including residential aged care is also required.

### ***Recommendation 1***

**That information about dementia target people at different stages of the dementia 'journey' including prior to acquiring dementia, being concerned about signs of dementia, and living with or caring for a person who has dementia.**

All the communities consulted and the literature shows that a multi-method approach needs to be used to provide information about dementia. Doctors particularly local GPs play a crucial role not only in diagnosing dementia but linking people with dementia and their carers to appropriate support and services.

A person's relationship with their GP as well as the time that the GP makes available for each consultation impacts on the timeliness of a dementia diagnosis and links to support and services.

As well as direct information from GPs, it was identified that doctors' surgeries are a key dissemination point of bilingual information on dementia and on services available.

Information needs to be provided through existing groups run by culturally specific organisations and programs, where it can be provided face to face and in a conversational way. Providing information to groups also supports the dissemination of information in the community through word of mouth.

Community workers and support workers are a trusted source of information and encouragement to seek support and services, and therefore need to continue to be provided with relevant and up to date information.

Many of the people consulted across the five communities thought that a forum/expo was a good way of providing information; some stated that the forum/expo can be provided through an existing group. Some would like information through a forum/expo or seminar needs to include one consultation so that people can discuss any concerns they have such as about loss of memory.

Community language media is widely utilised and a source of trusted information on a range of issues and therefore needs to be used to provide ongoing information.

Two of the community groups stated that posted or letter box personalised information is a useful way of providing information.

Ongoing information also needs to be provided through general community places such as supermarkets, pharmacies and libraries.

### ***Recommendation 2***

**That the Dementia Campaign adopts a variety of methods using both one way information and two way discussions, to provide information about dementia, including through doctors, a community language dementia specialist, existing groups and services, forum/expo/seminar, community language media, personalised mail outs and/or letter box drop, and through general community places.**

As many people obtain information from their sons and daughters and other family members, information needs to be available through channels and in a format relevant to them, including online and in English.

### ***Recommendation 3***

**That the Dementia Campaign provide information in both community languages and English and use the communication channels identified by each community.**

### ***Recommendation 4***

**That the Dementia Campaign provide through its messages, information channels and language, target both older people and their sons and daughters or younger family members.**

In recognition that many people obtain information about dementia and relevant services and supports through word of mouth and discussion with their friends, the provision of information by 'peers' may be a useful and innovative way of providing information, For example, through talks at a forum/expo, group, a video or on the radio by people with dementia and carers.

### ***Recommendation 5***

**That formats for providing information also include information from peers, such as talks by or videos of people with dementia and carers.**

Dementia Australia information was described as sensitive and useful, and also requiring strategies for broader dissemination.

Some community members view dementia as part of the ageing process while at the same time fearing it. Fear of dementia and associated stigma and exclusion contributes to people not seeking support. Some of the people consulted are active in helping themselves or a loved one with dementia through being physically and mentally, active, socialising and maintaining a healthy life style. Messages that state that "dementia can happen to anyone"

and that it can be part ageing, and which highlight the possibility of a quality of life with dementia, and the range of supports available to people with dementia and carers, may encourage people to consider and use available information.

### ***Recommendation 6***

**That messages about dementia highlight the possibility for quality of life for a person living with and people caring for a person with dementia.**

Information needs to be both local that is, referring to local community services and supports, and universal, that is, provided to all people. A universal system for providing information to all older people through an initiative similar the national bowel screening initiative and or through *My Health Record* data can ensure all people receive timely information.

While there are ethical and privacy issues in making health information available to an organisation to provide information to people with dementia, a universal information system that provides ongoing information can be explored. This would ensure people receive information when there are early symptoms and throughout their life with or time caring for a person with dementia.

### ***Recommendation 7***

**That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project advocate for the investigation of a universal system for providing information on dementia to all older people.**

Localising information also includes ensuring information and resources provided by organisation such Dementia Australia are also useful and accessible to people from culturally and linguistically diverse backgrounds. Ensuring the Dementia Australia Helpline is inclusive to people from culturally and linguistically diverse backgrounds through the availability and promotion of the availability of bilingual workers or interpreters, or the establishment of a language specific Helpline would be a valuable source of information, support and pathway to services for communities.

### ***Recommendation 8***

**That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project advocate for the availability of a dementia helpline for the five target communities.**

One of the communities consulted spoke of the need for children and young people to understand and respect older people including people with dementia, and that information on dementia should be provided through schools.

