Making Cultures Count:

Transforming Indigenous Health Data in Australia



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I hereby confirm that this work is my own, except where otherwise specified.

Author's note: Some sensitive information, including identifying details of groups and organisations discussed in the thesis, has been removed or edited for the publication of this monograph in the Oxford University Research Archive to protect the identities of participants in the Mayi Kuwayu Study. I provide an indication of where sections of text or a figure have been removed in situ.

Abstract

To date, national statistics have placed Indigenous Australians and their health in constant comparison with non-Indigenous Australians. This has generated a deficit discourse, reinforcing the notion of an 'Indigenous problem' in Australian society. In response, Indigenous and non-Indigenous health researchers have worked together to build momentum for 'strengths-based' research approaches, advocating for the positive influence which Indigenous cultures have on health outcomes, and the need to quantify this relationship at the population level to challenge the deficit discourse. This thesis focuses on the development of the first national survey to measure this relationship, designed and owned by Indigenous Australians — the *Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing.* Using an Indigenist research approach, this thesis navigates the influence of social, political, and historical factors on the development of the Mayi Kuwayu Study's methodology and survey structure. It draws on multi-sited observations of focus groups across Australia and interviews with its key researchers and Indigenous community stakeholders conducted between May 2017 and November 2018.

This thesis shows that the Mayi Kuwayu Study researchers strategically mobilised the concept of culture within their epidemiological framework. The focus groups they conducted with Indigenous community members helped to establish the credibility and validity of the metrics used in their survey. The Indigeneity of the researchers and stakeholders was seen to mediate this operational translation of culture from its lived experience. I found that the Indigenous leadership and ownership of the study altered the epidemiological research process and enhanced its potential to produce meaningful data, empowering Indigenous Australian communities and decolonising the wider Indigenous health narrative. While the survey's ability to 'save' culture was limited, it was able to

maintain a sensitivity to cultural diversity, and demonstrated that cultural determinants of health is a promising, strengths-based framework for large-scale epidemiological research.

Acknowledgements

This thesis marks the end of a journey for me which began when I was a teenager. At that time, my mum told me that my grandfather had aspired for her to go to England, though they did not have the money to make it happen. He wanted her to study at Oxford, which he said would 'improve the mind and develop the person'. He believed that if she were able to succeed at Oxford, she would succeed anywhere, and that it would open doors for her which were otherwise closed to Aboriginal people in Australia. My grandfather was an Aboriginal man, born in Broome in the 1920s in Western Australia, and had not benefitted from a formal education beyond primary school. He met my grandmother, a member of the Stolen Generations, in Perth in the early 1950s, when segregation between Aboriginal people and White Australians still in effect. They went on to raise five children, two of whom graduated from universities in Australia. My Aboriginal grandparents, on both sides of my family, knew that education was the way to achieve a good life and contribute towards the fight for equal rights for Aboriginal Australians. That I have been fortunate enough to live out my grandfather's dream means more to me than I can say in words.

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Acronyms

5D	Difference, Disparity, Disadvantage, Dysfunction, and Deprivation
ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AI	Assistant Investigator
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
AIDA	Australian Indigenous Doctors' Association
AIHW	Australian Institute of Health and Welfare
AMS	Aboriginal Medical Service
ANU	Australian National University
BADDR	Blaming, Aggregate, Decontexualised, Deficit, and Restricted
BMI	Body Mass Index
CEO	Chief Executive Officer
CI	Chief Investigator
CK&P	Cultural knowledge and practice
CLC	Central Lands Council
COAG	Council of Australian Governments
GERAIS	Guidelines for Ethical Research in Australian Indigenous Studies
IDS	Indigenous Data Sovereignty
IDG	Indigenous Data Governance
KT	Knowledge Translation
LSIC	Longitudinal Study of Indigenous Children
MJA	Medical Journal of Australia
MK	Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing
MLLS	Murray Local Land Services

NACCHO	National Aboriginal Community Controlled Health Organisation
NAIDOC	National Aborigines and Islanders Day Observance Committee
NATSIHP	National Aboriginal and Torres Strait Islander Health Plan 2013-2023
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NCEPH	National Centre for Epidemiology and Public Health
NHMRC	National Health and Medical Research Council
NSW	New South Wales
NT	Northern Territory
NTER	Northern Territory Emergency Response
PM&C	Department of the Prime Minister and Cabinet
QLD	Queensland
SEARCH	Study of Environment on Aboriginal Resilience and Child Health
TAS	Tasmania
TI	Thursday Island
UN	United Nations
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
WA	Western Australia
WHO	World Health Organisation

[This list has been modified]

Glossary

'Indigenous', 'Aboriginal', 'Torres Strait Islander' and 'Aboriginal and Torres Strait Islander people/s' are terms that are used interchangeably in this thesis and refer to the Indigenous status of the First Peoples of the land now known collectively as Australia. I acknowledge that these terms imply homogeny where in fact there is great diversity, and that they have been used in strategic ways by colonial powers in Australia to racially Other and administratively categorise First Peoples. In this thesis I predominately use 'Indigenous' for the purposes of brevity only. It is also intended to be a subtle reference to the similarities in the lived experiences of Indigenous peoples in Australia with those from other parts of the world. I use the plural 'peoples' to emphasise the diversity of Indigenous identities and cultures within Australia and elsewhere when appropriate.

Aboriginal Australians	The First Peoples to inhabit the continent of Australia, and whose ongoing custodianship of the land, seas, and sky is embodied by those from the past, present, and future.
Acculturation	The changes which occur to original cultural patterns when groups of individuals from different cultures interact. Typically used to describe how minority cultures and group members become acculturated with the dominant culture.
Aunty	A term of respect for Indigenous women, often used for those who are older and who keep special cultural knowledge about the Indigenous communities with which they identify and/or live in.

Colonisation This is a social and political process which began in Australia in 1788 when the first British 'settlers' arrived on Eora Country (Botany Bay, Sydney), and claimed the continent for Britain under the false premise of *terra nullius* ('land belonging to no one' in Latin). Imperial expansion across the continent led to the strategic and systematic genocide, abuse, and subjugation of Indigenous peoples by the Crown, and later the Australian Government. Colonisation is ongoing in Australia, and perpetuates itself through knowledge indoctrination which dismisses, dispossesses, and disadvantages Indigenous peoples and their Countries through all systems of governance and social progress.

Country Refers to the traditional homelands with which Indigenous Australians identify by blood, marriage, or long-term residence and acceptance by the local Indigenous custodians. Country is often considered to be the 'mother', 'parent' or 'caregiver' of Indigenous peoples, who passes on her knowledge through the environment, people, and animals that identify with her. This is a deep and reciprocal relationship for Indigenous people and is often expressed as 'connection to Country'. Country is capitalised throughout the thesis (except when referencing original sources) as recognition of its existence as a whole and living entity and to emphasise its importance to Indigenous Australians.

Culture	This is viewed by Indigenous peoples as a framework within which relationships to the past, ancestors, land, and the present are articulated through a variety of forms such as language, song, dance, storytelling, the maintenance of traditional homelands, beliefs, and kinship (after Salmon et al., 2018).
Decolonisation	A social and political process which operates at the individual and community levels to identify, challenge, and actively dismantle the institutions and instruments of colonialism.
Deficit discourse	Disempowering patterns of thought, language, and practice which represent Indigenous peoples in terms of deficiencies and failures (after Lowitja Institute, 2018: 1).
Elders	Indigenous people who are either formal or informal leaders in their communities and cultural knowledge keepers.
Enculturation	The extent to which individuals learn about and identify with their heritage culture.
Epistemology	The theory of knowledge, including its analysis and production using specific methods.
Indigeneity	The experience of being an Indigenous person in Australia as a lived experience as well as a form of expertise.

Indigenist research	Research by Indigenous Australians whose primary informants are Indigenous Australians and whose goals are to serve and inform the Indigenous struggle for self-determination (after Rigney, 1999b: 118).
Indigenous	Aboriginal and Torres Strait Islanders are the original inhabitants and custodians of the continent now known as Australia and its islands. For the sake of brevity, I have chosen to use the term 'Indigenous Australians' or 'Indigenous' in this thesis to refer collectively to Aboriginal and Torres Strait Islander people, except in reference to source material. I use 'indigenous' to refer to indigenous peoples generally in the global context. In Australia, 'Indigenous' is also a political category, sometimes defined by comparison with 'non-Indigenous' Australians.
Indigenous data governance	Refers to the right of Indigenous peoples to autonomously decide what, how, and why Indigenous data (information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually) are collected, accessed, and used. It ensures that data on or about Indigenous peoples reflects our priorities, values, cultures, worldviews, and diversity (after *Mayam nayri Wingara*, 2018).
Indigenous data sovereignty	Refers to the right of Indigenous people to exercise ownership over Indigenous data. Ownership of data can be

	expressed through the creation, collection, access, analysis, interpretation, management, dissemination, and reuse of Indigenous data (after *Mayam nayri Wingara*, 2018).
Indigenous health narrative	Describes the landscape of how Indigenous health in Australia is understood and reproduced through research, and the dissemination of its findings.
Indigenous health and wellbeing	A whole-of-life view, including the cyclical concept of life-death-life, which refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their community (after National Aboriginal Health Strategy Working Party, 1989: ix-x).
Indigenous intergenerational trauma	Trauma which is passed down through generations of an Indigenous family and their wider Indigenous community as a result of colonial practices.
Indigenous lived experience	The embodied experience of the social, political, historical, and cultural realities of Aboriginal and Torres Strait Islander people's lives as Indigenous people (after Walter, 2018: 258, in reference to *lifeworld*).
Lore/Law	Distinct from Australian law, Lore/Law governs the relationships between Indigenous people and their Country and does not change over time. Also known as Aboriginal

	Law or Customary Law, the conjoined Lore/Law has been throughout the thesis, reflecting its usage in the field.
Methodology/ies	The systems, reasoning, and philosophy (theory) underpinning the acquisition and communication of knowledge through methods.
Method/s	The activities undertaken to acquire knowledge.
Mob	An Aboriginal English term used to collectively refer to family and connections.
Native Title	The recognition by Australian common law that Indigenous peoples have rights and interests to their land under traditional laws and customs (Mason and McHugh JJ, in High Court of Australia, 1992).
Non-Indigenous	A collective term which is only used in comparison with an Indigenous collective. While 'non-Indigenous' often incorporates diverse cultural identities, it is mainly dominated by a White Australian identity.
Other/ing	'Other' or 'Othering' in the context of this thesis refers to the ways in which British/White/non-Indigenous individuals and structures have collectivised and racialised Indigenous peoples for the purpose of discrimination and is embedded within the colonial framework.

Salutogenesis	A research focus on factors which promote health rather than pathologising the health of individuals and communities (after Antonovsky, 1979).
Self-determination	In an Indigenous context this is the ability and power to exert control over one's own life and to have a role in shaping the lives of future generations and the wider Indigenous community.
Stolen Generations	Refers to Indigenous children who were removed from their families as a result of assimilationist policies enacted by Australian governments between 1910 and 1970.
Strengths-based	Research approaches which focus on individual and community assets, including resilience, protective factors, empowerment, holistic approaches, wellness and wellbeing, strengths-based counselling approaches and positive psychology, decolonisation methodology, and salutogenesis (after Fogarty et al., 2018b: vii).
Torres Strait Islander Australians	The First Peoples to inhabit the group of islands now known collectively as the Torres Strait Islands, located between Australia and Papua New Guinea, and their descendants who continue to embody the Lore and spirit of their islands, sea, and sky.
Uncle	A term of respect for Indigenous men, often used for those who are older and who keep special cultural knowledge

	about the Indigenous communities with which they identify and/or live in.
White	White is a racial category, relating to individuals and institutions with a worldview that explicitly and implicitly privileges Eurocentric/Western knowledge and lives.
Yarn	A term used by Indigenous Australians to describe informal but intentional conversations to share knowledge.

Chapter 1 — The Indigenous Health Narrative

This thesis follows the development of the first truly empowering national study of Indigenous Australian health. The Indigenous health narrative in Australia has always been dominated by the voices of non-Indigenous medical practitioners, public health researchers, and politicians. Fuelled by the collection of quantitative data which constantly compares Indigenous Australians with the non-Indigenous population and its norms, Indigenous individuals and communities have become characterised on a national scale as different, disparate, disadvantaged, dysfunctional, and deprived (see Walter, 2018). These data have fuelled a 'deficit discourse' in Australia, marked by 'disempowering patterns of thought, language and practice that represent [Indigenous] people in terms of deficiencies and failures' (Lowitja Institute, 2018: 1). This discourse has been facilitated by ongoing colonial power structures in Australia which work to systematically undermine Indigenous cultures and sovereignty.

The national surveys collecting these quantitative data are instruments of governmentality and of scientific power. French philosopher Michel Foucault argued that the ultimate focus of government is on its population, where 'In contrast to sovereignty, government has as its purpose not the act of government itself, but the welfare of the population, the improvement of its condition, the increase of its wealth, longevity, health, and so on' (Foucault, 1978 [2001]: 216-217). Drawing on Foucault's work, British historical geographer Stephen Legg argued that 'governments seek to exercise influence not through the individual and intense technologies of discipline, but by the distant and calculative means of governmentality' (Legg, 2005: 139). The purpose of administering surveys at the population level is to provide statistics which may be interpreted as a true representation of the population by governments, aligning with the positivist orientation of scientific

disciplines which seek to identify an objective reality. However, as Palawa woman and sociologist Maggie Walter has identified:

> The hard numerical form of statistics can support the illusion that they, and the research results they provide, are 'real' in ways that are objective, permanent and incontrovertible. This is patently not so. Data are data, but their political and social reality is framed by how they are garnered and interpreted, by whom, and for what purpose. Statistics do not lie, but neither do they always tell the same truth. (Walter, 2010: 53)

In Australia, all national surveys collecting data about Indigenous health have been created, administrated, and owned by the Federal Government — until now. In 2014, a group of Indigenous and non-Indigenous health experts and researchers met at Australia's premier Indigenous health research organisation called the Lowitja Institute in Melbourne. Together they discussed the possibility of a national study of Indigenous health which would focus on the strengths of Indigenous cultures and communities. In that year I was in Oxford undertaking my MPhil research on Indigenous experiences of obesity. It was by happy chance that I met with one of the key researchers from this meeting, Ray Lovett, who was in Oxford with his colleague to present a lecture on Indigenous smoking and health. Ray Lovett is a Wongaibon (Ngiyampaa) man and a social epidemiologist who specialises in Indigenous health. He told me about the national study he was just starting to develop with the Lowitja Institute and that I should get in touch if I wanted to be involved. And so it was with a ready mind that happy chance became a DPhil project.

The national study Ray was developing came to be called the *Mayi Kuwayu National Study of Aboriginal and Torres Strait Islander Wellbeing* (henceforth the Mayi Kuwayu Study or MK). *Mayi kuwayu* means 'to follow people over time' in the Ngiyampaa (Wongaibon) language, which is Ray's cultural heritage. It is the first large-scale epidemiological survey in Australia to measure the relationships between culture and the health and wellbeing of Indigenous

peoples *from an Indigenous research perspective.* It is led by a team of predominately Aboriginal researchers, including Ray, in partnership with Indigenous health experts, organisations and community groups. Together they have developed a survey to quantify the relationships between cultural practice and expression, social determinants of health, health behaviours, and health and wellbeing outcomes for Indigenous Australians (Jones et al., 2018a).

This thesis follows the processes, people and events which have shaped MK and its survey. It is an ethnographic example of meta-research, or simply 'research on research' (Ioannidis et al., 2015: 1). Culture is seen by Indigenous peoples as a framework within which relationships to the past, ancestors, land, and the present are articulated through a variety of forms such as language, song, dance, storytelling, the maintenance of traditional homelands, beliefs, and kinship (Salmon et al., 2018). This thesis seeks to understand how culture as a qualitative concept and lived experience may be transformed to produce cultural determinants of health for Indigenous Australians by focusing on the research processes undertaken within the Mayi Kuwayu Study. It explores the historical, political and social elements which have influenced MK's creation and details the ways in which Indigeneity (the quality of being Indigenous) became embedded within its epidemiological framework.

As a descendant of the Gidja and Gamilaroi peoples of Aboriginal Australia, I relished the opportunity to become part of a research endeavour which celebrated Indigeneity. Indigeneity as a concept has been discussed in a variety of ways in the literature as a complex legal and political tool in conversation with essentialist ideals (e.g. O'Sullivan, 2014, Paradies, 2006, Trigger and Dalley, 2010). In contrast, I use it here simply to refer to the experience of being an Indigenous person in Australia, as a lived experience as well as a form of expertise. It is a topic which will be developed throughout the thesis. The way I

have written this thesis reflects my experiences as an Indigenous person, whose positionality is inherently political in Australia, and in other colonised spaces like the Academy. The use of certain language or the way I position my arguments within the text is thus a reflection of the truth as I understand it as both an Indigenous person and as a scholar. This positioning — referred to as *Indigenous standpoint* — is common in the academic writing of Indigenous scholars, whose very existence challenges the ways in which Indigenous peoples have been and are still 'known' by the Academy (for examples, see Nakata, 1998, Rigney, 2006, Sherwood, 2010, Smith, 1999, TallBear, 2014, Wilson, 2001) (also Chapter 2).

Undertaking my doctorate at Oxford allowed me to see how experiences of Indigeneity transcend the local, and how a national study of Indigenous health designed by Indigenous researchers may be transformational in this space. Therefore, in this thesis I argue that the Mayi Kuwayu Study represents not only a unique moment in Australian history but contributes towards a wider global movement towards indigenous self-determination through research. The right to self-determination has been reinforced by forum discussions at the United Nations (UN) since the 1980s, and is now enshrined in the UN Declaration on the Rights of Indigenous Peoples (UNDRIP) (UN, 2007: Article 3). Australia was one of four nation states that initially opposed this document (along with Canada, New Zealand, and the United States), but these states have since changed their position to support the UNDRIP (UN, 2020).

The rights of Indigenous peoples in Australia have been and continue to be systematically undermined by the State. Despite Australia becoming a signatory to the UNDRIP in 2009, the UN Special Rapporteur on the Rights of Indigenous Peoples condemned the current situation, stating that:

> While the [Australian] Government has adopted numerous policies to address the socioeconomic disadvantage of Aboriginal and Torres Strait Islanders, those policies do not duly respect the rights to self-determination and to full and effective participation. The compounded effect of the policies contributes to the failure to deliver on the targets in the areas of health, education and employment in the 'Closing the Gap' strategy and fuels the escalating and critical incarceration and child removal rates of Aboriginal and Torres Strait Islanders. Comprehensive revision of the policies needs to be a national priority, and the consequences and prevalence of intergenerational trauma and racism must be acknowledged and addressed. Aboriginal and Torres Strait Islanders require better recognition and active participation in Australian society. (Tauli-Corpuz, 2017: 18)

It has been persuasively argued that the practice of culture is a key protective factor in the realisation of health and wellbeing for Indigenous Australians (Dudgeon et al., 2010, Salmon et al., 2018, Lowitja Institute, 2014). It is an integral part of the Indigenous lived experience, and maintaining, revitalising, embracing, nurturing and growing culture is important for Indigenous happiness, wellbeing, and for improving health outcomes (Salmon et al., 2018: i).

In 2012, the National Institutes of Health in the United States formulated a panel of over 30 experts from psychology, psychiatry, medicine, anthropology, sociology, public health, and nursing to discuss the conceptualisation and use of culture across the health sciences (Kagawa Singer et al., 2016: 238). They suggested that if cultural concepts and their influence on health can be operationalised as metrics or *determinants* at the population level, much of the thus far unexplained variance present within and across population groups may be explained (Kagawa Singer et al., 2016). Health statistics about Indigenous Australians are currently dominated by a deficit model which relies on 5D data (Difference, Disparity, Disadvantage, Dysfunction and Deprivation) to compare the Indigenous population against non-Indigenous norms (Walter, 2018: 258). This thesis explores what happens when Indigenous people are in control of the definition,

measurement and dissemination of these data, and how a different picture emerges telling a story of strength, resilience, and diversity in the face of sustained oppression. The creation of population statistics about the cultural determinants of health from an Indigenous perspective has the potential drive a fundamental shift in the ways in which Indigenous Australian health is conceptualised at local and national levels. In a system where data is power, *who* is in control of the data is key.

