

# **Dementia in Aboriginal and Torres Strait Islander Communities or 'Yagar smol loosing it'**

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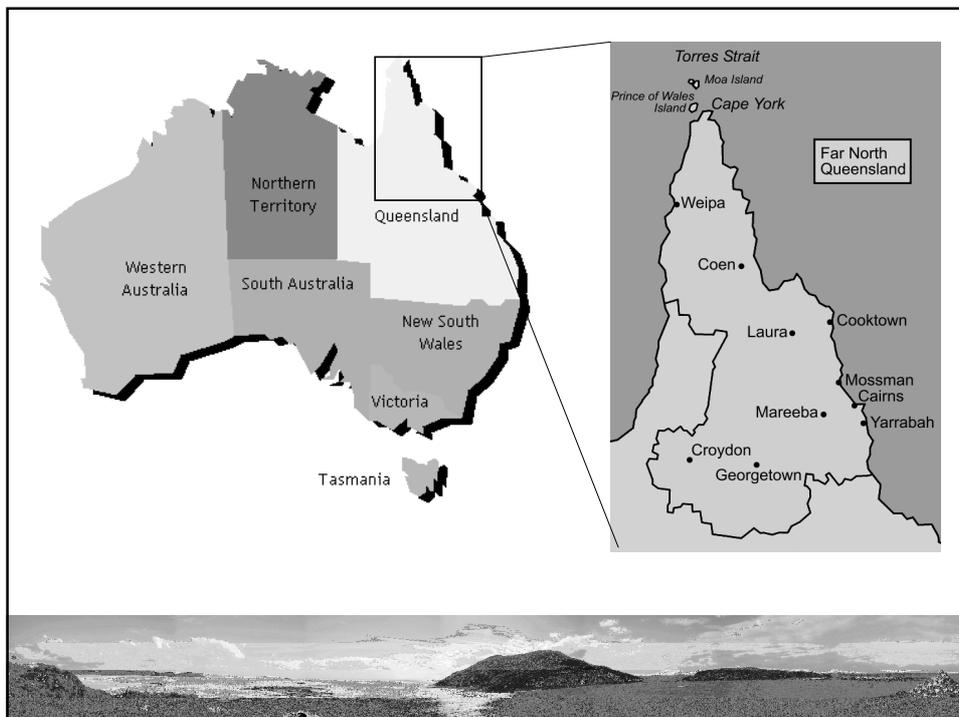


## **Acknowledgements and thanks**

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  - Judith Groube, Jean Little and whole team!
- Queensland Health

# Workshop Aims

- Introductions
- Setting the scene
- Ageing, Chronic Disease and Disability
- Dementia
  - Remote
  - Urban
- Case studies
- Prevalence
- Ways forward



## Setting the scene



## Population

- Total Population Far North Queensland  
– 233,848
- Aged 65 years or older  
– 23,151 (9.9%)
- Indigenous Origin  
– Total 25,752 (11%)  
– 3% (773) aged 65 years or older



# Older Persons Health Services

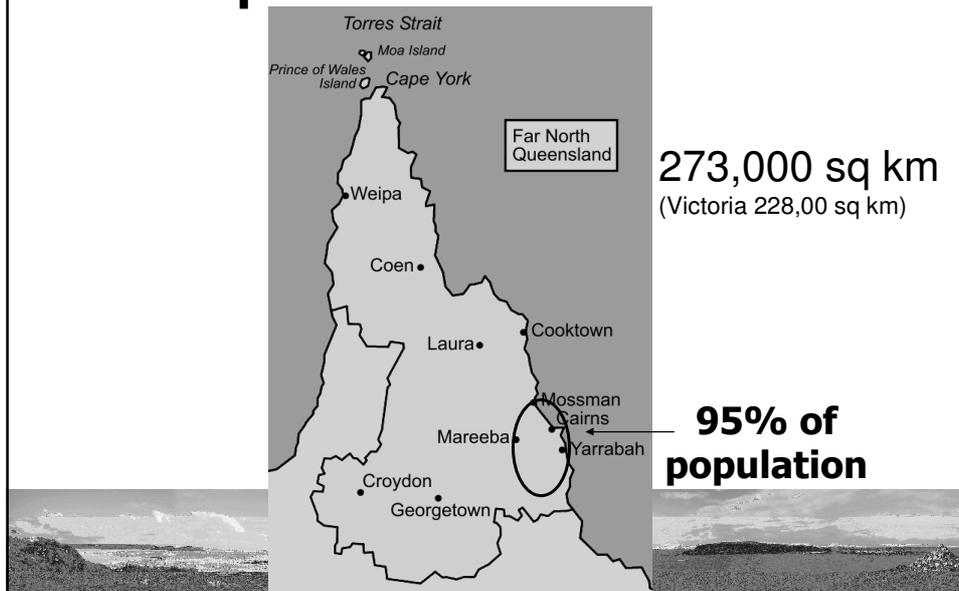
Cairns and Hinterland Health Service District

*Virtual Team*

- Aged Care Assessment Team
- Geriatric Medicine
  - 3 positions
- GEMS team
- Aged Care Health Services
- Outreach



## Population Distribution



## **Aboriginal and Torres Strait Islander Population**

- Australia
  - 386 049
  - 2.1% of total population
- Far North Queensland
  - 28 982
  - 11% of FNQ population



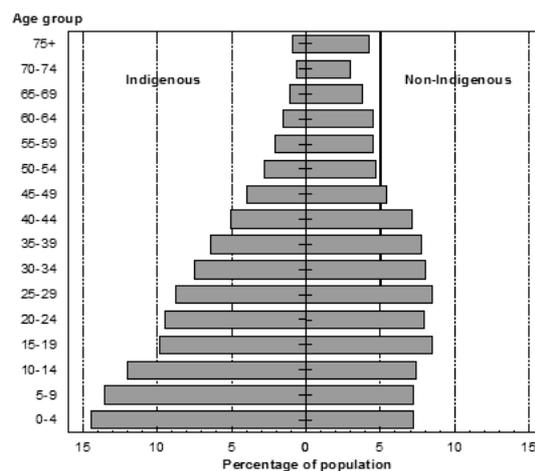
## **Aboriginal and Torres Strait Islander Population**

