



Koori Dementia CARE PROJECT

THE KOORI DEMENTIA CARE PROJECT (KDCP) - FINAL REPORT 2013

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La Prouse

Mervyn Davison - Aboriginal Dementia Knowledge Holder (Deceased January 2013)

Funded by Department of Ageing Disability and Home Care NSW and supported by the Dementia Collaborative Research Centres (DCRC) and Neuroscience Research Australia (NeuRA).

Aboriginal and Torres Strait Islander readers please note: these pages may contain the names and images of Aboriginal and Torres Strait Islander people now deceased

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Holly Mack (Project Manager KGOWS); Charmaine Moran (Aboriginal Health Worker); Sharon Wall (Project manager, KDCP); Mervyn Davison (Aboriginal Dementia Knowledge Holder LA Perouse Dec: January 2013) and Aunty Sue Hoskins (Aboriginal Dementia Educator Mid North Coast)

This final report is dedicated to Mervyn Davison: a proud Koori Man, a wonderful contributor to his community, a treasured family man and a wonderful colleague and friend.

Trek of Hope for a Dementia Cure

Mary Jane Page, an Aboriginal artist from La Perouse, was engaged by the Koori Dementia Care Project to portray dementia in a painting. Her artwork, *Trek of Hope for a Dementia Cure*, is rich in meaning and demonstrates a cultural understanding of the impact of dementia in Aboriginal and Torres Strait Islander communities. Mary describes her artistic process and the artwork below:



'My name is Mary Jane Page and I'm an Aboriginal artist. I was approached by Holly, Sharon, and Cecilia from the Koori Dementia Care Project to do a painting about dementia. I wondered to myself – 'How do you paint dementia?' So I just sat in quiet time and thought dementia is about the brain and it dies; the actual cells die. So I did it in an artistic way; best way I could do with heaps of feeling going into it. And I'm sure by looking at it you will see the feeling that went into this piece of artwork depicting a brain with dementia.

In the middle part of the brain is a black spot, which is the first sign of dementia and it spreads like a vortex through the other brain cells. The rest of the black around the brain is the other cells dying and the silver represents the minimum of brain tissue that is left. The red shapes represent the blood flow, the blood cells, and the veins. There are slight greens in there, which to me is always to do with mentality that acts like a calming. Also in the centre of the brain is the Eye of the Mind. We are all born with the Eye of the Mind and we will die with the Eye of the Mind. It's just part of our existence; the eye will always be there, even in sickness. The tracks in the top right and lower left hand corners symbolise the memory leaving the brain. The black in the background is the death of the brain tissues, everything's gone, and that's where it goes to when it dies. It symbolizes loneliness and how the person feels with dementia. We don't know where it goes to and that is what we are hoping to find out. The flowers represent hope; hoping one day there will be a cure for dementia. The red in the flowers is strength and power because we must have the strength and the power to have hope. The gold also means strength and it signifies the sun, hoping that the sunlight comes in, and that there will be a brighter day for those people suffering from dementia. This is my interpretation of dementia and I'm sure once people do take a very good, long look at it they will see what the artwork means.'

Subsequently, this painting has been revered as not only a beautiful artwork, but also as representative of the collaborative engagement with Aboriginal communities that underpins this project. *Trek of Hope for a Dementia Cure* proudly hangs in the Neuroscience Research Australia building in Randwick, Sydney.

Executive Summary

The Koori Dementia Care Project (KDCP) built on the work of the Koori Growing Old Well Study (KGOWS), a National Health and Medical Research Council (NHMRC) funded project. The KDCP aimed to translate the knowledge gained from the KGOWS into meaningful care and practice for six regional and urban Aboriginal communities.

This final report is a summary of the aims, objectives, outcomes and key deliverables of the KDCP and the activities undertaken in 2012 and 2013, at the completion of the project term. Furthermore, a report on each community that the project worked within is provided, and critical success factors, as well as challenges and barriers that need to be addressed for the future, are identified.

Despite the many challenges, the KDCP's achievements have surpassed the anticipated aims, objectives and outcomes. These gains are further outlined in this report. Importantly the project has increased capacity around dementia knowledge in the targeted Aboriginal communities. It has achieved this by:

- increasing dementia awareness and knowledge across the six communities;
- training and mentoring of ¹Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators and the project support staff in each of the communities;
- increasing acceptance of appropriate community services for those living with dementia and their families;
- translating knowledge gained in the KGOWS into capacity building for Aboriginal and non-Aboriginal service providers and health workers;
- developing and disseminating information and communication strategies about the topic of dementia to six urban and regional Aboriginal communities;
- improving the timely diagnosis of dementia;
- development and support of an Aboriginal specific Visiting Geriatrician Program initially within La Perouse Aboriginal Community Health Centre and Mid North Coast (Coffs Harbour and Kempsey) with progress in rolling this out in other Aboriginal communities, and
- an increase in the take-up of support for carers through increased community and family education and development of a person-centred (community centred) model of care within Aboriginal care.

Dissemination of the current knowledge around dementia has assured a response from the Aboriginal community. As people have been learning about the prevalence of dementia through the project, we have become increasingly aware that more people are having

¹ Aboriginal Dementia Knowledge Holders was the initial term used for this project and in subsequent project planning it was the accepted term used by the Campbelltown, Mt Druitt and La Perouse teams. Aboriginal Dementia Educator was the accepted term used by the Mid North Coast team. These positions had been the pivotal roles within the project and are respected as such.

conversations and communications with their doctors at the Aboriginal Medical Services (AMS) and their other health and social providers. This increased understanding has been discussed widely in yarnings with the community and is also being reflected in evaluations and surveys undertaken throughout project. Further information about this is provided in the evaluation component of this report.

Though the project team sought additional grants, to continue the work of translating KGOWS knowledge into practice for Aboriginal and Torres Strait Islander communities, further funding has not eventuated. This document, therefore, represents the final report for the project and the handover of resources collated during the project term. It is our hope that these resources will be maintained and shared with the broader Aboriginal and Torres Strait Islander community.

Project Description

The Koori Dementia Care Project (KDCP) was funded for two years (2012-2013) by the Department of Ageing Disability and Home Care and was supported by the Dementia Collaborative Research Centres (DCRC) and Neuroscience Research Australia (NeuRA). KDCP aimed to inform, educate and build capacity in the selected urban and regional Aboriginal communities in New South Wales (NSW), and with associated service providers, about the effects of dementia on older Aboriginal and Torres Strait Islander people, their families and their community.

This project involved partnerships between the KGOWS team, the KDCP project team, AMS partners, specific community leaders and identified information leaders within the Aboriginal communities. KDCP project sites are the NSW urban communities of La Perouse, Campbelltown, and Mount Druitt and the regional centres of Kempsey, Nambucca and Coffs Harbour on the Mid North Coast of NSW.

The project has worked to establish the dementia knowledge wants and needs of each community then target, train and collaborate with appropriate people within each community to provide that information. A community-focused approach was developed to acknowledge and respect the unique community structures, cultural history and networks of each Aboriginal and Torres Strait Islander partner community. In this way, the project unfolded uniquely in each community, depending on the specific needs and structure of that site.

The project team worked with local guidance groups in each community to ensure mutually respectful relationships were maintained. The project was overseen by a Sustainability (Reference) Group who contributed to strategies for ensuring that this dementia information remained within individual communities, beyond the lifespan of the project.

The pivotal component of the project was engaging Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators (ADKHs/ADEs). The ADKH/ADE positions were undertaken by highly respected members of each community and in most instances, were regarded as Elders of their community. Therefore, these ADKHs/ADEs were best placed to identify the needs of the community and drive the local implementation of the KDCP. They were each employed two days a week in their respective communities and were supported by project staff. As such, the structure of the project allowed a relationship of mutual mentoring to occur. The Project Manager and Project Team mentored the ADKHs/ADEs around dementia, while the ADKHs/ADEs mentored the Project Manager and Project Team around Aboriginal and Torres Strait Islander culture.

The Project Manager developed and delivered initial dementia education and training for the ADKHs/ADEs. This primary training was specifically designed for the ADKH/ADE cohort and, as such, contained relevant, culturally appropriate and sensitive information in an adult education style. Additionally, ADKHs/ADEs have undertaken further

education as available in their communities or as supported by the project. A complete list of education undertaken is contained in the appendices of this report.