This is the story of the Mayi Kuwayu Study.

Before we can begin to understand the uniqueness and importance of this study in Australia and internationally, we must first understand the historical, social, and political contexts in which it exists. The following section describes these contexts in Australia, pinpointing colonialism as the foundation of the deficit discourse within the wider Indigenous health narrative.

1.1. Colonisation as an Indigenous health determinant

Colonisation is a fundamental underlying determinant for indigenous experiences of health and its administration throughout the world (see Griffiths et al., 2016, Mowbray, 2007, Paradies, 2016). The measurement of the health of indigenous peoples by governments must therefore be considered as a form of governmentality alongside histories of colonisation and the racial categories created to advance the colonial agenda. Linda Tuhiwai Smith, a Māori academic from the Ngāti Awa and Ngāti Porou iwi, argued that colonisation is an 'expression of imperialism', and became 'imperialism's outpost' (Smith, 1999: 21-23). It was the lens through which Europeans came to understand indigenous peoples as 'primitive' and less than fully human (Smith, 1999: 25-28).

> Imperialism provided the means through which concepts of what counts as human could be applied systematically as forms of classification, for example through hierarchies of race and typologies of different societies. In conjunction with imperial power and with 'science', these classification systems came to shape relations between imperial powers and indigenous societies. (Smith, 1999: 25)

In the continent that came to be known as Australia, this mind-set was first enforced using the European doctrine of *terra nullius* or 'land belonging to no one' to extinguish the sovereignty of its original owners and claim the continent for the British Crown (for historical reviews of this period, see Banner, 2005, and Reynolds, 2003). This premise was the foundation of Australian governance, law, and policy practice for over two centuries until 1992, when a legal case was resolved by the High Court of Australia between a group of Meriam Torres Strait Islanders living on Murray Island (*Mer* in Meriam language) and the State of Queensland (see *Mabo v Queensland* (No 2) [1992] HCA 23 (3 June 1992)). The case led the High Court of Australia to rule that *terra nullius* should be abandoned, and recognised that under what came to be known as Native Title, Indigenous Australians have an entitlement to the land in accordance with traditional laws and customs, within the bounds of Australian common law (Mason and McHugh JJ, in High Court of Australia, 1992). Until this decision, the basic human rights of Indigenous people in Australia were violated systematically on a false premise, providing:

> the environment in which the Aboriginal people of the continent came to be treated as a different and lower form of life whose very existence could be ignored for the purpose of determining the legal right to occupy and use their traditional homelands. (Deane and Gaudron JJ, in High Court of Australia, 1992: 55)

There is an extensive historical and academic record of the colonial administration of Indigenous peoples in Australia, and the effect it has had on their health and wellbeing since 1788 (see Ella et al., 1998 [NSW and Australia-wide], Haebich, 1988 [WA], Nakata, 2007 [Torres Strait], Sherwood, 2013 [Australia-wide]). While it is beyond the scope of this

thesis to provide a detailed record of this history here, key events will be examined below in order to illustrate the colonial roots of the present day Indigenous health narrative in Australia.

Origins in the 'protection' agenda

Historically, the health of Indigenous Australians has been considered through the apparatus of protectionism by Australian governments. This was partly in response to the decimation of Aboriginal peoples through conflict and disease, and increasing public unease at their general mistreatment by White Europeans (Australian Law Reform Commission, 1986: Section 3.25, Ella et al., 1998: 30-31, Saggers and Gray, 1991: 384). The main intention, however, was to dominate and segregate Aboriginal people from the White colonists and to ease the passing, in their eyes, of a race on the brink of extinction.

> The violence and disease associated with colonisation was characterised, in the language of social Darwinism, as a natural process of 'survival of the fittest'. According to this analysis, the future of Aboriginal people was inevitably doomed; what was needed from governments and missionaries was to 'smooth the dying pillow'. (Human Rights and Equal Opportunity Commission, 1997: Chapter 2)

In the first years after the British invaded in 1788, they made very little effort to establish positive relations with Aboriginal groups (Reynolds, 2006). There were constant battles over land and waterways, including massacres of large groups of Aboriginal men, women, and children (Reynolds, 2006). By 1814, British Governor Lachlan Macquarie had established a 'Native Institution' in Parramatta, Sydney, to provide a basic British education for Darug children in the local area aged 4 to 7 years (Campbell, 1814) (the Darug people were the traditional Aboriginal custodians of this area). This Native Institution was the first structure in Australia designed specifically to colonise Aboriginal people. It was soon followed by the establishment of Christian missions across Australia

whose goal was to educate and administrate Aboriginal peoples, and from them create 'civilised' and productive members of the British Empire (Flood, 2006: 201).

In 1837 the House of Commons commissioned a report which recommended that certain officials, called 'Protectors', should be given the ability to rule for the general defence of Aboriginal people from British subjects and to provide rations, blankets, and medicine for Aboriginal people in New South Wales (NSW), South Australia (SA), and Western Australia (WA) (House of Commons, 1837). By the latter half of the nineteenth and early twentieth centuries, protection policies became formalised through legislation in Victoria (VIC) (1867), WA (1886), Queensland (QLD) (1897), NSW (1909), and SA and the Northern Territory (NT) (1910–11).

These policies resulted in the removal of Aboriginal people from their traditional homelands and the relocation onto reserves and missions to be segregated from the White European population. This control functioned to restrict contact between Aboriginal people and Europeans and to assist in the identification and assimilation of 'half-castes' and their children. Two hundred and eleven missions were established across the country to provide rations, health care, housing, education, religion, and some physical protection for Aboriginal people from the violence of neighbouring groups or White colonists (Flood, 2006: 203).

A few of these missions supported the continuation of Aboriginal cultural practices, but the vast majority sought to undermine Indigenous ways of being, including migratory patterns, interactions with the environment, cultural beliefs, languages, and spirituality (Bartlett, 1998). Aboriginal health and wellbeing suffered from this onslaught, as they began to lose control over their lives, traditions, and social relationships with the land and its plants and animals (Bartlett, 1998). Indigenous identities are inextricably tied to place, and so the removal of Aboriginal people from their traditional homelands by Australian

governments not only distanced those individuals from their ancestral connections, but their descendants as well. This is the source of the Indigenous/non-Indigenous identity divide in Australia, and one which continues to contextualise the relationship between Indigenous peoples and the rest of Australian society (this dynamic will be explored throughout the thesis).

The creation of an Aboriginal *population* through the use of government-administered definitions of Aboriginality served to homogenise Aboriginal peoples within a single category to be regulated, controlled, and governed from the early 1800s onwards. Islanders in the place which came to be known as the Torres Strait Islands were also profoundly affected by this process, as Torres Strait Islander academic Martin Nakata (2007: 195-196) writes:

> The viewing of Islanders as 'artefacts of the past' enabled them to be viewed as the legitimate and natural subjects and objects of study and of social, economic and political reorganisation.

State-based investigations into the health of the Aboriginal population occurred sporadically under the various policies of protection, with the first major report commissioned by Prime Minister Stanley Bruce in 1927. Undertaken by QLD's Chief Protector John William Bleakley, the report *The Aboriginals and half-castes of Central Australia and North Australia* (Bleakley, 1928) details the observations made by local White officials about Aboriginal population estimates, employment conditions, education, health, and living conditions. This report led to an era of intensive and co-ordinated Aboriginal population administration and control by the various Australian governments. At the 1937 Conference of Commonwealth and State Aboriginal Authorities held in Canberra, the State representatives agreed to enact an assimilation policy across the nation.

> This conference believes that the destiny of the natives of aboriginal origin, but not of the full blood, lies in their ultimate absorption by the people of the Commonwealth, and it therefore recommends that all efforts be directed to that end. (Commonwealth of Australia, 1937: 21)

The Conference also voted for a uniform definition of an Aboriginal person as anyone of Aboriginal descent, except for those described as 'quadroon' or 'less than quadroon' who do not associate with or 'lives substantially after the manner' of a 'full-blood' (Commonwealth of Australia, 1937: 21). A magistrate could order someone to be classed as a 'native' under this policy, and individuals could also apply to the relevant Minister to be classed as 'native' (Commonwealth of Australia, 1937: 21). The assimilation policy was enacted on this basis throughout Australia until the late 1960s, with NSW being the last devolved government to abolish their Aborigines Welfare Board and repeal their protection policy in 1969 (NSW Government, 1969). These policies 'sought to enforce modes of social behaviour, customs, and values that mirrored those of the dominant [White] population. Allowed little control over their lives, Aboriginal people were told where and how they could live' (Rosewarne et al., 2007: 117).

Under the protection and assimilation policies enacted across Australia many Indigenous individuals, families, and communities were forcibly removed from their traditional homelands. Numbers differ across the various States, but a recent report published by the Australian Institute for Health and Welfare (AIHW) revealed that between 1910 and 1970, 11–24% of all Aboriginal children were taken from their families and placed into government and church-run institutions for 're-education' and assimilation into the White Australian population (AIHW, 2018: xii). They became known collectively as the Stolen Generations, and today, over a third of Indigenous peoples report being descended from the Stolen Generations (AIHW, 2018: xiii) — including myself.

As non-Indigenous Australian historian Rosalind Kidd described, this policy directly led to the deaths of hundreds of Aboriginal children from physical or psychological abuse in these institutions (2000: 61). Some who survived this trauma grew up to self-medicate with alcohol and other drugs, had their own children removed, lived with violence or suicide, and 'were condemned to a life of grinding poverty and family neglect because the government discounted their labour and appropriated their earnings' (Kidd, 2000: 61). The collective suffering endured during these events has had a lasting impact on Indigenous peoples and the ways in which our identities and health are perceived by non-Indigenous Australians.

The events of colonisation have led to an intergenerational trauma as a result of the loss, disadvantage and discrimination we survived (for an evocative audio-visual representation of Indigenous intergenerational trauma developed by the Healing Foundation, see: https://youtu.be/vlqx8EYvRbQ [Accessed 9 July 2020]). The following section will discuss how this trauma has manifested as a statistical 'gap' between the health, education, economic, and social outcomes of Indigenous Australians and non-Indigenous Australians, and how it is reinforced by the deficit discourse which blames Indigenous peoples for their own disease burden (Sherwood, 2010).

The deficit discourse and the Indigenous health narrative

Colonial ideas have also informed the Australian health-care system. After researching articles from the *Medical Journal of Australia* (MJA) from 1914 to 1950, Franklin and White (1991: 24) concluded that medical views over this period were strongly influenced by the belief that Aboriginal people would die out, and therefore, that providing health services for them was not considered a priority. A more recent review of MJA publications by Thomas, Bainbridge, and Tsey (2014) confirmed this finding, adding that 'This belief in

the doom of the Indigenous population did create a sense of urgency for researchers to collect information about Indigenous people for science before it was too late' (Thomas et al., 2014: S1). This sentiment was so often pursued, that in the early 2000s the MJA editors considered imposing a moratorium on observational studies of Indigenous communities which, incidentally, were overwhelmingly deficit-focused (Armstrong, 2011: 491).

During the 1960s there were drastic changes in both public and government relations with Indigenous communities, sparked by the efforts of Aboriginal, Torres Strait Islander, and non-Indigenous human rights activists who fought for the recognition of Indigenous peoples as equal citizens in Australia (Franklin and White, 1991: 23-33). After widespread public protests across the country, the recognition of Indigenous people in Australia as citizens with all the same rights as other Australians culminated in the 1967 Referendum. This referendum saw over 90% of voters agree that the Commonwealth should be given the power to create legislation for Indigenous peoples and that they should be counted in the national Census (National Archives of Australia, 2016). Following the transfer of power from State governments over to the Federal Government after the referendum, and coordination through the Commonwealth Office of Aboriginal Affairs, Indigenous Australians and their health gained prominence on the national policy agenda and special funding was set aside for Indigenous health units to be established in each State government (Franklin and White, 1991).

This political shift led to the first comprehensive national report on the health of Aboriginal people being published in 1979 (House of Representatives Standing Committee on Aboriginal Affairs, 1979). In this report, the life expectancy at birth of Aboriginal people was estimated to be 50 years for both men and women, compared to 69.3 years for non-Indigenous men and 76.3 years for non-Indigenous women — a difference of more than 20 years (House of Representatives Standing Committee on Aboriginal Affairs, 1979:

11). Since this report, the 'gap' between Indigenous outcomes and those of the non-Indigenous population (itself homogenised into a single category) has been zealously researched and reported on by academic, health, and government organisations, who often use statistical data to describe the overwhelming disadvantage that Indigenous Australians experience.

The saliency of the 'Indigenous as compared to non-Indigenous' narrative using data science thus created a 'deficit discourse' in how Indigenous health has been monitored and reported through research (Fforde et al., 2013, Fogarty et al., 2018a). An article by a group of Aboriginal and non-Indigenous scholars argued that this deficit discourse is pervasive across contemporary social science research, policy, and the media in Australia, and can be described as:

> a mode of thinking, identifiable in language use, that frames Aboriginal identity in a narrative of negativity, deficiency, and disempowerment. … such a discourse adheres to models of identity still embedded within the race paradigm, and is interwoven with notions of 'authenticity', commonly expressed by language about who is a 'real Aborigine' and who, in deficit comparison, is not. (Fforde et al., 2013: 162)

The deficit discourse both contributes to and is reinforced by the notion that Indigenous peoples should be compared to the non-Indigenous population with non-Indigenous health outcomes as the standard. A recent report by Fogarty, Bulloch, McDonnell, and Davis (2018a) analysed this discourse across contemporary health and wellbeing policy in Australia, highlighting four policy 'moments' which reflected the various ways in which it operated. The first case study they investigated was the *Overcoming Indigenous Disadvantage* biannual series reporting on a range of Indigenous health and wellbeing indicators, overseen by the Australian Government's Productivity Commission. According to the researchers:

> The first five editions [2003, 2005, 2007, 2009, 2011], in particular, systematically compare Aboriginal and Torres Strait Islander Australians, in the aggregate, to non-Indigenous Australians. The reports reveal the politically diverse ways that emphasis on statistical disparities can be interpreted and deployed: deficit statistics can help to politicise issues of inequality by drawing attention to government failure in providing effective and culturally relevant services to citizens. However, they can also reduce rich and diverse populations to a singular entity that then becomes defined by a 'failure' to achieve 'normality' (benchmarked by a similarly singularised entity made up of everyone else.) (Fogarty et al., 2018a: ix)

Another case study they examined was the *National Aboriginal and Torres Strait Islander Health Plan 2013-2023* (NATSIHP) and the *Aboriginal and Torres Strait Islander Health Performance Framework*. They argued that the NATSIHP in particular countered the deficit discourse by undertaking a 'strengths-based approach' (Fogarty et al., 2018a: x). According to a companion report by Fogarty, Lovell, Langenberg, and Heron (2018b) a strengths-based approach in Indigenous health research incorporates a range of initiatives and themes including: Asset-based approaches, resilience, cultural appropriateness, social determinants of health and ecological theories, protective factors, empowerment, holistic approaches, wellness and wellbeing, strengths-based counselling approaches and positive psychology, decolonisation methodology, and salutogenesis (Fogarty et al., 2018b: vii) (see below and Chapter 2 for further discussion of strengths-based research).

The NATSIHP provides a policy framework for Australian governments to follow which has been informed by evidence collected by previous health initiatives and findings from the relevant literature. It was developed in consultation with a Stakeholder Advisory Group comprised of Indigenous and non-Indigenous representatives from government and community organisations. The group worked with the National Aboriginal and Torres Strait Islander Health Equality Council and the National Health Leadership Forum of the National Congress of Australia's First Peoples to advise the Minister for Indigenous Health on its development and implementation. However, Fogarty and his colleagues

(2018b) argued that the NATSIHP continues to be informed by the process of using statistics to measure disadvantage (Fogarty et al., 2018a: x).

> divorced from context and frequently reiterated, such statistics can… form a narrative that homogenises and dehumanises Aboriginal and Torres Strait Islander people into an intractable 'problem' to be 'dealt' with. Worse, they can form part of a narrative that situates responsibility for inequalities wholly with Aboriginal and Torres Strait Islander people themselves, obscuring the ways entrenched structural inequalities are affecting health. (Fogarty et al., 2018a: xi)

The presence of the deficit discourse in the development of Australian Government health policies has a damaging effect on the wellbeing of Indigenous communities, fuelling the idea that there is an 'Indigenous problem' present in Australian society (Gooda, 2011: 9, 79). An emerging literature highlights these negative effects across a range of areas, including the delivery of lower quality education to Indigenous students (Vass, 2012), discrimination in professional sport (Bamblett, 2011), negative news reporting (McCallum and Holland, 2010), and increasing lateral violence, or violence directed against one's peers within Indigenous communities as a result of being oppressed (Gooda, 2011: 78-80). Lateral violence is well-documented in marginalised communities around the world, and can manifest as gossiping, jealousy, bullying, shaming, and in other ways which undermine individuals, families, and groups (for a comprehensive overview of lateral violence in Australia and elsewhere, see Gooda, 2011: 50-98).

Fogarty and colleagues (2018a) pointed to the Northern Territory Emergency Response (NTER), also known as the Intervention, as an extreme example of the deficit discourse in action. The NTER was an initiative announced by the Government of Prime Minister John Howard in 2007 to address what was reported by the media and political leaders to be prolific child abuse within Aboriginal communities in the Northern Territory (Brough, 2007). It included measures such as alcohol restrictions on Aboriginal land, welfare reform

to 'stem the flow of cash going toward substance abuse', including compulsory income management, compulsory health checks for all Aboriginal children under the age of 16, banning of pornography, and improving housing and community living arrangements (Brough, 2007). The Intervention was preceded by a suspension of Part II of the *Racial Discrimination Act 1975,* which prohibits racial discrimination, including rights to equality before the law, access to places and facilities, land, housing and other accommodation, and provision of goods and services (Australian Government, 1975: 6-12). Fogarty and colleagues (2018a: 23-25) argued that the language used by politicians at the time cast all Aboriginal and Torres Strait Islander children in these communities as victims, and their parents and elders as abusers, and that extreme measures were needed to save them.

> In the political discourse surrounding the Intervention the idea of the vulnerable child was used reflectively to justify government action in the context of the uncivilised savagery of Aboriginal and Torres Strait Islander communities and the supposed neglect of children by their parents. Amid this discourse of deficit and parental failure, Minister [for Families, Community Services and Indigenous Affairs] Brough announced that the Northern Territory Emergency Response would intervene to protect the 'little children'. This intervention was described as a type of 'new paternalism' by the then Health Minister, Tony Abbott, in which the Federal government assumed the role of protector of vulnerable Aboriginal and Torres Strait Islander children. (Fogarty et al., 2018a: 24)

In 2010, the Australian Indigenous Doctors' Association (AIDA) conducted a health impact assessment of the NTER, and reported their results in the MJA (O'Mara, 2010). Their main findings were as follows (O'Mara, 2010: 546-548):

- The intervention could potentially lead to profound long-term damage, with any possible benefits to physical health largely outweighed by negative impacts on psychological health, social health and wellbeing, and cultural integrity;
- The increasing levels of mistrust caused by the Howard Government's ill-conceived and rushed implementation of the intervention will continue to compromise the [subsequent]

Rudd Government's ability to work in partnership with Aboriginal communities to achieve shared objectives; and

- The potential negative impacts of the intervention may be minimised, but only if governments commit to working in respectful partnerships with Indigenous people.

