Marrathalpu mayingku ngiya kiyi. Minyawaa ngiyani yata punmalaka; wangaaypu kirrampili kara [Ngiyampaa title]

In the beginning it was our people's law. What makes us well; to never be sick. Cohort profile of Mayi Kuwayu: the National Study of Aboriginal and Torres Strait Islander Wellbeing [English title]

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Abstract: *Culture is gaining increased research and policy attention as a determinant of wellbeing, following advocacy by Aboriginal and Torres Strait Islander peoples and communities. To date, the development of conceptual models and measurement tools concerning culture and wellbeing has been insufficient. Recent developments in measuring racism and trauma specific to the Aboriginal and Torres Strait Islander population highlight an interplay between culture and health. The Mayi Kuwayu Study aims to improve the understanding of the role cultural factors play in wellbeing and their interaction with standard health risk and protective factors. The study currently includes data on 9691 Aboriginal and Torres Strait Islander people, with broad representation from across Australia, and represents a nationally significant Aboriginal and Torres Strait Islander-led and owned data resource. This is the first time that novel cultural indicators, developed through extensive consultative processes, can be included in the story of what contributes to health and wellbeing in the population. Over time, the study aims to provide insights into how culture contributes to wellbeing and how oppression impedes health and wellbeing. These insights will be useful to inform health and wellbeing policy for individuals, communities and nations, in addition to governments.*

Aboriginal and Torres Strait Islander peoples maintain the oldest continuing cultures worldwide (Clarkson et al. 2017; Rasmussen et al. 2011), with estimates of cultural development and evolution occurring for at least the past 65,000 years (Clarkson et al. 2017). Across the continent there are hundreds of unique Aboriginal and Torres Strait Islander groups (sometimes referred to as mobs or nations) that have their own languages, cultures, traditions and defined land areas.

Colonisation by the British in 1788, as well as ongoing marginalisation, racism and inequity, has had devastating health and wellbeing impacts on Aboriginal and Torres Strait Islander peoples and continues today (AIHW 2016; Axelsson et al. 2016; Paradies 2016). 'Health inequities' refers to the unequal distribution of health resources and inaccessibility of health services that lead to poorer health outcomes for Aboriginal and Torres Strait Islander people compared to their non-Indigenous counterparts (Griffiths et al. 2016). This health inequity manifests in the higher mortality rates and lower life expectancy of the Aboriginal and Torres Strait Islander population compared to other Australians (Agostino et al. 2020; Bnads et al. 2020; Phillips et al. 2014, 2017; PM&C 2020; Prehn and Ezzy 2020; Sherwood 2013).

The discourse on improving the health and wellbeing of the Aboriginal and Torres Strait Islander population has historically centred on improving the social determinants of health, such as education, employment and socio-economic position (Marmot et al. 2008; WHO CSDH 2008). It is estimated that one-third to half of the inequity in general health and life expectancy is explained by the social determinants, meaning that between half and two-thirds of the inequity currently remains unexplained (AIHW 2014; Booth and Carroll 2005; Zhao et al. 2013). To reach equal life chances (as the stated national 'Closing the Gap' policy goal; PM&C 2020), we need to understand how other forces contribute to this inequity and how to modify these factors so that life chances are equitable.

Social determinants are embedded in culture/s. However, cultural elements have been poorly acknowledged in the approaches to the Social Determinants of Health (SDoH). This is because the SDoH were developed to address global health inequalities (Commission on Social Determinants of Health 2008), and therefore had limited engagement with Aboriginal and Torres Strait Islander peoples, cultures or knowledges. This is a major limiting factor in the application of the SDoH to Aboriginal and Torres Strait Islander peoples. Culture's importance as a determinant of health lies in the way that ideas, discourses and ways of acting become embodied (Banwell et al. 2013). If culture/s have been suppressed, controlled or are made subservient to another culture, such oppression could be embodied as spiritual, psychological and physical harm (Sherwood 2013). Given the known systematic suppression of Aboriginal and Torres Strait Islander cultures in Australia, the impact of this suppression needs to be examined to further elucidate its contribution to poor health outcomes.

Furthermore, as learned systems of meaning, Aboriginal and Torres Strait Islander cultures have largely been viewed as negatively influencing health. A growing body of work elucidates the ways in which Aboriginal and Torres Strait Islander identities are represented in a narrative of negativity, deficiency and failure throughout health policies and practices (Fforde et al. 2013).

The current state of Aboriginal and Torres Strait Islander data obstructs our voices, goals and ownership of data. It consists of data *about* Aboriginal and Torres Strait Islander peoples, with limited data *for* Aboriginal and Torres Strait Islander peoples (Walter 2018). This data failure is defined by Palawa scholar Maggie Walter (2018) as BADDR: data that is Blaming, Aggregate, Decontextualized, Deficit and Restricted. Internationally and domestically, however, increasing evidence shows that connection to culture, as manifested in maintenance or reclamation of culture, is associated with a variety of positive health and wellbeing outcomes for Indigenous peoples (Bourke et al. 2018; Shepherd et al. 2018). It is the case that some traditions can protect against health risks — these salutogenic (health promoting) factors, which may include cultural participation and expression, need to be understood to identify ways to improve health and wellbeing (Antonovsky 1979).

The Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing (Mayi Kuwayu Study) will provide a holistic quantitative understanding of forces driving Aboriginal and Torres Strait Islander wellbeing through a large-scale, national, comprehensive survey capturing concepts important to Aboriginal and Torres Strait Islander peoples, as determined by them.

Conceptual relationships

Bronfenbrenner's Bioecological Model of Human Development (Bronfenbrenner and Morris 2006), in conjunction with the Environmental Model, which acknowledges how the properties and composition of one's environment affects health outcomes (Daniel et al. 2011), has been adapted to form a conceptual model for the Mayi Kuwayu Study. The Mayi Kuwayu Study conceptual model adapts these two models, while also drawing on limited work from Australia (Eades et al. 2008; Zubrick et al. 2004) and advice from participating communities.

The Mayi Kuwayu conceptual model acknowledges the importance of the social determinants but goes further and asks how Aboriginal and Torres Strait Islander cultures and cultural domains interact directly and indirectly across health and wellbeing (Figure 1). This conceptual model is used to inform analyses relating to outcomes of interest, in keeping with the emerging recognition of the importance of conceptual models in statistical analyses relating to life-course epidemiology (De Stavola et al. 2006).