The Koori Growing Old Well Study – A Background

In 2008, the first rigorous study of dementia prevalence in Aboriginal people was published by the research team at the Western Australian Centre for Health and Ageing (WACHA; Smith *et al* 2008). This study showed that the prevalence of dementia in the remote Kimberley region of Western Australia was around five times higher than in mainstream Australia, at ages 45 years and older. The causes of dementia in this population were not always clear, but Alzheimer’s type dementia was frequently diagnosed. This study was extremely important as it provided the first reliable data on dementia in Aboriginal communities. However, as the majority of Aboriginal people in Australia do not live in remote communities, an important question remained: does this high prevalence of dementia also apply to Aboriginal Australians who live in non-remote settings?

Between 2010 and 2012, the Koori Growing Old Well Study (KGOWS) attempted to answer that question. They conducted a comprehensive survey of all Aboriginal men and women aged 60 years and over residing in five NSW Aboriginal communities (Radford *et al.*, *accepted for publication*). This study found that the prevalence of dementia in older Aboriginal people from urban and regional areas was three times higher than the rate of dementia in non-Indigenous Australians. The most common type of dementia diagnosed was Alzheimer’s dementia, followed by vascular dementia and dementia due to head trauma.

This finding would suggest that urban and regional Aboriginal Australians have a similarly high rate of dementia to remote Aboriginal peoples, and some of the highest rates observed worldwide. Our collective challenge - now that we are beginning to understand the importance of this issue - is raising awareness about dementia in urban and regional Aboriginal communities and improving dementia assessment and care for Aboriginal people, as is currently underway in remote areas. It was always a commitment of the KGOWS to report results and strategies back to the community and to increase capacity around dementia. This commitment formed the foundation of the proposal for the KDCP.

Setting up the KDCP

1. Sustainability Group (Reference Group)

From the outset, a most important element of this project was the ongoing sustainability of the knowledge and resources developed throughout the project. Most project members had been part of projects in the past where knowledge gained had not been put into practice nor translated in a way that had an impact on those it was meant to most influence once funding was completed. It was genuinely hoped by all that this project would be different in that way.

A component then of this project was the development of a Sustainability Group, which comprised of academics, professionals and consumers who would take responsibility for sharing the history and outcomes of this project for the duration.

It was anticipated that, within this role, members would:

- Determine the strategic directions of the project
- Bring individual skills to the table
- Provide guidance to the Project Manager and Project Team
- Reflect regularly on issues of the sustainability of the project
- Act collectively and provide a consensus of opinions regarding directions of the project
- Ensure accountability of project

It was further articulated that the commitment and level of engagement would entail:

- 3 – 4 monthly phone link ups across the life of project
- Response to group emails
- Sharing of resources, knowledge and specific skills
- Communication through Project Manager

Although rich in content, in reality only a proportion of the original Sustainability Group attended regular meetings and provided regular feedback. Nevertheless, the group did contribute high level skills to the project as it comprised of people representing Aboriginal ageing policy, dementia policy and a psychogeriatric academic.

2. Community Group (Guidance Group)

A Community Guidance Group had been established in each community as part of the KGOWS. This recognised that the respectful way to work with communities was by being introduced by leaders and Elders in each of the communities. It also acknowledged the uniqueness of each community and demonstrated the need for an individualised approach. Each Community Group had a representation of Elders, health education leaders, Aboriginal Medical Service representative(s), representative(s) from local HACC providers, aged care leader(s) and dementia service providers.

The articulated role of the Guidance Group was to:

- Assist the Project Team in community relationship building
- Provide local knowledge and local understanding to Project Team
- Act as a conduit between the Project Team and community

The level of commitment anticipated was participation individually and collectively as required, and participation in Project Team meetings as required, with communication being facilitated by the Project Manager.

3. Project Team

The Project Team was responsible for ongoing planning, monitoring and executing the deliverables of the project. The Project Team consisted of the Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators and project staff for each community, as well as: Gail Daylight (Area Manager of Aboriginal Health) acted as a link between Aboriginal community health and KDCP and as a cultural guide to the Project Team; Holly Mack (Project Manager of KGOWS) who was the financial manager of the project, the link between KGOWS and KDCP and assisted the Project Manager as required; Deserae Horswood (Project Assistant) who managed communication strategies for the project and assisted the Project Manager as required. Additionally, Danielle White (Alzheimer's Australia - NSW) was invited to be part of the Project Team. In the same round as KDCP, Alzheimer's NSW was funded to undertake some Aboriginal dementia-specific work, and therefore, because of similar goals and directions, it was a 'value add' for both projects to remain closely associated. The structure of the KDCP is represented in the diagram below.

4. Project Manager

Sharon Wall was the Project Manager and her role (undertaken 3- 4 days a weeks throughout the project) was to:

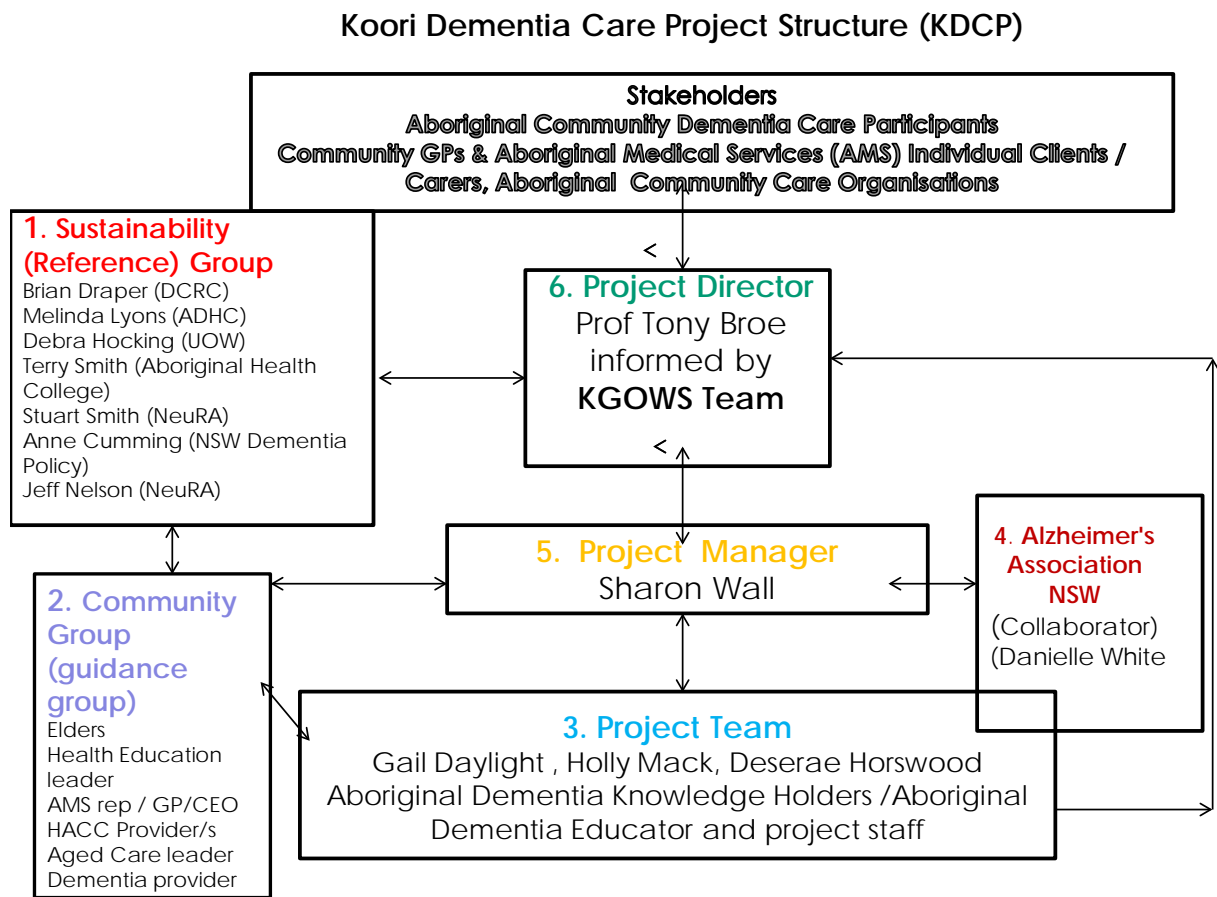
- Develop and maintain communication strategies between all project members
- Develop team roles and responsibilities
- Mentor the ADKHs/ADEs
- Ongoing monitoring of the project
- Maintain link between project and funding body
- Maintain link between Project Director and Project Team
- Evaluate throughout the project
- Report to Project Director

- Ensure accountability to timelines
- Ensure financial accountability

5. Project Director

The Project Director was Professor Tony Broe. His role was to act as a link between the KGOWS and KDCP and to provide the necessary strategic leadership of the project.

