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Aboriginal and Torres Strait Islander wellbeing projects: Murray LLS wellbeing survey & Mayi Kuwayu

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Outline

- Murray Local Land Services survey
 - Wellbeing and caring for country
 - Connection to Regional Wellbeing Survey
- Broader Background and rationale
 - Policy and research directions
 - Wellbeing outcomes/Socio-cultural determinants
 - What is known?
 - Mayi Kuwayu
- Methods and Conceptual framework
- Design
 - Community engagement
 - Questionnaire domains
 - Questionnaire development
- Outcomes



Background/rationale

- Connection to country and wellbeing
- Regional wellbeing survey Aboriginal participation
- Mayi Kuwayu project connections
 - Socio-cultural determinants of Aboriginal and Torres Strait Islander health and wellbeing

Broader policy and research directions

- National Aboriginal and Torres Strait Islander Health Plan 2013-2023
 - The Centrality of Culture and Wellbeing in the Health of Aboriginal and Torres Strait Islander People: “We represent an evolving cultural spectrum inclusive of traditional and contemporary practices. When we are empowered to do this, and where systems facilitate this reclamation, protection and promotion, we are healthy, well and successful and our communities thrive” Professor Ngiare Brown.



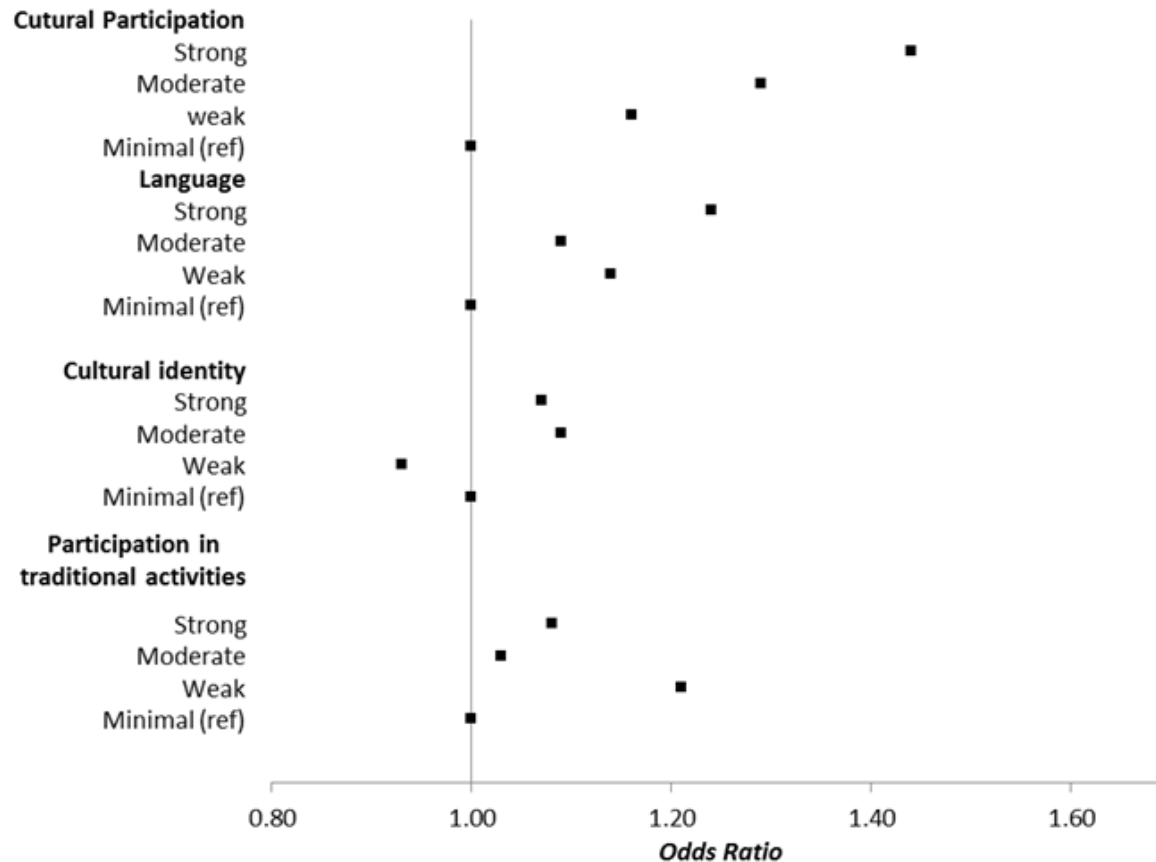
Research directions

- Cultural Determinants of Aboriginal and Torres Strait Islander Health Roundtable, November 2014 (Lowitja Institute)
 1. Clarify what the cultural determinants of Aboriginal and Torres Strait Islander health are;
 2. Consider strategies that could assist in strengthening culture as a determinant of Aboriginal and Torres Strait Islander health;
 3. Caring for Country;



What is known?