General awareness and understanding of dementia contributes to the reduction of stigma and quality of life for people with dementia.

***Recommendation 9***

**That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project investigate a broader community dementia campaign which includes the provision of information through schools.**

The consultations highlighted that information needs to be provided through a variety of methods and over a period of time. An action plan can guide information provision to each of the five communities, including the contribution of each of the services involved, the acquisition of additional resources required to produce information resources or make use of relevant information, and provide time frames for disseminating information.

***Recommendation 10***

**That the Multicultural Dementia Campaign Project Committee in partnership with the organisations involved in this project develop an action plan for the ongoing provision of information to each of the five target communities.**

## Preferences for Information for each of the Five Cultural and Language Communities

### Community from a Chinese Cultural and Language Background

<b>How to Provide Information about Dementia</b>	<b>A Forum/Expo on Dementia</b>
<ul style="list-style-type: none"><li>• GPs</li><li>• Existing groups including carers groups (to support word of mouth dissemination)</li><li>• Day Care Centre or other services used by people with dementia</li><li>• Chinese language and local newspapers</li><li>• TV ads</li><li>• Brochures</li><li>• Internet, including the 1688 website</li><li>• Information hotline for carers in Chinese languages.</li></ul>	<ul style="list-style-type: none"><li>• A forum/expo that is specifically dementia focused and in Chinese languages.</li></ul>

## Community from a Greek Cultural and Language Background

How to Provide Information about Dementia	A Forum/Expo on Dementia
<ul style="list-style-type: none"> <li>• GPs</li> <li>• Pharmacies</li> <li>• Speakers on dementia at existing groups (to support word of mouth dissemination)</li> <li>• Seminars</li> <li>• Greek language radio including SBS, 2MM, and 1683</li> <li>• Greek language newspapers</li> <li>• Through a national universal program like the bowel cancer screening program</li> <li>• Disseminate existing multilingual videos developed by Dementia Australia</li> <li>• Distributed to people on the Next of Kin Register maintained by the local police station</li> <li>• Information needs to be in plain language Greek and in English.</li> </ul>	<ul style="list-style-type: none"> <li>• Existing services such as Greek Day Care assist people to participate in a forum/expo</li> <li>• A forum/expo needs to be well advertised on SBS and other Greek language radio</li> <li>• Food needs to be provided.</li> </ul>

## Community from an Italian Cultural and Language Background

How to Provide Information about Dementia	A Forum/Expo on Dementia
<ul style="list-style-type: none"> <li>• Through Co.As.It</li> <li>• GPs</li> <li>• Media such as RAI TV including the Medicina 33 program</li> <li>• Italian community language radio</li> <li>• Existing services such as Dementia Cafes, Aged Care Assessment Team (ACAT), hospitals</li> <li>• Brochures at general community places, such as chemists and supermarkets</li> <li>• Written information posted or via letter box drop in Italian and in English</li> </ul>	<ul style="list-style-type: none"> <li>• A forum/expo held either by Area Health or Co.As.It.</li> </ul>

<ul style="list-style-type: none"> <li>• Through the <i>My Health Record</i>, or the establishment of a register similar to the Bowel Screen.</li> </ul>	
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### Community from a Korean Cultural and Language Background

How to Provide Information about Dementia	A Forum/Expo on Dementia
<ul style="list-style-type: none"> <li>• Information kit or flyers in local areas where people go everyday such as pharmacies, senior centres, libraries, Korean shops, and churches</li> <li>• Korean language hotline</li> <li>• Korean language online platform</li> <li>• Korean magazines</li> <li>• Korean language fridge magnet with information and contact numbers</li> <li>• Existing services such as Australian Korean Welfare Association (AKWA)</li> <li>• GPs</li> <li>• Through a dementia specialist located with a GP or a dementia centre.</li> </ul>	<ul style="list-style-type: none"> <li>• A forum/expo seminar in Korean similar to the one on diabetes held at the Lithuanian Club in Strathfield.</li> <li>• A forum/expo seminar in Korean in Croydon Park (AKWA's head office)</li> <li>• A forum/expo needs to include Korean language 'handouts' and the availability of an individual private consultation using a dementia (screening) 'checklist'.</li> </ul>