(Diagram 1)



A Review of Key Tasks

The KDCP set the following key tasks to be undertaken throughout the life of the project.

The Project Manager will develop an understanding of each community by exploring the culture of learning and by identifying information holders/educators, key service providers and potential collaborators.

This was an ongoing process throughout the term of the project. Each community had a different and unique culture of sharing information and learning and this was identified and respected. The ADKHs/ADEs have utilised these differences fully in the dissemination of knowledge into their communities.

Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators and Project Officers will be recruited from each community and trained and mentored by the Project Manager.

ADKHs/ADEs were engaged in La Perouse, Campbelltown, the Mid North Coast (Coffs Harbour) and Mt. Druitt. Two Project Officers were engaged in the Coffs Harbour site to supplement the ADE position, in order to allow service provision across the Mid North Coast, which incorporated Nambucca and Kempsey.

Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators and Project Officers (supported by the Project Manager) will undertake consultations with service providers and Elder groups to understand how dementia is experienced and to identify the needs of each community.

In each of the areas with engaged ADKHs/ADEs, relationships were formed with Aged and Aboriginal specific health providers, community members and organisations. Each team embedded itself in services and organisations depending on the particular structure of the community, to offer ongoing assistance and support to Aboriginal and Torres Strait Islander people living with dementia and their carers.

A Dementia Pathway will be developed for each community with identified collaborators. This may include the Aboriginal Medical Service, community services and mainstream health services, with an action plan of how the pathway can be improved.

A services pathway represents a series of service steps or 'sign-posts', including provision of information, coordination and delivery of clinical, educational and social support services. The service requirements should broadly reflect good practice in terms of services matching needs and requirements and should reflect requirements that all service recipients should expect. (KPMG, 2011)

A services pathway describes the services required to meet the needs of people living with dementia and their carers, across the dementia continuum. The development of service pathways by exploring the journey of an individual/s with dementia encourages

consideration of efficient and effective service delivery and coordination - keeping front of mind the experience of the person living with dementia and their carer.

The inaugural development of a pathway has been identified in each community. Informed by yarning with the community, each community demonstrated a distinctiveness in terms of how information was disseminated and shared. Additionally, the potential partners and collaborators in each community were different and often included collaborators who may not be involved in mainstream dementia provision. This is an important observation for future development of models around dementia in Aboriginal communities and requires further exploration in the future.

[A tailored education strategy for each community will be developed, with the support and mentoring of the Project Manager. These may include Yarning Groups with Elders, use of developed materials, focus groups, community displays, etc.](#)

Yarning Groups around dementia were held in La Perouse, Redfern, Campbelltown, and Mt. Druitt. Yarning is an informal conversation that is culturally friendly and recognised by Aboriginal people as meaning to talk about something, someone or provide and receive information (Bessarab & Ngandu, 2010). The emphasis of yarning is about story and this appeared to fit well with yarning around dementia in the community.

Additionally there was a one day workshop “Living with Dementia in Aboriginal and Torres Strait Islander Communities” developed by the Project Manager and the ADKHs/ADEs which was provided for HACC Aboriginal and non-Aboriginal providers in Redfern, La Perouse, Campbelltown, Parkes and Orange (NSW). This workshop was evaluated very highly by participants.

An “Aboriginal Dementia Training” workshop and evaluation survey was developed by the Mid North Coast Project Officers and Aboriginal Dementia Education Officer. The workshop was presented to local Elders groups and an Aboriginal organisation in Coffs Harbour.

A partnership was also formed with the Program of Experience in the Palliative Approach (PEPA). Presentations on dementia in Aboriginal communities as part of these workshops were undertaken in Redfern, La Perouse and Mt Druitt.

A specific brochure ‘The Brain and Dementia’ was developed by the team and widely distributed in all communities. This was initiated by the ADKHs/ADEs who identified that ‘looking after your brain’ was a message they wanted to get out to their communities.

A dedicated component of the NeuRA website was made available to the KDCP. This was continually updated and includes many resources, including a video clip specifically about the project. Many opportunities were utilised to share information about the project which are further outlined in Appendix 1.

[A project report will be submitted that describes each community and identifies critical success factors as well as challenges and barriers that need to be addressed at different levels.](#)

All activities were documented and evaluated for inclusion in this final report.

A Review of Key Outcomes of the Project

The project additionally set specific outcomes which are summarised as below.

[Increased dementia awareness and knowledge across the six communities.](#)

Relationships were developed in each of the six areas with mainstream aged care providers and Aboriginal specific organisations. Aboriginal dementia specific resources were developed and shared widely. Yarn ups and education and training sessions have been undertaken in each community in a diversity of settings.

As previously discussed, a tailored education strategy for each community has been developed, with the support and mentoring of the Project Manager. The Mid North Coast team was also mentored in dementia knowledge through their collaborations with Alzheimer's Australia- Coffs Harbour Branch. These have included Yarning Groups with Elders, use of developed materials, focus groups, community displays and community presentations as required and specific workshops for service providers.

Relationships have been developed with Aboriginal specific organisations as well as more strategic links with major mainstream aged care aged care providers. Appropriate culturally specific dementia resources were sourced and widely shared. A portfolio of resources were additionally developed (further outlined in this report in Appendix 1) and were widely disseminated. The Project Manager and Project Team presented at multiple conferences and forums and to the community at large an overview of which is provided as Appendix 2.

[The training and mentoring of Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators and the supportive project staff in each of the communities.](#)

Mentorship has played a pivotal role in this project. The Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators have been mentored by the Project Manager in the area of dementia whilst they have mentored her (and the rest of the project team) in Aboriginal Culture.

Initial and ongoing education and training for the ADKHs/ADEs has been provided by the Project Manager, who has a long and demonstrated background in the area of dementia. Additionally the Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators have been encouraged (and financially supported through the project) to undertake additional education and training to support their work in the area of dementia in their respective communities including increasing computer skills . As a consequence we

now have Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators with a high level of dementia literacy and competency working across the project communities.

[Increased acceptance of appropriate community services for those living with dementia and their families.](#)

There has been ongoing consultation with the community about the development of appropriate resources and services for Aboriginal people and their families living with dementia. The Koori Dementia Care Project has been instrumental in developing and supporting the visiting geriatrician program on the Mid North Coast and is facilitating communication with other sites and services regarding similar projects. This program (developed through funding from NSW Health -Connecting Care), has seen Prince of Wales Hospital act as a base for Geriatrician visits to our Aboriginal partners identified throughout the KGOWS and KDCP. This program will ensure ongoing access to community resources for Older Aboriginal people with dementia and their families.

This program commenced on the Mid North Coast in 2013, and it is anticipated that the same program will be replicated over time in the other study sites. This will ensure there are dedicated geriatricians who will attend to the needs of ageing Aboriginal and Torres Strait Islander people – simultaneously allowing them to become familiar with the local area and community needs, as they relate to ageing.

[Translation of knowledge gained in the KGOWS into capacity building for Aboriginal and non-Aboriginal service providers and health workers.](#)

The KGOWS has been represented on the KDCP by the Project Director (Professor Broe) who has also attended all steering committee meetings undertaken throughout the project.

Data from KGOWS continues to come on stream, attracting media attention, and has been utilised as a foundation for development of further capacity building around dementia through the ADKHs/ADEs. Capacity building has been viewed within this project as ‘an approach to the development of sustainable skills, organisational structures, resources and commitment to health improvement in health and other sectors, to prolong and multiply health gains many times over’ (Hawe et al, 1999).

Capacity building has been dependent on the development of respect, trust and the development of well-planned and integrated community-based strategies. This has been largely dependent on the creation of essential partnerships, seen as an integral component of this project. These partnerships honour the autonomous nature of each group and recognise that each community has a unique structure and unique set of needs.