- 36% live within Cairns
- 64% living in regions outside Cairns, many in remote rural areas of Cape York and the Torres Strait
- Heterogeneous group made up of both Aboriginals and Torres Strait Islanders
- Wide regional, cultural, linguistic and urban-rural variation



## Who Constitutes the Aboriginal and Torres Strait Islander Aged? *'Older, Younger' or 'Younger, Deader'*

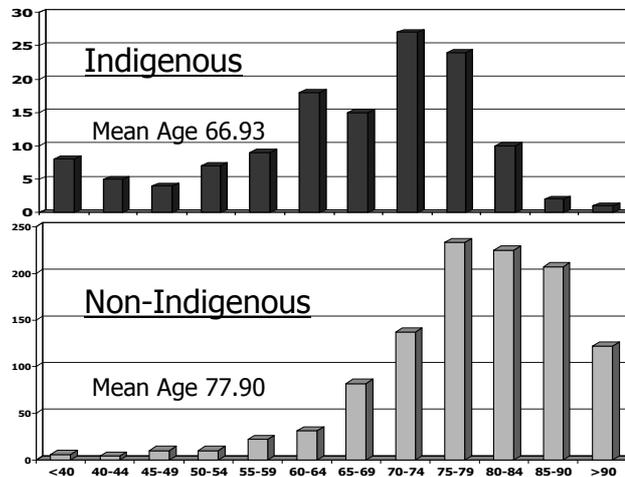
- Life expectancy reduced
  - Indigenous Males                    56.9 years  
    (All Australian Males            75.2 years)
  - Indigenous Females                61.7 years  
    (All Australian Females        81.1 years)
- Some 'diseases of ageing' occur younger
  - Cairns Indigenous Stroke Study (Johnson/Archer 2005)
  - Mean age of presentation 56yrs (vs 68yrs Non Indigenous)
- Only 3% >65 years of age
- 9.4% of indigenous population >50 yrs



Overview of Australian Indigenous Health Status 2009



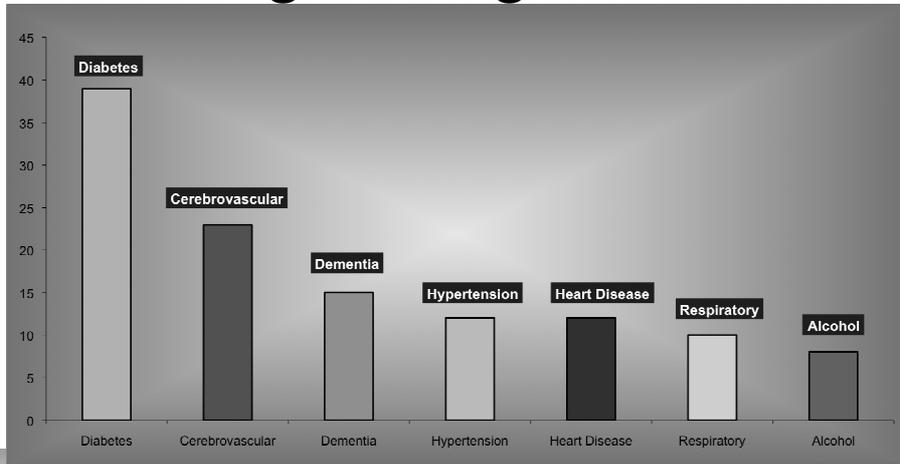
## Referrals-Age Distribution



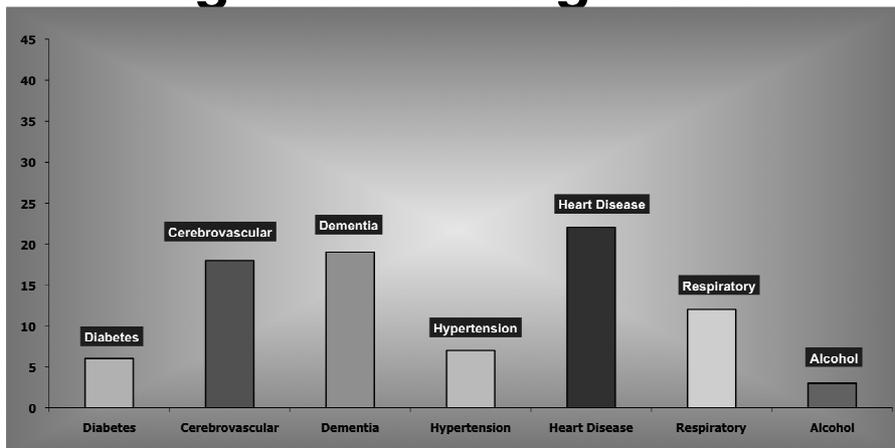
Workshop Task

**WHAT ARE THE MAIN HEALTH WORRIES FOR OLDER ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE?**

## Main Diagnoses -Aged Indigenous



## Main Diagnoses -Aged Non-Indigenous



## MORE STATS



## Standardized Mortality Rates

- Number of deaths 4 times higher than expected from age-sex-specific death rates
- High across all age groups but particularly high in young and middle adult years
- 75% of Indigenous males die before the age of 65 years (c/w 26%)



<b><u>Cause of death</u></b>	<b>Males SMR</b>	<b>Females SMR</b>
Circulatory	3.2	2.7
Injuries	2.9	3.5
Cancer	1.5	1.6
Endocrine, nutritional and metabolic	7.5	10.1
Respiratory	4.3	3.6
Digestive	5.8	5.1
Genitourinary	4.8	6.0
Nervous system	2.9	1.6
Mental and behavioural disorders	5.8	3.1
Infectious/ parasitic	5.1	5.0
All causes	3.0	2.9



