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.
ACKNOWLEDGEMENT OF COUNTRY

This conference was held on the land belonging to the Turrbul People. We acknowledge them as the traditional owners of this land and thank them for welcoming us for the purpose of this workshop.

We also acknowledge this country as belonging to the Aboriginal and Torres Strait Islander peoples of Australia. Australia is the only place in the world where Aboriginal and Torres Strait Islander Australians belong. There is no place in Australia where this is not true.

Acknowledgements

Report prepared and written by:
Sharon Wall and Deserae Horswood [Neuroscience Research Australia]

Photographs: Deserae Horswood and Sharon Wall
Design and layout: Gosia Connell
Printing: Hogan Print
Trek of hope for a dementia cure artwork by Mary Jane Page.

*Aboriginal and Torres Strait Islander readers are warned that this report may contain images of deceased persons.

NB Recent research has demonstrated that the term "Aboriginal and Torres Strait Islander" is preferred to the use of "Indigenous" by Australia’s first people. [Daylight, G. 2012]. In this report this term is used where possible and if the term Aboriginal is used it refers to both Aboriginal and Torres Strait Islander. It is recognised that statistical information often uses the term Indigenous and this is why it is included at times.
CONTENTS

Executive Summary 6
The Inaugural Aboriginal and Torres Strait Islander Honorary Membership Award 8
Introduction 10
The Third National Workshop 15
Reflections on Presentations 16
Reflections on Afternoon Workshop 30
Some good things that are happening 31
What needs to happen and what we still need to know 32
Evaluation 33
Moving forward – where to from here? 34
References 36
Feedback form 37
The Elder

By Patsy Jackson, Banyo, QLD

I gazed into the depths of his dark brown eyes
And wondered what secret within them lies
I wished I had the knowledge they hold
But I couldn’t ask, I’m not so bold.
Could he tell me how the sea birds know
There is water inland and it’s in full flow
Winding its way to Lake Eyre
And a myriad of birds lay their eggs there.
He can find food and water in the arid land
I look and all I see is brown dry sand
He knows the language of many tribes
And knows where the sand goanna hides.
The undergrowth is fired at a certain time
So the grasses next year will be prime
The seeds are crushed to make flour
Damper is made to eat at the evening hour.
The young like the music of the drum and the guitar
They think it is much better by far
But the Elders still prefer the didgeridoo
That fills the desert with sounds all through.
He is proud of the tribes people, who paint
Stories of the Dreamtime in lines and dots.
The stories that have been told by Elders
At night, by the glow of the fires’ embers.
He knows that tribal living must move on
The kids must get an education
Literacy and technology has to be taught
Along with dance, art, music and sport.
The kids must cross that great divide
Tell the world the Indigenous race is alive.
With education a message will send
That this is the beginning—not the end.

Source: ‘The Elder’, Koori Mail 497 p.23
The Australian Association of Gerontology (AAG)

The Australian Association of Gerontology (AAG) is Australia’s peak national body linking professionals working across the multidisciplinary fields of ageing. Since 1964, AAG has connected professionals with an interest in gerontology to help them collaborate and exchange information on ageing. The AAG’s goal is to expand knowledge of ageing in order to improve the experience of ageing. Members connect through forums, workshops, seminars and conferences, as well as through participation on committees and special interest groups. The multidisciplinary nature of the AAG is one of its key strengths.
EXECUTIVE SUMMARY

“Justice does not stand still.”

Hon. Michael Kirby

The third National Workshop of the Australian Association of Gerontology Aboriginal and Torres Strait Islander Ageing Committee (AAG ATSIAC) was held on 20 November 2012, in the Brisbane Convention and Exhibition Centre. The workshop preceded the AAG National Conference which commenced the following day. Ninety people attended this workshop, thirty of whom were of Aboriginal or Torres Strait Islander background.

The workshop centred on the key theme ‘Dementia in Aboriginal Communities: Translating Research into Caring and Practice’. Presentations were across diverse facets of aged care and dementia in Aboriginal communities and the majority of presentations were led by Aboriginal or Torres Strait Islander researchers.

At the commencement of proceedings, Professor Julie Byles, National President of the AAG presented Marj Tripp, of Adelaide, with the Inaugural Aboriginal Honorary Membership Award to acknowledge her amazing contribution to Aboriginal and Torres Strait Islander ageing issues. Presentations were followed by a yarn up, taking place to facilitate wider discussion of the issues raised.

The workshop showcased examples of research and practice that reflect current knowledge and understanding around dementia in Aboriginal and Torres Strait Islander communities. It also laid the foundation for an increased understanding of research and service responses required for the future.

The workshop was a collaborative effort sponsored by: the AAG and AAG State Divisions; Dementia Collaborative Research Centres (DCRCs); Department of Family and Community Services/Ageing Disability and Homecare; Alzheimer’s Australia; Australian Government Office of Aboriginal and Torres Strait Islander Health; Department of Health and Ageing; and Neuroscience Research Australia.

As has been customary of the previous two National Workshops, this document represents a comprehensive copy of proceedings and will be launched at the AAG National Conference in Sydney, November 2013. These proceedings will also be widely distributed and placed in its entirety on the AAG website.
“Communities are having the conversation – Aboriginal people are speaking and being heard.”
THE INAUGURAL ABORIGINAL AND TORRES STRAIT ISLANDER HONORARY MEMBERSHIP AWARD

Awarded to: Marj Tripp

Marjorie Tripp is a proud descendant of the Ramindjeri people of the Ngarrindjeri nation, whose country is around the mouth of the Murray River, in South Australia (SA). Marj has worked in the area of Aboriginal Health and Community programs for over forty years and has been instrumental in initiating many programs and institutions that benefit Aboriginal people, in SA and nationally.