[Development and dissemination of information and communication strategies about the topic of dementia to six urban and regional Aboriginal communities.](#)

All project teams have been committed to disseminating information within their respective communities as previously discussed. This has been done in a culturally appropriate way and in consultation with the community and Elders at all times.

[Improvement in the timely diagnosis of dementia; increase in the take-up of support for carers through increased community and family education and development of a person-centred \(community centred\) model of care within Aboriginal care.](#)

The dissemination of the current understanding around dementia has assured a response from the Aboriginal community. As people have been learning about the incidence of dementia, we are being told about an increase in conversations and communication that people are having with their doctors, at the Aboriginal Medical Services and their other health and social providers.

This improvement is particularly obvious in the Mid North Coast where the visiting Geriatrician Program has been so eagerly embraced. This has been discussed widely in yarnings with the community, as well as being reflected in evaluations and surveys undertaken throughout the project. Further information about this is provided in the evaluation component of this report.

Overview of each Community

La Perouse

Indigenous people account for more than one-third of the La Perouse population. Relationships with many Elders and service providers had already been established in this site through research undertaken by the Koori Growing Old Well Study.

An Aboriginal researcher and respected member of the Aboriginal community, Mervyn Davison, was engaged to be the ADKH/ADE in this area. He undertook the relevant training, mentored by the Project Manager, and continued to establish good links and relationships with the community, talking regularly about dementia. Mervyn maintained an office at NeuRA, which allowed him easy access and support from all members of the KGOWS. Furthermore, he had well established links with the La Perouse Aboriginal Community Health Centre, which assisted his work greatly.

Mervyn became unexpectedly ill while attending the Aboriginal forum 'Dementia in Aboriginal and Torres Strait Islander Communities – Translating Research into Practice', held in Brisbane in November 2012.

Sadly Mervyn died about six weeks later whilst holding the ADKH/ADE position: a great personal loss for the team and for his community. Because of the small funded time left in the project, and lack of budget options, it was not possible to replace this ADKH/ADE position. But knowledge has been embedded in this community through two largely

attended HACC training days on 'Dementia in Aboriginal Communities' and a number of PEPA workshops. Additionally, sponsorship was provided for an Aboriginal Health Worker from Prince of Wales Hospital (POWH) to attend the conference in Brisbane and another Aboriginal Health Worker undertook the ADKH/ADE training. This was done in an attempt to leave some of the skills and resources within the community at the cessation of the project.

Primary access points for dementia pathway collaborators in this community include:

- La Perouse Aboriginal Community Health Centre
- Aboriginal Health Workers based at Prince Of Wales Hospital (POWH)
- Dementia Clinical Nurse Consultants (hospital and community)
- Gail Daylight (Area Manager of Aboriginal Health)
- Aboriginal Community Geriatrician Program (provided by POWH)

Campbelltown

Aunty Margaret Anderson, a respected Elder of the Campbelltown community, assumed the ADKH/ADE position for Campbelltown.

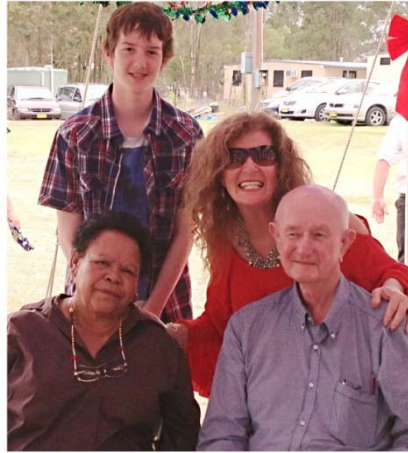
Aunty Margaret has a long history of being connected to community health organisations in Campbelltown and the surrounding area, and her background proved most valuable. Her position was accommodated in a mainstream community health setting at the Rosemeadow Community Health Centre, but she also had very well established links with Tharawal Aboriginal Medical Service who remained very supportive of the project. Her position within the Community Health Centre worked very well; she acted as a support and guide in many ways to various staff within that setting, and they, subsequently, for her.

Aunty Margaret became a well-respected spokesperson for dementia in her community. Not only was she an ADKH/ADE, but she also had a very personal experience with the disease, as her husband John suffered with dementia. She was her husband's carer; he sadly died last year.

Through the project, Aunty Margaret had the opportunity to tell her story on a number of occasions. Sharing her story through participation in forums, television appearances and in educational DVDs assisted others, as she relayed the message of dementia awareness to her community, and others, about dementia and its path in Aboriginal populations.

Primary access points for Dementia pathway collaborators in this community include:

- Rosemeadow Community Health Clinic
- Tharawal Aboriginal Corporation (Aboriginal Medical Service)
- Dementia Advisors
- Macarthur Disability Services
- Northcott Disability services



Aunty Margaret, James Broe, Sharon Wall and Prof Broe Tharawal AMS Christmas party 2012

Mid North Coast

Initially the project intended to have an ADKH/ADE in the three sites of Nambucca, Kempsey and Coffs Harbour. Aunty Sue Hoskins was engaged in the Coffs Harbour position, but recruitment proved to be difficult for the other two sites. It was subsequently decided that Aunty Sue would be supported by two Project Officers in Coffs Harbour, Emily Hindman and Leanne Williams, and that the team would attempt to cover Nambucca and Coffs Harbour sites together. This team was referred to as the Mid North Coast team.

This team have had a large representation at forums and expos, and have created many opportunities for mainstream and Aboriginal-specific, aged-care service providers to learn more about dementia in Aboriginal communities. Additionally, they have been instrumental in the development of the Aboriginal Geriatrician Program and have hosted the geriatricians on their visits to the Mid North Coast.

Aunty Sue, as a highly respected Elder, has been a valued spokesperson about dementia in her community and has developed and presented workshops in a number of settings. The Mid North Coast team developed a good partnership with Alzheimer's NSW – Coffs Harbour. The Dementia Educator and Dementia Counsellor located in Coffs Harbour have supported the Mid North Coast team in their knowledge of dementia symptoms, behaviours, and strategies for working with clients with dementia as well as their families and caregivers. This relationship has been crucial in the locally developed culturally appropriate dementia education workshop. Aunty Sue participated in the development of a community awareness DVD around Aboriginal dementia issues with the Alzheimers Australia- Coffs Harbour team.

Primary access points for dementia pathway collaborators in this community include:

- Galambila Aboriginal Medical Service (Coffs Harbour)
- Aged Care Assessment Team (Coffs Harbour and Kempsey)

- Durri Aboriginal Corporation Medical Service (Kempsey)
- Booroongen Djugun Limited (Kempsey)
- Darrimba Maarra Aboriginal Health Clinic (Nambucca Heads)
- Bawrunga Aboriginal Medical Service (Nambucca Heads)
- Coffs Harbour Council
- Abcare (Coffs Harbour)

Mount Druitt

Elaine Gordon was recruited by the project as an ADKH/ADE in early 2013. In that time, she has demonstrated an amazing work output; she has set up a number of dementia related projects and presented in many diverse forums.

Elaine has a well-established relationship with the Western Sydney Aboriginal Medical Service (based at Mount Druitt), and they have enthusiastically supported her in this role by providing office accommodation and ongoing support. This is a very busy organisation with a high commitment to older Aboriginal people, and she has been able to partner with the Golden Oldies Program to highlight awareness around dementia. Additionally, she has set up a Carer Support Group for Aboriginal clients with dementia and their carers. Elaine has taken more of a case management approach to dementia; she has developed relationships with as many Aboriginal people as possible who require assistance. She has been able to utilise her established background and skill base to greatly influence the lives of Aboriginal people living with dementia in her community.



Elaine Gordon – Aboriginal Dementia Knowledge Holder; Mt Druitt 2013

Primary access points for Dementia pathway collaborators in this community include:

- Western Sydney Medicare Local
- Dementia CNC community
- Aboriginal Medical Service – Western Sydney

- Westmead Hospital / Blacktown Hospital - Aged Care team

Evaluation

A project research plan was developed (Appendix 3) which set strategic goals for the evaluation process and has continued to be an ongoing component of the project.

A primary focus of the KDCP was to establish what each of the six communities needed and wanted to know about dementia (community dementia literacy) and then to target, train and mentor the appropriate people within each community to provide that information (a community readiness kit).