From the review of Australian Government policies above it is evident that the deficit discourse has had a profound and lasting impact on the Indigenous lived experience since colonisation. This has primarily been through the conception of an 'Indigenous population' in line with a colonial agenda which produced an 'Indigenous problem' represented through statistics and by their comparison with non-Indigenous numerical and social norms. The following section will begin to engage with the idea of such data as a form of truth and power in the Indigenous health landscape in Australia and the implications of having Indigenous people in control of the definition, collection, and dissemination of these data.

1.2. The power of data

The creation of quantitative data about Indigenous Australians is neither socially nor politically neutral (Walter, 2010: 45). Government health surveys which are created without the meaningful input of Indigenous Australian communities may be interpreted as a method of political control in line with the practice of governmentality and the continuing colonial project. In these surveys definitions of health are often based on biomedical models, which inevitably situate Indigenous bodies within a deficit system. As a case in point, current Australian Government surveys administered through the Australian Bureau of Statistics (ABS) do not take into account the diversity of Aboriginal and Torres Strait Islander cultural groups, often limiting identification to variations of a single question at the beginning of their forms — 'Are you of Aboriginal or Torres Strait Islander origin?' — which is known as the Standard Indigenous Question (see ABS, 2014). Working alongside

the etymology of the word 'population', which Legg (2005: 137) argued 'charts the tearing away from people and place', these surveys work to actively separate Indigenous peoples from their cultural identities and homogenise them within a single 'Indigenous' or 'Aboriginal and/or Torres Strait Islander' category (Kukutai and Walter, 2015: 318).

One way of analysing this deficit discourse would be to draw from the anthropology of power literature (for overviews of this literature, see Cheater, 1999, and Victoria, 2016). However, the direct ways in which the anthropological literature mobilises power as 'widespread differential capacities to produce society by relations of domination, exploitation, or subordination' (Victoria, 2016: 249) does not reflect the nuanced and specific ways in which it operates in the context of this thesis, which works predominately with culture from an Indigenous standpoint. The work of Maggie Walter most effectively theorises these power dynamics. She has authored a number of papers and book chapters specifically discussing the problematic political and racialised framing of Indigenous Australian statistics. She writes:

> As systematically collected numerical facts, statistics are much more than summarising numbers. Population statistics are foundational in defining a nation's self concept, affording the evidentiary base for the social/cultural envisioning of the land and entity that is, in this case, Australia. Statistics also provide an interpretative mechanism for societal understandings across social, cultural, economic, and political dimensions. It is from this non Indigenous ontological framework that Indigenous statistics emerge and are constrained by an inherently political terrain. From colonisation onwards Indigenous data have paradoxically reflected the physical presence and symbolic lack of presence of the Indigene within the Australian nation state. (Walter, 2010: 45)

Walter suggests that 'Statistics are social and cultural artefacts that emerge from, and are translated into, meaning via the norms of their producing and using society' (Walter, 2010: 46). Using the instrument of race capital as a new, fourth dimension of Bourdieu's *habitus*

(1984), she demonstrates that the Indigenous data space in Australia is in fact defined and controlled by non-Indigenous researchers and agencies who then have the power to collect and disseminate these data according to their needs and priorities (Walter, 2010). This has led to the situation in which 'Data is played as evidence in an assimilationist discourse driven by hard neo-liberalism', and that the 'Indigenous policy frame remains focused on applying market solutions to Indigenous social and economic arenas' (Walter, 2010: 50) (for a comprehensive critical analysis of race relations between Indigenous and White Australians, see Moreton-Robinson, 2015).

Most of the extant demographic, economic, and social data about Indigenous Australians comes from general Australian population surveys which use the Standard Indigenous Question to create an Indigenous sub-sample to generate statistics (Kukutai and Walter, 2015). This practice has led to a range of issues, including systematic under-counting of Indigenous peoples, and thereby increased likelihood of statistical error within the small samples of Indigenous participants who respond to these surveys (Kukutai and Walter, 2015: 319). This aggregation also means that there are no data which describe the historical, social, and cultural diversity of the over 500 distinct Aboriginal and Torres Strait Islander groups (e.g. Gamilaroi, Wiradjuri, Palawa, Arrernte), sometimes referred to as 'nations', in Australia (Kukutai and Walter, 2015: 321). In the literature and public discourse, there is an increasing use of the term 'nations' or 'First Nations' to highlight the diversity and unceded sovereignty of Indigenous groups in Australia. In this thesis it is only included to reference terminology used by source material.

The *National Aboriginal and Torres Strait Islander Social Survey* (NATSISS) was the first national survey in Australia specifically designed by the ABS to collect data from Indigenous people, with data gathered in 1994, 2002, 2008, and 2014 (Kukutai and Walter, 2015: 319). It was created following a recommendation from the Royal Commission into

Aboriginal Deaths in Custody for 'a special national survey covering a range of social, demographic, health, and economic characteristics of the Aboriginal population with full Aboriginal participation at all levels be supported' (Johnston, 1991: Recommendation 49).

The primary purpose of the NATSISS was to collect data about social wellbeing, but instead, its core objectives reflected the Australian Government's interests in quantifying Indigenous disadvantage and social inclusion to the exclusion of the needs and interests of Indigenous communities (Kukutai and Walter, 2015: 319). Walter (2013) asserts that 'As it stands Aboriginal and Torres Strait Islander peoples, despite roundtables and consultation, remain largely marginalised from the design, production and use of the NATSISS data'. The NATSISS survey has not been substantially altered since 1994 to adapt to the changing social realities of Indigenous Australians (Kukutai and Walter, 2015: 319), leading one critic to comment that 'It is a survey that is a mile wide and an inch deep' (Gray, 2012: 309).

The *National Aboriginal and Torres Strait Islander Health Survey* (NATSIHS) is another survey run by the ABS with a particular focus on physical and psychological health outcomes. It was run first in 1995 and then in 2001 as a supplementary version of the National Health Survey and had less than 2000 Indigenous respondents. The NATSIHS was then run independently in 2004–2005 with over 10,400 Indigenous participants, with the latest version in 2018–2019 recruiting 10,600 participants. This survey addresses a variety of health conditions (e.g. asthma, diabetes, heart disease) and behaviours (e.g. alcohol consumption, diet and exercise, smoking), alongside some measures of social and emotional wellbeing (Kessler 5, Short Form 36 Health Survey, Pearlin Mastery Scale [non-remote only], Multidimensional Scale of Perceived Social Support [non-remote only], impact of psychological stress on other factors, and health service use). Demographic information, as well as household, education, employment, income, and language use

information (English, Aboriginal, Torres Strait Islander, or Other) are also collected. It is common for government surveys to not distinguish between the 100+ Aboriginal and Torres Strait Islander languages spoken in Australia today (AIATSIS, 2019).

What the content and construction of these surveys illustrate is that in the landscape of national health statistics there is little data which reflects the diversity and depth of Indigenous lived experiences. Walter (2018: 258) refers to this experience as a *lifeworld*, defined as 'the embodied experience of the social, political, historical, and cultural realities of Aboriginal and Torres Strait Islander people's lives as Indigenous people'. The NATSISS and NATSIHS are arguably more targeted than past ABS health surveys which drew data about Indigenous peoples from the general population aggregate. Yet, they are still based on the epistemological framework of biomedicine and of epidemiology which prioritises discrete, measurable 'variables' and their responses, generating descriptive rather than explanatory data (e.g. able to quantify the number of people who smoke, but not why) (Kukutai and Walter, 2015: 319). Furthermore, their administration has been driven by the Australian Government's desire to form a basis of comparison with the non-Indigenous population, inevitably placing Indigenous peoples in a position which is almost universally disadvantaged according to non-Indigenous statistical norms.

The continual non-Indigenous framing of Indigenous data has led to five categories of data failure identified by Walter (2018: 258): Blaming, Aggregate, Decontexualised, Deficit and Restricted (BADDR).

> The Indigenous data paradox means that there is an enormous body of data *about* Aboriginal and Torres Strait Islander people but almost no data *for* or *by* Aboriginal and Torres Strait Islander people. … On the 'too much' data side we have data that: invariably contrast Indigenous and non-Indigenous, rating and blaming the problematic Indigene against the 'normal' Australian; are almost always aggregated at the national or state level, implying cultural and geographic

> homogeneity; are simplistic and decontextualised, focusing on individuals and families outside their context; are designed to capture deficits and service government priorities; and restricted and only available to government agencies. (Walter, 2018: 258, emphasis in original)

The *Longitudinal Study of Indigenous Children* (LSIC), also known as *Footprints in Time*, was an attempt by the Australian Government to collect more explanatory data about Indigenous children than could be gathered from the national Longitudinal Study of Australian Children (Thurber et al., 2015). LSIC collects qualitative and quantitative data about experiences in early childhood and their relationship to wellbeing, which can be used by policy makers to 'close the gap' between Indigenous and non-Indigenous outcomes (FaHCSIA, 2009: 6) (see below for further discussion of this policy agenda).

The study began in 2008 with two cohorts of participants aged between 6–18 months (B cohort) and 3.5–5 years (K cohort) from 11 sites in Australia representing urban, regional and remote geographies (for details see FaHCSIA, 2009: 10-13). Like other cohort studies, their sample is not intended to be representative of the Indigenous population, but uses purposively selected sites 'to be representative of the socioeconomic and community environments where Indigenous or Aboriginal and Torres Strait Islander children lived' (Hewitt, 2012: 2). The study interviews the children's primary caregivers and their schoolteachers on an annual basis, alongside additional recruitment. The total sample includes around 1,700 children participating in each data collection round, or Wave.

LSIC was designed under the guidance of a Steering Committee comprised of Indigenous and non-Indigenous Australians, including health, early learning, and child care experts, and incorporated consultations with urban, regional, and remote community members, organisations, and government departments in 23 locations around Australia (Thurber et al., 2015: Supplementary material A). Unlike the NATSIHS or NATSISS, Indigenous community perspectives were incorporated into the LSIC survey design during its

development, including in its underlying methodology and implementation (see Penman, 2006). The goal of these consultations was 'to ensure the design of the research reflected the interests of Aboriginal and Torres Strait Islander peoples, communities, and service providers and that the data would genuinely benefit the children and their families' (FaHCSIA, 2009: 14).

By incorporating Indigenous perspectives into the design of its research, LSIC represents a significant departure from the processes informing other Australian Government surveys and their data (Walter, 2018: 257-258). The consultation process which informed LSIC is the exception and not the rule when it comes to surveys of Indigenous health, and so the vast majority of Indigenous statistical data in Australia aligns with the 5D and BADDR categories described by Walter (2018). The overwhelming deficit discourse of Indigenous data in Australia is what I argue underlies the 'closing the gap' narrative which has governed the Australian public policy arena since the mid-2000s. While this objective is morally laudable in seeking equality between Aboriginal, Torres Strait Islander and non-Indigenous social, economic, educational and health outcomes, it is evident that the rhetoric of the 'gap' perpetuates the deficit framing of the Indigenous health narrative. The following section details this rhetoric and outlines major critiques.

Measuring the 'gap'

In 2005 the Aboriginal and Torres Strait Islander Social Justice Commissioner Tom Calma, a Kungarakan elder and member of the Iwaidja people, published a comprehensive report which called for Australian governments to invest in achieving health equality for Indigenous peoples by 2030 (Calma, 2005). This call to action was founded on a human rights perspective, emphasising that the disparities in health and life expectancy between Indigenous Australians and non-Indigenous Australians breached the philosophy that all

people of Australia should be able to enjoy and exercise their human rights (Calma, 2005). Article 25.1 of the 1948 Universal Declaration of Human Rights states that 'Everyone has the right to a standard of living adequate for the[ir] health and well-being', and was ratified by Australia along with other members of the UN (UN, 1948). Australia also committed to the 1966 International Covenant on Economic, Social, and Cultural Rights, which included a right to 'the enjoyment of the highest attainable standard of physical and mental health' (Office of the High Commissioner for Human Rights, 1966: Article 12.1). Calma's report argued for the acceptance of a 'holistic definition of Aboriginal and Torres Strait Islander health' (Calma, 2005: Recommendation 3), and that responsibilities for policy development and programme implementation should be shared with Indigenous communities and organisations.

Following this report, Calma worked to establish a social justice campaign in partnership with the Human Rights and Equal Opportunity Commission, the National Aboriginal Community Controlled Health Organisation (NACCHO), AIDA, the Congress of Aboriginal and Torres Strait Islander Nurses and Midwives, the Indigenous Dentists' Association of Australia, Oxfam Australia, and Australians for Native Title and Reconciliation, which together represented more than 40 Indigenous and non-Indigenous health and human rights organisations (Australian Indigenous HealthInfoNet, 2019). They called the campaign Close the Gap, focusing on the statistical gaps in health outcomes and life expectancy between Indigenous peoples and the rest of the Australian population.

In 2007 the Council of Australian Governments (COAG) launched their own campaign, which committed to 'closing the gap' in health outcomes and life expectancy, among other 'gaps' in education and employment identified by existing government statistics (Council of Australian Governments, 2008). Following widespread public promotion, the Australian Government led by then Prime Minister Kevin Rudd, endorsed the campaign and took

responsibility for administering and implementing the campaign's goals. In 2008 the campaign become officially recognised, and Australian Government officials, alongside some of the members of the Close the Gap initiative, signed a Statement of Intent to work together in eliminating the gap in health status and life expectancy between Indigenous peoples and non-Indigenous Australians by 2031 (Council of Australian Governments, 2008).

The COAG's Closing the Gap campaign was intended to create a structure for governments to take responsibility for rectifying past inaction and harm perpetrated against Indigenous Australians by their previous policies. However, after signing the Statement of Intent, the COAG did not follow through with its commitment to a fair and equal partnership with Indigenous stakeholders, and instead, set up its own targets and implementation plans for the campaign. Progress towards the Closing the Gap targets is reviewed by the Federal Government every year, with a report released to Parliament by the Department of Prime Minister and Cabinet which oversees the programme.

While references to Closing the Gap did not appear often in my ethnographic data, it is an important feature of the wider Indigenous health narrative, and thus worthy of some analysis here. The report from 2019 emphasised the failure and limitations of the campaign's progress up to that point. Four of the seven targets initially set by the COAG expired in 2018, and only two of the seven were on track to be achieved by the set deadline (Commonwealth of Australia, 2019):

- Halve the gap in child mortality rates by 2018 (not on track)
- Have 95 per cent of Indigenous four-year-olds enrolled in early childhood education by 2025 (on track)
- Close the gap in school attendance by 2018 (not on track)
- Close the gap in life expectancy by 2031 (not on track)
- Halve the gap in Year 12 attainment or equivalent by 2020 (on track)

- Halve the gap in reading and numeracy by 2018 (not on track)
- Halve the gap in employment by 2018 (not on track)

The Closing the Gap campaign's focus on 'measurable factors' raises concern about how change in Indigenous health may be assessed. In addition to the critique of such data by Walter and others discussed above, there are a number of practical issues which have been identified by the Australian Government's own department, the Australian Institute of Health and Welfare (AIHW), which cast doubt on the reliability of Indigenous statistics informing the campaign (AIHW, 2013).

The quality and quantity of statistics available about Indigenous Australians are known to be poor in comparison to the non-Indigenous population (in addition to the underlying concerns identified by Walter (2018: 258) above). One problem is under-identification, where individuals who are Aboriginal and/or Torres Strait Islander do not identify as such on data collection forms. Indigenous people who choose not to identify are suspicious of the purpose of such surveys and of the people administering them, due to the lack of transparency in the collection process and past experiences of being monitored or questioned by government authorities (Walter, 2005). Another issue is that survey forms can be inconsistent in the way they ask for identification from Indigenous people. Infrequent data collection rounds and formats also make it difficult to provide comparisons between samples over time and between geographical locations. Therefore, it is uncertain whether changes in identified 'gaps' will be observable through current statistical measures. According to the AIHW (2013), even if data collection methods are improved, data from previous collections may not be comparable.

It is also clear that a significant power imbalance shaped the Closing the Gap campaign. Though Indigenous organisations and individuals were initially involved in the process, the Australian Government took control over how both the 'gap' and 'progress' were defined

and measured through data collection and collation (Pholi et al., 2009). The process of monitoring progress for the campaign through data collection transferred responsibility on to Indigenous people to participate in surveys and to share personal details, including experiences of psychological distress, life stressors, and racial discrimination.

Fogarty et al. (2018a: ix) also pointed out that the Closing the Gap agenda was 'dominated by deficit metrics and statistical equality' which 'form a reductionist deficit narrative that homogenises and essentialises Aboriginal and Torres Strait Islander people'. Furthermore, while there used to be a council of Indigenous Australian health experts, called the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data, advising the ABS and AIHW on the collection of Indigenous data, this group was disbanded in 2017 (Lovett et al., 2019: 28). This means that there is now no national-level oversight by Indigenous people regarding the use of Indigenous data by the Australian Government (Lovett et al., 2019: 28).

However, at the time of completing this thesis there was a shift in the relationship between the COAG and peak Indigenous organisations. In January 2020, Australian Prime Minister Scott Morrison and his colleagues met with the Coalition of Aboriginal and Torres Strait Islander Peak Organisations (Coalition of Peaks) which included representatives from more than 50 Indigenous organisations to discuss the future of the Closing the Gap strategy (Prime Minister of Australia, 2020). This meeting was a result of the formal partnership agreement which had been signed in March 2019 by the COAG with the Coalition of Peaks, renewing their commitment to shared decision-making on the 'design, implementation and evaluation of a new Closing the Gap framework' (Coalition of Peaks, 2020). At the 2020 meeting, the Prime Minister and the COAG committed to developing a new national agreement with the Coalition of Peaks around three key reforms (Prime Minister of Australia, 2020, emphasis in original):

> **Priority Reform 1:** Developing and strengthening structures to ensure the full involvement of Aboriginal and Torres Strait Islander peoples in shared decision making at the national, state and local or regional level and embedding their ownership, responsibility and expertise to close the gap;
> **Priority Reform 2:** Building the formal Aboriginal and Torres Strait Islander community-controlled services sector to deliver closing the gap services and programs in agreed priority areas; and
> **Priority Reform 3:** Ensuring all mainstream government agencies and institutions undertake systemic and structural transformation to contribute to Closing the Gap.

Pat Turner, a Gudanji-Arrernte woman and Chief Executive Officer (CEO) of NACCHO and Co-Chair of the Joint Council on Closing the Gap, sees this as a 'historic partnership' but remains sceptical about whether the Federal Government will follow through on its commitments (Coalition of Peaks, 2020).

> The current cycle of failure is doomed to continue if this process of engagement and partnership is nothing more than window dressing for the status quo. The only way outcomes for my people will change is when governments are willing to challenge the structures and assumptions that got us here and embedded the disadvantage of Aboriginal and Torres Strait Islander people. (Turner, 2020)

The 2020 Closing the Gap report states that it is 'moving toward a strengths-based agenda — one that partners with Aboriginal and Torres Strait Islander people, enables more community control and embeds shared decision-making' (Commonwealth of Australia, 2020a: 9) (see below for a discussion of strengths-based approaches in research). While this acknowledgement seems to signal a change in the ways in which Indigenous data are collected, used, and discussed, it remains to be seen whether the Australian Government will share power with Indigenous representatives in governing the Closing the Gap agenda.