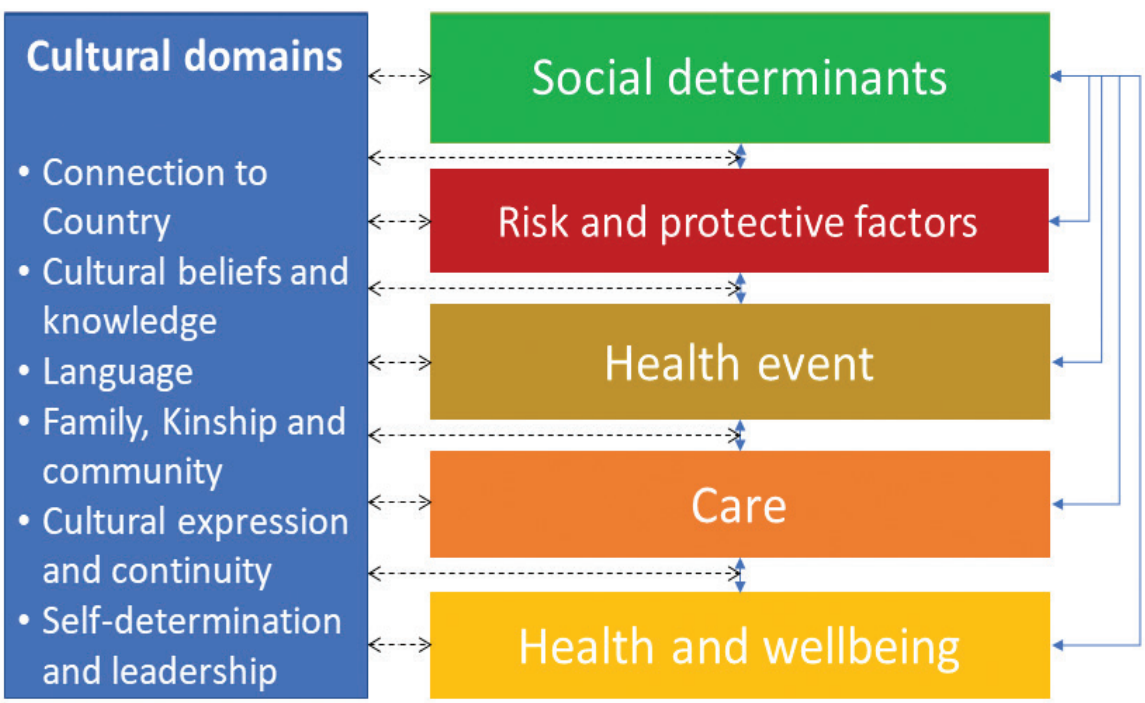

Figure 1: Mayi Kuwayu Study conceptual model

The Mayi Kuwayu Study includes a focus on the cultural domains and is designed to enable quantification of their relation to social determinants, risk/protective factors, health events, health care, and health and wellbeing. For example, for a given level of financial status or education, people with strong connection to Country may be less likely to smoke than people with a lower level of connection to Country. People with stronger family ties, compared to those with weaker family ties, may have better social and emotional wellbeing after experiencing stressful life events or racism. Assessing the contribution of culture can therefore present opportunities for prevention (Sawyer et al. 2012). Hence, existing knowledge underpins the need for research that identifies how Aboriginal and Torres Strait Islander cultures impact health and wellbeing.

Initial development process

Mayi Kuwayu in Ngiyampaa (Wangaaypuwan/Wongaibon) language means 'to follow people over time'. The initial stages of the Mayi Kuwayu Study conceptualisation and development occurred in early 2014 at the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS). The idea was for a national, large-scale quantitative survey to understand the relationship between culture and health and wellbeing outcomes. The idea was born in response to key policy, community and research agendas. In particular, culture and the contribution of culture to wellbeing were becoming more prominent in the research agenda of peak community organisations (Lowitja Institute 2014) and in national policy documents (Commonwealth of Australia 2013).

Items for the Mayi Kuwayu Study questionnaire, including indicators of Aboriginal and Torres Strait Islander cultures, were developed through reviewing the literature and through community consultations with 165 Aboriginal and Torres Strait Islander people who attended 24 focus groups across Australia from 2014 to 2017 (Salmon et al. 2019). Participants in this process were aged 16 years to 70-plus years and represent diverse contexts and lived experiences. Early versions of the Mayi Kuwayu baseline questionnaire were pilot tested in two 'proof-of-concept' studies with 160 and 209 Aboriginal and Torres Strait Islander participants respectively, to:

- establish a cultural item set
- assess face validity of all questionnaire items
- conduct preliminary analysis concerning the relationships between cultural items and wellbeing outcomes (convergent validity) (Jones et al. 2018b).

The final set of questionnaire items was reviewed by a panel of experts who ranked the priority of each item for inclusion in the final baseline questionnaire.

The final Mayi Kuwayu Study questionnaire used for baseline data collection includes a combination of:

- established instruments, where existing instruments had evidence of reliability and validity with the Aboriginal and Torres Strait Islander population; for example, self-assessed general health (Sibthorpe et al. 2001)
- modified instruments, where instruments existed but had limited reliability and validity established with the Aboriginal and Torres Strait Islander population; for example, the K5 measure (McNamara et al. 2014)
- new instruments developed through an iterative community consultation process identified above; for example, the cultural wellbeing items.

At the time of publication, no psychometric assessment has occurred for new instruments in the Aboriginal and Torres Strait Islander population; however, validation work is underway.

Cultural domains

Through the development process, six key cultural domains were identified (Salmon et al. 2019), and items and instruments were developed and included in the baseline questionnaire.

Connection to Country: the central factor in the Aboriginal and Torres Strait Islander physical, human and sacred world is connection to and relationship with Country (Sangha et al. 2015). The current available evidence, while limited,

indicates that stronger connection to Country and participation in on-Country activities is associated with improved mental health and wellbeing (Dockery 2011) and reduced cardiovascular disease risk (Burgess et al. 2008; Chandler et al. 2003). Expanding on this work, the Mayi Kuwayu Study will further explore the relationship between connection to Country and other health outcomes.