## **International Comparisons**

- Lower life expectancy than other 1<sup>st</sup> World Indigenous populations
- All cause mortality 2 x Maori and 2.3 x Native American
- Indigenous males in Australia live between 8.8 to 13.5 years less than in Canada, USA or New Zealand



# Health Transition Theory

- Dynamic relationship between epidemiological and demographic changes
- Approach to research examining the life expectancy gap
- 5 stages from infectious epidemics through chronic disease to degenerative disease

(Many thanks to Prof Tony Broe)



## 5 stages

1. Epidemics of Infectious Diseases
2. Declining Epidemics
3. Chronic systemic disease
4. Improved chronic disease survival
5. Increased neuro-degenerative diseases/dementia's



## What Improves Health Status

- Wealth
- Education
- Employment
- Health specific issues
  - Public Health
  - Specific disease interventions



## Socioeconomic Status

- Education
  - National Reading Standards Year 5
  - 63% Indigenous students vs 93% all Australians
- Employment
  - Excluding CDEP unemployment rate 5 times higher
- Income
  - 45% = lowest quintile



## What is Frailty?



“A physiologic syndrome characterized by decreased reserve and resistance to stressors, resulting from cumulative decline across multiple physiologic systems, and causing vulnerability to adverse outcomes”



“ Frailty is like pornography; its hard to define but you recognize it when you see it.”

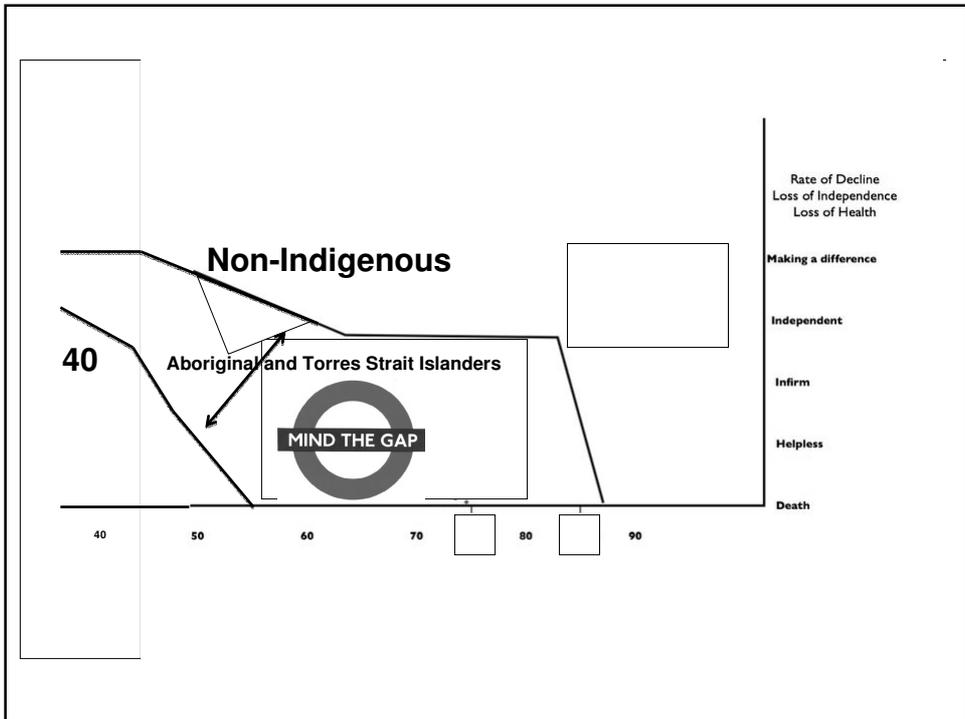
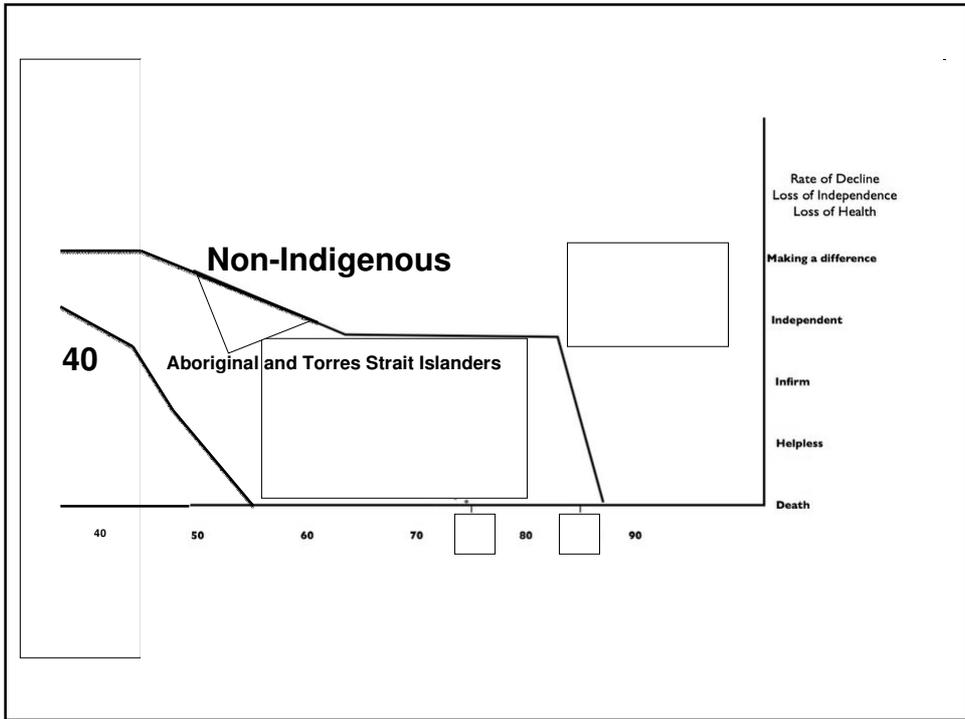
-anonymous clinician



