Acknowledgment of country

I would like to acknowledge and pay respect to the traditional owners of the land on which we meet the Gadigal People, and acknowledge that it is upon their ancestral lands that we are invited to talk today. My wish is as we share our own knowledge, teaching, learning and research practices we also pay respect to the knowledge embedded forever within the Aboriginal Custodianship of Country.
Koori Growing Old Well Study
From Research to Community Support

Please note that there may be pictures of people contained in the presentation who are now deceased.

Translating Dementia Research Knowledge into Care and Practice with Aboriginal Communities
What does the research tells us!!!

• About our Ageing Aboriginal and Torres Strait Islander populations
• And about dementia in Aboriginal and Torres Strait Islanders

8/09/2016
NeuRA https://www.neura.edu.au/
Ageing

What do we know about ageing in Aboriginal and Torres Strait Islander populations through our research
Are Aboriginal People Ageing?

- A young population overall BUT Indigenous population is ageing
- Proportion of Aboriginal population aged 60+ is 4% (non indigenous 14%)
- Number of older Indigenous people (age 55+) will more than double between 2006 and 2021 (ABS)
- At older ages, life expectancy closer to non-Indigenous (Cotter et al., 2012)

The health of Aboriginal People

A downside of living longer is - that with “population ageing” Aboriginal people may be at higher risk, than non-Indigenous people of comparable age, of dementia due to neurodegenerative diseases – such as Alzheimer’s disease (Broe, A)
Dementia

What do we know about dementia in Aboriginal and Torres Strait Islander populations through our research
Dementia In Indigenous Australians in the Kimberley

Prevalence of dementia: 12.4%
5.2 times greater than the overall Australian population rate of 2.4%

Dementia types (DSM-IV)
- Not otherwise specified: 24 (53%)
- Alzheimer’s type: 11 (24%)
- Vascular: 6 (13%)
- Alcohol induced: 2 (4%)
- Other medical conditions: 2 (4%)

The Aims of the Koori Growing Old Well Study (KGOWS)

1. Determine the prevalence of cognitive impairment and dementia in Aboriginal Australians aged 60 years and older

2. Assess the validity and relative performance of different screening tools for cognitive impairment and dementia in this population

3. Examine factors associated with cognitive impairment and dementia

4. Describe the use of formal dementia and aged care services in these communities, and the burden of dementia in family caregivers

5. Build capacity in dementia assessment and care, risk factor detection and prevention.
Partnerships were established with five Aboriginal communities in NSW with a 61% sample of population.

**Dementia Prevalence (age-standardized) = 21.0%**

**Three times** the general Australian dementia prevalence = 6.8% Similar to Remote Indigenous (KICA = 24%)

**Clinical Dementia Types** - similar in Urban & Remote Indigenous (KICA) and to dementia studies world wide

- Alzheimer’s disease (~70%)
- Vascular dementia (~20%)
- All other dementias < 10%
The important question - Why are dementia rates so high?

**KGOWS** confirmed that Urban Aboriginal people - 60 yrs+ have very high rates of dementia (21%) - 3 x non-Indigenous.

**Urban rates** are comparable to those in Remote people aged 60+ in the KICA Study (23.8%)

**High dementia rates** occur despite significant group differences between urban & remote Aboriginal people in - lifestyle, culture, language, education, social organisation & some health indices.

**What are the potential brain risk factors in common?** for urban & remote Australian Aboriginal people
KGOWS also examined potential dementia risk factors across the lifespan

Proximal factors in mid life (primarily biological) e.g. vascular/metabolic risks - which have been the focus of Aboriginal Health research to ‘close the gap’ - with some success (Thomas D 2006; ABS 2010)

Distal factors in early life (primarily social) affecting brain growth - may increase Aboriginal mid-life health risks and contribute directly to dementia pathology (Snowden 1996; Starr 2000; Felliti 2002; Danese 2009; Maselko 2010)
Recent conclusions of childhood adversity impact from the KGOWS

• **Childhood Trauma** is a likely independent contributor to high rates of **all-cause dementia & Alzheimer’s disease** in Indigenous Australians

• Data suggests a **direct pathway** from early life brain dysfunction to high rates of later dementia
  – Childhood Trauma is also associated with late life anxiety, depression, stress

• **Early social interventions** - *parenting, schooling, jobs* - an important focus in dementia prevention - in addition to standard mid-life biomedical risks

Summary of Research

• The number of older Aboriginal Australians is increasing rapidly - with most Aboriginal people (70%) living in urban (non-remote) areas of Australia

• The burden of dementia - particularly Alzheimer dementia - is very high, unrecognised, and requires better support systems for older Aboriginal people

• A process of cumulative social & biomedical dementia risks across the life-course is likely and needs study

• As well as current action on mid-life biomedical risks – child & family support, early & continuing education, & skilled jobs - are crucial to brain health & a better life
How then translate that research into community support??

Translating Dementia Research Knowledge into Care and Practice with Aboriginal Communities
What is (was) the Koori Dementia Care Project?

- Built on the work of the Koori Growing Old Well Study (KGOWS)
- Informed by evidence and translation of research
- Committed to inform, educate and build capacity in NSW Aboriginal communities and with associated service providers, about the effects of dementia on older Aboriginal people and their families
Essential elements of project

• Engagement of Aboriginal Dementia Knowledge Holders (Aboriginal Dementia Educators) in each community
• A co-mentoring model
• Development (or restructuring) of resources informed by Aboriginal and Torres Strait Islander communities
• Collaboration and partnership with Aboriginal specific and mainstream organisations
• Honouring of relationships built by the Koori Growing Old Well Study
Trek of Hope for a Dementia Cure

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. (Mary Page, Aboriginal artist, 2012 © Koori Dementia Care Project)
Walking together – mutual mentorship
Resource Development and support
So what does Jack Charles have to do with this??
Highlighting and depending on the resilience of Aboriginal people is not enough...
We have a moral imperative to act!!!

• We know the figures
• We need to know more about the whys
• We need to know more about the strategies that will assist in prevention and in care practices
• And we need to take that information to the community and work with the community to provide services and resources to match
Current and Future Directions

• KGOWS cross-sectional data
  • Health, aged care and dementia service use
  • Carer burden
• KGOWS cohort 5-year follow-up:
  • Incident dementia, MCI conversion rate, risk factors
• Koori Active & Healthy Ageing Project
  • Improving cognitive assessment
  • Healthy brain ageing and dementia prevention
• Meaning of dementia, dementia education and dementia care in urban/regional Aboriginal communities
  • Koori Dementia Care Project (KDCP)
With an emphasis on responding across the life span

We need to find the causes of profound stress, across the life span that have led to a smoking rate which is four times that of non-Indigenous people; rather than take the simplistic view that smoking cessation will in itself “close the gap”. We need to attack the socioeconomic causes of obesity, across the life span, rather than blame adult Aboriginal people for the high rates of mid-life diabetes. We need to recognise that a majority of Aboriginal people do not drink alcohol at all and that we therefore need to attack the underlying causes of alcohol and drug dependency; rather than focus only on the current “drinking problems” in some Aboriginal communities.

In particular we need to embrace methods to provide a secure family environment, equal access to early childhood programs, better educational opportunities for Aboriginal children, and quality jobs for Aboriginal youth, as essential to closing the gap - in addition to the importance of health measures and better health care in mid-life and old age. (Professor Tony Broe)
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