Cultural beliefs and knowledge: each Aboriginal and Torres Strait Islander mob has its own cultural traditions, ceremonies and Dreaming. Strong connection to Aboriginal or Torres Strait Islander beliefs, cultural practices and spirituality are linked to improved family wellbeing and cohesiveness (Lohoar et al. 2014). This study will provide clearer associations between culture and health.

Language: international evidence has shown that Indigenous language is an important protective factor for mental health and suicide prevention (Chandler and Lalonde 1998). The second National Indigenous Languages Survey, although not nationally representative, indicated that nearly all Aboriginal and Torres Strait Islander languages are in decline and that language use is associated with improved levels of health and wellbeing (Marmion et al. 2014). However, the full picture of language use/impacts on health and wellbeing is not known and this study will contribute further evidence on the role of Aboriginal and Torres Strait Islander languages in health.

Family, kinship and community: the bonds in Aboriginal and Torres Strait Islander communities and with the broader Australian community may influence health behaviours, although this is a relatively new research area (Reilly et al. 2008). Our previous research has identified that cultural participation significantly increased family wellbeing outcomes (Jones et al. 2018b). Additionally (and due to disruption by colonisation and exposure to racism), social cohesion, including family/kin function, may be significantly impacted through psychological distress levels reported at rates three times higher than in the general population (ABS 2014). The bi-directional associations between culture and health are central to this study, and the ways in which perpetual poor health and wellbeing impact on culture will be explored.

Cultural expression and continuity: evidence suggests that people who identify as belonging to an Aboriginal and/or Torres Strait Islander group and who have a positive Aboriginal and/or Torres Strait Islander identity, compared to those who do not, are less likely to experience mental health conditions; they also have lower suicide rates and fare better on general socio-economic indicators (Dockery 2011). Individualised concepts such as 'mental health' require expansion to include concepts appropriate to family and community, commonly referred to as social and emotional wellbeing (Dudgeon and Calma 2013). Focusing on culture, rather than the individual, this study will build on work examining the relationship between social and emotional wellbeing and culture.

Self-determination and leadership: Aboriginal and Torres Strait Islander peoples have the right to participate in decision making on issues that affect them (UN Assembly 2007). Often this will be through Aboriginal and Torres Strait Islander collectives (organisations) and political structures. However, there has been a long legacy of government interference in Aboriginal and Torres Strait Islander self-determination mechanisms in Australia (Anderson 2007). The broader social determinants literature shows links between higher levels of individual control and improved wellbeing (Marmot and Wilkinson 2005), and the study will contribute to this international body of work through exploration of community self-determination and health.

Drawing on the above domains, the baseline questionnaire includes measures necessary to provide a comprehensive quantitative understanding of Aboriginal and Torres Strait Islander health and wellbeing. Repeat survey of the population using follow-up questionnaires will enable understanding of changes in wellbeing over time. This includes individual questions (items) and instruments (grouped items) to capture key health and wellbeing domains and themes. Table 1 outlines the domains, items and instruments included in the baseline questionnaire for the Mayi Kuwayu Study. A licence is required to use cultural items and instruments developed during the study.[1]

Table 1: Overview of key Mayi Kuwayu Study questionnaire domains, items and instruments

Question domains	Key items and instruments*
Demographic factors	Age; gender; housing; education; employment; family financial situation; household composition
Cultural practice and expression	Country and connection to Country; cultural beliefs and knowledge*; cultural expression; self-determination and leadership; language*; family; kinship and community*; identity
Wellbeing, health conditions, medications health behaviours, health service use	Life satisfaction*; general health*; health conditions; medication use; psychological distress*; happiness; pain; functional limitations*; physical activity; alcohol use; tobacco use; health service use
Experiences and environments	Services in the community; everyday experiences of discrimination and racism*; community safety; environmental conditions; life events*
Family support and connection	Family cohesion and connectedness*; caring for others; Stolen Generations

*Indicates instrument.

Study governance, data sovereignty and funding

Strong community partnerships and community-controlled research are essential when investigating the health and wellbeing of Aboriginal and Torres Strait Islander communities. This is particularly important given the links between colonisation, exploitation and research in the absence of community control or consultation (Humphrey 2001). Aboriginal and Torres Strait Islander peoples and communities participating in research are protected by ethical guidelines (AIATSIS 2011; NHMRC 2003); a fundamental requirement is the involvement of Aboriginal and Torres Strait Islander peoples throughout all stages of the research process (Humphrey 2001).

The Mayi Kuwayu Study is hosted by the Aboriginal and Torres Strait Islander Health Program within the National Centre for Epidemiology and Population Health, Research School of Population Health, at the Australian National University. The study is governed by the investigator team, which includes key national and jurisdictional partners representing peak Aboriginal and Torres Strait Islander organisations:

- Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS)
- Aboriginal Health Council of South Australia
- Aboriginal Health Council of Western Australia
- Aboriginal Medical Services Alliance Northern Territory
- National Aboriginal Community Controlled Health Organisation (NACCHO)
- Tasmanian Aboriginal Centre
- Victorian Aboriginal Community Controlled Health Organisation
- Winnunga Nimmityjah Aboriginal Health and Community Services
- The Healing Foundation.

The study is conducted with ethics approval from the Australian National University, the Aboriginal Health and Medical Research Council, and AIATSIS. Additional ethics approvals at the state and territory level were also obtained.[2]

The Mayi Kuwayu Study team undertook a data governance development process in 2019 with the aim of making the data available for use subject to Indigenous data sovereignty principles (Maiam nayri Wingara 2017). The Mayi Kuwayu Data Governance Committee (MKDGC), an external panel of Aboriginal and Torres Strait Islander people, independently assesses applications for data use. Applicants must demonstrate the application of Indigenous data sovereignty principles in their proposals. All research must have appropriate ethical approval and community engagement, and conform to AIATSIS and other relevant legal and ethical research standards.

The Mayi Kuwayu Study has been supported by the Lowitja Institute (grant 1377) in development,

and the National Health and Medical Research Council (1088366, 1176261, 1122273) to conduct the cohort study baseline survey and first follow-up survey, and for the lead investigators' fellowships. In addition, Gandel Philanthropy supports additional recruitment of participants in Victoria and Tasmania, while The Ian Potter Foundation supports knowledge exchange and communication through a five-year grant.