## Frailty

- Everyone accumulates age-related adverse changes eg frank illnesses or decrements eg reduced muscle strength
- Very variable rate of accumulation
- Important both clinically and on a population basis
- Multiple approaches to both concept and measure of variable ageing





## Why bother?

- Ability to accurately classify frail vs. non-frail before irreversible disability occurs
- Allows intervention to occur
- Prevent/delay functional decline



## Measuring Frailty

- Standard Comprehensive Geriatric Assessment
- Frailty Index
- 'Count of What is Wrong' versus Specific Domain
- Clinical vs Biological markers



## Controversies

- Physical vulnerability alone
- Combine with social, psychological issues, disability and medical illnesses



## Frailty in Indigenous Peoples

- Reduced life expectancy and higher mortality
- Higher rates of chronic diseases
- Higher mortality rates with these diseases
- Higher and younger disability rate
- ?Rates of 'Geriatric syndromes'



## Frailty and Type II DM

- Diabetics develop conditions associated with frailty earlier, eg sarcopenia
- Indigenous diabetes and metabolic syndrome a major issue
- Fremantle Diabetes Study (2005)
- Indigenous Australians OR 4.33 predicting time of progression to disability



## Disability

**Proportions (%) of people needing assistance with core activities, by Indigenous status and age, Australia, 2006**

<b>Age group</b>	<b>Indigenous</b>	<b>Non-Indigenous</b>	<b>Ratio</b>
18-24	2.5	1.3	2.0
25-34	2.8	1.2	2.3
35-44	4.9	1.7	2.8
45-54	8.2	2.7	3.1
55-64	13.2	4.8	2.8
65 or older	20.2	13.4	1.5
All ages	8.4	4.1	2.1



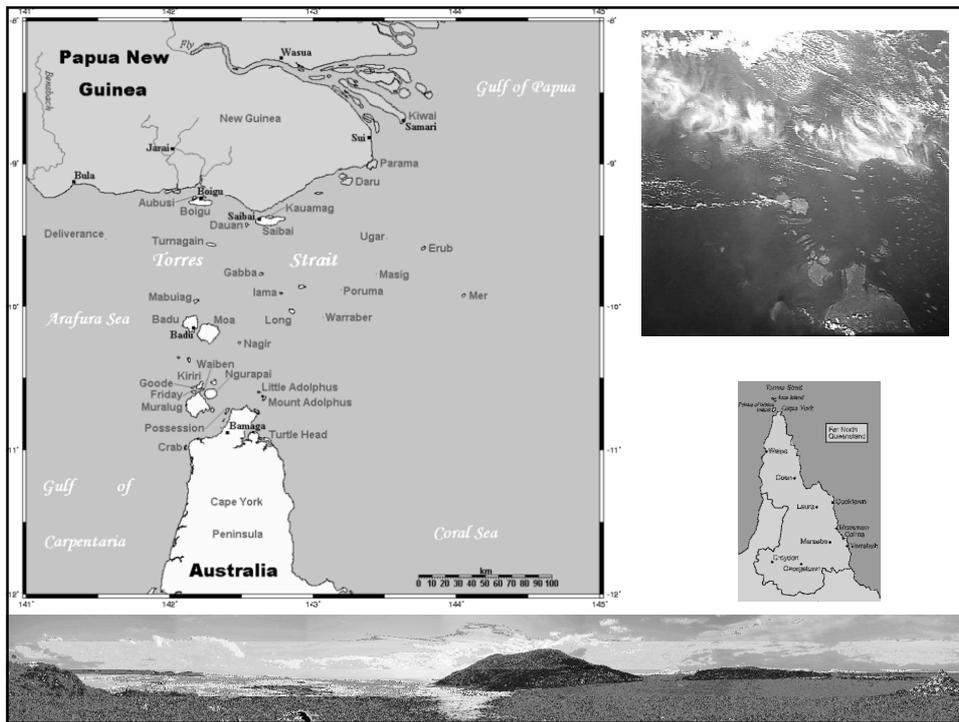
## Disability

- Median age for needing assistance
  - Indigenous Men 41 years (c/w 61 years)
  - Indigenous Women 49 years (c/w 75 years)
- BUT ?the same needs



## Healthy Ageing in the Torres Strait?





## Population

- The population of the Torres Strait region is around 10,000
- Thursday Island is the main population centre
- 88% are of Indigenous Australian origin (mainly Torres Strait Islanders)
- 4.4% are 65yrs and over
- 11% are 50yrs and over



### Descriptive Statistics

	<b>N</b>	<b>Mean</b>	<b>Min</b>	<b>Max</b>	<b>SD</b>
<b>Age</b>	49	71.1	54.0	91.0	7.67
<b>No Chronic Diseases</b>	47	2.4	0.0	7.0	1.41
<b>No Medications</b>	38	3.1	0.0	8.0	2.08
<b>Barthel Index</b>	46	92.2	2.0	100.0	17.92
<b>MMSE</b>	45	23.0	9.0	30.0	5.71
<b>Clock Face Score</b>	42	4.3	0.0	7.0	2.62
<b>Systolic BP</b>	46	133.9	95.0	190.0	19.94
<b>BSL</b>	43	8.2	4.1	19.9	3.65
<b>Weight</b>	40	77.3	48.0	110.0	14.91
<b>Height</b>	40	162.3	147.0	178.0	8.53
<b>BMI</b>	39	29.5	16.6	44.3	6.2



## Results

- Significant Correlations ( $p < 0.05$ )
  - MMSE vs Barthel Index
    - $r = 0.34$
  - MMSE vs Clock Face Score
    - $r = -0.38$
  - Number of Chronic Diseases vs BMI
    - $r = 0.48$
  - Number of Chronic Diseases vs Medications
    - $r = 0.47$



## Results- Torres Strait Islanders

- Prevalence of Chronic Disease Diagnoses
  - Hypertension 60%
  - Diabetes 52%
  - Diabetes 42%  
and Hypertension