To achieve that understanding, questionnaires were administered at public forums early in the project to determine the level of dementia knowledge amongst community members (Appendix 4). Additionally, when interacting with service providers a questionnaire was administered to accurately determine their needs in this area (Appendix 5). Responses demonstrated a high-level of interest and need for further information around dementia.

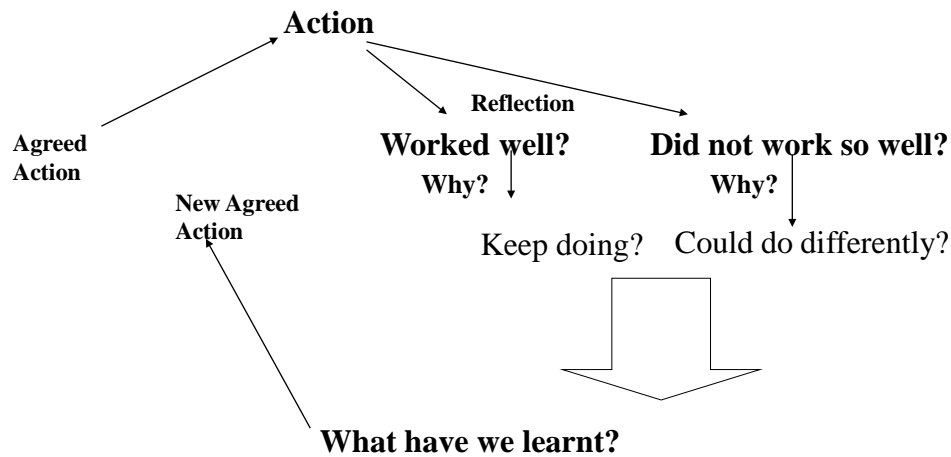
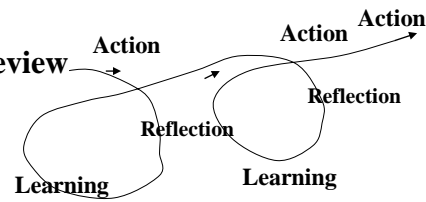
All formal education sessions had in-built evaluations within the presentation, as well as at the completion of the session. All programs were evaluated highly with the only negative comments relating to surroundings and environmental factors, rather than content.

Education provided for staff was rigorously evaluated and used as a platform for continual improvement (Appendix 6)

“This program was deadly and should be undertaken by all HACC workers working with Aboriginal people in our area.” (Participant - one day workshop – Campbelltown)

A monitoring cycle was undertaken throughout the project that attempted to **measure** where we were up to, **evaluate** where we planned to be and **correct** it by addressing what was required to get back on track. This approach is reflected in the diagram below.

**Cork Screw: Team Debrief
Post Implementation Review
Action Learning**



(Source: Dr Tom White)

Project meetings were held monthly with the project management committee and other invited participants. Later in the project, these became bimonthly. These meetings provided an opportunity to share successes and to evaluate, through the monitoring cycle, what needed to be changed or re-evaluated.

A survey, *Staying in Touch with Service Providers – Koori Dementia Care Project* (Appendix 6), was sent to a range of aged care service providers to evaluate the effectiveness of the program. The survey contained eight questions pertaining to the providers' awareness of and experience with different elements of the KDCP, as well as personal and service identifying items. The survey was hosted through online questionnaire software, Survey Monkey. Potential respondents were emailed a link, through which the survey could be accessed and completed. Fourteen people accessed the survey, and ten participants completed it fully. None of the respondents had participated in the Koori Growing Old Well Study (KGOWS). This is positive, suggesting that KDCP has reached new service providers outside of those affiliated with KGOWS, KDCP's parent project. Responses reflected a good awareness of the reach of KDCP: 90% knew of the work of KDCP; 70% were aware of the KDCP information, education brochures and resources; and 40% had themselves attended a KDCP event. One respondent personally knew an Aboriginal community member who had attended a KDCP event and four weren't sure. The remaining fifty percent reported they did not know members of their respective communities who had attended a KDCP event. It is important to note that none of these participants lived in KDCP project sites, therefore decreasing the likelihood of their community members' access to KDCP. Respondents also reported the type of information they would like to receive from

KDCP. Most responses related to the continuation of Aboriginal specific dementia education and resources, service linkage and targeted information for those suffering dementia and their carers. Finally, the survey asked about the Visiting Geriatricians or Ageing Specialist program. This budding program gives urban and rural Aboriginal communities access to an aged care specialist (Geriatrician) to service the specific needs of older Aboriginal and Torres Strait Islander people.

“I would like to say the geriatrician service has been utilised and was very supportive.” (Home Care Packages and Veteran’s Home Care)

Twenty percent of respondents already knew of the program, and 100% agreed that it would be beneficial for the Aboriginal communities concerned.

“This has been a wonderful boost for our community. Please tell me that it will continue as there is still so much work to do in the Aboriginal community around Dementia.” (Aboriginal HACC development officer)

Project Strengths

“Dementia is a sick spirit, a lost spirit looking for helpIt may not need to get fixed as long as the individual is safe and family and the community is safe.” (Mr Eric Deeral, Alzheimer’s Association)

Building capacity is a term used often with a sense of rhetoric. The strength of this project was to really examine what building capacity meant in the context of dementia information for these Aboriginal communities. For two years the project has supported a partnership between the Project Executive Team, Project Officers, Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators, specific community leaders and identified information leaders within the Aboriginal communities of La Perouse, Campbelltown (Tharawal), Kempsey (Dunghutti), Nambucca and Coffs Harbour (Gumbaynggirr) and Mt. Druitt. In addition, connections have been made with many other Aboriginal communities and services across NSW in urban, regional and rural areas.

The creation of partnerships was an integral component of this project. Partnerships honour the autonomous nature of each group and recognise that each community group has a unique structure and a unique set of needs.

The assumption that partnerships and collaborations just work is a pervasive one. Many organisations assume, particularly with fiscal pressures and finite resources, that participants can form partnerships and collaborations instinctively. Clearly though, successful partnerships and collaborations require specific work, commitment, planning and appropriate resource injections, including time, perhaps most importantly.

The Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators have been the drivers of the projects in their communities. They have each identified the dementia pathway within their community by working with and identifying collaborators, partners and organisations that can assist Aboriginal people living with dementia.

The first two years have involved a considerable level of relationship-building necessary to achieve the outcomes and deliverables identified in the original ADHC funding proposal in 2011. In addition, some key adjustments were required in order to make the capacity-building side of the work as relevant to each local community as possible. This has meant some deepening and broadening of our original objectives. An example of this is our support and engagement of the funded Visiting Geriatrician specialist services in the Mid North Coast, focusing on Kempsey and Coffs Harbour.

It had been anticipated that at the cessation of the current funding the project would be fully embedded in the communities, with a long term Aboriginal-specific community provider being prepared to take over the auspice in each community.

As the project has progressed this has become a less desirable option. It is now apparent that the ideal would be for each position/team to be embedded in partnership with a number of organisations, catered for differently in each community. What is important is that the skills obtained by the ADKHs/ADEs remain with the community, in order for the community to live more effectively with dementia.

To this end, the KADE for Mid North Coast and the ADKH/ADE for Campbelltown will have embedded positions as Aboriginal researchers within the ongoing Koori Growing Old Well Study. It is hoped that the ADKH/ADE for Mt Druitt will continue under the auspice of the AMS Western Sydney.

A desirable model to work towards would be to have a coordinator attached to the KGOWS, who could act as a conduit between the interface of Aboriginal dementia research and the ADKHs/ADEs in an attempt to provide a true translation of research into valuable, enhanced practice and capacity.

This would, additionally, provide a potential for the embedding of this model into other Aboriginal communities, thus impacting dementia capacity more widely and pervasively for Aboriginal peoples.

Project Challenges

Initially it was anticipated the KDCP would be implemented sequentially across the six nominated communities. What became evident from the outset was that communities wanted to be engaged immediately when they heard about the project, so communities were engaged simultaneously. Each community responded differently and at different pace, depending upon the engagement of the community guidance group, the ADKHs/ADEs, the Project Manager and the needs of that community.

Although this provided an immediate response in all areas, it ultimately slowed progress as lessons were simultaneously being applied rather than learning and then

moving on to another areas – with a specific model in place. Additionally, there was a high level input immediately, as the needs were so great, all of which depleted resources at a faster rate than was determined originally.