The only way in which Indigenous health outcomes can be improved is through Indigenous ownership and control over data and subsequent policy development (Fogarty et al., 2018b, Kukutai and Taylor, 2016, Kukutai and Walter, 2015, Morphy, 2016, Walter,

2018, Lovett, 2016). In 2017, more than 250 Aboriginal and Torres Strait Islander representatives from across Australia met in the NT at Uluru, on the lands of the Anangu people. At this historic gathering, the delegates discussed what changes could be made to the Australian constitution to incorporate Indigenous sovereignty. According to the *Uluru Statement from the Heart* which was produced following this meeting:

> This sovereignty is a spiritual notion: the ancestral tie between the land, or 'mother nature', and the Aboriginal and Torres Strait Islander peoples who were born therefrom, remain attached thereto, and must one day return thither to be united with our ancestors. This link is the basis of the ownership of the soil, or better, of sovereignty. It has never been ceded or extinguished, and co-exists with the sovereignty of the Crown. (First Nations National Constitutional Convention, 2017)

The delegates to this meeting reached a consensus on two political reforms to be made going forward:

- A voice to Parliament — Indigenous elected representatives would form an advisory body to the Australian Parliament to ensure Indigenous voices would be heard on political issues which affected Indigenous communities. This body should be enshrined in the Australian constitution, meaning that it could not be abolished without a referendum.
- A Makarrata Commission — This Commission would oversee agreement-making processes between Indigenous stakeholders and State and Federal Parliaments. It would also conduct an inquiry into the truth of Australian history to 'provide an avenue for experiences to be articulated and heard, to create a path for reconciliation between the First Nations and Australians' (Melbourne Law School, 2017: 5).

Makarrata is a Yolngu word which means 'two parties coming together after a struggle, to heal the wounds of the past, and to live again in peace' (Melbourne Law School, 2017: 5). There are already examples of such processes being undertaken in Australia and elsewhere. In New Zealand, all geographical areas are affiliated with both a general and a Māori electorate. There are currently seven Māori electorates, and only those on the Māori electoral roll may vote for these candidates. Furthermore, Māori MPs currently make up

24% of the New Zealand Parliament, which is proportionally higher than the 15% of the total population of New Zealand identifying as Māori (Stats NZ, 2015).

In the Australian state of Victoria, a First Peoples' Assembly was established in 2019 to develop a state-wide framework for treaty negotiations (First Peoples' Assembly of Victoria, 2020). In order to assign delegates to the Assembly, an Aboriginal Electoral Roll was established for Aboriginal people who had lived in Victoria for at least the previous five years. Twenty-one members of the Assembly were elected through this process, and a further 10 were appointed to reserved seats representing formally recognised Traditional Owner groups. All members are Traditional Owners of Country in Victoria (First Peoples' Assembly of Victoria, 2020). If this model proves successful, it would provide a framework for other States and Territories to use in establishing an Indigenous voice to Parliament.

The NT Government has also committed to undertaking treaty negotiations with its four Aboriginal land councils (Northern, Central, Anindilyakwa, and Tiwi) (Aboriginal Land Councils and the NT Government, 2018). In 2018 they signed a Memorandum of Understanding named the Barunga Agreement, in recognition of the 1988 Barunga Statement which was presented by the chairs of the Northern and Central Land Councils, Galarrwuy Yunupingu and Wenten Rubuntja to Prime Minister Bob Hawke (AIATSIS, 2020). The Barunga Statement was presented on behalf of all Indigenous peoples in Australia calling for the Australian Government to formally recognise the rights of Indigenous Australians (for an overview, see AIATSIS, 2020).

In South Africa, the Truth and Reconciliation Commission was a significant step toward a formal, national recognition of the violence and human rights abuses that occurred for all groups in South Africa during apartheid from 1960 to 1994 (Truth and Reconciliation Commission, 1998). A more recent example is the Truth and Reconciliation Commission

of Canada which ran from 2008 to 2015 to investigate the history and impact of Canada's residential school system on First Nations, Métis and Inuit children and their families across the country (Truth and Reconciliation Commission of Canada, 2015).

These cases provide a blueprint for the Makarrata Commission to properly account for the effect of colonisation on the whole of Australian society. To date, only the South Australian Labor party has pledged to institute the recommendations from the Uluru Statement within their parliament if they win the state election in 2022 (Wahlquist, 2019). Nevertheless, it is clear from the examples above that the priorities identified in the Uluru Statement are possible, and that the foundations are already being built in Australia to facilitate them.

Establishing Indigenous control over data is now the subject of a global movement towards Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG), which is linked to the UNDRIP:

> The concept of data sovereignty… is linked with indigenous peoples' right to maintain, control, protect, and develop their cultural heritage, traditional knowledge, and traditional cultural expressions, as well as their right to maintain, control, protect, and develop their intellectual property over these. … If indigenous peoples have control over what and how data and knowledge will be generated, analysed, and documented, and over the dissemination and use of these, positive results can come about. The collection and disaggregation of data on indigenous peoples and the documentation and transmission of their knowledge to younger generations can be facilitated. They can be the primary beneficiaries of the use of data, their knowledge, and their cultural heritage. (Tauli-Corpuz, 2016: xxii-xxiii)

Following the establishment of the UN Permanent Forum on Indigenous Issues in 2000, discussions about indigenous data have been facilitated in a series of workshops at the UN (Taylor and Kukutai, 2015: 1).

> At these events indigenous representatives had raised concerns about the relevance of existing statistical frameworks for reflecting their worldviews and they highlighted their lack of participation in data collection processes and governance. As a result, the collection of data on indigenous peoples is viewed as primarily servicing government requirements rather than supporting indigenous peoples' development agendas. (Taylor and Kukutai, 2015: 1)

This situation is clearly reflected in Australia based on the discussion presented above. Therefore, data in the context of IDS and IDG represent a form of self-determination in a sphere where previously it was only non-indigenous authorities and systems which defined the indigenous lived experience. Data collected according to these protocols would symbolise a form of power which may be used by indigenous peoples to advance their own agendas and decolonise health narratives. This is a dynamic which will be developed throughout the thesis at different levels as it appeared in the ethnographic record.

Increasing recognition of the deficit discourse and its impact in Australia has influenced a small but important re-orientation towards strengths-based research and policy agendas since the mid-2000s. This has worked in tandem with the movement towards IDS and IDG, resulting in an 'epistemological turn' in the wider Indigenous health narrative. This is a turn towards the recognition of Indigenous lived experiences, and the importance of having Indigenous people in control of health research and its outcomes.

Towards an Indigenous-directed health agenda

The Lowitja Institute, founded in 2010, has become Australia's premier centre for Indigenous health research (Lowitja Institute, 2020). It is an amalgamation of four Co-operative Research Centres which have been in operation since 1997. The Institute partners with 12 organisations across the country, including the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), the Indigenous Allied Health

Association (IAHA) and AIDA to facilitate health research, knowledge translation, and the development of Indigenous researchers. It is primarily funded by the Australian Government through the Cooperative Research Centres Programme of the Department of Industry, Innovation, and Science. According to a history of the Institute:

> Its roots lay in calls by Aboriginal and Torres Strait Islander people over many decades for real change in health status and health delivery for their communities. Paramount to that was the need for a new research paradigm, amid a growing sense and concern that research into the alarming evidence of health disparity for Aboriginal and Torres Strait Islander peoples was descriptive and too often serving the priorities of researchers and non-Indigenous people. In other words, for too long research had been done on Aboriginal communities not by or with Aboriginal communities. At the time, Aboriginal and Torres Strait Islander people argued they had been 'researched to death' with little benefit. (AIATSIS and the Lowitja Institute, 2017: 1)

Based on achieving social justice and equity for Indigenous Australians, the Lowitja Institute's core research principles are (AIATSIS and the Lowitja Institute, 2017: 56):

- Beneficence — to act for the benefit of Aboriginal and Torres Strait Islander peoples in the conduct of our research
- Leadership by Aboriginal and Torres Strait Islander people
- Engagement of research end users (Aboriginal and Torres Strait Islander organisations and communities, policymakers, other potential research users)
- Development of the Aboriginal and Torres Strait Islander research workforce
- Measurement of impact in improving the health of Aboriginal and Torres Strait Islander peoples.

The creation of an Indigenous-directed health research institute reflected the strong relationship that had been established between research and rights-based activism seeking Indigenous control over Indigenous outcomes (see above). This positioning is a direct challenge to the deficit discourse which has guided the Indigenous health narrative since colonisation. A key avenue for activist-research in Indigenous health has been the

strengths-based approach, which is related to a focus on assets, resilience, holistic health, wellness and wellbeing, protective factors, empowerment, and culture in the literature (for an overview of this literature see Fogarty et al., 2018b: 9-15). Strengths-based research is underpinned by decolonising approaches which involve "'speaking back" to, and "speaking beyond", simple problematics of health to recognise and fully embrace Indigenous worldviews including interconnectivity' (Fogarty et al., 2018b: 13). This ties in with the concept of *salutogenesis*, which focuses on factors which promote health, rather than pathologising the health of individuals and communities (Antonovsky, 1979).

In pursuing a strengths-based research agenda, it becomes necessary then to understand how Indigenous people themselves define health, wellbeing, and key influences. This will be one of the main themes explored by the thesis, and so it is important to provide a starting point here for the ethnographies which follow later. To date, there is only a small body of literature that explicitly defines or describes Indigenous Australian concepts of health, wellbeing, and culture, and how these interact with each other (Salmon et al., 2018: 1). Most of these studies provide either very general descriptions, or are highly contextualised within specific communities (for an overview of this literature, see Salmon et al., 2018). Given that this thesis engages predominately with national health narratives, it is those generalised concepts of health and wellbeing which are the most relevant here.

A foundational document in this literature was the 1989 *National Aboriginal Strategy* which was developed by the National Aboriginal Health Strategy Working Party following consultations with Aboriginal organisations and community groups across the country (NATSIHC, 2003: i). This document stated that:

> 'Aboriginal health' means not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being,

> thereby bringing about the total wellbeing of their Community. It is a whole-of-life view and includes the cyclical concept of life-death-life.… Health to Aboriginal peoples is a matter of determining all aspects of their life, including control over their physical environment, of dignity, of community self-esteem, and of justice. It is not merely a matter of the provision of doctors, hospitals, medicines, or the absence of disease and incapacity. (National Aboriginal Health Strategy Working Party, 1989: ix-x)

Similar definitions have been published since which emphasise that Indigenous concepts of health are based in spiritual wellbeing, encompassing the relationships an individual has to their family, community, ancestors, and the environment (NACCHO, 2011, Swan and Raphael, 1995). The quote above is an example of how 'health' and 'wellbeing' are used together or interchangeably in the literature to describe Indigenous experiences, and so this thesis will follow this pattern throughout (see 1.3. for further explanation).

The emphasis on culture as a foundation of Indigenous health and wellbeing has gained momentum in Australia as a result of Indigenous leadership, activism, and advocacy in the health domain. In the early days of anthropology as an academic discipline, the nature of culture was enthusiastically pursued. An example of this is the study of acculturation, a term first officially defined by Redfield, Linton, and Herskovits (1936) in the journal *American Anthropologist*. They described it as 'those phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original cultural patterns of either or both groups', distinguishing it from culture change, assimilation, and diffusion (Redfield et al., 1936: 149). The culture concept in anthropology has since been a hotly debated topic. Positions range from describing culture as providing 'the core conceptual framework for understanding all of human behaviour' (Winkelman, 2009: 20) to the argument that the culture concept is an invention of anthropologists, created to legitimise and sustain their independence from other academic fields (Wagner, 2016).

Current anthropological debates about the culture concept tend to focus on phenomenological approaches, describing culture as a dynamic process rather than as a stable entity (Rapport, 2014: 124-125). However, what have traditionally been missing from these debates are the voices of indigenous peoples themselves. As discussed further in Chapter 2, the lives and cultures of indigenous peoples have very often been conceptualised *for* them, not *by* them. For Indigenous peoples, culture is an integral part of the lived experience, and it is on this basis that the thesis engages with the culture concept.

The cultural determinants of health

In the Indigenous health narrative, culture has become operationalised by Indigenous-directed organisations through *cultural determinants of health*. The use of this terminology is a reflection of the widespread acceptance of social determinants in the public health sphere and the political power that epidemiological frameworks of health are able to generate. Social determinants of health is an established research framework in population and public health, following the work of British epidemiologist Michael Marmot and his colleagues studying health inequalities in the UK (e.g. Marmot et al., 1991, Strategic Review of Health Inequalities in England post-2010 (SRHIE), 2010) and across the world (e.g. CSDH, 2008, Marmot and Wilkinson, 1999, 2005). The social determinants framework has been used to advocate for changes in professional health practice (e.g. Davis and Chapa, 2015) and for the development of national policy strategies to reduce health inequalities (e.g. Marmot et al., 2020: 140-147).

However, there is conceptual ambiguity around the term 'social determinants' and how it is used in academic, health, and policy settings, leading to confusion over whether it relates to the determinants of health or the determinants of inequalities in health, or both (see Islam, 2019). Further, it has been argued that social determinants are inadequate for

explaining the influence of cultural factors which should to be considered determinants of health in their own right (Bethune et al., 2018, Chaturvedi et al., 2011, Park and Jacobs, 2018). While social determinants are often used to compare Indigenous peoples with non-Indigenous Australians, contributing to the deficit discourse (e.g. Burbank, 2011, Marmot, 2011), cultural determinants of health are specifically linked to strengths-based research approaches (see Kingsley et al., 2018, and Vance et al. 2017). As a novel framework, cultural determinants of health therefore offers an alternative to social determinants, and lends itself to the incorporation of Indigenous concepts of health and wellbeing into research, health practice, and public policy strategies (see Chapter 7 for further discussion). As this thesis will later demonstrate, it is also a framework which requires specificity in conceptualising what culture is to whom and how it may be measured.

In both medical anthropology and epidemiology:

> Cultural concepts provide an important corrective to the prevalent view that biology determines health, behaviour, and intergroup differences… Culture affects health through **risk factors**, conditions associated with an increased likelihood of diseases…, and **protective factors**, behaviours that reduce disease risks… (Winkelman, 2009: 20, emphasis in original)

Epidemiology in particular aims to understand patterns of human health and disease within a population, providing evidence that can indicate 'causal' or 'conditional' pathways within a quantitative framework. This quantification relies on the identification and development of 'variables', which must be scaled in such a way as to be calculable. The idea of culture, if it is to be useful in epidemiological research, must then be incorporated within this framework. It must become measurable and meaningful, at least to extent that the researchers can reasonably claim to have examined 'cultural determinants of health'.

In epidemiology, determinants refer to the 'causes', 'risk factors', and 'modes of transmission' which create health or disease within a population (Centers for Disease Control and Prevention, 2012). This epidemiological terminology is the most dominant form of scientific language in the Indigenous health narrative, alongside biomedical terms. *Social epidemiology* focuses on the health effects of social factors such as income, wealth, stress, class, and inequality, among others, and *cultural epidemiology* on the influence of localised cultural beliefs and behaviours (Trostle, 2005: 5) (see a discussion of these based on the ethnography in Chapter 3).

In 2014 the Lowitja Institute held a roundtable discussion to clarify the cultural determinants of Indigenous health and to consider the role of the Institute in supporting research addressing these determinants (Lowitja Institute, 2014). This roundtable was attended by Indigenous individuals only, and included Lowitja employees and 18 delegates representing community, professional, academic, and government stakeholders. The principal reason given for convening the roundtable was to move on from the general rhetoric about social determinants and to discuss the specific nature of cultural determinants of health for Indigenous peoples in Australia (Lowitja Institute, 2014: 1).

The key issues from the discussion that are described in the report include: the complexities of defining culture and how it is practiced across Australia, and the tension between culture as a positive influence and colonisation as a negative one (Lowitja Institute, 2014: 2) (see Figure 1), and the need for an evidence base to better understand the impact of culture on health.

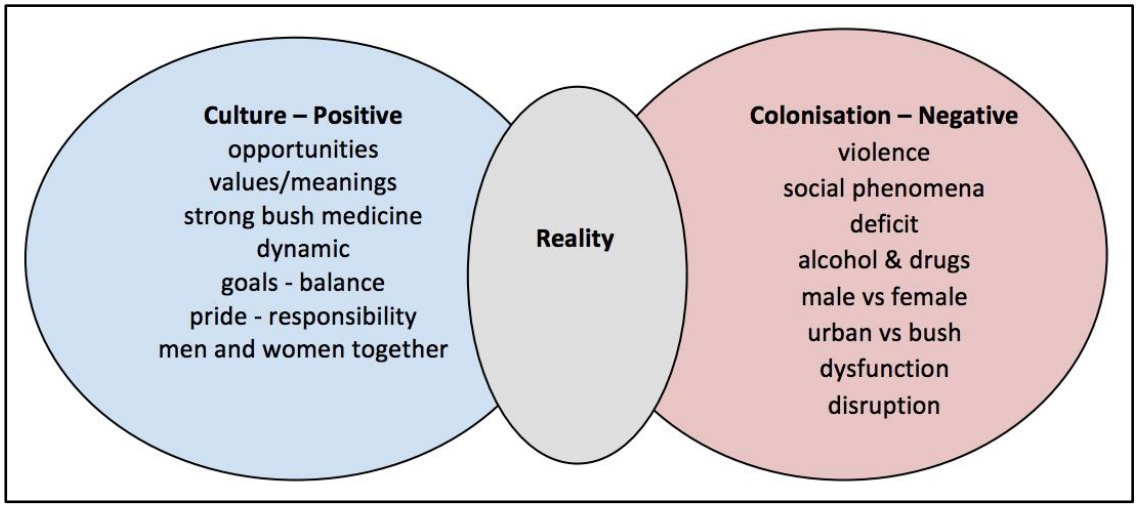


Figure 1. Model of tensions between culture and colonisation (Lowitja Institute, 2014: 2, Figure 1)

The report does not elaborate on the 'reality' dimension depicted in Figure 1, though the figure appears in the context of a discussion about 'dysfunction and deficit', stating that 'It was agreed that while it is critical to acknowledge trauma, we do not want to encourage people to constantly re-live it. We need to address the tension between dysfunction and deficit in safe spaces, with respect' (Lowitja Institute, 2014: 2). Juanita Sherwood, who is a Wiradjuri woman, referred to an Aboriginal Australian reality in her PhD thesis, *Do no harm: Decolonising Aboriginal health research* (2010), as representing an Indigenous worldview where the past, present and future exist alongside each other in a 'living cultural continuum' (Sherwood, 2010: 61). Therefore, the reality described in the Lowitja report may be interpreted as the lived experience of Indigenous Australians, where culture — as a positive reinforcement for health and wellbeing — exists alongside the negative outcomes of colonisation.

One of the key messages from their discussion was the importance of finding commonalities in culture across the diversity of Indigenous Australian cultures relating to land, people, and spirit (Lowitja Institute, 2014: 2). To this end, part of the research agenda agreed upon at the roundtable was a mixed-method longitudinal study or series of studies to establish an evidence base. The need for evidence of what Indigenous people have said

for a long time speaks to the dominance of Western scientific paradigms of 'truth' in Australian health policy development, where quantitative data is considered to be a more legitimate form of knowledge than qualitative data (Walter, 2005: 30).

This roundtable led to the creation of the largest study in Australia to focus specifically on understanding cultural determinants of Indigenous health — the Mayi Kuwayu Study. The development of this research endeavour is the primary focus of this thesis, which also looks at the ways in which MK reproduced Indigenous Australian concepts of culture, health, and wellbeing within its framework as a national epidemiological survey. The sections above have considered the changing character of the Indigenous health narrative in Australia, including its outcomes (data) and its underlying historical, political, and social influences. The following section will introduce the Mayi Kuwayu Study and begin to describe its positioning within this narrative.

1.3. Overview of the Mayi Kuwayu Study

The initial aim of the Mayi Kuwayu Study was to address a knowledge and evidence void in the literature about the cultural determinants of Indigenous health and wellbeing. MK is the first large-scale attempt to identify and measure the most important aspects of Indigenous cultures which may impact on a range of health and wellbeing factors in Australia. Crucially, it does not include non-Indigenous Australians and therefore does not engage with the deficit discourse.