## Kimberley Data

- Hypertension 45-50%
- Diabetes 43-58%



## Torres Strait

- Metabolic Syndrome
  - Prevalence 43% Men, 53% Women
- Diabetes
  - Incidence 29 per 1000 patient years
  - 6 times higher than non Indigenous Australians



## Indigenous Dementia

- Too much or too young?
- Competing Hypotheses:
  - Low life expectancy= Low rates
  - High levels of vascular disease and other stressors = High rates



## **Indigenous Australian dementia prevalence was unknown**

Dementia prevalence (65 yrs+):

- **6.5%**- Overall Australian population (AIHW, 2006)
- **20%** - Indigenous Nth Queensland survey (Zann,1994)
- **15%** - Cairns Aged Care Referrals (1999)
- **4.2%**- Cree Indian survey (Hendrie et al, 1993)



## **Indigenous Dementia- what do we know?**

- NT Alzheimer's Assoc report findings (2002):
  - Indigenous Australians not being diagnosed until late stage dementia

***Why?***



Workshop Task

## **WHAT ARE THE CHALLENGES IN DEMENTIA DIAGNOSIS?**



### Key Issues

- Geography
- Awareness
- Assessment tools and process



## 1. Language and Cultural factors

- Standard English not always spoken by older people.
- Multiple languages/Creole used
- Lack of formal schooling
- Educated in law, land and culture
- Remember things that are important and meaningful.



## 2. High tolerance for behaviour change

- Family may think behaviour change is due to cultural reasons.
- Concerned that the family member will be sent to the nursing home, want to keep them within family environment.
- Think behaviour and memory change is a normal part of ageing.



### 3. Lack of an Indigenous specific assessment tool

- KACS-
  - Adapted family IQ code
  - MMSE- for Caucasian culture and education
  - CIBIC- not validated, PBS medn- CIBIC + MMSE of 9 or less.
- Zann (1994) Queensland study.
  - Used adapted PAS
  - Not validated
- Sheldon (1997) NT article
  - Not validated
  - Not formed into assessment tool.
- Strivens (1999/2000)
  - Demonstrated potential bias in use of MMSE in FNQ



### Comparison of Cognitive and Functional Assessment Scores in Two Patient Groups in Far North Queensland

	<b>MMSE Score</b>	<b>Barthel Index</b>	<b>Correlation Coefficient</b>
<b>Non Indigenous</b>	23.97	82.07	0.48
<b>Indigenous</b>	17.69**	83.12#	0.23*
	*p<0.05	**p<0.01	#p=non significant



# Culturally Appropriate Assessment Tools



Workshop Task

## **COGNITIVE ASSESSMENT**



## Barriers to Assessment

- Location
- Language
- Education
- Culture



## **KICA- Kimberley Indigenous Cognitive Assessment**

- Developed in response to need for a validated cognitive screening tool for older (>45), rural indigenous people
- Divided into a number of sections involving client and family reports
- Cognitive assessment section has been validated in Kimberley, Darwin/NT, Far North Queensland



## **KICA development in WA**

- Ethics and community approval
- Consultation
- Walmajarri translation
- Involve and train local people
- Interpreters



## **KICA Components**

- Client assessment and carer reports of
  - Medical history
  - Alcohol and smoking history
  - Cognition
  - Depression
  - Carer report of daily function



Thanks to WACHA Group

## **KICA VIDEO**



## **KICA-screen**

- Orientation                      season/ community/ pension week
- Free and cued recall          picture based
- Language                        naming tasks
- Verbal fluency                 animals (to hunt)
- Frontal executive fn         alternating xo
- Praxis                              comb use



## **KICA-carer**

- 8 Questions
- Informant Questionnaire based on the IQ Code
  - eg Have you noticed that she is forgetting a lot of things



## **Validating the KICA screen in Far North Queensland**

## Methods

- Ethics and local community approvals
- Community partnerships
- Involvement of Traditional Owners and Councils
- Interpreters and Cultural Support persons
- Visits by Project Officer, Indigenous Consultant and Geriatrician to identified communities interested in participating
- Education key component pre and post visits

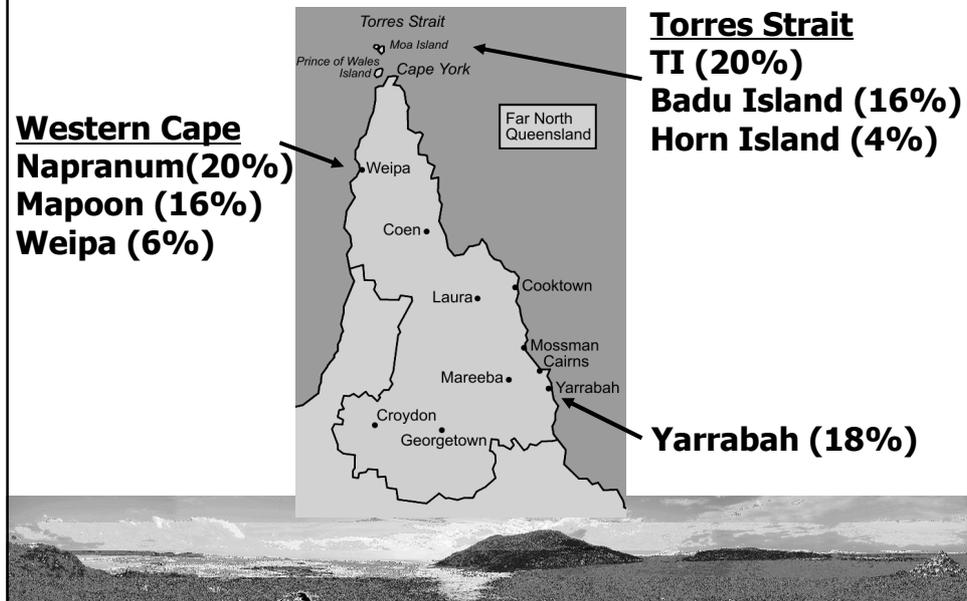


## Validation Process

- 55 participants
- Range of cognitive levels
- Individual consent
- At home or in HACC/PHCC centers
- Client and family apart
- KICA screen, KICA carer, and ADL
- Geriatrician Medical Review blinded to the results
- Consensus diagnosis
- Report to doctors & clinic
- Referrals to health services
- Feedback to Council and Clinics