### Community from a Vietnamese Cultural and Language Background

How to Provide Information about Dementia	A Forum/Expo on Dementia
<ul style="list-style-type: none"> <li>• Vietnamese language newspaper</li> <li>• Vietnamese language radio including SBS and 2VNR</li> <li>• Through existing groups and community organisations such as the Vietnamese Seniors Association</li> <li>• Through community meetings and gatherings</li> <li>• Flyers/brochures in Vietnamese and English mailed to people's homes</li> <li>• Libraries and online (to support word of mouth dissemination).</li> </ul>	<ul style="list-style-type: none"> <li>• A forum/expo needs to be both in Vietnamese and English</li> <li>• A forum/expo needs to include opportunities for discussion and to receive answers</li> <li>• Transport needs to be provided for people who needed.</li> </ul>

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## Appendix 2: Interview Guides

### Community Consultation Interview Guide: Community Members

#### Interview Questions

##### *General*

1. Do you or anyone you know **have dementia**? If yes:

##### *For People who have or know someone with Dementia*

2. Can you please tell me a little about what that is **like**? Prompt: Experience of dementia/caring for a person with dementia, what their life is like, services/support they receive.
3. If you know someone with dementia or might have dementia or are interested in knowing about dementia **where** do/did you **get** information or help? Prompt: How you found out that was the place/s to go/to look for information. How long ago.
4. What was **most useful, less useful**?
5. Thinking about **information** about dementia, **how** would you like/have liked that? Prompt: In writing, on the radio, through a group like this, etc.
6. How do you think dementia is **seen** in the community? Prompt: general community, your cultural community.
7. How do you think **how dementia is seen affects** if/how people seek information or support?
8. What do you think **other people** (such as families, people in the community) need to **know** about dementia?
9. What do you think are the **best ways** for letting people **know** this?
10. For **you** what are **good ways of communicating information** about dementia?
  - a. Who you think this (method) would suit the most?
  - b. What should we need to say/include?
11. How **useful** do you think a **forum/expo** is? (Explain forum/expo)
12. If you **have been** to a **forum/expo** how did you **find out about** it/them?

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13. If you have **not been** to a **forum/expo** and think a forum/expo is the **most useful** way of providing information (or most useful for some people) what do you think a forum/expo needs to **include**?
  14. What do you think we need to say to **encourage** people to **go** to a forum/expo?
  15. At the forum/expo what do you think we need to **say** about **dementia**?
  16. Is there **anything else** you would like to say?

***For People who don't have or don't know someone with Dementia*** (no to first question)

2. If you had concerns about someone who has or might have dementia or are interested in knowing about dementia **where** would you go/who would you turn to for **information** or **help**?
3. How can we make it **easy** for people to **seek** and **receive information** and **help** about dementia? Prompt: what do we say, how we say it, where, to whom (such as family members)
4. How do you think dementia is **seen** in the community? Prompt: general community, your cultural community.
5. How do you think how **dementia is seen** affects if/how people seek information or support?
6. What do you think **other people** (such as families, people in the community) need to **know** about dementia?
7. Is there anything you would like to **know** about dementia? If yes, **what**?
8. For **you** what are **good ways** of **communicating information** about dementia?
  - a. Who you think this (method) would suit the most?
  - b. What should we need to say/include?
9. How **useful** do you think a **forum/expo** (explain forum/expo) is for giving **information** about dementia, putting people **in contact** with **help**, putting people **in contact** with **other people** with similar experience?
10. If a forum/expo is the **most useful** way of providing information (or most useful for some people) what do you think a forum/expo needs to **include**?
10. What do you think we need to say to **encourage** people to **go** to a forum/expo about dementia?

11. Is there **anything else** you would like to say?

## Community Consultation Interview Guide: Staff

### Interview Questions

1. What have the people who use your service/their family/carers with dementia or might have dementia or are interested in knowing about dementia told you about **where they got information** or help? Prompt: How they find about the place/s to go/to look for information.
2. What have you heard was **most useful, less useful**?
3. How do you think dementia is **seen** in the community? Prompt: general community, your cultural community.
4. How do you think **how dementia is seen affects** if/how people seek information or support?
5. What do you think **other people** (such as families, people in the community) need to **know** about dementia?
6. What do you think are the **best ways** for letting people **know** this?
7. What do **you** think are **good ways of communicating information** about dementia?
  - a. Who you think this (method) would suit the most?
  - b. What should we need to say/include?
8. How **useful** do you think a **forum/expo** is? (Explain forum/expo)
9. What do you think we need to say to **encourage** people to **go** to a forum/expo?
10. At the forum/expo what do you think we need to **say** about **dementia**?
11. Is there **anything else** you would like to say?