MK's lead researcher, Ray Lovett, initially conceived of this project as a national longitudinal survey which would draw upon his expertise and that of his academic networks in epidemiology and public health. With this collective input, research and funding proposals were put together, and MK eventually won almost three million

Australian dollars in initial funding from the Lowitja Institute and the National Health and Medical Research Council (NHMRC) to support its development and the first mail out of the survey. To realise its goals, MK partnered with various Aboriginal and Torres Strait Islander community groups, and local, State-based and national health organisations, including the Lowitja Institute, AIATSIS, NACCHO, and the Healing Foundation, among others (for the full list, see: https://mkstudy.com.au/partners/ [Accessed 10 June 2020]).

Epidemiological studies of indigenous cultures and their influence on health and wellbeing has been undertaken previously in Canada. The *Our Health Counts Urban Aboriginal Health Database* project began in 2008 as a collaborative effort between different Indigenous Canadian organisations in Ontario, and was aimed at addressing the lack of population-based data about the health of Indigenous Canadians (Smylie et al., 2011). Funded by the Canadian Institute of Health Research, *Our Health Counts* surveyed 790 Indigenous community members living in Hamilton (Smylie et al., 2011) and 1,800 Indigenous people living in Toronto (Well Living House, 2018). The project utilised methods such as community-based participatory research, concept mapping, respondent-driven sampling, and data linkage to gather their baseline data. In the initial stages of developing MK, the Australian researchers sought advice from the Canadian researchers who designed the *Our Health Count*s project. At the same time one of the Canadian researchers, Janet Smylie, was recruited as a Chief Investigator (CI) for MK to provide advice and support.

Stage One of MK involved the development of its governance structures, conducting community-based indicator development and refinement workshops, and pilot testing its survey. Stage Two involved the recruitment of the first cohort of participants through the Medicare Australia database, which included over half a million self-identified Aboriginal and Torres Strait Islander individuals in 2017, which is around 68% of the Indigenous population in Australia (Jones et al., 2018b: 2). Medicare is an administrative branch of the

Australian Government which provides low-income Australians with subsidised access to health services. MK mailed their survey out to 20,000 individuals for the first pilot in late 2018 (for a demographic analysis of who responded to this mail out, see Wright et al., 2020). MK then mailed out the final survey to a further 180,000 people in 2019. This was in addition to online and face-to-face recruitment to access individuals who may not have been in the Medicare database. Given that Stage One of MK is the focus of this thesis, and that its protocols have already been published elsewhere (Jones et al., 2018b), only a brief background and overview of MK will be provided here.

To generate an evidence base of Indigenous cultural determinants of health, the size of MK and its applicability across a wide range of cultural contexts were vital aspects of its design. The MK researchers initially estimated that they would have a national baseline sample of 16,000–40,000 participants (Jones et al., 2018b: Figure 1). MK intends to distribute a follow-up survey every 3 to 5 years, recruiting more participants each time. In October 2019, over 7,500 surveys had been completed and returned to the MK team (R Lovett 2020, personal communication, 14 April), which is based at the Australian National University (ANU). This grew to 10,000 by May 2020. While this number is below the predicted sample size, it is still equivalent to the most recent NATSIHS collected by the ABS. Furthermore, the researchers have now decided to transform MK into a 'living cohort' study, which means that participant enrolment would be ongoing, rather than in waves like LSIC (R Lovett 2020, personal communication, 15 January). Recruitment of participants into MK at the national level relies mainly on advertising through TV, radio, and social media. MK incorporated Aboriginal and Torres Strait Islander Ambassadors into this advertising, showcasing prominent individuals known locally or nationally to reinforce MK's strengths-based cultural messaging (Figure 2) (see a selection of their video advertising at: https://mkstudy.com.au/ambassadors-and-elders/ [Accessed 10 June

2020]). MK also set up a free hotline which participants or interested others could call to find out more about the study.

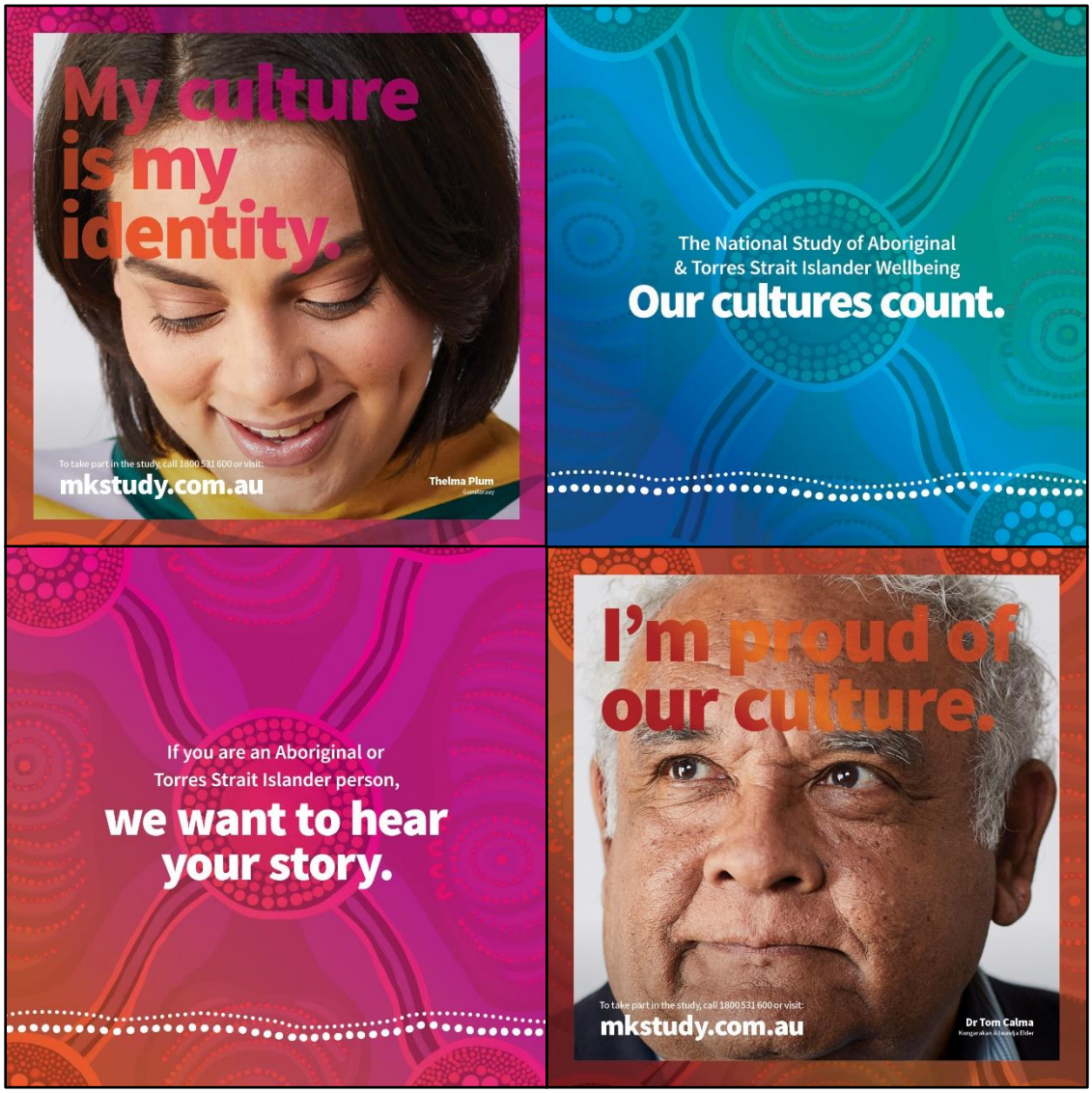


Figure 2. Advertising from the Mayi Kuwayu Study (used with permission)

MK is founded on privileging Indigenous knowledges and voices throughout the research process. As the lead researcher, Ray endeavoured to make MK a leading example of how research with Indigenous peoples should be conducted. In addition to adhering to the NHMRC's *Indigenous Research Excellence Criteria* (NHMRC, 2014) and the AIATSIS *Guidelines for Ethical Research in Australian Indigenous Studies* (GERAIS) (AIATSIS, 2012), MK sought additional ethics clearances from the peak Indigenous research bodies in all the

jurisdictions in which it operates. MK also incorporated 'good data' practices, which relate to Indigenous research and data governance protocols (after Lovett et al., 2019). These protocols were designed to ensure that the development and direction of MK would be in the hands of Indigenous stakeholders, rather than determined by non-Indigenous institutions. While MK and its full-time staff are located at the ANU, neither this institution nor the study's primary funding bodies have control over MK or its data.

MK uses IDS and IDG as platforms for managing the data gathered from the survey. As highlighted above, Indigenous data sovereignty and governance are a response to the colonial and deficit discourses which have plagued statistics about Indigenous peoples since data were first collected (Lovett et al., 2019: 26-27). As the MK lead, in authorship with others, Lovett stated:

> Data governance is the power and authority over the design, ownership, access to and use of data. … For Indigenous peoples, whose traditional modes of governance were disrupted by Western modes of democratic governance, re-asserting themselves through self-determined governance structures is critical. … Indigenous peoples' ownership is integral to autonomy. (Lovett et al., 2019: 27)

MK adheres to IDS and IDG protocols in a number of ways (for full details, see Lovett et al., 2019: 32-33). First, its primary objective was to develop survey questions which represent Indigenous interests in cultural expression and practice (see below). Second, as mentioned above, it has modelled itself on best practice frameworks for working with Indigenous peoples in Australia, including recognising Indigenous knowledge as intellectual property with the rights and benefits this entails. Third, access to and use of the data is managed by the Mayi Kuwayu Study Governance Committee, comprised of Indigenous community members and stakeholders from across Australia, whose expertise in Indigenous health is contributing to the development of further protocols for data storage, access, analysis, and dissemination.

Legg (2005: 143) referred to 'the politicisation of numbers' through statistical data, where 'numbers need not just be tools of rule, but can be mobilised against a state to demand justification, explanation or provision'. By collecting new numbers in line with a strengths-based, decolonising methodology, MK's survey aims to mobilise its statistics to challenge currently upheld 'truths' and re-structure health norms around the issues which are of importance to Indigenous peoples. As stated in their protocol, MK aimed to 'enable quantification of associations and pathways between cultural practice and expression, social determinants of health, health behaviours, and health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples' (Jones et al., 2018b: 2). To meet this objective, MK was designed to generate (adapted from Jones et al., 2018b: 2):

1. Indicators of Aboriginal and Torres Strait Islander cultural practice and expression that capture diversity and maintain meaning across contexts.
2. Large-scale data on cultural practice and expression, sociodemographic factors, health and well-being, health behaviours, experiences and environments, and family support and connection, both cross-sectionally and over time.
3. A state-of-the-art data resource for investigating Aboriginal and Torres Strait Islander well-being, which can also serve as a framework for policy and programme planning.

This thesis focuses on the processes which informed the first outcome, which were being undertaken by the MK researchers at the time of my fieldwork in 2017–2018. Some of the survey items (indicators) were based on established or modified instruments already employed in other Indigenous health surveys in Australia and elsewhere (Jones et al., 2018b: 5). New items were developed through literature reviews (Salmon et al., 2018, Bourke and Wright et al., 2018), two early 'proof-of-concept' studies (n = 369 participants) (Jones et al., 2018a, Lovett et al., 2017), and 28 Aboriginal and Torres Strait Islander community consultations (n = 197 participants) in the form of focus groups held across Australia between 2014 and 2017. Using an iterative qualitative process within a strengths-

based framework, the MK researchers then finalised the items included in the baseline survey released in October 2018.

A comprehensive literature review about the cultural determinants of Indigenous health was published by affiliates of MK in partnership with the Lowitja Institute in 2018 (see Salmon et al., 2018). The review identified a number of key aspects of culture which influenced Indigenous health outcomes, including (adapted from Salmon et al., 2018):

- *Connection to Country* — refers to the land/s which people are bound to through their ancestors and encompasses the 'emotions, culture, and spirituality where Aboriginal and Torres Strait Islander Peoples have positive connections such as the ability to "get answers from nature" and have a "sense of welcome"' (Salmon et al., 2018: 10). This can be reinforced by collecting and using traditional foods and medicines, living on Country, establishing land rights and autonomy, and caring for Country through land management activities and reinforcing social and spiritual relationships.
- *Beliefs and knowledge* — includes spiritual and religious beliefs, traditional knowledge, traditional healing, and knowledge transmission and continuity.
- *Language* — incorporates both continuing language use and revitalisation activities.
- *Family, kinship, and community* — this can be specific or general, as Nyungar man and Aboriginal health expert Ted Wilkes has described:

  > The Aboriginal community can be interpreted as geographical, social and political. It places Aboriginal people as part of, but different from, the rest of Australian society. Aboriginal people identify themselves with the idea of being a part of a 'community'; it gives us a sense of unity and strength. Sometimes, issue based groups are perceived as a community — but that is not the case, it is a re-configuration of some parts of the existing community. When I think of the notion of Aboriginal community, I think of us all together as a political and cultural group. It includes everyone no matter what 'faction' or local group they are affiliated with, or which part of our diversity they live in. It is a national concept. (Wilkes, T. in Dudgeon et al., 2002: 2)

- *Cultural expression and continuity* — incorporates connection to Country and community, respect for elders, kinship and family connections, gender and age roles, identity, language, art and ceremony, music and dance, sport, spirituality, and storytelling.

- *Self-determination and leadership* — relates to notions of cultural safety and community control.

It is these aspects of culture which will be referred to throughout the thesis, with the plural *cultures* used to highlight Indigenous cultural diversity where applicable, unless otherwise stated.

The Mayi Kuwayu Study is both conforming and subversive, using the epidemiological tools of government (quite literally through the use of government databases like Medicare) to establish new norms representing Indigenous lived experiences. This is a fertile ground for an anthropological exploration of how culture and Indigeneity itself may be conceptualised, all within the highly political landscape of Indigenous health in Australia. By focusing on how Indigenous perspectives transform and are transformed within the Mayi Kuwayu Study, this thesis explores how Indigeneity can become embedded in health research, and how data as power can support Indigenous self-determination.

Chapter 2 — An Indigenist Methodology

Anthropological methodologies (systems of methods) and methods (activities used to collect knowledge) have long been criticised by indigenous peoples. A song called *Here come the anthros* (1969) by singer, actor, and political advocate Floyd Red Crow Westerman, who was a member of the Sisseton-Wahpeton Sioux Tribe of South Dakota summarises this critique. The opening lyrics are:

> And the anthros still keep coming
> Like death and taxes to our land;
> To study their feathered freaks
> With funded money in their hand.

In a chapter also titled *Here come the anthros* (King, 1997, reprinted in Robben and Sluka, 2012: 207) after Westerman's song, Cecil King who is Odawa from the Wikwemikong First Nation, wrote: 'We have been observed, noted, taped, and videoed. Our behaviours have been recorded in every possible way known to Western science, and I suppose we could learn to live with this if we had not become imprisoned in the anthropologists' words'. King goes on to describe the ways in which anthropological terms have redefined indigenous lived experiences within Western constructs:

> Anthropological terms make us and our people invisible. The real people and the real problems disappear under the new rhetoric. Indian, Métis, and Inuit problems defined incorrectly lead to inappropriate solutions, irrelevant programs, and the reinforcement of the status quo. (King, 1997, in Robben and Sluka, 2012: 208)

Western constructions of indigenous realities, truths, and knowledges have had a profound impact on indigenous peoples and have served to perpetuate harmful norms and colonial agendas. As discussed in the introductory chapter, epidemiology is implicated in the construction of the 'statistical Indigene' in Australia, cast as the problematic Other in

comparison to the non-Indigenous population (Walter, 2010: 51) (see below for a discussion of *othering*). Knowing this, I needed to re-examine the disciplinary norms used in my practice to more effectively decolonise my research and re-centre it from an Indigenous standpoint. My identity as an Aboriginal Australian has had a significant influence on my thinking and approaches to this thesis. I have occupied a number of social roles during my study and fieldwork and have had to adapt my approaches to fulfil both the goals of my research and my socio-cultural responsibilities as an Indigenous person.

This complex positionality enabled me to examine how an Indigenous researcher might develop anthropological practice by addressing some of the methodological issues in both 'being' and 'doing' anthropology (after Medicine, 2001: 3). To undertake my work with the Mayi Kuwayu Study it was crucial that I frame my research in ways which spoke to my Indigeneity and the Indigeneity of my participants, within the broader world in which we as Indigenous people and researchers live and work. This chapter elaborates on the theories I have chosen to guide my work and contextualises the specific methods I used to collect my data. My research aims to contribute to an increasingly dynamic, reflexive branch of modern anthropological enquiry undertaken by, with, and for indigenous peoples.

2.1. Anthropology and othering

Anthropology as a discipline problematises the world in which people live. The complexities of what constitutes anthropological knowledge has been extensively debated since the 1980s through the postmodern movement (for examples, see Clifford, 1983, and Freeman, 1983). This movement, also known as the 'postmodern turn' across the social sciences (Seidman, 1994), occurred in anthropology as a result of increasing critiques of

the authority of anthropologists to represent non-Western peoples and methodologies based on *othering* (Clifford, 1983). As German anthropologist Johannes Fabian stated:

> othering expresses the insight that the Other is never simply given, never just found or encountered, but *made*. For me, investigations into othering are investigations into the production of anthropology's object. (Fabian, 1990: 755, emphasis in original)

Othering is based on social stereotypes, and in historical anthropology, was closely tied to the study of culture in seeking to objectify and characterise the lives of the exoticised 'out-group' (Dervin, 2012). Although anthropology has always been diverse in its practices, the legacy of past research continues to have a negative impact on the lives of indigenous peoples today. The history of anthropology's influence on indigenous peoples has been discussed in several publications by indigenous academics (e.g. Kovach, 2009, Medicine, 2001, Nakata, 2007, Smith, 1999). This section summarises findings from related texts in this field and elaborates on the framing of Indigeneity in the Australian context.

British social science theorist Andrew Sayer (1992: 13, emphasis in original) wrote about four common misconceptions in the production of knowledge in the natural and social sciences, which form the basis of much of the critique from the above-mentioned scholars:

- That knowledge is gained purely through contemplation or observation of the world.
- That what we know can be reduced to what we say.
- That knowledge can be safely regarded as a *thing* or *product*, which can be evaluated independently of any consideration of its production and use in social activity.
- That science can simply be *assumed* to be the highest form of knowledge and that other types are dispensable or displaceable by science.

Specifically, it is the Western philosophical framing of science and scientists as 'objective' which is problematic, given its use by non-Indigenous agents to 'bolster white possession

and nullify Indigenous humanity' (Walter, 2010: 52). The seminal work *Decolonizing methodologies* by Linda Tuhiwai Smith (1999), a Māori academic from the Ngāti Awa and Ngāti Porou iwi, directly criticised the work of anthropology, which she argued 'made the study of us into "their" science' (Smith, 1999: 11). She wrote:

> The ethnographic 'gaze' of anthropology has collected, classified and represented other cultures to the extent that anthropologists are often the academics popularly perceived by the indigenous world as the epitome of all that is bad with academics. (Smith, 1999: 66-67)

The anthropologist's ethnographic gaze in its most basic form is an attempt at scientific observation, and thus reduces and essentialises its object — indigenous peoples in this case (Smith, 1999). In the early days of anthropology as a discipline, the anthropologist was thought to be in the privileged position of 'outsider' in the field, who would be able to objectively engage with participants in the field without becoming 'part of the field' (Moore 2012: 87). The ethnographic writing of the anthropologist's observations of what occurred during their time in the field formed the basis of their contributions to the Academy and professional reputation (and still does). As American anthropologist James Clifford (1983: 120) stated 'ethnographic writing enacts a specific strategy of authority'. Following on from these assumptions, the interpretation of the anthropologist came to represent a valid account by a *bona fide* scientist of an otherwise mysterious and unknowable Other.