Study aims

The Mayi Kuwayu Study aims are outlined in Jones et al. (2018a:2). We briefly describe them below.

Aim 1: to undertake comprehensive item development and psychometric assessment of items following the Mayi Kuwayu Study development process. This will ensure that the items and measures developed by Aboriginal and Torres Strait Islander peoples are robust and are assessed for their applicability for Aboriginal and Torres Strait Islander mobs. It will ensure that measures empower self-determination and are strengths-based, protective and respectful of Aboriginal and Torres Strait Islander peoples, in line with Indigenous data sovereignty principles (Maiam nayri Wingara 2017).

Aim 2: to quantify cultural, health risk, health status and other factors, and their inter-relationships, among the study population. Analyses will be guided by the study's conceptual model, community input and policy agenda. Prevalence of key exposures and outcomes, and their relationships, in an order determined by community and policy priorities will be quantified. Analysis of cross-sectional data from baseline will start with the established priorities of cultural connection, trauma and racism. Further priorities for analysis will be developed iteratively with study investigators and partners.

Aim 3: to quantify changes in cultural factors and health and wellbeing outcomes over time. Changes over time in individuals will be assessed using data from follow-up questionnaires (every two to three years) and data obtained through linkage to administrative data collections.

Aim 4: to create a collaborative resource for Aboriginal and Torres Strait Islander health research and action. The data from the study are being made accessible collaboratively for Aboriginal and Torres Strait Islander health research.

Participant recruitment and questionnaires

Any Aboriginal and/or Torres Strait Islander person aged 16 years and older is eligible to participate in the Mayi Kuwayu Study. The baseline questionnaire can be completed in paper form or online. The study uses multi-mode recruitment, which includes a national postal mail-out of paper questionnaires, in-community recruitment through community partner organisations and an online platform where the questionnaire can be completed any time. The questionnaire is conducted either independently or with the help of a community researcher where language or other barriers to participation exist. All Mayi Kuwayu Study participants provide free and informed consent before participating. No items in the questionnaire are compulsory and a participant is able to withdraw from the study at any time. The details of the postal survey strategy have been published previously (Jones et al. 2018a; Wright et al. 2020). Here we provide a brief summary of the process.

Paper questionnaires were mailed out nationally using a two-stage process (Wright et al. 2020). First, a preliminary distribution of 20,000 questionnaires to Aboriginal and Torres Strait Islander people in the Medicare Australia Enrolment Database was conducted, stratified by age, gender and remoteness. The Department of Human Services, now Services Australia, mailed questionnaires to individuals, randomly selected from the total pool of eligible persons in each age – sex – remoteness stratum. The survey pack included a prepaid return envelope, an eight-page questionnaire and an information sheet. An additional distribution of 180,000 questionnaires (total N=200,000) was sent to the age – sex – remoteness stratum with the highest response rate in the preliminary mail out, in order to maximise total response (see Wright et al. 2020 for details).

To supplement the mail-out, community-based recruitment has occurred through communities and local organisations self-nominating to be involved. The Mayi Kuwayu Study team engages local community organisations (and conducts training in survey administration), which then

run local recruitment. There are also web-based and social media engagements with options for Aboriginal and Torres Strait Islander peoples to complete the questionnaire online.

The study employs a rolling recruitment strategy, with enrolment available to new participants at any time. Follow-up questionnaires are conducted every two to three years or as funding allows.

Participants are asked to consent to linkage of their baseline questionnaire data to health and health-related records. Linkage includes morbidity (hospital and registry data) and mortality data on a state-by-state basis.

Retention and re-contact strategies are based on best practice for cohort maintenance and prior research experience with Aboriginal and Torres Strait Islander peoples. Participants who opt in to communication will receive newsletters and additional electronic contact, including on social media. We can also contact participants through a secondary nominated contact provided at baseline should this be needed for re-survey. Appropriate social and Aboriginal and Torres Strait Islander media will be used to inform participants of study progress and key outcomes.

Who has taken part so far?

As of May 2020 (Data Release 2.0[3]), the Mayi Kuwayu Study cohort consists of 9691 Aboriginal and Torres Strait Islander people. This sizeable sample makes the Mayi Kuwayu Study the largest contemporary cohort study on the health and wellbeing of Aboriginal and Torres Strait Islander peoples in Australia. Most participants (n = 9026 or 93.1%) completed the questionnaire in paper form. About 7% of participants completed the questionnaire online (n = 665).

Participants self-nominate to be followed-up on their baseline questionnaires. Eighty-three per cent (n = 8020) of participants have consented to follow-up. Consent for data linkage has been provided by 80.1% (n = 7765) of participants.

Across most survey items, the prevalence of missing data ranges from 1% to 15%. Items with the highest prevalence of missing data include mobility issues (11.5%), family financial status (10.5%), age (8.8%) and time spent on Country (8.8%).

Participant characteristics

Mayi Kuwayu Study participants represent a wide diversity of Aboriginal and Torres Strait Islander mobs — more than 150 mobs have been reported by participants to date. Figure 2 shows the 40 most commonly reported mobs. The larger size words indicate a higher representation of mobs. Figure 2 also captures some of the variations in spelling in mobs/groups.

Figure 2: Most common Aboriginal and Torres Strait Islander mobs reported by Mayi Kuwayu Study participants

Females comprise 59.5% of Mayi Kuwayu Study participants and 37.9% are males (Table 2). Most participants live in regional areas (47.2%). New South Wales accounted for the largest percentage of participants (35.8%), followed by Queensland (25.7%) and Western Australia (11.3%; see Figure 3). When the required geographic data are available, we intend to present distribution of participants by nation.