This includes establishing the Council of Aboriginal Elders of SA, the Tandanya National Cultural Institute in Adelaide, the National HACC Aboriginal and the Torres Strait Islander Reference Group in 1992 which has since provided a consultation model for all Federal Government programs. Over the past five years, her energy has been dedicated to chairing the National Aboriginal War Memorial Committee. They have raised over one million dollars and the construction of the memorial is underway.

During the past thirty years, however, Marj’s greatest passion has been aged care. Marj has worked at both state and national levels.
representing the interests of Aboriginal people with the goal to ensure that Aboriginal people (and all people) are able to receive care: when, where and how it is most appropriate. Over this time she has become a great friend of the AAG.

In 1963, Marj was the first Aboriginal woman to join the Australian Navy, and was an ATSIC Regional Councillor for nine years. She has been awarded two Australia Day Medals – in 1983 and 1993 – for her contribution to the Aboriginal community. In 1999, Marj was an ambassador for the International Year of the Older Person and received a Centenary Medal for her community work over thirty-seven years. Marj lives in Adelaide and, although semi-retired since 2005, remains on state and national committees working for older members of the Aboriginal community. Marj still speaks at numerous conferences including the AAG’s 2007 National Conference in Adelaide where she gave the David Wallace Address. In 2010, Marj was named the SA Aboriginal Elder of the year, was the NAIDOC Public Service Award winner and NAIDOC Community Service Award winner.

For the AAG, Marj has worked for nearly thirty years to encourage Aboriginal and Torres Strait Islander participation. She believed, well before it became common discourse, that Indigenous people should speak for themselves at conferences and present their good news to their non-Indigenous colleagues. She has also advised about presentation and programming to suit Aboriginal and Torres Strait Islander participants. Her contributions have helped the AAG to become a trusted non-government forum for Aboriginal and Torres Strait Islander aged care discussion to achieve better planning and policy. Marj’s work honours the spirit of her people; those that have fought in the services, in communities for more respect and in aged care for a good quality of life for her people. We today wish to acknowledge these many years of hard work and to show our respect and support for Marj’s efforts and achievements.
INTRODUCTION

“Injustice anywhere is a threat to justice everywhere.”

Martin Luther King Jr

According to census data, there were almost 550,000 Aboriginal and Torres Strait Islander people in Australia in 2011, comprising approximately 2.5% of the population. Of these, 2.25% are Aboriginal, 0.15% are Torres Strait Islanders and 0.1% people identified themselves as both Aboriginal and Torres Strait Islander (Australian Bureau of Statistics, 2011a).

Aboriginal and Torres Strait Islander people have poorer health and higher rates of disability than non-Aboriginal people. In addition, there is a significant gap in life expectancy between Aboriginal and Torres Strait Islander Australians and non-Aboriginal Australians. This means that a lower percentage live to old age than do non-Aboriginal people. In 2011, fewer than 4% of the Aboriginal and Torres Strait Islander population were aged 65 years and over, compared to 14% of the population as a whole (ABS, 2011a). The population of older Aboriginal and Torres Strait Islander people is, however, ageing rapidly and there are a growing number of ‘survivors’ over the age of 75.

Multiple interconnected historical, social, economic and political factors influence the ageing experience of Aboriginal and Torres Strait Islander people and contribute to poorer health and the gap in life expectancy.

Colonisation, combined with the discriminatory and racist policies of early Australian governments and the forced removal of Aboriginal and Torres Strait Islander children from their families, culture and country, has led to ongoing physical, spiritual and emotional harm and high levels of intergenerational disadvantage. Barriers to education, training, economic and social participation have led to high levels of poverty and poor living conditions, which in turn increases the risk of disability and early death from chronic disease (AIHW, 2011b).

Dispossession from land and country meant that Aboriginal and Torres Strait Islander peoples lost their access to food, water, traditional medicine and shelter, as well as the displacement of their spiritual connection to country. This has had lasting effects. The forced removal of children – the Stolen Generations – was not a single event but occurred over decades (Haebich, 2000). It continues to have a significant impact on the social and emotional wellbeing of older...
Aboriginal and Torres Strait Islander people today, many of whom were they themselves removed from family and country (Purdie et al., 2010). The impact of these losses may compound, or be compounded by, poor physical or psychological health that develops as part of the ageing process. All of these factors additionally impact on the nature of research in the Aboriginal community.

“Research in Aboriginal contexts remains a vexed issue given the ongoing inequities and injustices in Indigenous health. It is widely accepted that good research providing a sound evidence base is critical to closing the gap in Aboriginal health and wellbeing outcomes. However, key contemporary research issues still remain regarding how that research is prioritised, carried out, disseminated and translated so that Aboriginal people are the main beneficiaries of the research in every sense.”

(Dudgeon et al.)

The History of AAG ATSIAC Workshops

At the 40th National AAG Conference in Adelaide, 22 November 2007, the ATSIAC General Meeting agreed that a National Workshop would be organised during 2008 by the co-Chairs of the Ageing Committee, Tony Broe and Lisa Jackson Pulver. The task was “promoting healthy Aboriginal ageing” and addressing “the causes of current poor Indigenous health and reduced life span including both socio-economic and health related factors operating across the life span.”

Growing Old Well was the title of the Inaugural National Workshop of the ATSIAC of the AAG. It provided a unique opportunity to bring together Aboriginal peoples, service providers and policy makers all working toward answering key questions around Aboriginal longevity. It addressed life cycle risks and protective factors for healthy ageing in Indigenous peoples, with a focus on translating conclusions into actions.

The outcomes and challenges developed from that workshop informed the second workshop held in 2010 titled Growing Old in Aboriginal Communities – Research and Services.