Australia: Self-assessed health by cultural factors, NATSISS 2008



Source: Dockery, 2011 pp23

What is known?

Healthy country, healthy people: the relationship between Indigenous health status and “caring for country”

	Caring for country participation		P
	Odds ratio (95% CI)	Regression coefficient (95% CI)	
Health behaviours			
Greater exercise participation	2.90 (1.60–5.25)	—	< 0.001
Greater bush meat consumption	4.23 (2.05–8.74)	—	< 0.001
Greater bush fruit and vegetable consumption	3.36 (1.78–6.35)	—	< 0.001
Clinical outcomes			
Difference in body mass index	—	-2.83 (-4.56 to -1.10)	0.001
Having abdominal obesity	0.43 (0.26–0.72)	—	0.001
Difference in systolic blood pressure	—	-7.59 (-12.01 to -3.17)	0.001
Difference in diastolic blood pressure	—	-3.15 (-6.17 to -0.14)	0.04
Having type 2 diabetes	0.12 (0.03–0.52)	—	0.001
Difference in HbA _{1c} level	—	-0.45 (-0.79 to -0.11)	0.01
Difference in HDL cholesterol level	—	0.06 (0.01 to 0.12)	0.02
Difference in lipid ratio (levels of total to HDL cholesterol)	—	-0.07 (-0.35 to 0.21)	ns
Having ACR > 3.4 mg/mmol	0.28 (0.13–0.60)	—	0.001
Difference in K5 psychological distress score	—	-0.97 (-1.64 to -0.31)	0.002
Difference in 10-year absolute CHD risk	—	-0.72 (-1.79 to 0.35)	ns
Difference in NZGG 5-year CVD risk category*	—	-0.77 (-1.43 to -0.11)	0.023

HbA_{1c} = glycated haemoglobin. HDL = high-density lipoprotein. ACR = urinary albumin to creatinine ratio. K5 = five-item version of the Kessler Psychological Distress Scale. CHD = coronary heart disease. NZGG = New Zealand Guidelines Group.²⁰ CVD = cardiovascular disease. ns = not significant.

* Each unit of change represents a change in CVD risk of 5% over 5 years.

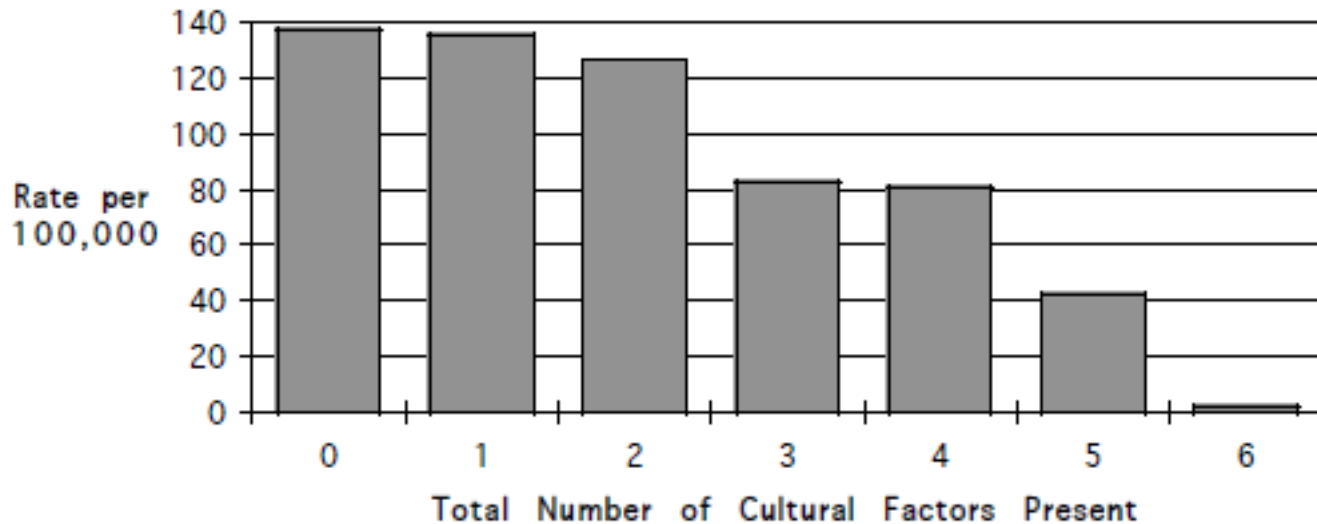
‘Greater participation in caring for country activities is associated with significantly better health’.