Working with the ADKHs/ADEs in this project has been a particular privilege. It was indeed a targeted strategy and the engagement of honoured and respected Elders has been particularly successful. It has ensured that the project is driven by wisdom and local knowledge and has created an environment of mutuality, of respect and of mentorship. That being so, there are challenges in this model also.

As well as the time intensity of developing relationships committed to trust and respect, working predominantly with Elders means that they too have to balance their work with other community business and quickly changing priorities. As the ADKHs/ADEs are all older and respected members of their communities, they often have competing community issues to address and to continue to be engaged in. This is particularly true in times of sorry business; for example, after there has been a death in the community. Additionally, some may not have the IT skills or administrative backgrounds that many take for granted, thus requiring an ongoing review of communication systems and styles, any of which can be supported by targeted training. Attention to these skills requires additional resources and time.

We also recommend that dementia education programs dedicate additional time and training to cultural awareness during the course of the project in order to recognise and respect communities' cultural differences and processes, and achieve a better understanding through ongoing community engagement.

Closing reflections - where to for the future

“As your mob already knows it’s hard for the community to really understand what dementia is about and that it’s bigger than just the person that has the illness, especially when it comes to our mob. I’m very interested in knowing more about your project and what you have developed with the new Dementia Education workshop. Knowing that this is working in your part of the woods, would the workshop work out west?” (Aboriginal Dementia Advisor, Far West)

Data from the Koori Growing Old Well Study indicated that urban Aboriginal people in NSW have an age-adjusted dementia prevalence rate of 21% or three times the non-Aboriginal rate. Specifically, the major sub-types identified were Alzheimer’s disease (44%), vascular dementia (17%), dementia related to head trauma (7%), and mixed dementia (29%).

With data from KGOWS coming on-stream and attracting media attention, this is the time to extend and promote the benefits of the KDCP to the non-Indigenous community, as well as to Aboriginal and Torres Strait Islander communities. There is clearly a heightened necessity to translate information obtained from the KGOWS to continue building dementia capacity in Aboriginal communities and to develop prevention programs. A model of

undertaking this and moving forward would be to fund additional positions to focus on research translation into meaningful resources, practice and services around dementia for Aboriginal communities.

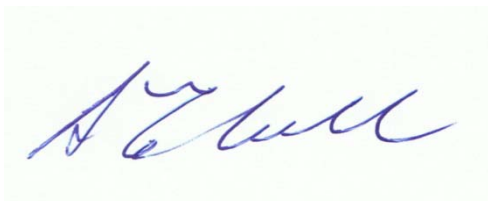
This information, particularly when added to our previous understandings in rural and remote communities indicates a need to substantially extend the work already undertaken in the KDCP. What is required is an emphasis on capitalising the findings and outcomes of this project (complimented by the Koori Growing Old well Study) into the broader policy domain, specifically addressing dementia issues in Aboriginal and Torres Strait Islander communities.

The emphasis could be supporting and mentoring ADKHs/ADEs as well as developing additional Aboriginal positions in other geographical areas. This would serve to keep collective knowledge and wisdom around dementia in these communities maintained and supported. Additionally, education and training through tailored workshop programs would be provided to the wider community around issues to do with both dementia prevention and living with dementia in Aboriginal and Torres Strait Islander communities. It would be particularly valuable for these positions to be embedded in the NeuRA Aboriginal Health and Ageing Research program stream to ensure that they sit at the cutting edge of research in this area. This is vital as it ensures the information taken to the community has currency, relevancy and demonstrates respect for its recipients.

What is clear from the work undertaken in the KDCP is that it is time to genuinely translate research into practice for Aboriginal families and communities living with dementia. Additionally, now that information has been realised in the community, funded service responses are required to meet the increasing needs of this community in this area.

It is hoped that the outcomes from this project and the resources developed and shared contribute in some way to meeting the increasing needs of the Aboriginal population living with dementia.

Finally we would like to thank the funding body and auspicing bodies of this project, the wonderful and vibrant team and, most importantly, the very generous and giving Aboriginal people who assisted us so generously with their time, their caring and their sharing.

A handwritten signature in blue ink, appearing to read 'Sharon Wall', is centered on a light green rectangular background.

Report prepared by Sharon Wall (project manager)
sharon@ageingbycaring.com.au



Aboriginal Dementia Workshop participants with Sharon Wall – Orange NSW 2013



Launch of Painting (Trek of hope) La Perouse 2012

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Dementia Services Pathway

<http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-dementia-services-pathways-2011-toc.htm~ageing-dementia-services-pathways-2011-intro.htm>

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"Proposed" Alzheimer's Australia (NSW) Association Van with Trek of Hope displayed for rural visits.

Appendix 1

KDCP resources

The following list provides an overview of resources collected, collated and created as part of the KDCP. It is hoped that these products will continue to be utilised by Aboriginal communities in highlighting and supporting those living with dementia.

Project Newsletters have been disseminated widely throughout the project providing ongoing information to a wide range of service providers and consumers in issues to do with dementia in Aboriginal communities. Copies of the KDCP newsletters can be found at this web link:

<http://www.neura.edu.au/koori-dementia-care-project/publications-and-resources>

A brochure on the Brain and its behaviour

<http://www.neura.edu.au/koori-dementia-care-project/brain-and-dementia>

Participation in a HACC training DVD

Koori Growing Old Well - a small video clip on Aboriginal Health and Ageing is available at:

http://www.youtube.com/watch?feature=player_embedded&v=yOnr8w9zR4A

Working with older Aboriginal and Torres Strait Islander people (Research to Practice Briefing no 8)

<http://www.neura.edu.au/sites/neura.edu.au/files/page-downloads/BenSocBriefing.pdf>

This Briefing was prepared by Sharon Wall and the Koori Growing Old Well Study Project Team at Neuroscience Research Australia, in partnership with The Benevolent Society. This Briefing presents evidence from research to guide mainstream community aged care organisations and practitioners on working in a respectful and culturally sensitive manner with Aboriginal and Torres Strait Islander people. It aims to help enhance the quality of care by ensuring it is underpinned by reflection, knowledge, understanding and respect. However, this Briefing should not be understood as a universal set of protocols, or as a prescription for care, as Aboriginal and Torres Strait Islander cultures are complex and extremely diverse, and accepted protocols vary across communities.

Two paintings commissioned by the project and prepared by local artist Mary Jane Page.

These paintings have formed the foundation of understanding around Dementia in Aboriginal communities and have assisted in developing a theme for materials produced by the

project. Information about the primary painting “Trek of hope for a dementia cure” can be found at:

<http://www.neura.edu.au/koori-dementia-care-project/the-hope-for-a-dementia-cure>

KDCP web site

The KDCP website provides a background to the project as well as access to publications and resources.

<http://www.neura.edu.au/koori-dementia-care-project/about>

Dementia in Aboriginal and Torres Strait Islander Communities Translating Research into Caring and Practice: A report of the third National Workshop of the Aboriginal and Torres Strait Islander Ageing Committee (ATSIAC) of the Australian Association of Gerontology.

Held on Tuesday, 20 November 2012 at Brisbane Convention and Exhibition Centre.

Report prepared and written by: Sharon Wall and Deserae Horswood (Neuroscience Research Australia)

<http://www.aag.asn.au/community/group/aboriginal-and-torres-strait-islander-ageing-advisory-group>

A dementia in Aboriginal Communities one day workshop for HACC providers

This has been delivered in Orange, Condobolin, Campbelltown, Redfern and La Pouse with other areas being negotiated currently

KDCP Summary paper (awaiting publication)

Wall, S., Mack, H., Radford, K., and Broe, G. A. (under revision) Raising Awareness, Part 2: Dementia Education and Care for Urban and Regional Aboriginal Australians, *Australian Journal of Dementia Care*.

If hard copies of these resource are required please contact Holly Mack at h.mack@neura.edu.au or Sharon Wall at sharon@ageingbycaring.com.au

Appendix 2

Summary of key presentations - Koori Dementia Care Project (KDCP)

There were multiple presentations, yarning, discussions undertaken at a local level in each of the communities. Opportunities were sought at every opportunity to disseminate information at mainstream events as well as Aboriginal specific events including Close the Gap, NAIDOC, Sorry Day and sporting celebrations (including the Rugby League Aboriginal knockout). Additionally the following more strategic presentations took place undertaken by the Project Manager and members of the project team.