This workshop was held on 11 August 2010 in Darwin and preceded the AAG Northern Territory conference, “The Ageing North”, held on 12 and 13 August 2010. This conference also included significant content and robust discussion around issues impacting on Indigenous Ageing.

These three workshops have bought Aboriginal service providers, health professional researchers and consumers together with non-Aboriginal colleagues to discuss many issues around ageing in Aboriginal and Torres Strait Islander communities.

Dementia in the Aboriginal and Torres Strait Islander community

“Dementia is a sick spirit, a lost spirit looking for help … It may not need to get fixed as long as the individual is safe and the family and the community is safe”

Mr Eric Deeral

Until recently, the issue of dementia in Aboriginal and Torres Strait Islander communities was rarely considered. Where it was considered, it was often underpinned by inaccurate assumptions related to alcohol, despite no evidence to support this association (Arkles et al. 2010).

In 2008, the first rigorous study of dementia prevalence in Aboriginal people was published (Smith et al. 2008). This 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. In general, dementia diagnosis was associated with a history of stroke, head injury or epilepsy. Older age, male gender, lack of formal education and current smoking were also linked to dementia, but current alcohol use was not. This study was extremely important; it provided the first reliable data on dementia in Aboriginal communities and began to demystify this issue.

Between 2010 and 2012, the Koori Growing Old Well Study (KGOWS) conducted a comprehensive survey of all Aboriginal men and women aged 60 years and over residing in five NSW Aboriginal communities (Radford et al. Under review).

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. About one in three cases received a mixed dementia diagnosis (i.e. two or three types of dementia indicated/identified). Alcohol abuse contributed to some mixed dementia cases, but this was much less common than these other dementias. As would be expected, the prevalence of dementia increased with age, but many were diagnosed relatively young (i.e. two in every five cases had dementia onset before age 65). There was no difference in the rates of dementia between urban Sydney, on the one hand, and regional cities, towns and rural areas, on the other. Further exploration of other factors associated with dementia in this population is currently underway.

Up to date information regarding KGOWS can be found at: www.neura.edu.au/research/themes/broe-group

When Mary Jane Page, an Aboriginal artist from La Perouse, was engaged by the Koori Dementia Care Project to portray dementia in a painting she provided the following poignant description. This definition is rich in meaning and cultural understanding of the impact of dementia in Aboriginal and Torres Strait Islander communities.

**Trek of hope for a dementia cure**

_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 symbolises 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._

Mary Jane Page
Trek of hope for a dementia cure

Artist – Mary Jane Page
What do we mean by ‘translating research into care and practice’?

Urban and regional Aboriginal Australians have similarly high rates of dementia to remote Aboriginal peoples, and some of the highest rates observed worldwide. The broader challenge now is to translate these research findings into practice. This is achieved by raising awareness about this increased dementia prevalence as well as improving dementia assessment and care services for Aboriginal people living with dementia, in a way which is meaningful for Aboriginal communities. As we were reminded by the magnificent work of Dr Fred Hollows, when working with Aboriginal communities it should be “No survey without service”.

This requires an approach which aims to build capacity within Aboriginal communities around information and knowledge about dementia as well as influencing the development of appropriate services to assist individuals and families living with dementia.

Capacity building is defined as an approach to “building sustainable skills, resources and commitments to health promotion in health care settings, community settings and, in other sectors, health promotion workers prolong and multiply health gains many times over.” (Hawe et al. 2000).

Capacity building is dependent upon reciprocity and the principles of consultation, respect and appreciation of the diversity of Aboriginal and Torres Strait Islander communities. At an organisational level, building genuine relationships through respectful consultation is the cornerstone of developing appropriate, targeted and responsive services (Radford et al.)

“A lot of Aboriginal people who age are not being cared for properly. If we were better equipped with services [we’d] have a better quality of life.”

Participant in the Koori Growing Old Well Study
THE THIRD NATIONAL WORKSHOP

The third National Workshop of the AAG ATSIAC was held on 20 November 2012 in the Brisbane Convention and Exhibition Centre. The workshop preceded the AAG National Conference which commenced the following day. Ninety people attended this workshop, thirty of whom were of Aboriginal or Torres Strait Islander Background. Out of a total of thirteen presenters, eight were Aboriginal or Torres Strait Islander people.

The workshop centred on the key theme *Dementia in Aboriginal Communities: Translating Research into Caring and Practice*. Presentations were across diverse facets of aged care and dementia in Aboriginal communities and the majority of presentations were led by Aboriginal or Torres Strait Islander researchers.

The workshop was a collaborative effort sponsored by: the AAG and AAG State Divisions; the Dementia Collaborative Research Centres (DCRCs); Department of Family and Community Services/ Ageing Disability and Homecare; Alzheimer’s Australia; Office of Aboriginal and Torres Strait Islander Health – Department of Health and Ageing; and Neuroscience Research Australia.

At the commencement of proceedings, Professor Julie Byles, National President of the AAG presented Marj Tripp, of Adelaide, with the Inaugural Aboriginal Honorary Membership Award to acknowledge her amazing contribution to Aboriginal and Torres Strait Islander ageing issues.

A number of presentations then followed. Presenters included:

- **Tony Broe**, Professor of Geriatric Medicine, Prince of Wales Hospital and University of NSW; Senior Principal Research Fellow, Neuroscience Research Australia (NeuRA), Sydney NSW, who introduced the program.

- **Keynote Speaker: Paul Pholeros**, Adjunct Professor of Architecture, University of Sydney, NSW; Director of Healthabitat, Sydney NSW.

- **Aunty Sue Hoskins**, Research Assistant, Koori Growing Old Well Study [KGOWS] and Koori Dementia Care Project [KDCP], NeuRA, Coffs Harbour NSW and **Sharon Wall**, Project Manager, KDCP, NeuRA, Sydney NSW.