Source: Burgess et al, 2009.



What is known?

Canada: Cultural Continuity as a Hedge Against Suicide in Canada's First Nations (1998) Youth suicide by number of factors present in the community



Source: Chandler et al, 1998 pp 20



Proposed design

Mayi Kuwayu

- Prospective cohort study
- Repeated measures design
- Community indicator development (15 sites)
- Use of national database & community orgs for recruitment

Murray LLS

- Cross sectional study
- Community indicator development (2 sites)
- Use of existing community infrastructure for recruitment

Mayi Kuwayu aims

1. Develop appropriate cultural wellbeing indicators with Aboriginal and Torres Strait Islander people
2. Quantify prevalent cultural, health risk, health status and other factors, and their inter-relationships, among the study population
3. Quantify changes in cultural factors and health and wellbeing outcomes over time
4. Investigate prospectively the relationship of cultural and health risk factors to health and wellbeing outcomes, and any mediating role of culture in risk factor-outcome relationships
5. Create a collaborative resource for Aboriginal and Torres Strait Islander health research/action

Mayi Kuwayu 'determinants of the determinants' approach

- **Relationships with country/spirituality/rituals:** (Assembly of First Nations, 2002; Burgess, Berry, Gunthorpe, & Bailie, 2008; Ganesharajah, 2009; Knibb-Lamouche, 2012; Prout, 2011)
- **Identity and identity representation/racism:** (Chandler, 2003; Cunningham & Paradies, 2012; Fforde, Bamblett, Lovett, Gorringer, & Fogarty, 2013; Hallett, 2007; Henry, 2004; Paradies, Harris, & Anderson, 2008; Reading, 2009; Zubrick et al., 2014)
- **Heritage language:** (Chandler, 2003; Hallett, 2007; Reading, 2009)
- **Agency/self-determination/empowerment/fate control:** (Arctic Social Indicators (ASI) Working Group, 2010; Hallett, 2007; Knibb-Lamouche, 2012; Reading, 2009; Taylor, 2012)
- **Cultural continuity:** (Assembly of First Nations, 2002; Chandler, 2003; Knibb-Lamouche, 2012; Reading, 2009)