While many modern anthropologists would no longer consider their research to be objective in this way, this history and its underlying assumptions continues to negatively impact Indigenous communities. The representation of Indigenous peoples in historical anthropological writing has led to the construction of an 'ethnographic present' which cast Indigenous people 'in a stilted, static stance' (Medicine 2001: 290). As has been pointed

out by several indigenous and non-indigenous scholars, anthropologists and their knowledge are not value-neutral (Clifford, 1983, D'Amico-Samuels, 2010, Davies, 2008, King, 1997, Medicine, 2001, Smith, 1999, Tedlock, 1991, Wagner, 2016). Reflecting on research in the twentieth century, Margaret Kovach, a Plains Cree and Saulteaux academic from Saskatchewan, argued that:

> ethnographical research design was employed as qualitative 'objective' studies of the 'other. … These early qualitative studies were responsible for extractive research approaches that left those they studied disenfranchised from the knowledge they shared. (Kovach, 2009: 27)

This process of othering and the lack of attribution for the intellectual property of indigenous participants in research remains a very real concern for indigenous communities who are approached by anthropologists and other researchers today.

> A continuing legacy of what has come to be taken for granted as a natural link between the term 'indigenous' (or its substitutes) and 'problem' is that many researchers, even those with the best of intentions, frame their research in ways that assume that the locus of a particular research problem lies with the indigenous individual or community rather than with other social or structural issues. … For many indigenous communities research itself is taken to mean 'problem'; the word research is believed to mean, quite literally, the continued construction of indigenous peoples as the problem. (Smith, 1999: 92)

All of these factors combine to make it very challenging for an Indigenous person to undertake anthropology, which becomes a double bind when they seek to work with Indigenous peoples as an anthropologist. A number of indigenous authors have written on this subject, and it is their writing which I reflect on in the following section to situate myself as an Indigenous person working with other Indigenous people for my research.

Positioning Indigeneity in anthropological research

My positionality does not fit neatly into traditional anthropological conceptions of insider-outsider research for this thesis. It is common for Indigenous researchers working on Indigenous issues to experience a complex positionality as individuals and researchers, and this was the case for a number of my participants from the Mayi Kuwayu Study (see Chapter 3). The Indigenous experience in Australia facilitates dynamic identities which respond to the social environments in which we live. This adaptability has always been possible with an Aboriginal identity according to Wergaia and Wamba Wamba elder Eleanor Bourke:

> it is not simply a reaction to opposition, the identification of yourself as one with other victims of European invasion. It is the original identity that comes with a relationship to this particular land. That identity is multiple, but able to be totalised. At the same time, Aboriginality adapts to a changing present; it participates actively in a variety of social processes, the result of which is that both black and white identity are modified. (Bourke E, in Gardiner and Bourke, 2000: 43)

Insider-outsider research has been widely critiqued in the literature for its oversimplification of researcher identities and interactions (for examples, see Medicine, 2001, Narayan, 1993, Nelson, 1996). A common theme across these texts are experiences of hybridity or multiplexes of identity which come into play for 'insider' anthropologists working with participants at 'home'. Beatrice Medicine, anthropologist and descendant of the Sihasapa and Minneconjou bands of the Lakota Nation, discussed the complexities of being an indigenous person and doing anthropology in her book *Learning to be an anthropologist and remaining "native"* (2001). She wrote: 'The ambiguities inherent in the two roles of being an "anthro" while at the same time remaining a "Native" need amplification. They speak to the very heart of "being" and "doing" anthropology' (Medicine, 2001: 3).

Medicine goes into detail about how her indigenous identity had an impact on her role as an anthropologist (and vice versa). She emphasised the importance of analysing anthropological 'truths', and the influence of the Indigeneity of the researcher on creating new ways of conceptualising indigenous lived experiences.

African-American scholar Linda Williamson Nelson (1996: 184) described doing research as a 'native' anthropologist as experiencing 'gradations of endogeny', and that:

> By looking inward as well as outward at the subject under study, we are able to see ourselves as cultural actors and potential objects of study. This inward focus can provoke our consideration of the ways in which the researcher's identity unavoidably contributes to the kind and quality of the information we gather. Paradoxically, such multifaceted vision can only be fully actualized after we first acknowledge that native status is not a fixed constant with the same intensity from informant to informant and from place to place. (Nelson, 1996: 184-185)

This suggests that we should not distinguish between 'insiders' and 'outsiders' in anthropology, as all researchers, whether in the natural or social sciences, are integrated into their research (Davies, 2008: 3). Researchers are both insiders and outsiders, not on a spectrum, but within a dynamic web of relations. As Indian-born American anthropologist Kirin Narayan (1993: 671) argued, 'we might more profitably view each anthropologist in terms of shifting identifications amid a field of interpenetrating communities and power relations'.

Undertaking this approach through my research aligns with what Narayan called 'enacting hybridity' (Narayan, 1993: 681). Drawing on the work of other authors, Narayan breaks the term down to explain that 'enacting' means that when the researcher relates their experiences through text, it embodies theory, and that 'hybridity' represents the inclusion of both the personal and professional identities of the author into their writing. As Eleanor Bourke described above, Aboriginal identities have always been able to adapt (Bourke E,

in Gardiner and Bourke, 2000: 43). Therefore, in the writing of this thesis I have endeavoured to make evident the influence of my Indigeneity on the text in conversation with the identities of my participants. The theoretical framework I have used to contextualise these identities draws from the literature on Indigenous paradigms of research, which is explored in the following section. To reflect its use in the literature I capitalise the 'I' when referring to 'Indigenous paradigms of research', including Indigenous epistemologies and methodologies.

Indigenous paradigms of research

As an Indigenous researcher working with other Indigenous people, I must understand the points of conflict and congruence that anthropology may have with Indigenous paradigms of research. Kovach (2009: 29) argued that 'There is a fundamental epistemological difference between Western and Indigenous thought, and this difference causes philosophical, ideological, and methodological conflicts for Indigenous researchers'. For guidance in how to navigate these complexities, I explored some of the literature on Indigenous paradigms of research.

The first thing which distinguishes an Indigenous paradigm is that knowledge is regarded as relational, or collectively owned by all, rather than the property of an individual researcher (Wilson, 2001: 176). In acknowledging this, researchers must consider their relational accountability to people, places, and others when conducting research (Wilson, 2001: 177). Kovach expanded on this concept when she wrote:

> An indicator of a relational approach in research can be found within process and content… Indicators that this holistic epistemology is present include explicit reference to personal preparations involving motivations, purpose, inward knowing, observations, and the variety of ways that the researcher can relate her own process undertaken in the research. Another way to assess process is to see

> the inclusion of story and narrative by both researcher and research participant. (Kovach, 2009: 34-35)

An Indigenous research paradigm can therefore be defined as being relational, in so much as the research reflects the positionality of the researcher (Wilson, 2001, Kovach, 2009, Smith, 1999, Medicine, 2001). This raises issues for the traditional one-author approach to publishing in anthropology, which privileges the viewpoint of the anthropologist above the participants with whom they co-produce knowledge. In contrast, scientific publications, including those by the Mayi Kuwayu Study researchers, often list all individuals who have contributed to the publication as authors, whether they engaged in the writing process or simply provided professional feedback and input. Multiple authors reflect a relational practice, fitting with the ethos of an Indigenous paradigm in disciplines where authorship conveys authority.

Anthropology generally does not encourage this kind of relationality, and may in fact actively discourage it, as in anthropology authorship through ethnography is very much considered to be an individualised creation (as opposed to description) of what the author/anthropologist believes to exist (Plemmons, 2011: 391, Graeber, 2010). An Indigenous anthropological practice might distinguish itself as a collective, group pursuit rather than the work of a lone researcher. However, given the limitations of this thesis as a DPhil endeavour, relationality had to be practised via other means (see below).

Indigenous research paradigms must also demonstrate evidence of process and content (Kovach, 2009: 32). Both of these aspects require a 'critical reflexivity' (Herising, 2005: 136), which as a form of self-reflection, requires researchers to be aware of their positionality in their research. This ability is central to good social science inquiry (Dahms, 2008) and the concept of reflexivity is well-established in anthropology (for a comprehensive discussion, see Davies, 2008). Reflexivity has been described as 'process of

reflection, which takes itself as the object… of provocative, unrelenting thought and contemplation' (Nazaruk, 2011: 73) and 'a turning back on oneself, a process of self-reference' (Davies, 2008: 4). Here we can see how an Indigenous research paradigm may fit alongside anthropological inquiry, through a process of acknowledging why and how research has been conducted, and in the writing of ethnography to expand on it.

In addition, Kovach (2009: 35) argued that Indigenous paradigms of research utilise the ideology of respect. Respect in this context goes beyond adhering to institutional ethics protocols. It touches upon indigenous cultural concepts which, as Mi'kmaq academic Marie Battiste has highlighted, include the responsibility to ensure indigenous knowledges are protected, and a responsibility to the indigenous collective you work with in the production of research (Battiste, 2007). This collective responsibility means conducting yourself in a way that your indigenous family and ancestors would recognise and approve of, and when enacted, represents a continuation of your cultural connection to them.

> we can only go so far before we see a face — our Elder cleaning fish, our sister living on the edge in East Vancouver, our brother hunting elk for the feast, our little ones in foster care — and hear a voice whispering, 'Are you helping us?'. (Kovach, 2005: 31)

These paradigms of inquiry provide guidance for an Indigenous anthropologist to navigate the complexities of positioning themselves in research. My Indigeneity motivated me to undertake this research and acted as a guide for navigating the representation of others within my thesis. This has been a liberating process for me, and I have taken it as a chance to learn more about myself as an Indigenous person in the world, and as an opportunity to use my research to benefit other Indigenous people. The other aspects of my identity, including being female, young, an Oxford University student, and more, have also needed to be acknowledged and negotiated constantly throughout the research process.

At times, making one or more of these identities salient (e.g. by identifying as an Aboriginal person when meeting participants) became a strategic tool for my data collection to engender trust or to contribute to the making of a culturally safe space for participants (see Chapter 4 for examples). However, it has been a struggle at times to maintain emotional distance from my research. Working in the field of Indigenous health involves wading through decades of literature which reinforces the deficit discourse, positioning Indigenous peoples — and therefore myself — as the Other, worthy of 'protection' but not autonomy.

When Indigenous Australians move outside their stereotyped spaces of existence, they lose their authenticity as being truly 'Indigenous' in the eyes of White Australians and some Indigenous people who have internalised these stereotypes. Yin Paradies (2006), an Aboriginal-Asian-Anglo Australian academic, has written an excellent account of this identity conflict, using his own Indigeneity as an example:

> Due, in large part, to my grandmother being a member of the Stolen Generations, I do not speak an Aboriginal language, I do not have a connection with my ancestral lands or a unique spirituality inherited through my Indigeneity, I have little contact with my extended family, and the majority of my friends are non-Indigenous. Also due to this same history, I am a middle-class, highly educated professional working in the field of Indigenous research. As such I am frequently interpellated as Indigenous and called upon to deploy my Indigeneity in a professional context, while at the same I am labelled by some as an inauthentic 'nine-to-five black' or a 'coconut', who has stolen the place of a 'real Aborigine'. (Paradies, 2006: 358)

Paradies refers to two terms which are used as insults against Indigenous people, either by non-Indigenous people or, more commonly, as a form of lateral violence. 'Nine-to-five black' is used to indicate an Indigenous person who does not socialise with other Indigenous people outside work (Oxenham et al., 1999: 112), and 'coconut' implies that a

person is Black on the outside (i.e. skin colour or superficial behaviour) but White on the inside (i.e. personality, beliefs, etc.) (Dudgeon and Oxenham, 1989, as cited by Paradies, 2006: 364). The personal impact of being made to feel what I call *unIndigenous* (i.e. not 'Black' enough to be Black, but not 'White' enough to be White) cannot be understated. It is in challenging this discourse, and by researching how others do so within MK, that I am able to optimise my agency.

There are a few ways in which my research does not or cannot fit with international Indigenous paradigms of research. Firstly, given the nature of my research as a DPhil project, there are limits to the ways in which the thesis can be relational. For example, I must be the sole author of my thesis, as within academia the thesis represents my original contribution as an academic to the field of anthropology. Therefore, I aim to adhere to the ideology of relationality as Kovach (2009: 34-35) has suggested by relating my research processes through the text and by including the narrative of my participants alongside my own. One method I use to achieve this is to identify those individuals who have contributed to my theoretical foundations or data collection in the text (see *A note on participant identification* below). Another is to ensure that I reproduce my research in forms which are easily accessible to my participants. This will be done primarily through a report summarising my research findings, which I will prepare and submit to MK following the examination of my DPhil. I also plan to publish aspects of my work in collaboration with some of the MK researchers.

Secondly, Kovach argued that a 'tribal epistemology' should be the starting point of an Indigenous research methodology (Kovach, 2009: 35). Writing within the Canadian context, she said that true Indigenous methodologies must be based within a tribal knowledge system, and that this is part of what makes Indigenous methodologies legitimate and distinctive (Kovach, 2009: 36-38). Undertaking a specific 'tribal

epistemology' is not possible for my research in the Indigenous Australian context. The main reason is that the notion of an Aboriginal tribe or tribes in Australia is complex, and inextricably tied with imperialist perceptions of Indigenous peoples. I have met with Aboriginal people who easily and proudly use the term to describe themselves and their traditional ties, as well as others who avoid it specifically because of its colonial connotations. Even the anthropological history of the word 'tribe' itself is problematic (Béteille, 1998, Sneath, 2016). As Indian sociologist Andre Béteille (1998: 187) wrote:

> The 19th-century view was that the tribe represented not only a particular type of society but also a particular stage of evolution. The presumption with which most anthropologists then worked was that the tribe was an isolated, self-contained, and primitive social formation.

My personal feeling aligns with this interpretation, and so I would not use the word 'tribe' to describe any part of my identity or academic practice. Another reason I would not undertake a specific 'tribal epistemology' in my research is because the Indigenous context of the Mayi Kuwayu Study is multi-cultural, or even pan-cultural, as it does not place emphasis on any one Indigenous group or philosophy. However, if I were to interpret Kovach's use of the term 'tribe' as a reclaiming of terms which in the past have been used against Indigenous people (much like the word 'Black/Blak' which Indigenous peoples use to refer to themselves, imbued with a sense of solidarity against White Australians) then it is possible to undertake an *Indigenous Australian epistemology* in my research (see discussion of Indigenist research below).

Another aspect of grounding research in Indigenous epistemologies is the use of Indigenous languages (Kovach, 2009, Medicine, 2001). Indigenous Australian language terms rarely appeared in the ethnographic data I collected, as the Mayi Kuwayu Study — including the focus groups and the survey itself — was conducted in English. Where an

Indigenous language word was used by participants in the focus groups in conversation with the researcher, they also gave an English translation and description. Furthermore, the language of the Academy from which I have written this thesis is English, and it is the mastery of this language which has enabled me to undertake a doctorate. Nevertheless, it is worth acknowledging that because MK has not integrated Indigenous languages into their outputs to date, local Indigenous cultural concepts were also not incorporated. The implications of this are discussed in context in Chapter 4.

As more Indigenous people experience the world through English, so then do Indigenous cultures and concepts come to be represented in English. As an Aboriginal person and anthropologist I appreciate the limits and the opportunities which communicating Indigenous knowledges in English provides. Here is a space in which I may use my Indigeneity and my lived experience as an Indigenous person as tools to appreciate and contextualise the lived realities of other Indigenous people.

Growing awareness of the deficit discourse in Indigenous Australian research, including increasing pressures from Indigenous communities and organisations, has led to the ethical requirement for researchers in Australia to seek partnerships with relevant communities (AIATSIS and the Lowitja Institute, 2013). However, in the highly politicised domain of health, the deficit discourse continues to dominate the field (see Chapter 1). In challenge to this norm, Indigenous researchers together with non-Indigenous researchers have established a strengths-based research agenda which aims to highlight the positive impact that Indigenous knowledges, cultures, and ways of being have on Indigenous lives (Fforde et al., 2013) (see Chapter 1). It does not try to deny the realities of Indigenous experiences of disadvantage in Australia, but strives to disrupt dialogues which focus on narratives of failure and the inferiority of Indigenous individuals and communities (Fogarty et al., 2018b: vi).

A strengths-based approach also has the potential to reconfigure anthropological practice undertaken with Indigenous peoples. As a starting point for my research I have relied on my academic training in psychology, biological anthropology, and medical anthropology, and how these work alongside a developing and complex Aboriginal identity, and a desire to explore what this means within the Academy. This research is better conducted within an amalgamated framework, reflecting both the authors' positionality, that of MK and my participants, as well as the nature of research which seeks to incorporate Indigenous paradigms with anthropological approaches. Therefore, I have decided to employ a strengths-based approach to frame my research questions and the methods used to answer them. Throughout this thesis I use my analyses to expand on the strengths of Indigenous communities and cultures, and to challenge the deficit discourse wherever possible.

Combining Indigenous paradigms together within a strengths-based approach in the Australian context may be described as *Indigenist research* (Rigney, 1999b). Lester-Irabinna Rigney, a descendant of the Narungga, Kaurna, and Ngarrindjeri peoples of South Australia and Professor of Education at the University of South Australia, argued that 'Indigenist research is research by Indigenous Australians whose primary informants are Indigenous Australians and whose goals are to serve and inform the Indigenous struggle for self-determination' (Rigney, 1999b: 118). According to Rigney (1999b: 116), Indigenist research is informed by three key principles:

- Resistance against oppression of Indigenous Australian perspectives
- Political integrity, and the undertaking of research by Indigenous Australians
- The privileging of Indigenous voices in the writing up of research

By undertaking Indigenist research, the complexity of my positionality may exist and operate. There is no single Indigenous research epistemology or ontology (Rigney, 2006: 39). However, there are common themes which I utilise in this thesis — relationality,

reflexivity, respect, and resistance — alongside a strengths-based approach to form an Indigenist research approach (Figure 3). This framework aspires to inform my practice of medical anthropology to facilitate a dynamic analysis and critique of MK.

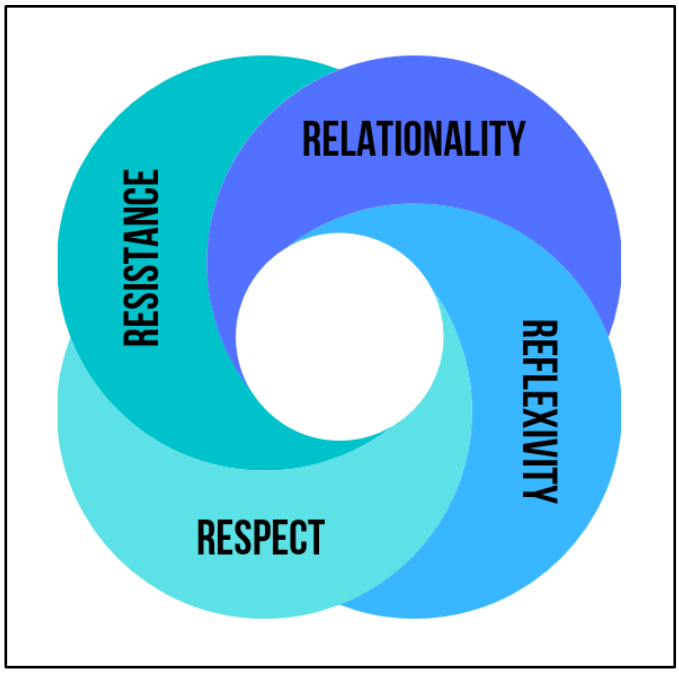


Figure 3. Bourke's Indigenist research approach

The four dimensions of my Indigenist research approach are inter-related and draw from the literature detailed above on relationality (after Kovach, 2009, and Wilson, 2001), reflexivity (as defined by Davies, 2008), respect (discussed by Kovach, 2009) and resistance (Rigney, 2006, Smith, 1999). In this thesis I hope to demonstrate relationality by acknowledging that the research I have conducted is built upon the endeavours of those who came before me, and that the knowledge produced here should be disseminated to become part of the collective. I practice reflexivity by looking inwards at the ways in which my Indigeneity shaped my research and by making these influences explicit through my writing. I seek to show respect through acknowledging the intellectual property of others by name where possible in my research, and by conducting myself in a way which my Aboriginal ancestors and community would recognise and be proud of. Finally, I endeavour to resist the deficit discourse of Indigenous Australian health research by

utilising decolonising thoughts and practices from a strengths-based perspective in this thesis. As an example, I refer to Indigenous or other non-White authors whenever possible in my thesis to make my use of their knowledge more salient. I have also worked to counter the traditional power imbalance between anthropologist and participant by giving my participants more control over the data I collected from my observations and interviews (see below).