- **Lena Morris**, Executive Manager, Rumbalara Aged Care and Disability Services and Rumbalara Elders Facility, Mooroolbark VIC.

- **John Reid**, Indigenous Research Fellow, Poche Centre for Indigenous Health, Flinders University, NT and **Melissa Lindeman**, PhD, Senior Research Fellow, Centre for Remote Health, Flinders University, NT.

- **Gail Garvey**, Associate Professor and Leader of the Division of Epidemiology and Health Systems, Menzies School of Health Research, Brisbane, QLD; Research, Program Leader at the Lowitja Institute, Brisbane QLD.

- **Betty Sagigi**, Research Assistant, Thursday Island, NT and **Eddy Strivens**, Adjunct Associate Professor, School of Medicine and Dentistry, James Cook University; Clinical Director for Older Person Health Services, Cairns and Hinterland Health Service District, QLD.

- **Venessa Curnow**, Member, National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG), Alzheimer’s Australia, QLD.

Following these presentations, a yarn up was chaired by Kerry Arabena (Professor and Head of Research, Harvest Alliance School for Indigenous Health, Medicine and Nursing, Monash University, Melbourne VIC) to facilitate further discussion.

A wrap of the day was facilitated by Gail Daylight (Manager of Aboriginal Health, South Eastern Sydney Local Health District, Sydney NSW) and **Leon Flicker** (Professor of Geriatric Medicine, Director of Western Australian Centre for Health and Ageing [WACHA]; and Western Australian Institute for Medical Research, University of Western Australia, Perth WA).
REFLECTIONS ON PRESENTATIONS

What is home for Aboriginal people?

KEYNOTE SPEAKER: PAUL PHOLEROS

As our keynote speaker, Paul’s presentation focused on the importance of ‘home’ for Aboriginal people and the pioneering work of Healthabitat. Research shows that living environments impact health outcomes across the lifespan. Therefore, Healthabitat aims to improve the health of Aboriginal Australians by improving housing. Healthabitat are working to create efficient and effective structural intervention to create healthy living environments in Aboriginal communities.

This presentation highlighted a number of key points:

- ‘Home’ for Aboriginal people is culturally embedded. These considerations must be taken into account in the planning phase of housing projects.

- There is a strong link between housing standards and health. To have even a chance at functioning in full health, an individual needs a house with adequate water drainage, a functioning toilet and an electrically-safe, working kitchen.

- Issues or illnesses developed early in life (0-5 years old) due to unhealthy living environments are linked with worse health and chronic conditions later in life.

- Healthabitat research has demonstrated that the majority of houses do not meet the nine Healthy Living Requirements. For example, of 7490 houses inspected across 188 locations, only 10% were electrically safe, only 35% had a working shower and only 6% had a working kitchen.

- Myths perpetuated about Aboriginal residents do not account for the dysfunction and low standards of housing. Healthabitat research determined that deficits are largely due to routine wear (70%) and faulty or poorly constructed houses (21%) as opposed to damage or neglect from residents.

- These problems are not “too big or too hard”, as is commonly perpetuated; issues can be fixed efficiently and for relatively low cost. Healthabitat implemented a program whereby houses were repaired to comply with national standards, at a cost of $7500 per house. Members of the local Aboriginal
communities were recruited and trained to carry out these repairs. In comparison, the National Partnership Agreement on Remote Indigenous Housing spent an average of $75,000 per house and many failed to comply with the National Indigenous Housing Guide prior to tenant access.

- A recent report by NSW Health quantified the health benefits of these housing projects as seen over the past ten years. Most notably, those who received Healthabitat’s Housing for Health intervention showed a 40% reduction in hospital separations for key infectious illnesses that are related to environmental factors. This is a drastic improvement compared to the rural NSW Aboriginal population who did not receive the intervention. There is a clear translation of structural housing repairs to health improvements.

- Changes to federal policy are required to incorporate the ‘Housing for Health’ principles. These principles should guide the planning stages of large-scale, national Indigenous housing projects.

Paul’s presentation left participants with a clear sense of the importance of safe housing and the urgency of change required at a federal level. Addressing housing is a crucial step if we are to impact the health inequalities that are extant in Australian society.

If you would like to be further inspired by Paul’s work – see his TED’ presentation: www.ted.com/talks/paul_pholeros_how_to_reduce_poverty_fix_homes.html

TED conferences bring together the world’s most fascinating thinkers and doers, who are challenged to give the talk of their lives (in 18 minutes or less).
Aunty Sue and Sharon outlined the work of the Koori Dementia Care Project (KDCP), which aims to educate and build capacity around dementia in six Aboriginal communities in New South Wales. Under the KDCP model, members of the community are trained as Aboriginal Dementia Knowledge Holders (ADKHz). Then, in collaboration with the Project Manager (Sharon) and team, the ADKHzs identify the dementia needs of the community and develop responses. The project operates simultaneously in the communities of Coffs Harbour, Nambucca, Kempsey, Western Sydney, La Perouse and Campbelltown.

This presentation highlighted:

1. An emphasis on ‘capacity building’. The needs of the community inform the dementia education strategies used and their implementation. Furthermore, it is imperative that the work is embedded into the community and sustainable beyond the lifespan of the KDCP.

2. KDCP is informed by principles of:
   - Mutual mentorship;
   - Health research among Indigenous Australian populations;
   - Culturally appropriate awareness campaigns and targeted educational interventions for dementia awareness.

3. The creation and utilisation of culturally appropriate dementia learning resources is crucial.

KDCP also works with associated service providers to educate the community about the effects of dementia on older Aboriginal people and their families. The project builds on the work of the Koori Growing Old Well Study and is overseen by a Sustainability (Reference) Group and Community (Guidance) Group to ensure ongoing community ownership of the program.