Participation in the Mayi Kuwayu Study broadly correlates with the percentage of Aboriginal and Torres Strait Islander people residing in each state and territory according to the 2018 Australian Bureau of Statistics estimation (ABS 2020). Compared to the total population, the Mayi Kuwayu Study baseline sample has an under-representation of people in younger

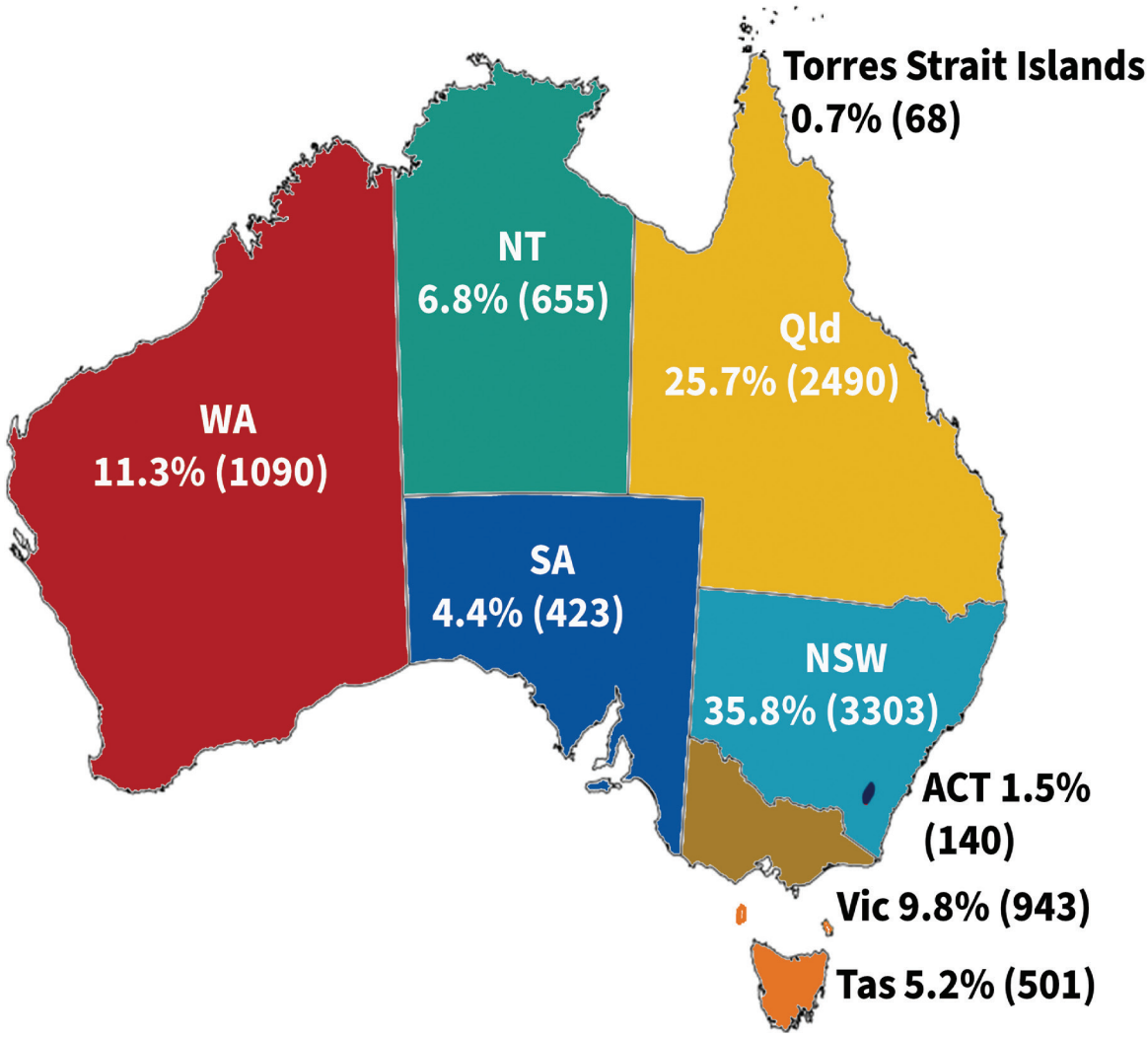

Figure 3: Mayi Kuwayu Study participants by jurisdiction May 2018 – May 2020 (Data Release 2.0)

age groups, males, those from the Northern Territory and South Australia, and those renting a home; and an over-representation of older people, females, those from Victoria and Tasmania, those from regional areas, those with higher levels of school and university education, and those who own their home. On average, household size was 3.5 people in the Mayi Kuwayu Study (Data Release 2.0) compared to 3.2 nationally (Table 2).

Data are presented by identification as Aboriginal, Torres Strait Islander, or both Aboriginal and Torres Strait Islander. As analysis progresses, data will be presented by further disaggregated forms, including by nation, in order to provide data that are meaningful and locally relevant.

Table 2: Characteristics of Mayi Kuwayu Study participants (2018–20) compared with the estimated Aboriginal and Torres Strait Islander population 2018[a] or Census 2016[b]

	Mayi Kuwayu Study sample (aged ≥16 years) (N = 9691)		Estimated national Aboriginal and Torres Strait Islander population aged ≥15 years, 2018[a, b] (N = 524,032)	
	n	%	n	%
State/territory				
ACT	140	1.5	5511	1.0
NSW	3,303	35.8	181,699	32.9
NT	655	6.8	54,790	9.9
Qld	2,558	26.6	150,156	27.2
SA	423	4.4	29,230	5.3
Tas.	501	5.2	19,792	3.6
Vic.	943	9.8	40,283	7.3
WA	1,090	11.3	70,762	12.8
Missing	78	0.8	–	–
Age group				
16–24	942	9.7	160,537	29.1
25–34	1,171	12.1	122,884	22.2
35–44	1,304	13.5	87,854	15.9
45–54	1,700	17.5	84,163	15.2
55–64	2,134	22.0	57,975	10.5
65–74	1,354	14.0	28,193	5.1
75+	278	2.9	10,826	2.0
Missing	808	8.8	–	–
Gender				
Male	3,677	37.9	272,913	49.4
Female	5,763	59.5	279,519	50.6
Unspecified	11	0.1	–	–
Missing	240	2.5	–	–
Remoteness level				
Major city	3,994	41.2	209,919	38.0
Inner & outer regional	4,580	47.2	237,001	42.9
Remote & very remote	959	9.9	105,512	19.1
Missing	158	1.6	–	–
Highest educational attainment				
No school	75	0.8	4,256	1.0
Primary school	351	3.6	–	–