2012

- Training program with Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators February
- NSW Health Dementia leadership forum March (Mervyn and Sharon)
- Coffs Harbour Senior week celebrations and KDCP launch March
- Presentation Booroongen Djugun Kempsey 2nd March
- Community meeting Western Sydney May
- Ageing Well Living Well Expo - Coffs Harbour – August
- Presentation Yarn up on Dementia- Tharawal - September
- North Coast Koori Interagency Meeting - Tweed Heads - October
- Western Sydney Area Dementia Planning Forum
- AAG ATSIAC meeting 20th November
- AAG National meeting 21st November

2013

- NSW Aboriginal Community Gathering Group 2nd February
- Launch of geriatrician programme –presentation to community of Coffs Harbour 2nd March
- Palliative Care Day (PEPA) – La Perouse Land Council 28th March
- Palliative Care Day (PEPA) Redfern 4th April
- HACC training day south Western Sydney (with Sharon , Aunty Elaine and Aunty Margaret) 9th April
- Yarn up at Tharawal Land Council 17th April
- Palliative Care day (PEPA) Mt Druitt 2nd May
- Benevolent Society paper launched and presentation at ACS conference 8th May
- NSW falls prevention workshop 24th May 2
- One day workshop in Orange 31st May
- Yarn up Redfern Friday 7th June
- One day workshop in Redfern 28th June
- Dementia and Delirium State Workshop 26th July 2
- Launch of video “Aboriginal dementia care” South Western Sydney HACC 14th August
- HACC training Aboriginal Dementia Workshop Condobolin 13th September
- AAG Illawarra symposia 9th November

- AAG conference 27th - 29th Sydney November 2013

Mid North Coast team presentations and forums attended 2012

- Gumbayngirr National Dementia Resources Advisory Committee - 26th April
- Ageing Well expo - 29th August
- Dementia Behaviour Management Advisory Services meeting - 12th September
- Koori Radio - 15th September (Aunty Sue Hoskins)
- North Coast Koori Network meeting – October
- 3rd National workshop of the AAG Aboriginal and Torres Strait Islander Ageing committee - 20th Nov (Aunty Sue Hoskins)

Mid North Coast Team presentations and forums attended 2013

- Workshop presentation to Elders at Abcare - 26th February
- Coffs Harbour Aboriginal Social Events committee meeting - 5th March 2013 -
- Geriatricians Meetup Land Council Hall – 13th March (Tony Broe and Aunty Sue Hoskins)
- Workshop Aboriginal Family Wellbeing Service 2nd April
- Coffs Harbour Aboriginal Social Events committee meeting- 9th April
- Aboriginal Services Expo Medicare Local Maclean 17th April
- Information session Bowraville Elders Group - 24th April
- Stuart Island Elders Day Bucca Bucca Mural - 9th May
- Local Health District Health Expo - 16th May
- Aboriginal Service Providers Forum Medicare Local - 23rd May
- CHASE Committee Meeting - 25th June 2013
- Alzheimer's Australia Engagement Plan Launch - 28st June
- Galambila NAIDOC Day - 9th July
- Who Ya Gonna Call NAIDOC Health Forum - 10th July
- KDCP and Alzheimer's Australia Elders Morning tea - 11th July
- Living Well Expo - 28th August
- Dementia Awareness Week - 11th September
- Koori Growing Old Well Study Community Feedback -10th October 2013 (Tony Broe and Aunty Sue Hoskins)

Appendix 3

Evaluation of the Koori Dementia Care Project – A Research Plan

Aims of the project

Our **key research question** is:

What impact have our capacity building activities had on our partner communities' understanding of and approach to dementia within their own, local communities?

Our aims are to

- develop, in consultation with our partner communities a set of evaluation tools suitable to each of these communities and pre-test these;
- evaluate the impact of our specific capacity-building activities in our partner communities;
- identify which activities have worked well and the reasons for this;
- determine whether there has been an impact on diagnosis of dementia in each community;
- determine whether there has been an impact on the development of services for people living with dementia and their carers;
- identify a set of guidelines and/or recommendations for others in working in the area of dementia capacity building with Aboriginal communities;
- report back the findings to the DCRC, our partner communities and the wider Aboriginal health sector on those outputs.

Background and Significance

In developing and implementing the Koori Growing Old Well Study, our research activities have identified a number of gaps which assist in providing evidence for a project of this type and the importance of evaluation in conducting work with Aboriginal communities. In addition the Dementia Education and Knowledge Translation project has identified specific needs which require response. This proposed project is thus a product of (1) background research and literature reviews; (2) research project development; (3) in-field research; (4) capacity-building activities; and (5) community and community organisation feedback. These, and the evidence for them, are briefly outlined as follows:

a. The timely diagnosis of dementia

Dementia has been identified as a significant health problem and concern for Indigenous communities (Alzheimer's Australia, 2009; Henderson and Broe, 2010) although research indicates there is a consistent lack of understanding of dementia in Aboriginal communities (Arkles, R et al. 2010). Currently among all Aboriginal communities any diagnosis is being done at very late stages of dementia regardless of age. In Aboriginal communities dementia is perceived and experienced in many different ways, but is often not recognised as a medical condition. Very few Indigenous people with dementia access mainstream government community programs in comparison to the rest of the population (Broe et al, 2009). Best practice for timely diagnosis includes diagnosis at the earliest stages of

dementia. The timeliness of diagnosis clearly impacts significantly on the response options offered. It is anticipated that this project would be able to further expand on the work of the KGOWS to identify triggers within urban and regional Aboriginal communities that indicate assessment and diagnosis is required. Additionally, the project will aim to provide sensitive and appropriate resources and to suitably train community dementia champions who will ensure ownership and sustainability of these skills and resources within their community.

b. Support for Carers

Growth in Aboriginal dementia is projected to be substantial (Access Economics, 2005). The Dementia rate among Indigenous Australians over the age of 65 is 27 percent as compared with 5.4 percent in the general population. There is a strong Aboriginal belief that a life 'out of balance', having lost the connection to the land and to traditional relationships causes sickness; some have described dementia as a 'sick spirit'. Our solutions to the problem of dementia need to take account of cultural perspectives and approaches to wellness. Many Indigenous carers and families lack understanding of what causes dementia and are fearful of the medical system. These as well as language and cultural differences prevent many from using early intervention services. Some experience the behavioural changes of dementia as "childlike" or "sickness" or "madness", but communities become very distressed and often call for help when the person with dementia breaks cultural taboos and norms. (Broe et al). The introduction of information about dementia to Aboriginal communities requires sensitivity to the issues of assessment, diagnosis and also to the provision of appropriate resources. All of this needs to be considered in the light of the individual community and that community network. This project will aim to create an increased understanding of the community networks and the needs of carers within them.

c. Person Centred Care

Person Centred care is founded on the ethic that all human beings are of value and worthy of respect irrespective of their level of disability. Person centred care puts the person at the centre of care. The application of person centred practice to dementia in Aboriginal communities has some challenges and requires further reflection. McMillan, Kaspers, D. Traynor, V. and Dewing, J. (2010) remind us that "it is important that Westernized person-centred care approaches do not repeat the fundamental errors of the Western biomedical approach to dementia care by: (i) assuming universality of models and frameworks; (ii) assuming this is the only or dominant discourse; (iii) valuing individuality over collectivism and (iv) imposing existing Westernized values. This project aims to use the foundation of country, community and spirit to engage extensively with communities to ensure that any work undertaken within Aboriginal communities reflects that communities' view of person (or country, community, spirit) centred practice. A further outcome of this project will be an increased understanding of person (community) centred practices in dementia in Aboriginal communities. The model proposed by McMillan et al will be utilised as an underpinning philosophy on which to build the understanding of person centred practice throughout this project.

Research Strategy

An evaluation strategy will be developed which will undertake pre and post project evaluation activities in order to identify measurable change in the key intervention stages of

the Koori Dementia Care Project. Evaluations will incorporate general wellbeing as well as evaluating the impact of the project and strategies on referrals to services and subsequent service development. Additionally each community will be individually evaluated against the key deliverables. A literature and resource search is already underway to further inform the directions of this project.