For more information about the KGOWS and the KDCP:
www.neura.edu.au/research/themes/broe-group
“There is growing awareness of dementia in the community and interest in healthy ageing and dementia prevention.”
Rumbalara Aged Care and Disability Service and Elders Facility

LENA MORRIS

Lena gave an insight into the development of the new health service facilities at Rumbalara Aboriginal Cooperative. Based in Shepparton, Victoria, this project saw an expansion of the existing services available to the Aboriginal community. This pioneering project embeds aged care, palliative care, disability and assisted living programs alongside cultural and educational programs. At Rumbalara, Elders can now receive a high standard of care while remaining an active part of the community throughout their lives.

The expansion of Rumbalara was conceptualized by Elders and driven entirely by the community. Rumbalara now incorporates health, family, housing, justice, support and education services in conjunction with their newly developed aged care and disability facilities. Furthermore, construction of the facility incorporated an Indigenous employment program: over thirty community members were hired for full time construction and labouring jobs. The health service employs over fifty staff.

Lena highlighted that the aged care programs will be utilised by Aboriginal people from as young as fifty-years-old, due to pervasive chronic illness in the community. Many programs at Rumbalara take a preventative focus, as the health service aims to increase life expectancy in the population.

The expansion of Rumbalara allows Elders to maintain dignity and connectedness with family and culture. Rumbalara, the community’s vision, should be considered a model for culturally-appropriate aged care.

To view an ABC 7.30 report presentation of Rumbalara see:
www.abc.net.au/7.30/content/2011/s3342854.htm
“We need person centred care – not task ... If they don’t want to eat or are not ready yet don’t force them.”
Researching Aged and Dementia Care in Central Australian Indigenous Communities

ASSOCIATE PROFESSOR MELISSA LINDEMAN AND JOHN REID

Melissa presented research from the Centre for Remote Health and presented work on behalf of John Reid who was unable to be there on the day. This research is guided by the notions of Indigenous mind, cultural safety and the principles of knowledge translation, whereby research and practice continue to inform one another.

This presentation highlighted outcomes for the following research projects:

• Evaluation of dementia awareness resource for use in remote Indigenous communities;
• Carer Needs Study;
• Development of pathways for care for Aboriginal people living with dementia;
• Remote aged care assessment;
• Recognising and responding to dementia in Indigenous communities: an education program – a two-day interactive workshop.

The research program detailed by Melissa highlighted a ‘locally responsive’ approach with clear emphasis on knowledge translation principles (i.e. using best available information; attention to context; end user involvement and participatory processes in the program’s development and implementation; use of educational strategies proven to be successful). The Centre for Remote Health will next address the coordination of care and the question “How do we develop a model for ‘case management’ or ‘key worker’ approaches that are person-centred and culturally safe?” This will be addressed in the qualitative Dementia Key Worker Study to be commenced in 2013.

INDIGENOUS MIND

“Indigenous Mind is a particular way of viewing, interpreting, and making meaning of the worlds in which we live as Indigenous Australians, whether those lifestyles are traditional, semi traditional, contemporary, urban, rural, remote or very remote.”

John Reid
CULTURAL SAFETY

“My core cultural values of respect, reciprocity, and relationships... play a big role in shaping my thinking about the need to make primary health research and practice more culturally respectful of Indigenous ways of knowing, being and valuing: and thus culturally safe.”

John Reid
Dementia in Aboriginal and Torres Strait Islander Communities

ASSOCIATE PROFESSOR GAIL GARVEY

Gail focused on the current understanding of dementia and service provision in the Aboriginal community. She presented results from two of her studies to give a clear picture of the deficits of understanding in the general community and lack of culturally-appropriate care for Aboriginal people with dementia:


2. Scoping Survey of Health Services – to investigate the extent of support and care in aged care facilities for Aboriginal and Torres Strait Islander people with dementia.

This presentation highlighted:

- Aboriginal and Torres Strait Islander understanding of dementia includes: ‘white fella sickness’; ‘no meaning’; and ‘sick spirit’.

- Data from Garvey and colleagues (2010) highlights that overall understanding of dementia in the Aboriginal community was poor and misconceptions about Alzheimer’s disease were common.

- That there is a need for awareness specific campaigns and targeted educational interventions.

- Uptake of dementia services by Aboriginal and Torres Strait Islander people is estimated to be poor.

- Data that mainstream dementia services have few Indigenous clients, only 58% of services collect information about client’s Indigenous status, culturally specific support for Indigenous clients is limited, non-existent, or inappropriate, and only 45% of services employed Indigenous staff.

This presentation made clear the need for dementia services to encourage and support Aboriginal people to access their services. Strategies to implement community education campaigns and also to overcome barriers to culturally appropriate care are very much needed.
“Lot of family grief is caused by lack of knowledge about dementia, how it affects people, their behaviour, their relationships, [and] their ability to care for themselves. Need to advertise or promote the issue at a community level.”
Eddie highlighted the dearth of dementia specific knowledge in the Torres Strait. Research has found that the prevalence of chronic disease is high, however no previous studies have investigated the rate of cognitive disorders in the Torres Strait or Torres Strait Islanders.

A pilot study was carried out on Hammond (Keriri) Island, with twenty residents (average age = 65.8 years, all > 45 years age) to address this knowledge gap. This study aimed to trial a survey tool (based on the KICA Survey tool) and trial a study design towards the quantification of rates of cognitive disorders in the Torres Straits.

The presentation highlighted:

- High rates of chronic disease diagnosis in Torres Strait Island (hypertension, diabetes – incidence six times higher than non-Indigenous Australians).

- Competing hypotheses for rates of dementia in the Torres Strait:
  - Low life expectancy = low rates of dementia versus high levels of vascular disease and other stressors = high rates of dementia.