## Communities

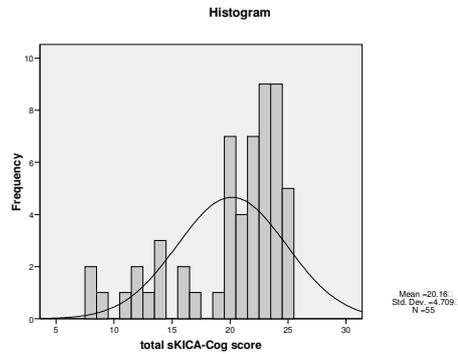


## Subject Characteristics

- Mean Age 69.6 (45-95)
- 63.6% women
- Majority received formal schooling (89%) and spoke English as first language(91%)

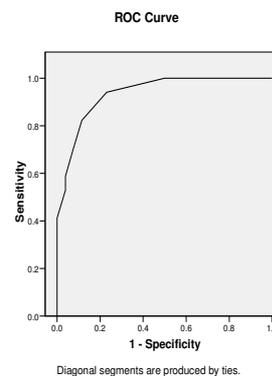
## KICA-screen Results

- Mean score 20.16 (/25)
- Consensus diagnosis
  - 47% No cognitive impairment
  - 31% Dementia
  - 22% Cognitive impairment not fulfilling criteria for dementia (CIND)



## KICA-screen Results

- Internal consistency alpha 0.76
- **Sensitivity 82.4%**
- **Specificity 88.5%**
- Score below 22 indicated cognitive impairment/possible dementia
- Area under the ROC curve 0.936



## Aboriginal vs. Torres Strait Islanders

- Similar sensitivity/specificity
  - Aboriginals 90%/89%
  - Torres Strait Islanders 100%/88%
- Cut off different
  - Aboriginals <23/25
  - Torres Strait Islanders <21/25
- Small numbers but appears valid screening test for both groups



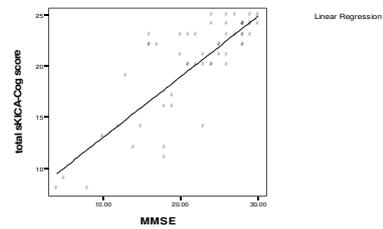
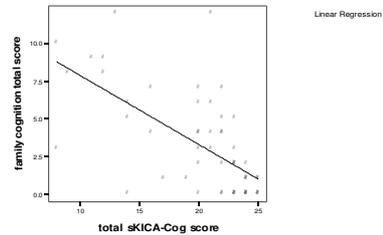
## KICA-carer Results

- Mean KICA-carer score 3.2 (/16)
- The most discriminating KICA-carer questions (classified 88.4% of all dementia diagnoses correctly) were
  - ‘Can they remember which week is pension week?’
  - ‘Have you noticed that they forget a lot of things?’
- Sensitivity 88.2%, Specificity 84.6%



# Correlations

- KICA-screen and KICA-carer
  - Spearman's rho = -0.67
  - r squared = 0.42
- KICA-screen and MMSE
  - Spearman's rho = 0.76
  - r squared = 0.66
- KICA ADL and Barthel Index not strongly correlated



# Conclusions

- The KICA-screen and the KICA-carer appear to be appropriate screening tests for the presence of cognitive impairment in the Indigenous Populations of FNQ
- Despite initial concerns regarding specific items in the KICA-carer, it performed well across the communities
- The KICA-screen/KICA-cog has now been validated in Indigenous communities across the Top End

**Comparison of the KICA-Cog validity results of the Kimberley studies (2003 and 2006), Northern Territory and Far North Queensland Studies**

	Kimberley 2003 n=70	Northern Territory n=47	Kimberley 2006 n=363	Far North Queensland n=55
Alpha- internal consistency	0.87	0.81	0.912	0.76
Cut off score	31/32	31/32	33/34	21/25
Sensitivity, specificity	90.6 % , 92.6 %	82.3%, 87.5%	93.3%, 94.8%.	82.4%, 88.5%
Area under ROC curve	0.95	0.95	0.98	0.94
Discriminant questions	<ul style="list-style-type: none"> <li>• pension week,</li> <li>• recall</li> <li>• free recall</li> </ul>	<ul style="list-style-type: none"> <li>• season question,</li> <li>• verbal fluency,</li> <li>• free recall</li> </ul>	<ul style="list-style-type: none"> <li>• pension week,</li> <li>• registration, recall,</li> <li>• copying xo,</li> <li>• free recall</li> </ul>	<ul style="list-style-type: none"> <li>• Free recall</li> </ul>
Discriminant questions correctly categorise %	85.7%	90.9%	96.7%	88.4%

Workshop Task

**CASE STUDIES**

## Case Study 1

- 78 year old Aboriginal lady from a remote, former mission based, community
- Reports from the local health worker
  - Personality changes
  - Getting lost around the community
- How would you go about assessing this lady?