Questionnaire domains & testing



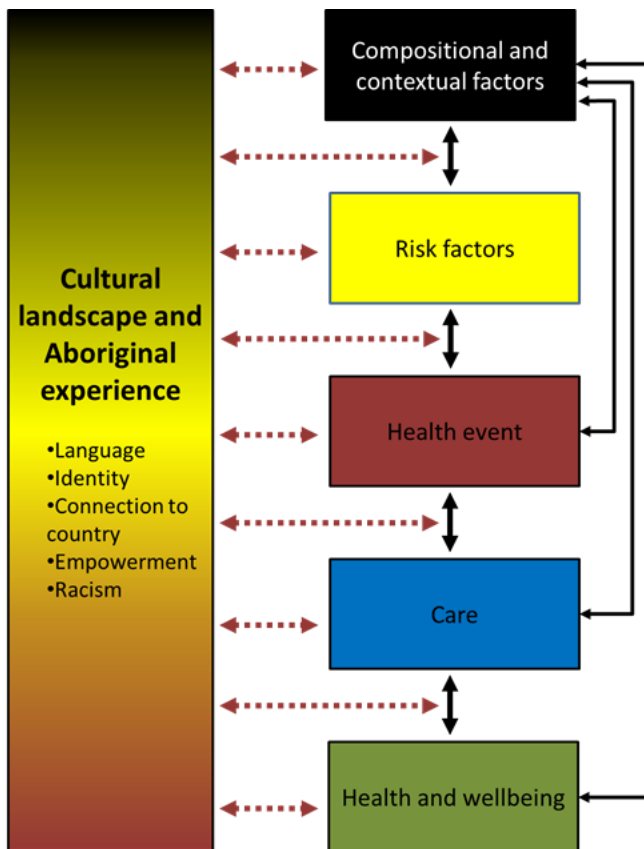
Pilot study

- Questionnaire acceptability and validity (core survey)
- Consent for linkage

Recruitment methods

- Community organisation recruitment
- Medicare
- Paper, online electronic

Conceptual model



Adapted from framework by Daniel, Lekkas, Cargo, Stankov, & Brown in 'Environmental risk conditions and pathways to cardiometabolic diseases in Indigenous populations'.

The cultural landscape and Aboriginal experience are likely to directly influence compositional and contextual factors (such as education and housing), risk factors, health events, care, and/or health and wellbeing.

- Do people who have retained or revived traditional language have improved education outcomes?
- Does strong connection to country mean lower rates of smoking?
- Do those with strong family ties experience a lower burden of mental health problems after experiencing stressful life events?
- Or do these factors mediate the relationships between the layers?

Sampling

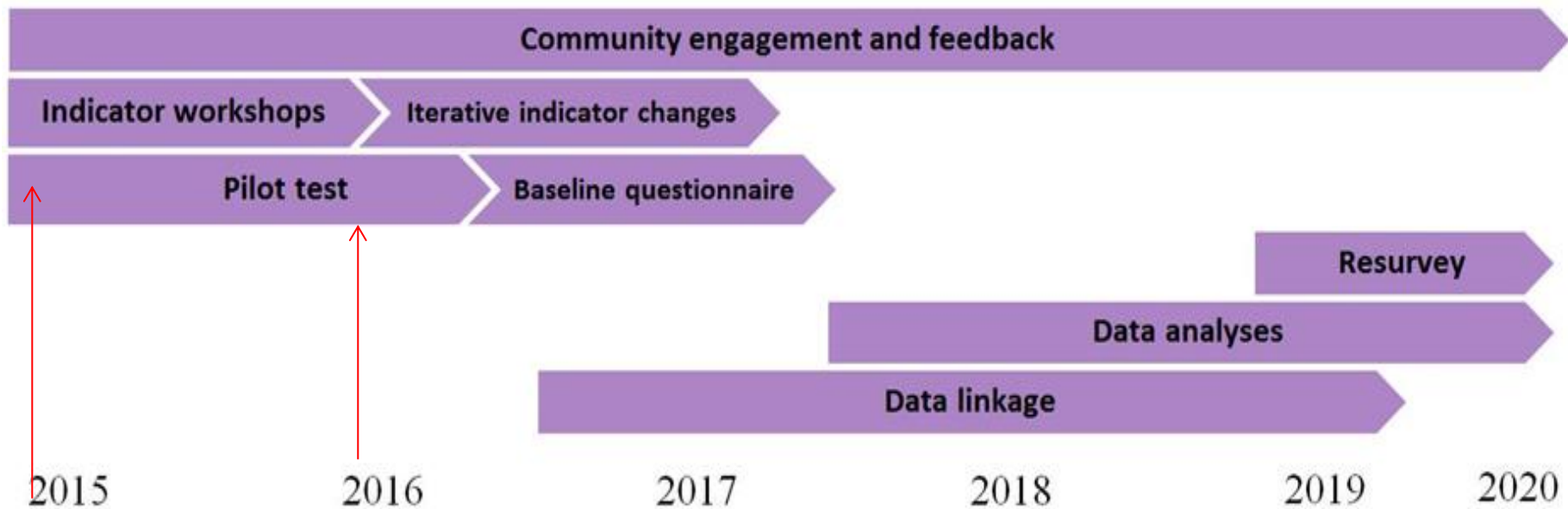
Mayi Kuwayu

- Sampling frame (registered with the Medicare≈360,000 or 60% of the population)
- Oversampling for areas with anticipated lower response rates (remote areas)
- Medicare Australia post study materials on behalf of the investigator team to (200,000 people)
- Complete survey in hard copy, online and phone
- Provide consent for data linkage and follow up
- Anticipated response: 24,000-36,000

