

National Cross Cultural Dementia Network (NCCDN) A Knowledge Network of value

*One in eight Australians with dementia do not speak English at home.
Dementia does not discriminate; it affects all people regardless of race, culture or ethnicity.*

This brief paper highlights the value of the Network to Alzheimer's Australia and the Commonwealth in its strategic and grass roots role in supporting people living with dementia from a culturally and linguistically diverse background.

An overview of NCCDN

The National Cross Cultural Dementia Network (the Network) was formally established in 2003 and receives funding under the National Dementia Support Program (NDSP).

The Network provides Alzheimer's Australia (AA) with a pool of knowledge and expertise that is of benefit for all Australians living with dementia. The Network acts as a platform for AA, the Commonwealth and other relevant government services, and non government organisations by providing professional, expert and strategic advice across a broad range of issues relating to people from culturally and linguistically diverse backgrounds (CALD) who live with dementia.

The Network facilitates, discusses and advances the issues relating to people with dementia and their families to ensure that they are part of the mainstream agenda.

The Network provides advocacy and advice to Alzheimer's Australia's and its member organisations regarding the direction of cross-cultural issues, and access and equity within its programs and services. The Network also promotes research which focuses on the special needs of people from CALD backgrounds and advocates that general research includes consideration of the special needs of people from CALD backgrounds.

The Network members also promote the work of Alzheimer's Australia, and encourage partnerships with organisations offering services to people from CALD backgrounds.

Membership

The National Cross Cultural Dementia Network membership is multidisciplinary and represents a diverse mix of cultures and ethnicities. Members come from a range of professions such as geriatrics, clinical psychology, nursing, residential aged care, education, social work, community work, and knowledge and information management. They represent organisations such as Migrant Resource Centers, Area Health Services, Partners In Culturally Appropriate Care (PICAC) and Aged Care Assessment Teams (ACAT) as well as Alzheimer's Australia.

The Network also draws on experts external to Alzheimer's Australia and the Network who bring additional skills, experience and expertise which enriches the work of the Network and increases its knowledge base.

A strength of the Network's membership is its diversity. This diversity of skills, expertise, backgrounds and sector knowledge ensures robustness in discussion, activities and outputs from the Network. This strength is further reflected in Alzheimer's Australia seeking the opinion/advice of either the Network as a group, or individual members on specific issues, policy papers and submissions. Members also act as representatives of the Network on specific task forces, projects or agencies, such as the Dementia Collaborative Research Centres, National Health and Medical Research Council (NHMRC) projects, and KPMG projects.