	Mayi Kuwayu Study sample (aged ≥16 years) (N = 9691)		Estimated national Aboriginal and Torres Strait Islander population aged ≥15 years, 2018 [a, b] (N = 524,032)	
	n	%	n	%
Some high school	1,610	16.6	64,604	15.1
Year 10	2,308	23.8	77,265	18.0
Year 12	1,155	11.9	59,949	14.0
Certificate or diploma	2,377	24.5	96,184	22.4
University	1,618	16.7	24,911	5.8
Missing	197	2.0	56,698	13.2
Employment				
Full-time	2,618	27.0	106,960	48.0
Part-time	985	10.2	61,049	27.4
Unemployed	1,187	12.2	40,486	18.2
Family financial situation				
Has a lot of savings	579	6.0	–	–
Has some savings	3,494	36.1	–	–
Has just enough money until next payday	3,074	31.7	–	–
Runs out of money before payday	1,220	12.6	–	–
Spends more than they get	308	6.2	–	–
Missing/Unsure	1,016	10.5	–	–
Housing				
Owns home	4,216	43.5	100,130	38.1
Rents home	4,540	46.9	150,832	57.3
Visitor	416	4.5	–	–
Homeless	121	1.3	–	–
Missing	398	4.1	–	–
Average number of people per household				
	3.5	–	3.2	–

[a] Projected population aged 15 years and over, Aboriginal and Torres Strait Islander Australians 2018 (ABS 2020).
[b] Data from the 2016 Census is used where data from a more recent source is not available.

Selected cultural characteristics

Speaking any Aboriginal or Torres Strait Islander words or languages was reported by 35.5% of participants (Table 3). Six in ten (60.4%) participants reported not speaking any Aboriginal and/or Torres Strait Islander words or languages. Aboriginal or Torres Strait Islander language as a first language was reported by 6.2% of participants. Almost one-quarter of Torres Strait Islander participants (23.4%) reported speaking a Torres Strait language as their first language. Around one in ten participants reported that their families (9.5%) and communities (6.9%) wanted, but were unable to, keep their languages strong.

Overall, 35.9% of participants know their totem or Dreaming. Forty-six per cent of Torres Strait Islander people know their totem or

Dreaming, while 35.8% of Aboriginal people and 41.0% of people who are both Aboriginal and Torres Strait Islander reported knowing their totem or Dreaming. Almost one-third of participants (29.2%) reported spending a moderate to high amount of time on cultural practice.

Just under one-third of participants (29.6%) live on their mob's Country, consisting of 30.6% of Aboriginal people, 14.0% of Torres Strait Islander people and 25.3% of those who are both Aboriginal and Torres Strait Islander. Half of all participants (50.1%) spend some time on their mob's Country, with 25.9% reporting that they spend no time on their Country. The percentage reporting spending at least a little bit of time on their mobs' Country was 51.1% for Aboriginal people, 44.5% for Torres Strait Islander people and 47.6% for Aboriginal and Torres Strait Islander people. When asked whether they had cultural responsibilities for Country, 19.2% of participants reported cultural responsibilities for their mothers' Country and 14.2% reported cultural responsibilities for their fathers' Country. Just under half of participants (48.8%) reported no cultural responsibilities for Country.

Table 3: Selected cultural practice and expression attributes of Mayi Kuwayu Study participants by identity

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
Speaks any Aboriginal/Torres Strait Islander words or languages				
Yes (a little to a lot)	35.0	53.9	44.4	35.5
No	62.0	40.9	51.9	60.4
Missing	3.1	5.2	3.7	4.17
First language				
Aboriginal/Torres Strait Islander	5.7	23.4	7.2	6.2
English	90.3	69.8	87.8	88.6
Other	1.0	3.3	0.5	1.1
Missing	3.0	3.6	4.5	4.1
Family is keeping language strong				
Yes (a little to a lot)	41.9	53.3	48.4	42.9
No	19.2	13.3	16.2	18.7
Want to but can't	9.7	8.1	8.5	9.5
Missing	29.1	25.3	26.9	29.7
Community is keeping language strong				
Yes (a little to a lot)	41.8	52.6	45.5	41.9
No	15.3	12.0	14.6	15.0
Want to but can't	7.1	5.2	6.7	6.9
Missing	35.8	30.2	33.2	36.2
Knows totem or Dreaming				
Yes	35.8	46.1	41.0	35.9
Unsure	20.6	19.2	23.4	20.5
No	31.9	25.0	26.6	31.1

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
Don't have one	7.7	19.2	23.4	7.5
Missing	4.0	3.9	4.0	5.1
Cultural practice and knowledge exposure				
High	7.8	13.3	7.5	7.9
Moderate	21.3	25.7	26.6	21.3
Low	46.1	35.1	41.5	44.6
None	12.6	10.4	9.8	12.3
Missing	12.3	15.6	14.6	13.7
Lives on mob's Country				
Yes	30.6	14.0	25.3	29.6
No	59.9	78.6	63.3	59.8
Unsure	7.1	3.9	8.2	7.0
Missing	2.5	3.6	2.9	3.6
Amount of time spent on Country				
Wants to but can't	15.1	17.5	15.4	15.4
A little to a lot	51.1	44.5	47.6	50.1
None	26.2	26.3	25.3	25.9
Missing	7.3	11.7	11.7	8.7
Has cultural responsibilities for Country				
Mother's Country	19.2	24.4	21.5	19.2
Father's Country	14.0	21.4	15.2	14.2
Other Country	2.5	2.3	2.1	2.4
No	49.9	41.9	43.6	48.8
Unsure	19.6	17.5	24.2	19.4

*206 participants with missing data for Aboriginal and/or Torres Strait Islander identity are included in the total.

Selected health and wellbeing behaviours

The majority of participants (86.7%) reported being satisfied with their lives (a little bit, a fair bit or a lot), with 5.2% stating they were not at all satisfied (Table 4). Prevalence of life satisfaction was similar across identification. Only 8.3% of participants self-reported poor general health; conversely, 31.1% of participants reported very good to excellent general health. Just over one-quarter (26.8%) of participants indicated low levels of psychological distress, while 29.1% indicated moderate levels and 36.2% indicated high to very high levels of psychological distress. The prevalence of psychological distress was relatively consistent across Indigenous identification. The majority of participants reported limited concerns about their mobility. Half of all participants (50.5%) reported exercising five to seven days a week, with similar prevalence across Indigenous identification.