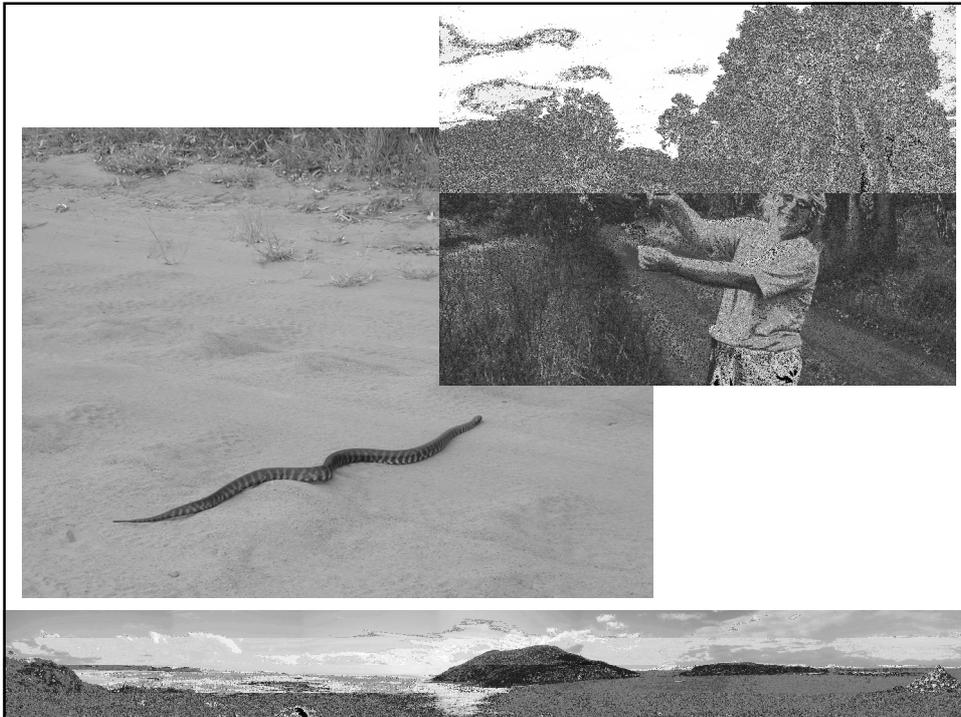
## Case Study 2

- 85 year old Badu Islander (Torres Strait) referred by the local Base hospital
- Admitted with a Cardiac Condition
- MMSE done by the RMO shows a score of 14/30
- What are your next steps?



## Case Study 3

- 58 year old Aboriginal man from local community
- Referred by community services due to reported recurrent admissions to hospital with uncontrolled COPD
- Concerns regarding compliance with meds and requests to 'look at his 'capacity''



## Case Study 1

- 78 year old Aboriginal lady from a remote, former mission based, community
- Reports from the local health worker
  - Personality changes
  - Getting lost around the community
- How would you go about assessing this lady?



## Key Points

- History, history, history
- Informal vs formal cognitive assessment
- Functional abilities



## Case Study 2

- 85 year old Badu Islander (Torres Strait) referred by the local Base hospital
- Admitted with a Cardiac Condition
- MMSE done by the RMO shows a score of 14/30
- What are your next steps?



## Key Points

- MMSE scores.....
- Over and underestimating deficits
- Language/cultural bias
- Is there a problem?



## Case Study 3

- 58 year old Aboriginal man from local community
- Referred by community services due to reported recurrent admissions to hospital with uncontrolled COPD
- Concerns regarding compliance with meds and requests to 'look at his 'capacity''



## Key Points

- Capacity assessment
- The competent can make poor decisions



Indigenous Dementia Workshop

# WHERE TO FROM HERE



?Prevalence



## Kimberley Prevalence Study

- 45yrs+ dementia prevalence = **12.4%**. (2.6%)
- 65yrs+ dementia prevalence = **27%**. (5.4%)



## Dementia Prevalence

Age (yrs)	Dementia numbers (n)		Dementia prevalence rates		Dementia prevalence ratio
	Sample	Australia	Sample	Australia	
45-59	5	3600	0.026	0.001	26.0
60-69	12	12300	0.169	0.008	21.1
70-79	11	49700	0.164	0.043	3.8
80+	17	108700	0.567	0.165	3.4
total	45	174300	0.124	0.024	5.2



## Dementia types (% of all dementia diagnoses)

- Dementia not otherwise specified 53%
- Dementia of the Alzheimer's type 24%
- Vascular dementia 13%
- Dementia due to multiple aetiology 4%
- Alcohol induced persisting dementia 4%



## Risk factors for Dementia

Multivariate OR[CI]

<input checked="" type="checkbox"/>	Age	
<input checked="" type="checkbox"/>	Male	3.1 [1.4 - 6.8]
<input checked="" type="checkbox"/>	No formal education	2.7 [1.1 - 6.7]
<input checked="" type="checkbox"/>	Stroke	17.9 [5.9 - 49.7]
<input checked="" type="checkbox"/>	Head injury	4.0 [1.7 - 9.4]
<input checked="" type="checkbox"/>	Epilepsy	33.5 [4.8 - 232.3]
<input checked="" type="checkbox"/>	Current smoker	4.5 [1.1 - 18.6]



## Other variables associated with dementia

- |                      |       |               |
|----------------------|-------|---------------|
| ▪ Poor mobility      | 13.4  | [4.1, 33.9]   |
| ▪ Falls              | 2.7   | [1.2, 6.1]    |
| ▪ Incontinence day   | 116.8 | [21.9, 622.8] |
| ▪ Incontinence night | 87.4  | [18.4, 415.7] |



## Conclusions

- High prevalence of dementia especially in young age groups
- Males predominant
- Multiple risk factors including head injury
- Poorer access to health services
- Need to develop and evaluate Indigenous dementia specific services.
- Health promotion
- Prevention at early stage



# **Dementia in the Torres Strait**

Steps towards estimating prevalence of cognitive disorders

## **Dementia in the Torres Strait -Background**

- No previous studies have looked at rate of cognitive disorders in the Torres Strait or in Torres Strait Islanders
- Vascular risk is high, ? Dementia risk
- KICA Screen previously validated in the Torres Strait



## Hammond (Keriri)

- Hilly island, 15 mins by ferry from TI
- No Primary Health Centre or resident medical/nursing staff
- 2 trained first responders
- PARAC visit weekly with monthly MO visit
- Small shop and primary school (Prep-Yr 5)