- Plans for the future:
  - Scale up study for larger prevalence research 2013-14;
  - A National Expert Working Group underway to examine the face validity of KICA items and look at format of items for use in wider settings.

Furthermore, Eddie issued a call toward the development of a National Indigenous Dementia Strategy. This inclusive strategy would comprise: Community Awareness and Prevention; Care and Support; Research; Diagnosis, referral and treatment; Workforce issues; Partnerships and collaborations.
Aunty Sue Hoskins, Lena Morris and Professor Eddy Strivens yarning.

Professor Leon Flicker and Gail Daylight summing up the workshop themes.

“\textit{It is about allowing Elders to maintain dignity and connectedness with family and culture.}”
In terms of holistic community development, it is important to care for Elders with dementia in their communities for as long as possible. Older people are crucial to the social fabric of Aboriginal and Torres Strait Islander communities; they hold generational knowledge and wisdom that may not be accessible elsewhere. With this in mind, Alzheimer’s Australia is one organisation working to strengthen aged care in the Aboriginal community. They aim to “improve equity and access to culturally safe services for Aboriginal and Torres Strait Islander people with dementia, their carers and families and communities using a wellness approach to successful ageing”.

Venessa looked at the progress of dementia care in the Aboriginal population. In November 2006, dementia was established as a national health priority for mainstream populations by COAG. Alzheimer’s Australia ran a workshop to determine the pertinence of dementia within Aboriginal communities, given the various other issues that warrant attention. From the workshop, it was ascertained that: addressing dementia should be a priority; and better evidence and targeting of resources was needed. Key developments from this workshop have guided the proliferation of services into Aboriginal communities. In particular, the establishment of NATSIDAG has since functioned as a method of gaining ongoing advice and strategic planning for dementia services across Australia.

Finally, Venessa detailed Alzheimer’s Australia’s current research program. Their main priority is to aid researchers through funding, collaboration, and disseminating findings and evidence through the industry to increase the evidence base and ensure better practice methods. The development of a national, systematic approach to training delivery is also a focus; the Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities was under review in NSW at the time of presentation. Alzheimer’s Australia work to distribute resources widely including the Aboriginal and Torres Strait Islander Dementia Newsletter, e-learning resources and partnership with Australian Indigenous Health Infonet.
“In terms of holistic community development, it is important to care for Elders with dementia in their communities for as long as possible.”
In the afternoon workshop, participants gathered in small groups for collaborative discussion. Three general topics were given, regarding the state of dementia care in Aboriginal and Torres Strait Island communities, to stimulate conversation:

- What good things are happening?
- What still needs to happen?
- What do we still need to know?

This yarn up was expertly facilitated by Kerry Arabena, Professor and Head of Research, Harvest Alliance School for Indigenous Health, Medicine and Nursing, Monash University, Melbourne VIC.
SOME GOOD THINGS THAT ARE HAPPENING

Thematically, the development and proliferation of culturally-appropriate resources, such as pamphlets and DVDs, was well cited. This conversation extended to the importance of training, education and resources for health workers as well, to allow cultural safety and appropriate care.

Two themes emerged that reflected a sense of sustainable gains: increased dementia awareness in the communities; and greater community/carer involvement in the development and running of programs.

Most participants noted that knowledge and diagnosis of dementia in their communities, or the communities they work with, had improved. Furthermore, that greater community involvement, for example in yarn ups, workshops and service delivery, was allowing the community a sense of ownership and a feeling of “being heard”.

The effective collaboration between services and organisations, both locally and nationally, was discussed. In general, the effectiveness of services and facilities was praised and many individual programs were mentioned as examples of best practice.

The importance of research was reiterated; that research be appropriate, sensitive and contribute to a greater understanding of need was emphasised.

Participants additionally highlighted the increasing emphasis of developing person centred care models which reflect the unique needs of Aboriginal people living with dementia.

“Two themes emerged that reflected a sense of sustainable gains: increased dementia awareness in the communities; and greater community/carer involvement in the development and running of programs.”
From this conversation many gaps in current knowledge and practice were highlighted.

The issue of housing in Aboriginal communities was a key feature of the discussion, following themes inherent in Paul Pholeros’s presentation. Housing standards in general were discussed but, more specifically, the importance of appropriate accommodation for dementia sufferers. Staying on country is particularly important for Elders; the lack of appropriate care facilities does not enable this.

Dementia education within Aboriginal communities emerged as a priority. The discussion reflected that many families would benefit from greater dementia awareness, support and assistance in making decisions about care pathways.

“Lot of family grief is caused by lack of knowledge about dementia, how it affects people, their behaviour, their relationships, [and] their ability to care for themselves. Need to advertise or promote the issue at a community level”

“Information should be made available at a level each person can understand (i.e. simplify the medical terms)”

Enhancing capacity around dementia within each community was noted as particularly important. Community members and health workers must both be included for sustainable, community leadership on the issue.

“Leadership needed in small communities to help direct care in all areas of aged care (home, community, residential) and to provide culturally appropriate approved providers”

Discussion reflected that, in particular, engaging with Elders is key in the process of aiding respectful and effective aged care in Aboriginal communities.

“We need to ask older Aboriginal people what they want”

“Listen to the Elders”

Cultural appropriateness across aged care was another recurrent theme. This emerged in

the need for increased cultural knowledge for those working with Aboriginal clients. Cultural sensitivity training is important in order to support aged care workers to provide quality care.

“More cultural appropriateness from non-Indigenous at all levels. Needed for management as well as workers”

The training of Indigenous workers in aged care was a key part of the conversation.