Table 4: Selected wellbeing and health behaviours of Mayi Kuwayu Study participants by identity

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
Life satisfaction				
A lot	30.4	30.8	28.5	30.3
A fair bit	39.4	40.3	39.1	39.4
A little bit	21.9	18.2	23.7	17.0
Not at all	5.1	5.5	6.4	5.2
Missing	3.2	5.2	2.4	3.3
General health status				
Very good/Excellent	31.3	31.2	28.2	31.1
Good	35.1	36.7	43.1	35.4
Fair	22.8	20.8	19.2	22.6
Poor	8.4	7.1	7.2	8.3
Missing	2.4	4.2	2.4	2.6
Psychological distress				
Low	27.0	22.4	23.9	26.8
Moderate	29.3	30.2	24.5	29.1
High/Very high	36.1	36.7	41.2	36.2
Missing	7.6	10.7	10.4	8.0
Mobility				
None/Not relevant	37.3	38.3	39.4	37.1
Low	38.0	34.1	36.4	37.7
Moderate	10.8	12.3	9.6	10.9
High	2.8	3.9	3.2	2.9
Missing	11.2	11.4	11.4	11.4
Physical activity per week				
5–7 days	50.2	51.6	54.0	50.5
3–4 days	16.3	15.6	14.4	16.1
1–2 days	11.7	11.7	13.0	11.8
0 days	21.8	21.1	18.6	21.6

*206 participants with missing data for Aboriginal and/or Torres Strait Islander identity are included in the total.

Selected health conditions, medications, health behaviours and health service utilisation

Participants averaged six visits to a general practitioner (GP) in the past six months (Table 5). Asthma and arthritis were two of the most commonly reported health conditions in the Mayi Kuwayu Study, at 22.7% and 21.4% respectively. The most common medications taken by participants were blood pressure medication (27.9%), pain medication (21.7%) and cholesterol medication (21.7%). Three-quarters of all participants were not current smokers, and one-third of participants did not drink alcohol. The majority of participants (70.1%) reported that their usual non-urgent health care provider was a GP. The second most commonly reported non-urgent health care provider was an Aboriginal Medical Service (AMS) (33.0%). Participants indicated a desire to receive non-urgent health care from an AMS and a traditional healer more often than they currently do.

Table 5: Health conditions, medications, health behaviours and health service utilisation of Mayi Kuwayu Study participants by identity

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
Health conditions				
Heart disease	11.1	9.1	11.4	11.1
Diabetes	17.3	20.8	13.0	17.3
Asthma	22.9	17.9	23.1	22.7
Arthritis	21.6	17.2	20.2	21.4
Hearing loss	12.7	7.1	8.5	12.4
Number of GP visits in last six months (average)	n = 6.2	n = 5.6	n = 5.5	n = 6.2
Most common medications				
Blood pressure	28.1	22.1	24.5	27.9
Pain	22.0	17.2	20.5	21.7
Cholesterol	21.9	18.2	20.0	21.7
Alcohol use				
Never a drinker	18.4	14.9	15.7	18.2
Past drinker	20.7	24.7	18.1	20.9
Current drinker	58.0	55.5	63.8	57.8
Missing	2.9	4.9	2.4	3.1
Tobacco use				
Never a smoker	39.8	36.0	39.4	39.4
Past smoker	32.0	36.4	33.2	32.1
Current smoker	25.8	23.1	25.3	25.8
Missing	2.5	4.6	2.1	2.7
Usual non-urgent health care provider^				
AMS	32.6	33.8	41.0	33.0

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
GP clinic	70.7	63.6	62.5	70.1
Hospital	10.1	16.2	12.5	10.4
Traditional healer	2.3	1.0	1.9	2.3
Preferred non-urgent health care provider^				
AMS	48.7	46.4	50.8	48.7
GP clinic	56.1	51.3	50.3	55.7
Hospital	10.6	17.2	12.0	10.9
Traditional healer	9.3	7.5	8.0	9.2

*206 participants with missing data for Aboriginal and/or Torres Strait Islander identity are included in the total.
^Participants could select multiple options so percentages total greater than 100.

Experiences and environments

Seventy-eight per cent of participants reported a fair bit to a lot of control over their lives (Table 6). At the community level, however, there was less of a sense that the local mob had a say in decisions (40.4% reporting a fair bit or a lot, and 24.6% being unsure). When asked if government has the final say in local community decisions, almost half of participants (44.5%) said this was the case a fair bit or a lot of the time, with 29.2% being unsure.

Four out of every ten participants reported no experience of discrimination (37.9%), with 43.5% experiencing low levels of discrimination. One out of every ten (10.7%) participants reported moderate to high levels of discrimination.

Table 6: Selected self-determination and discrimination characteristics of Mayi Kuwayu Study participants by identity

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
Feels in control of life				
A lot	42.2	42.2	43.4	42.1
A fair bit	35.8	35.7	35.6	35.9
A little bit	16.2	13.0	15.2	16.0
Not at all	2.5	3.9	2.7	2.6
Missing	3.3	5.2	3.2	3.5
Where I live local mob make community decisions				
A lot	20.5	28.9	20.2	20.5
A fair bit	20.3	19.5	17.8	19.9
A little bit	16.2	14.0	20.0	16.1
Not at all	9.9	7.5	9.6	9.8
Unsure	25.3	15.3	22.1	24.6
Missing	7.9	14.9	10.4	9.2
Where I live the government have final say				
A lot	30.5	35.4	33.0	30.4

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
A fair bit	14.1	14.9	15.7	14.1
A little bit	8.2	8.1	6.7	8.1
Not at all	8.5	5.2	6.1	8.3
Unsure	29.8	22.4	29.3	29.2
Missing	8.8	14.0	9.3	10.0
Experience of everyday discrimination				
High	2.3	1.6	2.1	2.3
Moderate	8.2	7.1	12.0	8.4
Low	43.6	43.5	47.9	43.5
No discrimination	38.2	37.0	32.5	37.9
Missing	7.6	10.7	5.6	7.9

*206 participants with missing data for Aboriginal and/or Torres Strait Islander identity are included in the total.

Family support and connection

Almost half (47.8%) of participants reported high family wellbeing (Table 7). Just under 30% of participants reported being a carer for a sick or disabled family member or friend, and 52.6% of Mayi Kuwayu Study participants had at least one member of the Stolen Generations in their family. The most commonly reported Stolen Generation was two generations back (25.8%), for a participant's grandparents or great-grandparents. Participants were also asked if, in the past year, anyone in their close family had children taken away. Just over one in ten participants (10.3%) reported this occurring.