There is an expanding field of research in the area of evaluation in Aboriginal community work but aged care and especially dementia care remain relatively under-researched and evaluated. The key focus of our evaluation activities in the Aboriginal communities identified in this proposal would be focused on the following:

1. Community consultation, information and education sessions to identify key issues associated with understanding dementia and timely diagnosis for sufferers;
2. Education and training sessions for community workers and health workers to build broader levels of competence in and capacity to work with dementia patients, carers and services – including Train the Trainer sessions (TTT);
3. Media promotion of key issues to health workers, services and Aboriginal communities to promote a base level of dementia literacy and knowledge translation of known Aboriginal community specific scientific knowledge (eg. rates, symptoms etc);
4. Development and coordination of a series of resources for current and potentially interested communities (including internet use and distribution of direct-to-community programs.)
5. Mentorship and coaching of potential Aboriginal dementia community champions.

The methods would be finalised in consultation with our community partners but would include a mix of quantitative and qualitative data collection methods. The key techniques will be implemented based on those community discussions but are likely to include:

- Yarning Groups;
- community displays;
- focus group discussions;
- face-to-face and telephone surveys methods;
- semi-structured interviews at community events;
- brief survey tools in plain English at specific capacity-building events eg. training workshops;
- structured survey tools with service providers including Aboriginal controlled community health organisations, Aboriginal Medical; Services, Aged Care Service Providers and HACC service providers;
- other methods based on consultation and discussions which would be detailed in the final report.

The data collected would be analysed using methods appropriate to the collection processes. We would specify the techniques in the final report including any modifications to standard research protocols and practices required in adapting evaluation tools to our partner communities. We anticipate that some of this information would find its way into the guidelines document as part of (1) a contribution to the science of evaluation in

Aboriginal communities and (2) the objective of knowledge translation within and between the various audiences as indicated by the DCRC.

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Appendix 4

Community Survey (KDCP)

Participating in this small survey will assist us to get some information about how dementia impacts on Aboriginal people in your community and help us to create resources to assist in the future. Please circle your response to the next two questions.

1. Have you heard the word dementia? **Yes** **No**

2. Has an Aboriginal person you know in your community had dementia? **Yes** **No**

3. Please tick the things that you think happen to people who have dementia (you may tick more than one)

- a) Forgetting things
- b) Not able to cook anymore
- c) Getting lost
- d) Getting angry
- e) Having family trouble
- f) Is there anything else that you know of?

.....

4. Who would you go to for more information about dementia? (you may tick more than one)

- a) The Community nurse
- b) The Doctor
- c) The Aboriginal Medical Service
- d) A Friend
- e) Is there anyone else?

5. Would you agree to talk to one of the KDCP team members about your experience with dementia in your community? (Can you leave your name and phone number). We will only contact you if you give us permission to do so.

.....
.....

Thank you for your time, it is greatly respected

Please do not forget to leave your name (and number) for the lucky draw

Please contact

Sharon Wall - KDCP (Project Manager) for further information about this project including the name and contact details of your local Dementia Knowledge Holder/Dementia Educator.

0419849101: sharon@ageingbycaring.com.au

The information obtained from this survey will be used in confidence and with sensitivity

Appendix 5

Service Provider survey

Dear Service Provider

Thank you for taking the time to respond to these few questions to assist in the development of dementia services for Aboriginal members of your community.

Could you please fax this information to: (02) 80039290

Or scan and email to: sharon@ageingbycaring.com.au

Or post to PO Box 95 Austinmer, NSW 2515

- 1. How has your service dealt with disseminating information and health education around other “illnesses” to Aboriginal clients (e.g. diabetes)?**

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- 2. Who have been the key people responsible for providing that information to the community?**

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- 3. Who are some of the people I could talk to about how they have done that?**

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- 4. What is the knowledge of dementia amongst Aboriginal people in your community?**

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5. Who would Aboriginal people go to now to talk about dementia?

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6. What do you think are the community barriers to seeking help for dementia in Aboriginal communities?

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7. What do you think the Aboriginal community wants to know about dementia?

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8. Who could I talk to about what the community wants to know about dementia?

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9. How many Aboriginal people (approx) have you interacted with in your community who have a probable diagnosis of dementia?

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10. Your name and position

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11. Your contact details

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Thank you for assisting:

This information will be used in confidence and with sensitivity

Appendix 6

First Aboriginal Dementia Knowledge Holder/ Aboriginal Dementia Educators Training

When?

Tuesday 10th July, Wednesday 11th July and Thursday 12th July 2012

Where? Neuroscience Research Australia (NeuRA)

Who? Aboriginal Dementia Knowledge Holders/Aboriginal Dementia Educators of the Koori Dementia Care Project and Aboriginal Community Health workers. Program developed and facilitated by Sharon Wall, assisted by Holly Mack.

Aims and Objectives

To prepare participants to work with their communities to understand dementia and its impact on Aboriginal people

It was proposed that at the end of the training workshop participants would have an increased understanding of

- What dementia is
- The impact of dementia on Aboriginal people
- How to communicate more effectively with someone living with dementia
- How it may feel to have dementia
- Resources which are available to assist you and your community to know more about dementia

Outcomes

Two participants attended all of the training (Aunt Sue Hoskins and Mervyn Davison) whilst Charmaine Moran (Aboriginal Health Worker) attending 1.5 days. Apologies were received on the first day from Colleen Cawood (AHW) and Aunt Margaret Anderson (ADKH/ADE-) because of sickness. Dr Holly Mack attended three days whilst Deserae Horswood (new KDCP staff member) attended day one.

Evaluation

An informal evaluation was undertaken - by asking participants what were the key messages they understood from the training. Responses included:

Aunt Sue: Better understanding of dementia; that it is a brain disease, there is no cure, and things will get worse as progresses and that it is a slow process. There are things families/carers can do. That carers look after themselves and convince need a break themselves. There are different resources to keep loved one safe (wrist bands). *I'm clearer on what dementia is and more confident and talk to people in the community about dementia and the future of people with dementia.* Mervyn: Agreed and added that the carers to do the right thing and look after themselves since need to organise care for person with dementia. Mervyn felt that the training reaffirmed some of the things he already knew. Charmaine agreed with the sentiments expressed above. She saw the main message of keeping family members

safe that have dementia and provide protection, and opportunity to go back to country.

How they see their Role:

Sue: Like the painting postcard as a way of explaining it to health workers and community members. The postcard has a Koori perspective to it and can go from there. Just letting services know I'm there and available. Could do workshop with Abcare (Garry Matthews)

Mervyn: Feels comfortable with material. Have workshop with material in La Perouse with Tony and emphasise to chat with community.

Discussion was created around wandering behaviour (in three specific cases) and whether that might be more common in Aboriginal people living with dementia. Additionally a formal quantitative evaluation elicited the following:

Could you please work through the following questions and circle the most appropriate numerical response.

To what extent did the workshop meet your expectations?

Very	5	4	3	2	1	Not at all
	2	1				

How applicable will the workshop be to your ongoing work role?

Very	5	4	3	2	1	Not at all
	3					

How clearly and effectively was the content presented?

Very	5	4	3	2	1	Not at all
	3					

How effective was the facilitator in providing guidance and support to the group?

Very	5	4	3	2	1	Not at all
	3					

How appropriate for your needs was the amount and depth of the information presented?

Very	5	4	3	2	1	Not at all
	3					

Were there any aspects of the workshop that you thought were particularly good?

some of the content...and yet when I asked them to reflect on learning's - I was always pleased with their responses. That being so - two and a half days is long period of face to face learning and at times they certainly demonstrated some signs of education fatigue. I think on reflection, had there been more participants as planned, and had I been able to utilise more group process, learning could have been enhanced and participants could have been more actively engaged.

That being so, I think with some minor adjustments the module as developed stands to provide a good entry of learning around dementia for this cohort. I think this learning can be further enhanced by the development of additional resources and aids as per this evaluation.

My own learning's were immense from the opportunity of working with this small but highly engaging group. I was very humbled by the stories of their own lives and their stories of interactions with their communities including people who may have dementia. I am convinced that they will be wonderful knowledge holders/educators in this area. Additional training will be ongoing throughout the funding of the project to build on this workshop and maintain currency of information.

Where to from here?

- Review materials in light of evaluation
- Undertake suggestions from participants
- Plan additional training calendar for ADKHs/ADEs
- Sharon to talk to Danielle White (Alzheimer's Association) and graphic artist about advancing some of these suggestions



Sharon Wall, Project Manager KDCP
July 2012