The ethical aspects of this research have been approved by the University of Oxford Central University Research Ethics Committee (SAME_C1A_17_024) and the ANU Human Research Ethics Committee (Protocol 2016/767). I have also followed the fourteen principles contained within the GERAIS (AIATSIS, 2012) where possible within the limitations of this research as a DPhil thesis.

2.2. Working with the Mayi Kuwayu Study

My first contact with what was to become the Mayi Kuwayu Study was in 2014, when Ray Lovett and his colleague were visiting Oxford to present their research findings about smoking and alcohol use by Indigenous Australians. As an Aboriginal Australian and MPhil student in Oxford at the time, I was introduced to Ray at a social gathering following their presentation. At the time he mentioned that he was working on developing a large-scale Indigenous health project — 'top secret' as he described it — and said that I should get in touch with him when I was back in Australia if I wanted to get involved. In 2015, Ray returned to Oxford to take up a six-month Endeavour Research Fellowship. He wanted to learn more about how to develop a large-scale longitudinal cohort study from the epidemiologists who created the *Million Women Study*, which is a national study of women's health in the UK with more than one million participants aged 50 years and over (University of Oxford, 2018). I met with Ray a few times to discuss his research and he

offered to become an advisor or supervisor for my doctoral research if I wanted to continue working on Indigenous health issues.

I took a break from my studies following the MPhil and it was during this time that I developed the idea for a DPhil project whose methodology and subject was based within a strengths-based framework. After talking more with Ray about my ideas he offered his project, the newly named Mayi Kuwayu Study, as the focus of my DPhil. My research would provide an independent, anthropological analysis of how MK was developed, and would focus on the researchers and their survey. He also offered his support in getting access to the other individuals involved with MK, as well as fieldwork funding through grants allocated to developing the skills of Indigenous researchers.

I was unsure initially about how to write about Ray's positionality in my research, given his inter-related roles as advisor, mentor, facilitator and participant. I discussed this early on with my Oxford supervisor Stanley Ulijaszek, as well as Ray, and we decided that Ray's role would be dual: firstly, to facilitate my research as an advisor in Australia by providing me with access to MK and its researchers; then as a participant, as to exclude him from my research would be to exclude a major part of MK.

This created additional complexities for me as a researcher during my fieldwork in Australia, as conceptually switching Ray's role from advisor to participant in everyday interactions took some practice, and the boundaries were not always clear at the time. As I discuss in more detail later, I systematically selected the contexts in which I would conduct my participant observations (e.g. taking notes during team meetings or focus groups). As Ray and I met several times to discuss the practicalities of my research in his role as an advisor, there were often times when our discussion would become something that I would want to include in my observations. After this happened a few times, we decided the best way to switch roles would be to use a verbal cue. For example, if we began

discussing some of the history behind how the survey started during an advisory meeting, and I wanted to take notes for my research I would say 'Do you mind if I take notes on this?' With his verbal assent we would switch roles — he from advisor to participant, and I from student to anthropologist.

During my fieldwork, Ray would often make some interesting points in casual conversations with his staff members and the other researchers. In these situations, as I elaborate on below, I would make a note and ask him about it later in an interview setting. Ray's direct involvement in my research ended when I returned to Oxford after my final period of data collection in Australia, when I began the writing up process under the supervision of Stanley. It was during this time that I was able to process the ethnographic data I collected and Ray's role in my research. Because of the care I had taken to create boundaries for my observations and to incorporate peripheral ideas which came up in casual conversations into my formal interviews with Ray, his contributions as a research participant were clear in my ethnographic record, and I could confidently incorporate them into my writing alongside those of the other participants. As an advisor, I continued to keep in touch with Ray to get updates on MK, and to discuss how I was progressing with my writing. I also asked Ray to read through the final version of my thesis before submission to check that what I reported about MK was factually accurate, extending my practice of respect.

My positionality as a researcher also shifted in certain contexts in the field. For example, during a couple of team meetings when I was conducting participant observations, the MK researchers would begin discussing a question in the survey on which I had some expertise (e.g. questions related to obesity). In these situations Ray noticed my interest and asked me to 'take off my anthropologist's hat' to contribute to the discussion. After providing my input I would return to recording my observations. As this only happened twice, and in

the context of reviewing specific survey questions, it did not have a significant impact on my ethnographic data. Instead I felt it fitted in with my Indigenist research approach, in which I was able to use my knowledge to contribute to the work of my research partners.

Another complexity to be resolved was the relationship between my research, and myself as a researcher, and MK. Before I began my DPhil data collection I spoke with Stanley and Ray about the goals of my research and how that would tie in with the needs of MK. From June 2016 I began working on a paper with Ray and some of his staff at the time which would contribute to the body of literature underpinning MK (Bourke and Wright et al., 2018). During this time I became familiar with their project and what work was already underway. My anthropological scholarship was very different from anything that any of the MK researchers were undertaking at the time. From their perspective, the development of their survey was an automatic, largely non-theoretical process. They viewed my work as a kind of evaluation of their study, albeit from an anthropological perspective which they were largely unfamiliar with. My thesis therefore offers a unique take on how MK and its instruments were developed.

I decided to use the concept of meta-research to frame this thesis and its ethnography. Meta-research is an emerging discipline which aims to improve the quality of scientific research, particularly in biology, bioengineering, and the data sciences, by studying 'its methods, reporting, reproducibility, evaluation, and incentives' (Ioannidis, 2018: 1). To the best of my knowledge, this thesis is the first ethnographic application of the meta-research principle, and may be more relevant to the field of applied health research. In particular it speaks to the intersection of anthropology and epidemiology, and adds to a growing body of literature which demonstrate how anthropological perspectives may provide important insights on epidemiological frameworks (see Béhague, Gonçalves, and Victora, 2008, and Porter 2006).

I do not use the meta-research concept in the same way that Ioannidis and his colleagues (2015) do, as a critical analysis of multiple studies and their research practices to identify patterns of bias and advance research quality. Instead, I apply its focus on research methods, reporting, reproducibility, evaluation, and incentives to a single study, and challenge traditional scientific ideas, such as the notion that bias inhibits the production of reliable research. Across all scientific disciplines, researchers consider bias in data collection to be a threat to the production of reliable scientific knowledge (Hunter and Schmidt, 2004, Ioannidis et al., 2015). However, this thesis details how 'bias' *towards Indigenous perspectives* produced a closer reflection of the reality of Indigenous health determinants and outcomes. This was a conscious and theoretical form of bias which sought to incorporate Indigenous perspectives and ways of thinking into MK's epidemiological instrument.

To be clear, for the statistical data itself the MK researchers followed conventional epidemiological practices which seek to maximise data validity and reliability (see Chapter 3). What I suggest here is that the scientific concept of bias is itself biased towards a Western, positivistic lens. In seeking to incorporate Indigeneity into its survey, MK introduces a new, counter form of bias — or *expertise* — which in fact improves the validity and reliability of its findings. This process, which I refer to as *embedding Indigeneity*, will be explored throughout the thesis.

Writing a relational, peopled ethnography

An important process in conducting ethnographic research lies in constructing the object to be studied (Desmond, 2014: 548). This thesis focused on the Mayi Kuwayu Study survey as the ethnographic object and aimed to understand it by observing and analysing the interactions of the individuals, contexts, and materials associated with its development.

While the actual construction of MK's survey occurred over a linear time period, the development of its content was non-linear. Questions in the survey were changed, refined, and changed again many times over due to the influence of various researchers, focus group participants, and the shifting landscape of Indigenous health research in Australia and internationally. For example, some of MK's measures were taken from other surveys conducted in Australia and Canada, tested in the focus groups, and then modified again according to their feedback (see Chapters 4 and 5). Focusing on MK as an object to be studied offered a unique opportunity to write an ethnography which crossed traditional boundaries of space, time, and place.

My ethnographic approach needed to take into account both the linear and non-linear nature of the survey development, and to capture the dynamic interactions between the multiple actors, places, and phenomena which generated the survey. *Relational ethnography* offered some useful ideas for constructing these dynamic interactions, giving 'ontological primacy, not to groups or places, but to configurations of relations' (Desmond, 2014: 554). The theme of relationality works across this thesis through its methodology and in the development of the survey. An important task of my ethnographies then was to reveal these layers of relationality. The way the survey has been designed through a series of processes offered a way in which this relationality could be demonstrated, and by separating these processes out, I was able to create a clear framework on which to build my chapters (see section 2.4.).

A similar model to relational ethnography, which I followed in my research, was utilising a *peopled ethnography* (Brown-Saracino et al., 2010, Fine, 2003). This form of ethnography has been used to examine the interactions of small groups whose behaviour operates within a particular kind of structure, and to use this interaction to ground theoretical propositions. Coined by American sociologist Gary Alan Fine (2003), a peopled ethnography 'suggests

that it is not the individuals being observed who direct our interest but rather their position within a group or social system: the set of actors and their group "peoples" the ethnographic analysis and description' (2003: 43). The mechanisms through which MK (i.e. the structure) has been created by the interactions of people in small groups (e.g. professional staff, researchers, focus group participants) met these criteria. Furthermore, it was these groups and their interactions which gave insight into the larger goal of the survey to define and measure cultural determinants of Indigenous health and bring about change in the Indigenous health narrative.

The majority of my time in Australia was spent in Canberra at the ANU where MK is based. I was born in Canberra and lived there until arriving in Oxford for my graduate studies. The ANU is my undergraduate university, and so I began research for my DPhil on familiar ground. During my time in Canberra I was able to observe the dynamic of MK's research and professional teams and how MK and its survey progressed day-to-day. I found that while the relationships between the various actors was concrete on paper, in practice many of MK's CIs, Associate Investigators (AIs), and partners had only minor or irregular input into the survey development.

Only two people — Ray Lovett and Jan Chapman — were regularly involved in the community consultations or focus groups. As the study's lead researcher, Ray oversaw all aspects of MK's development, including survey revisions and engaging in public outreach through TV and radio appearances. Jan Chapman, a Taungurong woman from Victoria, acted as an executive assistant to Ray alongside managing the community relationships and coordinating the focus groups. The other professional staff worked on administrative details related to the development of the survey and MK's public profile. The CIs and AIs offered their expertise in the development of the survey and helped to facilitate funding applications. The community partners were representatives from peak Aboriginal and

Torres Strait Islander organisations and used their networks to promote MK and acted occasionally to advise on survey revisions.

Before arriving in Canberra for my first block of primary data collection in April 2017, I had hoped to interview all 12 of the CIs associated with MK at the time, including Ray Lovett as the lead. However, in three cases we could not find a time that was convenient for them in their busy schedules. I was able to touch base with the majority of the 12 AIs and research stakeholders who had been involved up to that point, either in person, over the phone, or via Skype, and recruited five of them as interviewees. The professional staff were easier to contact as they were in the same office corridor at the ANU, and so all of the full-time and part-time staff who were employed at the time of my fieldwork were recruited as interviewees. I was also able to return to Australia eight months after concluding my primary data collection to conduct follow-up interviews with some of the researchers and affirm my theoretical findings. A list of all the interviewees and dates of their interviews are listed in Appendix 1. Figure 4 below is a representation of the positions of my interviewees within the overall structure of MK.

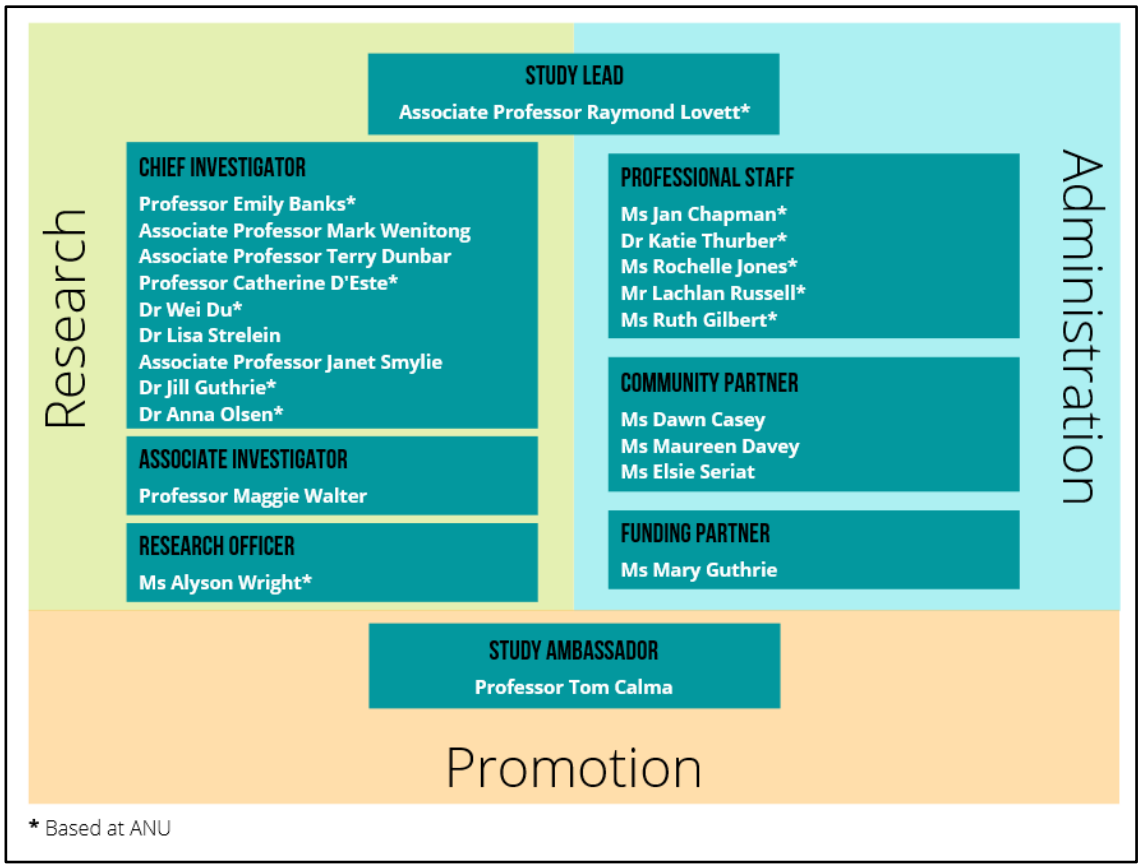


Figure 4. Mayi Kuwayu Study interview participants

Of the professional staff it was only Ray Lovett, Jan Chapman, and Lachlan Russell who worked on MK full-time in the same corridor at ANU, with the other professional staff and Alyson Wright working on a part-time basis. All of the other stakeholders were engaged on a casual or irregular basis from their offices elsewhere. The key people I interacted with day to day were Ray Lovett and Jan Chapman, who also conducted all of the focus groups I attended. I also spoke regularly with Katie Thurber and Lachlan Russell into order to grasp the more practical aspects of running MK, including how the survey was being modified and the process for ethics applications undertaken with multiple organisations.

Triangulating the data

To understand how these different individuals interacted with each other, it was necessary to incorporate interviews and an electronic archive with participant observations as an alternative to an ethnography which relied on extended, time-consuming participant observation, which would not have been appropriate in the Mayi Kuwayu Study's professional setting. Combining these methods within a relational, peopled ethnography allowed me to understand the multi-layered nature of MK, and to gain insights on those aspects of the project which I could not directly observe (see Brown-Saracino et al., 2010: 551).

Combining these different materials together allowed for the triangulation of data. This process supported my theoretical findings and allowed me to identify gaps in the researchers' knowledge, my knowledge, or between participants. A major criticism of triangulating data in the social sciences is that it does not necessarily provide a more complete, objective, or congruous representation of the situation, as each data perspective is still highly contextual, both methodologically and in its representation of a lived reality (Barbour, 1998). Taking this into account, triangulation may still be useful for qualitative research, especially within the framework of meta-research. As American sociologists Japonica Brown-Saracino, Jessica Thurk, and Gary Alan Fine (2010) have suggested:

> Interviews, texts, and quantitative data can reveal perceived and real limitations on (and facilitators of) action that may not be apparent from the ethnographic observation of interaction. In interviews, respondents reflect upon their actions, giving insight into the constraints they perceive given their location in the social system. Analyzing texts, artefacts, and quantitative survey or network data may reveal limitations on action of which social actors are unaware. Texts may be reified and have consequences for action long after their individual authors are gone; the architecture and planning of the built environment patterns action whether or not social actors perceive it; and an actor's location in a broader social

> network may also constrain or enable action independent of that actor's perceptions. Further, finding systematic differences in data from different types of sources may be theoretically important. (Brown-Saracino et al., 2010: 551)

While in Oxford I was able to keep up with major developments via email and Skype, and in Australia I was able to observe team meetings and focus groups, and conduct interviews with the majority of MK's researchers. Nevertheless, there were a number of meetings I was not permitted to be present for (e.g. with government representatives, or in private meetings between researchers and staff members). Furthermore, as stated above, it would not have been appropriate for me to look over the researchers' shoulders in their offices while they were modifying the survey or writing up supporting documents on their computers.

I was given access to drafts and final versions of these documents and so have a detailed record of what happened to the survey and when. Analysing electronic data, such as the minutes of meetings or survey drafts may be useful for monitoring progress but lacks contextual data about *how* things occurred. In these cases, triangulation was useful for situating these data within the context of the events I was able to observe. By asking about these events in casual conversations or interviews, I was also able get a sense of their overall impact on MK. Despite its limitations, triangulation was useful for my analyses of the data from MK, which encompassed the contributions of several participants and others during face-to-face meetings and through electronic interactions taking place over the course of years. I argue that this triangulation of multiple forms of data, collated at different times and by different people, is an important part of ethnographic meta-research.

(Dis)Locating 'the field'

The notion of the field as existing outside of a place has been explored in anthropology since the 1970s, with the general consensus being that the field exists inside the anthropologist's consciousness (for an overview of this literature, see D'Amico-Samuels, 2010). It has been argued by American anthropologist Deborah D'Amico-Samuels (2010: 72) that the 'mythology of the field' has persisted in anthropology as a result of the practice of racism, classism, and other forms of prejudice inherent in the concept of the ethnographer as the objective, authoritative observer. As D'Amico-Samuels puts it, the notion that an anthropologist can come 'back from the field' serves to:

> perpetuate the notion that ethnographers and those who provide their data live in worlds that are different and separate, rather than different and unequal in ways which tie the subordination of one to the power of the other. (D'Amico-Samuels, 2010: 75)

Feeding into the process of othering, 'the field' as existing within a bounded space and time 'preserves distance, difference and distinction as the normal state of cross-cultural affairs' (D'Amico-Samuels, 2010: 75). Therefore, in order to continue the work of decolonising anthropology, one must question and critique the validity of such boundaries.

The idea that 'the field' should not (or could not) be bounded was congruent with my research experience. MK by its very nature was an entity which existed across multiple temporal, geographical, and material contexts. Therefore, it was fitting that my data collection would take place across these modes as well. The practice of multi-sited ethnography (Marcus, 1995) has a long history in anthropology, and lent its concepts well to the present research. At the beginning of my research my plan was to simply follow the development of MK's survey. Due to the electronic/online nature of much of this process, I was able to collect data remotely from Oxford periodically throughout my DPhil in

addition to eight months of in-country data collection undertaken from April–June 2017, October 2017–March 2018 and October–November 2018.