“Up skilling Indigenous people for dementia care services”

“Increase the number of Aboriginal workers in Indigenous Aged Care”

Many participants expressed the need for additional services and facilities to better support the dementia needs of communities; a full transcript of these suggestions has been kept on file to inform further workshops for the future.

In particular, the desire for carer respite programs was a common. As always, the need for appropriate/increased funding to adequately provide these services and facilities remains pertinent.

Gaps in research were identified. Participants highlighted that further exploration is required into the high rates of dementia in Aboriginal communities, causes and the potential risk/protective factors, and alternative models of care for rural and remote communities. If and when this information becomes evident, participants also stressed that knowledge translation to the mainstream is imperative. The issue of gender was also raised: further information is needed in approaches to care and how to offer support to older men and women.

These discussions will further inform the ongoing pursuit to translate research and knowledge to service in Aboriginal communities.
EVALUATION

In total, ninety people attended the workshop. At the conclusion of the sessions, participants were asked to complete a comprehensive evaluation of the day. Items included specific questions regarding elements of the workshop and about their personal experience as participants.

These responses were rated on a Likert scale ranging from 1 (Not at all) to 4 (Very) for most items, and 1 (Very poor) to 5 (Very good) on the remaining (see below). In addition, participants were afforded the opportunity to respond to qualitative items including: “What are the three main things you will take home from today?”, “Suggestions for future workshops” and “Any other comments”.

The evaluations were overwhelmingly positive. The responses to the Likert items were all at the extreme high end of the scale, indicating more positive assessments. Mean response ratings are shown in Table 1 below.

Similarly, responses to the qualitative questions reflected an extremely positive experience of the workshop.

Responses to the ‘three main things’ questions revealed the major learnings of the workshop from the participant’s perspectives. Thematically, these were:

- specific project information from the speakers (especially the work of Healthabitat by Paul Pholeros and Rumbalara by Lena Morris);
- current progress in Aboriginal Aged Care;
- the importance of understanding Aboriginal issues and perspectives (such as culture and community);
- access to and knowledge of resources;
- new knowledge gained;
- building aged care capacity in communities;
- the real world impact of work in Aboriginal aged care;
- networking;
- and challenges for the future.

Responses to the ‘future suggestions’ question was also encouraging, including much considered and constructive feedback. Suggestions included: locations for the next workshop; requests for more frequent and local workshops; ideas for future sessions/presentations; and strategies to structure group sessions in future workshops.

‘Other comments’ highlighted praise and ‘thank-yous’ for the day. Negative feedback concerned, for the most part, structural issues pertaining to the venue, particularly the cold temperature of the air conditioning.

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>MEAN RESPONSE</th>
</tr>
</thead>
<tbody>
<tr>
<td>How interesting did you find today’s workshop?</td>
<td>3.8/4</td>
</tr>
<tr>
<td>How valuable did you find the opportunity for networking?</td>
<td>3.5/4</td>
</tr>
<tr>
<td>How relevant was the workshop to your work?</td>
<td>3.6/4</td>
</tr>
<tr>
<td>How suitable was the venue?</td>
<td>3.7/4</td>
</tr>
<tr>
<td>Overall, how beneficial was participating in today’s workshop to you?</td>
<td>3.6/4</td>
</tr>
<tr>
<td>Please rate how well you thought the workshop was organised.</td>
<td>4.5/5</td>
</tr>
<tr>
<td>Please rate how well you thought the workshop was facilitated.</td>
<td>4.6/5</td>
</tr>
</tbody>
</table>
MOVING FORWARD – WHERE TO FROM HERE?

“In order to succeed, people need a sense of self-efficacy, to struggle together with resilience to meet the inevitable obstacles and inequities of life.”

Albert Bandura

Where we have been

The first formal meeting of the AAG ATSIAC took place at the 39th National AAG Conference in Sydney, November 2006. The Committee agreed that its first task was:

“to promote healthy Aboriginal ageing, within the cultural context of Aboriginal communities”.

This was seen as consistent with the broad role of the AAG to expand the knowledge of ageing and to put this knowledge into policy and practice to benefit the Aboriginal community.

To advance those tasks it was determined that the role of chairing the Committee would be shared by:

• (then Associate) Professor Lisa Jackson Pulver of the Muru Marri Indigenous Health Unit of the University of NSW; and
• Professor G A (Tony) Broe of the Ageing Research Centre, POWMRI (now NeuRA) and University of NSW, a role which Professor Broe has maintained over this time.

The three workshops (held over the previous years) have formed a significant foundation for activities undertaken by the AAG ATSIAC committee but there have been other tasks undertaken concurrently. These have included the development of partnerships with Aboriginal and Torres Strait Islander individuals, researchers and organisations who can contribute to enhancing the life of older Aboriginal people. Importantly an ongoing dialogue of discussion at National Council level has been an important focus. Additionally, much work has been achieved in challenging the culture of the AAG to be more embracing and representative of Aboriginal and Torres Strait Islander issues, including within its National Conference program and as part of decision making at the national level.

There has also been an important representation – through the Chair – on the National Aboriginal and Torres Strait Islander Indigenous Dementia Advisory Group (NATSIDAG), auspiced by Alzheimer’s Australia.

A key objective of the Chair (Professor Broe) and the Honorary Secretary (Sharon Wall) over the previous twelve months has been to build on partnerships and engage Aboriginal and Torres Strait Islander individuals and organisations to have a more active role in the committee. The intention of ATSIAC has always been that it should be Aboriginal led with Aboriginal membership so as to genuinely reflect and meet its goals and objectives.

Where we are going

One of the methods used to support this important direction has been the inclusion of an Aboriginal and Torres Strait Islander closed meeting at each of the National Workshops undertaken. These meetings have provided a forum for Aboriginal leaders to discuss direction for this committee. At its most recent meeting it was proposed that the committee previously known as ATSIAC should become an Advisory Group and the Advisory Group nominated Mark Elliott as its Inaugural Chair.