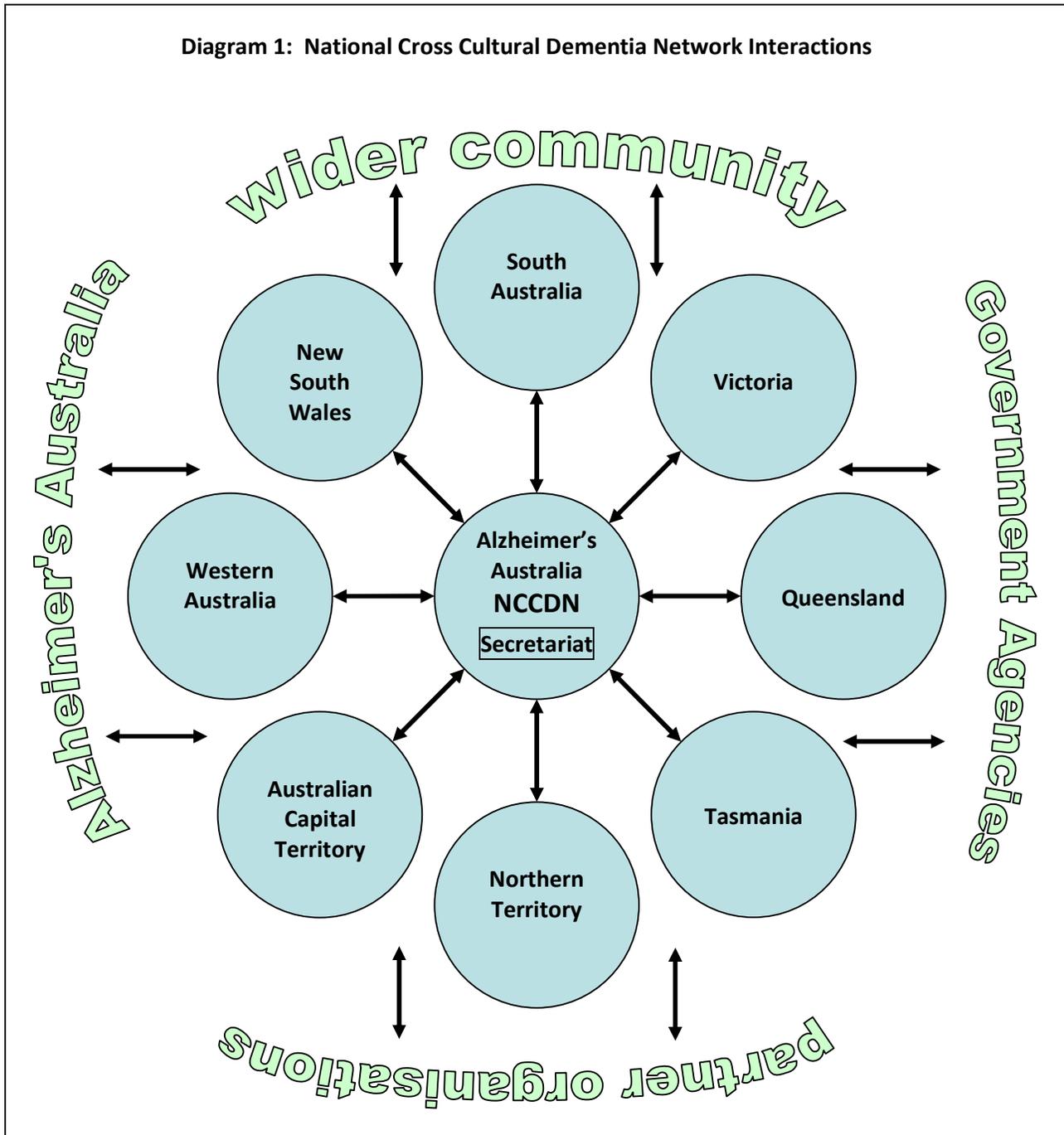
NCCDN as a Knowledge Network

The Network can be considered a 'knowledge network' as its members share a common interest and goals as defined by the Network objectives and terms of reference, freely share ideas, exchange and develop good practice, provide advice and support to each other to problem solve, and work to bridge 'islands of knowledge' in Alzheimer's Australia, partner organisations, community organisations and government agencies.

The Network Secretariat plays a key role to ensure members are kept up to date with issues and information on a national level. Collaboration amongst members and partner organisations at a local level is encouraged as it strengthens external relationships and as a consequence, provides additional knowledge and information back into the Network. This continual communication cycle ensures members are better equipped to represent and speak on behalf of people with dementia and their families. Additionally, this capacity building is transferred to CALD communities and individuals at the local level.

The diagram below illustrates the way in which the National Cross Cultural Dementia Network supports and provides advice to Alzheimer's Australia, Department of Health and Ageing and related government and non government agencies, Dementia Collaborative Research Centres and other partner organisations and importantly, how it reaches back into the wider community (individuals, families and organisations) in each State and Territory.

Diagram 1: National Cross Cultural Dementia Network Interactions



NCCDN members, depending on their expertise, will work on key Network initiatives through working groups, which vary according to strategic imperatives including:

- Clinicians Working Group (diagnostic and assessment sub-group)
- Research Working Group
- Information & Education Working Group

Key Achievements

The NCCDN has been successful and is a key part of National Alzheimer's Australia. The work of the Network benefits the wider community, Alzheimer's Australia, partner organisations and government agencies. The strong internal and external working relationships ensure success across key areas of: diagnosis and assessment, research and resource development. Additionally, the Network successfully demonstrates its capacity as a knowledge network in information, networking and partnerships, and its national advisory role.

Culturally Appropriate Assessment

- Two papers on the "Guidelines on Screening and Assessment of CALD communities" (2007) have been completed by the Diagnostic and Assessment sub-group of the Network and NARI. (SA, NT and NSW Network members)
- Supported and lobbied for the second validation of the Rowland Universal Dementia Assessment Scale (RUDAS).
- The Network members actively work in each State and Territory promoting the usage of the RUDAS screening tool and its uptake.
- RUDAS research team presented at the International Psychogeriatrics Conference September 2007, reporting on the second validation of the RUDAS project.
- Production and distribution of the RUDAS DVD and placement on the National website in partnership with South Western Sydney Area Health Service. (NSW and SA Network members)
- NCCDN was consulted on the development of the (DBMAS) "Best Practice Guidelines for People with Dementia from a Culturally and Linguistically Diverse Background who have Challenging Behaviours".
- Involvement by Network member (SA) with the Dementia Outcomes Measurement Suite (DOM's) Project.