## Hammond Island

ABS 2005

- Total Population 224
- 65+yrs 14 (6%)
- 45+yrs 49 (22%)



## Study Design-Pilot

- Trial survey tool and study design
- Based on KICA Survey tool used in Kimberley Prevalence Study
- KICA Cog pictures adapted to be more appropriate in Torres Strait Islanders



## Methods

- Partnership with Primary Health Care Centre on TI, PARAC Team and Council
- Pre and post survey visits and education to residents and health teams
- Health survey completed by researcher and cultural support worker
- Blinded medical review by Geriatrician



## KICA Health Survey

- Demographic info
- Medical History
- Smoking and Alcohol History
- Cognitive Assessment
- Functional Assessment
- Family Report



## Tools

- KICA Carer
- Zarit Burden Scale
- Elderly Falls Screening Test (EF)
- FROP Com (done by Geriatrician)
- Modified PHQ9 Depression Scale
- MMSE (Geriatrician)





## Pilot Study 2012

- Identified population >45 yrs 28
- 20/28 participated
- 9 Male 11 Female
- 90% Torres Strait Islanders
- 35% born on Hammond



## More Demographics

- Average age 65.8 yrs (SD 9.46, Range 45-85)
- 100% spoke English as 1<sup>st</sup> or co-primary language
- Mean formal education 7.45 years

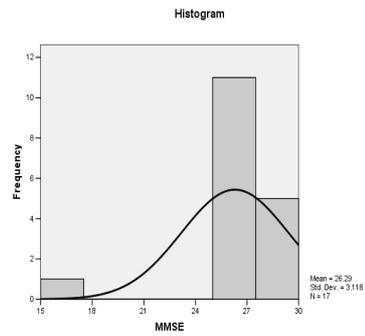
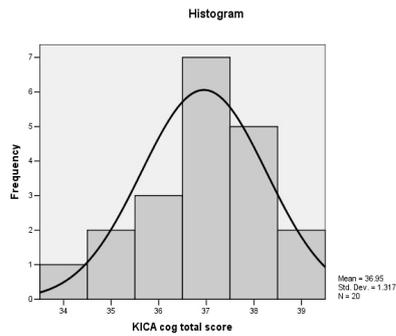


## Cognition

Age	Diagnosis		
	Normal	CIND	Dementia
<65 (n=6)	6	0	0
65-69 (8)	6	2	0
70-74 (3)	1	1	1
75-80 (2)	1	1	0
80+	1	0	0
<b>TOTAL</b>	<b>15</b>	<b>4</b>	<b>1</b>



# KICA Cog and MMSE Scores



# Medical and Lifestyle Factors

	<b>CIND/Dementia</b>		<b>Normal Cognition</b>
Sensory Loss	60%		0%
Vascular risk factors	100%		73%
Type II DM	40%		27%
Heart Disease	40%		13%
Renal Disease	60%		20%
Head Injury	40%		20%
Current smoker	40%		27%
Moderate to Heavy Alcohol Use	40%		7%

## Function

- 65% Independent
- 20% Minor assistance
- 15% Dependent on at least one ADL



Workshop Task

**HOW DO WE INCREASE  
ACCESS TO DEMENTIA  
SERVICES?**



## Ways Forward

- Chronic Disease management
- Culturally appropriate care
- Equity of access to/funding for health care services
- Community Controlled Health Organizations



## Chronic Disease Management

- High prevalence of chronic but preventable/ameliorable disease
- Lack of access to primary and specialist medical services
- Reduced opportunities for primary and secondary prevention and early intervention



## Culturally Appropriate Care

- Lack of Indigenous people in the health care workforce
  - 0.18% of all Medical Practitioners
- Need for integration of cultural competency and cultural safety principles into physician training
- Indigenous Specific Assessment Tools



## Funding/access equity

- Less money spent on people with worse health
- 70c to every \$1 spent on Federally funded health programs
- Investment in Primary Care and Prevention
  - ?Healthier Ageing
- Specialist services



## Community Controlled Health

- Community based holistic approach to health
- Coordination and collaboration across health and welfare sectors



## Apunipima

- Apunipima Cape York Health Council
- Health Action Teams established in several remote Cape York communities
- Working with RFDS to transition control and coordination to local groups
- Liaises with Cape York Institute (Noel Pearson) regarding wide health and welfare issues

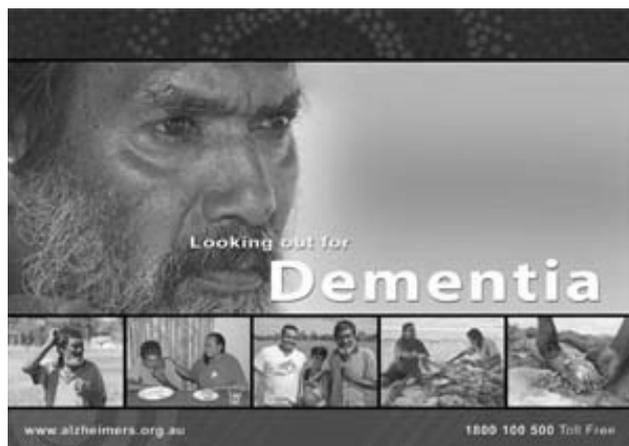


## Cape and Torres ACAT Process

- Partnership Model – ‘Buddy System’
  - ~ Community/Health Worker Business
  - ~ ACAT Business
  - ~ Shared Business
- Culturally Appropriate Assessment Tool – Aboriginal & Torres Strait Islander Assessment Tool (A&TSIAT)



## Dementia Awareness



## Active Current Research

- Koori Growing Old Well Study
  - Burden of dementia in urban Indigenous Australians



## Active Current Research

- Health Outcomes of Older Indigenous Australians
  - Looking at rates of geriatric syndromes, disability and functional decline
- Torres Strait Prevalence Study
  - Pilot study



## In summary

- Indigenous Ageing
- Dementia diagnosis
- Ways forward



## Contacts



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