Murray LLS

- Community org mailing lists
- Community org based recruitment
- Complete Survey Tablet, online, phone, paper
- Anticipated response:≈300
- Assumptions re mode of recruitment

Timeline (Mayi Kuwayu)



Data items

Variable	Measure
Participant report of family/community environment at baseline and follow up	
Demographics ²⁸	Age; sex; income; education; employment; financial benefits
Family and relationships ²⁸	Number of children; family/household structure; social capital.
Cultural factors	Identity; cultural knowledge and practice, cultural knowledge exchange; caring for country; community involvement and cohesion; racism; ^{31, 34} heritage language.
Housing	Environmental/housing conditions; ^{28, 43} homelessness.
Participant report of health issues and risk/protective behaviours at baseline and follow up	
Overall health of person and Health conditions ^{28, 41, 43-45}	Self-rated health; disability; health conditions, other long term conditions; medications; operations; screening.
Mental health and Wellbeing ²⁸	Diagnosed mental health conditions, age of diagnosed mental health condition ⁴⁰ ; Kessler-5; Personal Wellbeing Index; quality of life.
Tobacco, alcohol ⁴⁶	Lifetime and current smoking behaviour; alcohol consumption
Cardiometabolic factors ^{28, 44}	Height; weight; physical activity; sedentary behaviours; fruit/veg intake
Life events, resilience	Occurrence of stressors ¹ ; resilience scale ¹⁸ ; life events; violence, incarceration
Health outcomes and exposures ascertained through data linkage	
Health services use	MBS consultations; hospitalisations; emergency department attendance
Health outcomes	Wide range, including: mortality, hospitalisation, cancer, emergency department presentations, medications for specific health problems

Progress to date

Mayi Kuwayu

- Literature review
- Grants (NHMRC, Lowitja Institute)
- Proposed Study Governance group (AIATSIS, NACCHO, Lowitja Institute, ANU)
- Community and Technical Panels
- Planning for 15 site workshops
- Development of statistical capacity building component
- Ethics (community workshops)

Murray LLS

- Initial site meetings (Albury/Wodonga & Deniliquin)
- Swan Hill, Robinvale & Mildura (28-31 October 2014)
- Questionnaire workshops (January 2015 in Albury/Wodonga and Deniliquin)
- Local org to partner in workshop organisation/facilitation
- Ethics: survey early 2016

Understanding wellbeing – what is proposed for the survey?

Understand the role of community – people and place

- **Geographic community**
 - Is it a great place? A place people feel part of? A safe place?
- **Aboriginal & Torres Strait Islander community**
 - Sense of belonging, cohesion, being welcomed, being recognised as part of the community by other Aboriginal and Torres Strait Islanders

What are your views about the community you live in?	Strongly DISAGREE				Strongly AGREE			Don't know
	①	②	③	④	⑤	⑥	⑦	
My community is a great place to live	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This community has a bright future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel proud to live in this community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There's good community spirit around here	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I like the environment and surrounds I live in	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
This is a safe place to live	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a high crime rate in this community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Many people in this community drink too much alcohol or misuse drugs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Understanding wellbeing – what is proposed for the survey?

Culture and identity

- ‘Core’ culture and identity
 - Identifying with mob, country, relationship to country, following mother or father’s country, totems/dreaming, men and women’s business

Do you have special things you do for making young men and women? (initiation)	<input type="radio"/> Unsure <input type="radio"/> Prefer not to answer <input type="radio"/> Yes <input type="radio"/> No
Has this happened to you?	<input type="radio"/> Prefer not to answer <input type="radio"/> Yes <input type="radio"/> No

Understanding wellbeing – what is proposed for the survey?

Cultural knowledge and practice

- What cultural knowledge and practices do people engage in (food, medicine, law, special places, ceremony, art, music and more)
- Challenge – what is cultural knowledge?

The next questions are about your cultural knowledge and practice. Answer based on how you feel, rather than comparing yourself to previous generations or others. To be practicing culture, you don't have to use traditional methods – culture changes over time, and it's still cultural practice if you use modern technology.



Understanding wellbeing – what is proposed for the survey?