Table 7: Selected family support and connection, Stolen Generations and removal characteristics of Mayi Kuwayu Study participants by identity

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
Family wellbeing				
High	47.9	51.3	48.7	47.8
Moderate	21.1	19.5	21.3	21.0
Low	6.8	6.2	5.9	6.7
Missing/unsure	24.3	23.1	24.2	24.5
Carer for a sick or disabled family member/friend				
Yes	29.1	26.3	32.5	29.1
No	68.7	71.8	66.0	68.4
Missing	2.2	2.0	1.6	2.4
Stolen Generations				
Current generations (self, sibling, cousin, child, grandchild)	11.2	4.2	6.1	10.8

	Aboriginal (N = 8801) %	Torres Strait Islander (N = 308) %	Aboriginal and Torres Strait Islander (N = 376) %	Total (N = 9691*) %
One generation back (parent, aunty/uncle)	15.2	2.9	13.0	14.7
Two generations back (grandparent/ great-grandparent)	26.4	13.3	27.4	25.8
At least one Stolen Generation (total, including 'other')	53.6	26.0	55.6	52.6
Children taken away from close family member (in the last 12 months)				
Yes	10.2	9.4	10.9	10.3
No	76.7	74.7	75.8	76.3
Not relevant	7.6	9.1	9.0	7.7
Missing	5.5	6.8	4.3	5.8

*206 participants with missing data for Aboriginal and/or Torres Strait Islander identity are included in the total.

What are the main strengths and weaknesses of the Mayi Kuwayu Study?

A major strength of the Mayi Kuwayu Study is that the study has been conceptualised, designed, conducted and analysed by Aboriginal and Torres Strait Islander people for our mobs. The study and data are governed by an Aboriginal and Torres Strait Islander committee, and data can only be released under application to that committee (the MKDGC) and in accordance with the data governance procedures and principles of Indigenous data sovereignty. This protects the sovereignty of the data.

Other strengths include the large size of the cohort, the wide range of cultural, demographic, health and wellbeing variables represented, and the strong community engagement focus of the study. Maintaining a sizeable and comprehensive database on the health and wellbeing of Aboriginal and Torres Strait Islander peoples that is intended to be used for evidence production to inform community, services and policy across sectors means less burden on the communities than various researchers conducting multiple individual studies. Another strength is that validated novel instruments from the Mayi Kuwayu Study can in time be incorporated into other data collections that currently use instruments that have not been validated for use with the population.

Furthermore, following participants up through both re-survey and data linkage allows extensive data collection over a long period, regardless of follow-up questionnaire participation. This approach decreases participant burden and increases the range and integrity of data included in the study.

Limitations of the Mayi Kuwayu Study include under-representation of some Aboriginal and Torres Strait Islander peoples, including those in younger ages groups and from remote and very remote areas, and the use of novel instruments (at the current phase of the study) that have not yet undergone psychometric validation. Retention rates may be affected by high mobility in the population; therefore, participants are regularly reminded to update their contact details. However, high retention rates have been achieved in existing surveys of the Aboriginal and Torres Strait Islander population (Gubhaju et al. 2016). As a self-report questionnaire, data about medical conditions and medications may not be as accurate as clinical data. However, this will be complemented though linked data records. Overall, the self-report questionnaire method enables a rich, subjective data collection with individual prospective information on

exposures (Hafferty et al. 2018; Richardson et al. 2013; Teteh et al. 2017).

How can I access the data and where can I find out more?

The Mayi Kuwayu Study was developed to inform Aboriginal and Torres Strait Islander communities and organisations and all levels of government. The data resource is therefore designed to be available for Aboriginal and Torres Strait Islander communities, organisations and governments wishing to use Mayi Kuwayu Study data, subject to meeting the application for use guidelines and MKDGC approval.

To maintain the confidentiality of participants and ensure that studies protect Aboriginal and Torres Strait Islander data and cultures, those seeking to use the data need to apply to the MKDGC. The data application process is detailed on the 'Apply for data' page of the Mayi Kuwayu website (https://mkstudy.com.au/dataapplicationprocess/). Questions about applying for data should be directed via email (mkdgc@anu.edu.au) or by telephone (1800 531 600). When an application is successful, the Mayi Kuwayu Study team will perform the applicant's study analysis and provide the results. This process ensures that other organisations can conduct their own studies, but the integrity and confidentiality of the data remain intact.

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The Mayi Kuwayu Study team is located in Canberra, on the traditional lands of the Ngunnawal and Ngambri peoples. We pay our respect to the Ngunnawal and Ngambri Elders, past and present, and acknowledge their ongoing connection to this Country and their communities.

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NOTES

1 A licence is required to use cultural items and scales developed by the Study. A complete list of survey items can be found at: <https://mkstudy.com.au/wp-content/uploads/2020/07/MK-External-Data-Dictionary.pdf> Contact the team at <mkstudy@anu.edu.au> for further details about licensing of cultural items and scales from the Mayi Kuwayu Study questionnaire.

2 Australian National University (ANU) Human Research Ethics Committee (HREC) (2016/767), approved 28 February 2017. Aboriginal Health and Medical Research Council: 1268/17, approved 25 May 2017. Aboriginal Health Research Ethics Committee SA: AHREC 04-17-723, approved 14 August 2017. ACT Health 2018/ETH/00205, approved 25 October 2018. AIATSIS: E030/22052015, approved 19 January 2017. Central Australian Human Research Ethics Committee CA-17-2810, approved 27 April 2017. Metro South, Queensland: HREC/2019/QMS/56115NT, approval in progress. Department of Health and Menzies: 2017-2804, approved 22 May 2017. Nunkuwarrin Yunti, approved 3 October 2019. St Vincent's Hospital Melbourne HREC: 132/17, approved 17 August 2017. University of Tasmania (UTAS): H0016473, approved 21 July 2017. Western Australian Aboriginal Health Ethics Committee: 787, approved 26 June 2017. Metro South Queensland, approved 18 September 2019.

3 Mayi Kuwayu Study data is released on an ad hoc basis as determined by the Mayi Kuwayu Study data management team. The first data release (Data Release 1.0) includes 7526 participants whose data was processed from April 2018 to July 2019. The data presented in this paper is from the second data release (Data Release 2.0), which includes 9691 participants whose data was processed by May 2020.

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