Research

- Working in partnership with the South Western Sydney Area Health Service, Alzheimer's Australia National Office, National Ageing Research Institute (NARI) and Royal Adelaide Hospital in the second validation of RUDAS. (SA and NSW members)
- Involvement with the NHMRC CALD Carers project with Queensland University and South West Sydney Area Health Service, 2009/2010/2011. (NSW and SA Network members)
- The Network supported the 2006 Access Economics Report "Dementia Prevalence and Incidence among Australians who do not speak English at home".
- Network member (NSW) is a representative of the Primary Dementia Collaborative Research Centre's (DCRC) Advisory Committee & Consumer Advisory Committee.
- Network members (NSW) on the Advisory Committee for the Department of Ageing, Disability and Home Care (DADHC) CALD Dementia Strategic Planning and DADHC Planning Ahead Research.
- NSW and SA members contributed to the DCRC expert forum on "Strategic directions in CALD Communities".

- Contribution by NSW member to DCRC published article "Future research on dementia".

Resource development

- Research and publication of the "CALD Resources Report" (2005) which identified dementia and dementia related resources that are available in Australia and suitable for use by people and agencies from CALD backgrounds. (NSW Network member)
- Input into the development of culturally appropriate resources through the National Resources Committee and other partner organisations. (Vic and NSW Network members)
- Supported the report of the "National Audit of the Training and Education Needs of carers and people from Culturally and Linguistically Diverse backgrounds with Dementia" by Kate Barnett (2004). (Qld, NSW, SA, Vic Network members)
- In partnership with Pino Migliorino of Cultural & Indigenous Research Centre Australia (CIRCA) developed a culturally appropriate media framework (2009).

Information, Networking and Partnerships at a National and local level

- A NCCDN specific newsletter, *Cultural News*, disseminated electronically, was launched in June 2006, highlighting CALD dementia initiatives nationally.
- Established and maintain the Cultural Diversity section on the AA website.
- Facilitation of partnership activities/links with a range of agencies around Australia namely, Federation of Ethnic Communities Council of Australia (FECCA) (Memorandum of Understanding established between the two agencies, 2008), Diversity in Health (DIH), Australian Multicultural Foundation (AMF), Partners in Culturally Appropriate Care (PICAC), Dementia Collaborative Research Centres (DCRC), Telephone Interpreting Services (TIS), Victorian Transcultural Psychiatry Unit and several Universities.
- Presentation of a key note paper by Pino Migliorino (President, Federation of Ethnic Communities Council, FECCA) at National Alzheimer's Australia Conference 2009, which was facilitated by the Network.
- Facilitated National AA Conference held workshops for conference participants and members of the community to inform and consult on issues for people with dementia from CALD backgrounds and their carers.
- Collaboration with and between National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) and National Consumer Advisory Committee (NCAC).
- There has been International recognition of the Network and the way that it operates. Both our colleagues in the USA and also Alzheimer's Disease International (ADI) have commended the structure.

National Advisory role

- Two members of the Network (ACT and Vic) sit on the Minister's National Advisory Group on Dementia.
- Input into Alzheimer's Australia's submissions and papers such as "Budget Submission for 2010 Dementia: facing the epidemic", and "Respite Care for People Living with Dementia" (2009).

- The Network challenges the thinking of Alzheimer's Australia, Government and non government agencies in how they respond to the needs of people from culturally and linguistically diverse backgrounds.

Culturally and linguistically diverse communities continue to face barriers to accessing services.



National Priority Areas

The Network has identified five key areas to promote access to dementia care services and programs for those who come from culturally and linguistically diverse (CALD) backgrounds:

1. Community education and awareness raising for CALD communities
2. Cross Cultural Co-ordinators in all State and Territory AA offices
3. Culturally and linguistically appropriate assessment and diagnosis
4. Increase in community care places
5. Increase in research into issues affecting CALD people with dementia and their families.

The National Cross Cultural Dementia Network, as a **knowledge network of value**, is ideally placed as a key contributor to advance the strategic intent of Alzheimer's Australia and the Commonwealth in its endeavours to support people from CALD backgrounds and provide socially inclusive programs and services for people living with dementia.