Caring for country

- Overall importance of caring for country compared to other things in the community
- Living on, visiting and having responsibilities for mother's/father's/other country
- How healthy is country at the moment? (water, soil, animals, plants, climate...)
- Types of on-country activity engaged in
 - How does engaging on country make people feel?
 - Does it enable social interaction (good or bad), exercise, improved health (people-country), cultural learning & practice, income earning...
- Barriers to getting engaged in on-country activity
 - Physical (transport, health), social (being welcome), confidence in skills/knowledge, legal (permission/permits)



Understanding wellbeing – what is proposed for the survey?

Caring for country into the future

Would you like to be involved in caring for country in any of the ways listed below in the future?		Yes, on country I currently live on	Yes, on other important country	No	Unsure
Environment	Improving river health, protecting river banks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Getting rid of weeds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Caring for native vegetation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Reducing erosion	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Protecting native animals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Controlling feral animals (e.g. foxes, cats, pigs, rabbits)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Protecting wetlands	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recognising history	Identifying massacre sites and protecting them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Identifying, protecting sites where people were removed from country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Protecting Aboriginal artefacts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Culture	Protecting cultural sites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Passing on culture to others in community e.g. songlines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Ceremony (e.g. smoking ceremony, dancing, music)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Arts and traditional skills	Gathering fibres, weaving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Canoe building	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Tool making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Food and medicine	Collecting seeds, storing seeds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Learn about, use bush medicines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Learn about, collect, eat traditional foods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Earn income from country	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Selling goods produced from country e.g. crafts, foods	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Understanding wellbeing – what is proposed for the survey?

Health & wellbeing

- Using several commonly used measures to enable comparisons
- K5, general health, life satisfaction, self-efficacy
- Alcohol, smoking, diagnosed health issues

Understanding wellbeing – what is proposed for the survey?

Language

- Use of Aboriginal/Torres Strait Islander language
 - Own
 - Family
 - Community
- Confidence and feeling associated with use of language

Understanding wellbeing – what is proposed for the survey?

Racism

- Yin Parities – Mire questions
- Frequency of experience
- Response
- Internalising/ values

Please indicate how much you disagree or agree with each of the following statements. There are no right or wrong answers.	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I feel accepted by other Indigenous people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Indigenous people have less opportunities than other Australians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Indigenous people should try to think and act more like other Australians	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel good about being an Indigenous person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Australians think that Indigenous people are better off because they get special treatment from the government	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other Australians think they are better than Indigenous people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is hardly ever anything good about Indigenous people in the media (TV, radio, newspapers, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I often witness racism	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Understanding wellbeing – what is proposed for the survey?

Involvement in & leadership of local community

- Aboriginal and Torres Strait Islander community
- Non-Aboriginal and Torres Strait Islander community
- Leadership & collaboration in community

	Strongly DISAGREE		
	①	②	③
There are people I can go to in my community if there is a problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Local Aboriginal groups and organisations around here are good at getting things done	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The local Aboriginal community copes pretty well when faced with challenges	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are places in this community where it is easy for Aboriginal people to come together and meet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The people who make decisions for the local Aboriginal community represent the whole community, not just part of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can get involved in local Aboriginal community discussions if I want to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community leaders around here are able to get everyone working together	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I trust the people who act as leaders in my local Aboriginal community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am listened to by others in the community if I want to speak up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are respected Elders with cultural knowledge I can go to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Understanding wellbeing – what is proposed for the survey?

Family and carers

- Family connection, relationships and coping
- Type of carers experienced growing up

Understanding wellbeing – what is proposed for the survey?

Family member removals and the Stolen Generation

- Experience of removals and Stolen Generation
- Self and others in family



Understanding wellbeing – what is proposed for the survey?

Sociodemographics

- Gender, age
- LGBTI
- Geographic location
- Marital status
- Household composition
- Employment, studying, caring responsibilities
- Educational attainment
- Income and self-rated financial prosperity

Challenges/expectations

- Distance
- Multiple ethics approval processes/stages
- Community navigation/Community priorities
- Ownership/custodianship of data and results
- Timeframes for consultation

Potential outcomes

- Prevalence
- Reliable data on:
 - Cultural determinants
 - Culturally valid measures of wellbeing
 - Associations: culture and wellbeing
 - Caring for country priorities
- Correlation between policy/program implementation and outcomes
- Empowered communities
- Information we currently don't have





Questions?

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