A proposal was subsequently put forward by Sharon Wall and Professor Broe at the AAG Incoming National Council meeting held on 20 November 2012 that the name of the group become the “Aboriginal and Torres Strait Islander Ageing Advisory Group” (ATSIAAG). This direction was subsequently endorsed by the (then) Council.
It was further determined at that meeting that council would support the Chair of the ATSIAAG committee having a full and dedicated position on the Board from 2014. Until that time ATSIAAG would report to the Board through its Chair (Mark Elliott) in an ex-officio position. The interim committee will canvas with appropriate Aboriginal ageing professionals their interest in becoming members of this advisory group so as to be truly representative of the needs of the Aboriginal community.

This is an important time to move forward in synchronicity with changes occurring within the broad organisation. The AAG has undertaken changes to convert from an association to a company limited by guarantee with a new constitution and management structures. This signals a supportive landscape to embrace these new directions in the formation of ATSIAAG.

Sharon Wall has offered to remain Honorary Secretary for a year to assist in the transition period and Professor Broe has offered mentorship and support to the Chair and the Advisory Group.

**Mark Elliott** is currently the Acting Manager of the Aboriginal Primary Health Care Unit in Murray Bridge South Australia. He has been involved with ageing and dementia in various roles for the past five years since he helped to design and deliver the “Strengthening Dementia Care in Indigenous Communities” program while working as the Aboriginal Project Officer for Alzheimer’s Australia SA. This program attracted international attention and won an honorable mention in the Mentor International Awards.

Mark was one of the founding members of the National Aboriginal Dementia Advisory Group (NADAG) which later became the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) and continues to be a South Australian representative on this group. Mark also co-delivered the national pilot training of the Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities in early 2012 at the Aboriginal Health Council of SA and is a qualified trainer/assessor.

**Directions for the future**

This report marks the first stage of follow up from the third National AAG ATSIAAC Workshop. It is anticipated that this report will be widely disseminated to all partners, participants and interested others and feedback sought and collated. The discussion and comment flowing will further inform directions for the AAG ATSIAAG.

It was determined by consensus that another forum would be planned within a two-year cycle (2014). This will prove a valuable forum to present outcomes from research currently being undertaken as well as providing a voice to issues that continue to arise on the ageing of Aboriginal peoples in the intervening time. It will importantly allow the Aboriginal and Torres Strait Islander Ageing Advisory Group to lead those discussions and debates and to set the agenda for future work in advising the AAG.
REFERENCES


• Arkles, R., L. Jackson Pulver, H. Robertson, B. Draper, S. Chalkley and G. Broe (2010). Ageing, Cognition and Dementia in Australian Aboriginal and Torres Strait Islander Peoples. Sydney, Neuroscience Research Australia & Muru Marri Indigenous Health Unit, UNSW.

• (Mr Eric Deeral), Chairperson, Elders Justice Group, Hopevale Community, Queensland, In, Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities, 2007.


FEEDBACK FORM

Please feel free to use this form to provide any feedback regarding this forum and subsequent report, or any other forum or strategy for the future related to *Growing Old Well for Aboriginal and Torres Strait Islander Peoples* and to the work of the Aboriginal and Torres Strait Islander *Ageing Advisory Group* of the Australian Association of Gerontology (AAG).

1. **Do you have any comments regarding the workshop and this report?**

2. **Do you have any thoughts and ideas for future workshops and forums?**

3. **Do you have any general thoughts around Aboriginal and Torres Strait Islander Ageing?**

4. **Is there any information you would like to feedback to the ATSIAAG?**

**PLEASE SCAN AND EMAIL TO:**

ATTENTION: AAG ATSIAAG

Email: enquiries@aag.asn.au  |  Phone enquiries: + 61 3 9939 8693
Today we honour the Indigenous peoples of this land, the oldest continuing cultures in human history.

We reflect on their past mistreatment.

We reflect in particular on the mistreatment of those who were stolen generations – this blemished chapter in our nation’s history.

The time has now come for the nation to turn a new page in Australia’s history by righting the wrongs of the past and so moving forward with confidence to the future.

We apologise for the laws and policies of successive parliaments and governments that have inflicted profound grief, suffering and loss on these our fellow Australians.

We apologise especially for the removal of Aboriginal and Torres Strait Islander children from their families, their communities and their country.

For the pain, suffering and hurt of these stolen generations, their descendants and for their families left behind, we say sorry.

To the mothers and the fathers, the brothers and the sisters, for the breaking up of families and communities, we say sorry.

And for the indignity and degradation thus inflicted on a proud people and a proud culture, we say sorry.

We the Parliament of Australia respectfully request that this apology be received in the spirit in which it is offered as part of the healing of the nation.

For the future we take heart; resolving that this new page in the history of our great continent can now be written.

We today take this first step by acknowledging the past and laying claim to a future that embraces all Australians.

A future where this parliament resolves that the injustices of the past must never, never happen again.

A future where we harness the determination of all Australians, Indigenous and non-Indigenous, to close the gap that lies between us in life expectancy, educational achievement and economic opportunity.

A future where we embrace the possibility of new solutions to enduring problems where old approaches have failed.

A future based on mutual respect, mutual resolve and mutual responsibility.

A future where all Australians, whatever their origins, are truly equal partners, with equal opportunities and with an equal stake in shaping the next chapter in the history of this great country, Australia.

There comes a time in the history of nations when their peoples must become fully reconciled to their past if they are to go forward with confidence to embrace their future.

Our nation, Australia, has reached such a time...

[then] Prime Minister Kevin Rudd, MP
13th February 2008
Translating Research into Caring and Practice