A note on participant identification

I obtained ethics approval to give my participants the option of being identifiable through their full name, a pseudonym, or to remain anonymous. This was because I wanted to give these individuals the opportunity to share in our co-developed intellectual property generated from interviews, and for them to be able to use my research as a platform for communicating their knowledge. Furthermore, giving Indigenous people in particular the opportunity to be named for their contribution to collective knowledge fits within the tradition of oral cultures (Kovach, 2009: 49). I believe that the anonymising of participants, while important for particular topics of research, can also serve to erase, in some ways, their contribution in the anthropologists' writing. It is a process which gives the researcher enormous power over how participants are represented in text. If the contributions of participants can be explicitly attributed, this makes the researcher accountable to them and others in the research and writing process. Naming people in my thesis makes the participants' presence here undeniable and is an outcome of applying my Indigenist research approach (Figure 3) outlined above.

As a part of MK's research process, all data collected from the focus group participants was anonymised. Therefore, I have chosen not to name the focus group participants here, even when permission was sought and given to me by them for my work. I did this for two reasons:

1. To name focus group participants in my research would invalidate their anonymisation in MK, and therefore may be a breach of ethics.

2. My intention in identifying people was to attribute quotations to them in my research, but for all the audio recordings and transcripts collected by the MK researchers no one was identified, and their quotations are not attributable.

Consequently, the only participants identified herein are those with whom I conducted interviews and who have given permission for their names to appear in the thesis. Where I have used quotations from interviews, each quotation was sent via email to those individuals for confirmation before submission of the thesis. If a participant did not respond to my email within the specified time frame of two weeks, I then assumed that they were content with the quotations. As it happened, only two of my participants did not respond to my email, while others requested only minor changes to be made. This self-imposed protocol was an extension of my Indigenist research approach rather than a matter of research ethics, which had been fulfilled when full and informed consent was obtained in the first instance. This protocol ensured that I had an ongoing conversation with these individuals about their participation in my research, and created further accountability for the context in which I represented them in this thesis. I would also like to add that when introducing an identified participant, I provide a short bio which includes their Indigenous or non-Indigenous heritage. This was to make salient the participation of my Indigenous participants in particular, and to privilege their voices and knowledges within this text.

2.3. Methods

This section presents a detailed explanation of the methods that I have chosen to develop and use with respect to the issues discussed above. By applying these methods, this thesis aimed to create ethnographies which captured the dynamic, multi-layered nature of MK and its research processes. These are the methods I used to collect my ethnographic data

and to conduct the analyses I present in later chapters. Where they draw from data collected by the MK researchers (e.g. focus group transcripts) this is clearly stated.

Participant observation

As an Indigenous person I was acutely aware of the effect of the anthropologist's gaze on Indigenous people and was eager to adapt the participant observation technique in a way that was more culturally and ethically appropriate for my research. Therefore, I used participant observation to observe processes involved in developing the Mayi Kuwayu Study's survey (e.g. focus groups, survey review meetings) with the aim of verifying other data and dialogues (e.g. previous focus groups, survey drafts).

I specifically did not observe and take notes of everything I witnessed in the hope that some detail may be relevant to my analyses later. This practice aligns with a common theme in Indigenist research which actively 'rejects the notion that research on Indigenous people is for the sake of knowledge itself and is for the academy, by the academy and in the interest of the academy' (Rigney, 1999a in, Henry and Foley, 2018: 214). Rather, I wanted my observations to build on or contradict my existing hypotheses, or provide context for something a participant had mentioned in an interview or during casual conversations that was relevant to my research. To explain it another way, I observed processes and the relationships amongst people and used these observations to support data triangulation (e.g. interviews, focus groups, electronic records).

With this aim I established boundaries for my participant observations to observe specific situations and interactions, including focus groups, research team meetings, and conference presentations. The benefits of this approach were that the participants would be aware of when and where they were being observed, and importantly, when and where they were not. In this way I was able to give my participants a measure of control over my

observations, during a process which by its nature privileges the researcher and their perspective.

I think this made data collection easier to some extent, as my participants were able to anticipate when I would be present to observe. For example, if an important meeting was coming up I would be sent meeting agendas or relevant documents ahead of time to review. Also, I think that having a personal identity in addition to a professional one meant that people were more easily able to relate to me (e.g. knowing of my family and talking about their family with me) and felt more comfortable with me in the professional context. It was my intention that during the participant observations I would be treated as an anthropologist and autonomous researcher. Outside of this I hoped to be perceived and treated as a fellow Indigenous person and/or colleague. There were times during my fieldwork when I struggled with these boundaries, particularly when I was a part of interesting conversations in a casual setting, which I would have liked to record formally. I relied on my intuition to guide me in these cases, as to what would have been appropriate to take note of, either professionally or culturally, and what should be left out of the ethnographic record. Such boundaries allowed me to create a space for observations in a way which made me — and potentially my participants — more comfortable and aligned with my sense of integrity.

However, while I was able to control my conduct I was not able to control how all of my participants perceived me. For example, during one of the focus groups I observed, some of the participants asked me to explain what some of the questions in the MK survey meant when they were filling it out (see details of the Perth focus group in Chapter 4). This occurred after explaining my research and its independence from MK and providing separate information and consent forms. Moreover, in interactions with staff members outside of my observation periods there would sometimes be jovial comments like 'Are

you taking notes on this?' or 'Don't write that down'. My reply to this would be along the lines of 'Don't worry. I would have told you and be writing in my notebook now if I was'. Therefore, even though I outlined in what contexts I would be taking notes when I first sought consent, it seemed I was still sometimes perceived as collecting formal data even when I was not. This did not create problems for my data collection, but I do think it meant that I was not able to counteract the effect of the anthropologist's gaze through this method as much as I had hoped.

I believe that part of the ambiguity in people's perceptions of me came from the participants being inexperienced with participating in this kind of research, even though several of them were researchers themselves. For instance, some of my interviewees commented that they had never been interviewed before and one person seemed unsure initially about how my style of interviewing differed from the types of interviews journalists conduct. I took care to explain to all my interviewees the reasons why I was interested in talking to them and outlined how I would use their interviews for my research. I believe that providing everyone with full transcripts of their interviews and the opportunity to edit them alleviated some of the anxiety they may have felt initially about what sort of information I was collecting.

With this in mind, I undertook participant observations during:

- Focus groups — I attended eight community focus groups conducted by the MK researchers in Bunbury (on two occasions), Cairns, Thursday Island, Alice Springs, Canberra, Perth, and Risdon Cove between April and December 2017. This included a collective total of 50 participants, in addition to the two researchers (Ray Lovett and Jan Chapman) who ran the focus groups. For all of the focus groups I attended (except Perth – see Chapter 4 for details) there was an audio recorder used initially by the researchers, and so I focused my written observations on individual body language, the general dynamic of the room, and the characteristics of the interaction between the MK researchers and the participants which would not be recorded elsewhere. The MK audio

recordings and transcripts were later made available to me to use for my research. As discussed in Chapter 4, in three of the focus groups I attended (Canberra, ACT — 14/11/17; Bunbury, WA — 27/11/17; Risdon Cove, TAS — 9/12/17) the researchers' audio recording failed (see Chapter 6 for a discussion of the implications of this for my work). At the end of the MK focus group process I asked two questions of my own to gain an understanding of how the participants viewed this process and its impact:

1. Why do you think other Aboriginal or Torres Strait Islander people would want to participate in the focus groups?
2. Why do you think the researchers are running the focus groups?

- Team meetings — I attended six team meetings between May 2017 and February 2018. This included a total of nine staff and researchers in various combinations. These team meetings were either to review a draft of the survey, or to check in on how MK was progressing, with each team member reporting to the group what had been accomplished since the last meeting.
- Annual CIs and Partners meeting — I attended this meeting in October 2017, which included 18 participants. I also attended the meeting in October 2018 as part of my follow-up research, preceding the official launch of MK and its survey, with 12 participants.
- Conference presentations — I observed three conference presentations between April 2017 and February 2018, with four of the MK researchers. I also observed one forum presentation during my follow-up research in November 2018.

Semi-structured interviews

The purpose of using interviews for my research was to facilitate a focused, informative discussion of relevant topics with my participants, and to create an opportunity for me to clarify their perspectives within the context of my research questions. The interview method has been critiqued for its formal format, which constrains conversations, and again, places the locus of control and power with the researcher. In order to address these critiques I employed a semi-structured format which used guiding questions to allow participants to elaborate on topics which were meaningful to them. The questions I asked participants varied according to their professional role in the Mayi Kuwayu Study (see Appendix 2). I used a portable MP3 audio recorder to record all of these interviews and

later created full transcriptions using Microsoft Word. To address the power imbalance, I provided participants with these transcriptions and allowed them time to edit or add to them before including them in my analyses.

This process gave the interviewees the opportunity to reflect on their responses and some control over how they were represented in my thesis text. While most simply requested that the 'um's' and 'ah's' be removed, a few took the opportunity to add to or edit their initial responses. While this process may be criticised for allowing participants to censor themselves, I believe that the responses resulting from this process are more reliable for addressing my research questions about their professional roles within MK. This process also allowed me to ask further questions of participants once I had time to reflect on their responses.

It is my view that interviews should be considered to be shared intellectual property between researchers and participants. Research participants should be given the opportunity to own data about them as much as the researcher does, both in theory and in practice. This is an under-researched area in anthropology (Briggs, 2007), but aligns well with my theoretical framework. It also aligns with the ideology of Indigenist research which empowers Indigenous peoples by giving them control over their representation in the written record (Rigney, 1999b: 119).

I conducted 32 interviews with 22 participants between May 2017 and November 2018. I initially intended to interview people associated with all aspects of MK including researchers, funding bodies, focus group participants, and community partners. However, due to practical and financial limitations and non-responses, the vast majority of the interviews were with the MK researchers (13 participants) and professional staff (four participants) working on MK, in addition to three community partners, one funding

partner, and one of the MK Ambassadors. These interviews were mainly conducted face-to-face (23 interviews), with five over the phone, three via Skype, and one over email.

Digital archive

With Ray Lovett as an advisor I was granted access to the shared electronic folder used by all of the Mayi Kuwayu Study researchers and professional staff members based at the ANU. This folder included details of funding applications, ethics applications, team meeting agendas and notes, focus group transcripts and notes, study protocols and survey questionnaire drafts from January 2016 to January 2018. I was also in communication with various research team members between October 2016 to May 2020 to request additional information, updates, and documents. Some of these sources contained minor spelling mistakes and typos which I corrected for use in the thesis.

This digital archive provided me with a snapshot of key moments in the development of MK. In utilising and analysing these documents I have been able to triangulate my participant observation and interview data, and to get information about events I was not present for. Of particular interest were the transcripts and notes from the focus groups I did not attend. As outlined by Brown-Saracino and colleagues (2010: 551) above, the use of these additional data were important for the development and clarification of my theoretical findings, highlighting social and systemic processes which otherwise may not have been identified.

As an example, in Chapter 6 I present a diagram depicting the key aspects of culture discussed during the focus groups conducted by the MK researchers. The qualitative data analysis methods I used to analyse the focus group data is from the grounded theory work by Corbin and Strauss (2008). Given that this involved comparing a number of focus groups to each other in order to understand their common themes, the method entailed a

detailed reading of the available data from the focus groups and an open coding strategy which identified key words and phrases used by the participants related to the overarching concept of culture. I also conducted a comparative analysis to identify the similarities and differences in expression from these initial keywords. A process of theoretical comparison grouped these keywords and phrases into key aspects of culture.

This interpretation drew from my own knowledge and experience within an Indigenist framework alongside my anthropological training. The data sources I included in my analyses were all of the audio transcripts available from nine of MK's focus groups conducted in Alice Springs (NT), Bunbury (WA), Cairns (QLD), Cowra (NSW), Canberra, Thursday Island (QLD), and Ulladulla (NSW) (for details, see Appendix 5). I also decided to incorporate the butcher's paper notes collected from seven focus groups at the national Indigenous health conference in Perth, WA, as these are the most complete record of the conversations which took place on the day. For the remaining 12 focus groups conducted by the MK researchers, there was no detailed record of the discussions other than what the researchers themselves chose to write down, which in all cases was simply dot points about what themes were touched upon in the conversation (e.g. Family, Language, Traditional foods, etc.).

I validated my diagram using a second comparative analysis with the transcripts, to assess whether it provided a fair representation of the focus group discussions and to check for details overlooked in my original search. Appendix 3 contains a detailed table of the themes I identified from the focus group transcripts, including key words and phrases I assigned to each theme. In developing this summary I drew on both the context in which the participants discussed cultural influences, as well as my own knowledge and experience (see Chapter 6 for further information). This table is representative of my qualitative analyses conducted for the purposes of this thesis only. It was not intended to be wholly

representative of all Aboriginal and Torres Strait Islander cultures, the way others may analyse these transcripts, nor the way the MK researchers may organise the data they collected from the focus groups.

Qualitative analyses

The analyses I present in Chapters 5 and 6 draw directly from versions of Mayi Kuwayu Study's survey (see the full baseline survey in Appendix 4). Therefore, it is important to give a general overview of the survey's structure here before it is analysed later. The 110 items included in MK's baseline survey were designed to address six 'domains' or key aspects of the Indigenous lived experience of health and wellbeing (Table 1) (adapted from Jones et al., 2018b: 5).

Domain	Contents
Cultural practice and expression	Country and connection to Country, Indigenous beliefs and knowledge, cultural expression, self-determination and leadership, language, family, kinship and community, identity
Sociodemographic factors	Age, sex, housing, education, employment, financial situation, household composition
Health and wellbeing	Life satisfaction, health status, health conditions, medication use, social and emotional wellbeing, functional limitation
Health behaviours	Physical activity, alcohol and tobacco use, health service use
Experiences and environments	Services in the community, experiences of racism, community safety, environmental conditions, life events
Family support and connection	Family cohesion and connectedness, caring for others, Stolen Generations

Table 1. Key domains and their contents included in the MK baseline survey

These items were then organised into six sections within the survey, including: *Identity, language, culture and community* (Q1–27); *About you* (Q28–46); *Health* (Q47–59); *Alcohol, smoking and gambling* (Q60–91); *Your experiences* (Q92–102); *Family support and connection*

(Q103–110). Many of the main questions are 'matrix' questions, which incorporate several sub-questions with the same response scale.

The *Identity, language, culture, and community* section incorporates 27 questions which ask participants to describe their identity, their understanding of what Aboriginal or Torres Strait Islander culture is to them, and their connection to Country and culture. It also includes items about language use, cultural knowledge and practice (as detailed in Chapter 5, section 5.3) and experiences of the participants' local Aboriginal/Torres Strait Islander community. Interwoven through this section are items which test the contribution of these aspects to the participants' holistic wellbeing, including negative experiences such as:

16. Do you feel pressure to meet cultural obligations?
17. Do you feel torn between your culture and non-Indigenous culture?
26. Have you ever felt disconnected from Aboriginal/Torres Strait Islander culture?

The *About you* section incorporates standard demographic questions including gender, date of birth, living arrangements and household composition, height, weight, relationship status, employment, and education, among others. It also touches upon overcrowding which is a major issue for Indigenous households in remote areas. Australian Government statistics from 2016 indicate that on average 10% of Indigenous Australian households are overcrowded, which increases to 14.5% for remote households and 32.3% for those in very remote areas (AIHW, 2019: Table S2.6) (an 'Indigenous household' is defined as one where at least one resident has identified as Aboriginal or Torres Strait Islander; see ABS, 2016d). However, while the NATSISS defines overcrowding as households which require at least one additional bedroom (ABS, 2019), the MK survey asks for the participants opinion on whether their home is crowded and to what extent: 'not at all', 'a little bit', 'a fair bit', 'a lot', or 'not relevant'. This allows for the individual to decide what overcrowded means to them, rather than imposing an external value system on the term.

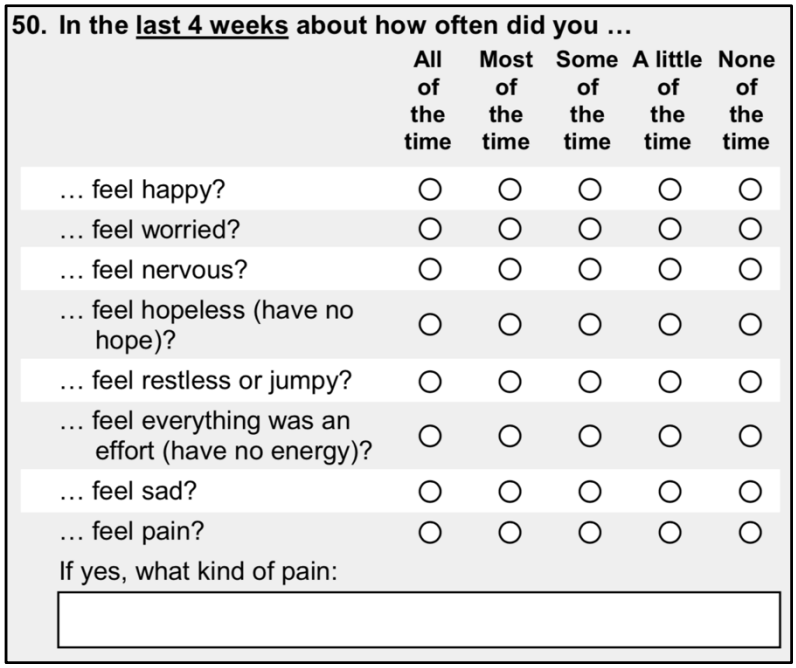
This section also asks, 'Which words best describe your family's money situation?' (Q43), with the following response options:

- We have a lot of savings
- We have some savings
- We have just enough to get us to the next payday
- We run out of money before payday
- We are spending more than we get
- Unsure

The phrasing of this question and its responses measure perceived financial stability or stress. This is preferable to comparing Indigenous household incomes to non-Indigenous Australian averages, which contributes to the deficit discourse. There is evidence that the factors which contribute to financial stress or poverty for Indigenous Australians are not adequately measured by current national surveys (Hunter, 2012). Indigenous households experience higher levels of financial stress than non-Indigenous households (Breunig et al., 2019). It is a cultural norm that Indigenous people will share money alongside other resources with their relations on a regular basis. This means that even if a household's income may be comparatively good, they may still experience financial difficulty (Breunig et al., 2019).

Some of the metrics included in the *Health* segment are already widely used for Indigenous Australian population health studies, such as self-rated health (AIHW, 2017) (Q47) and self-reported life satisfaction (Manning et al., 2015) (Q48). Another commonly used measure of psychological stress, the Kessler-5 (Kessler et al., 2002), has also been

incorporated into the survey (Q50), with the addition of three responses about feeling happy, sad, or pain (Figure 5).



50. In the last 4 weeks about how often did you …

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
… feel happy?	○	○	○	○	○
… feel worried?	○	○	○	○	○
… feel nervous?	○	○	○	○	○
… feel hopeless (have no hope)?	○	○	○	○	○
… feel restless or jumpy?	○	○	○	○	○
… feel everything was an effort (have no energy)?	○	○	○	○	○
… feel sad?	○	○	○	○	○
… feel pain?	○	○	○	○	○

If yes, what kind of pain:

Figure 5. Question 50 from the MK baseline survey (Mayi Kuwayu Study, 2018a: 4)

Given the significant negative impact of alcohol abuse and smoking on wellbeing, it should be expected that some questions about these behaviours would be included in a national health survey. This is why the *Alcohol, smoking and gambling* section was incorporated into MK. ABS health surveys and other large-scale quantitative health surveys like the *45 and Up Study* (Sax Institute, 2019) only ask questions which quantify incidence and usage (e.g. number of cigarettes per day or alcoholic drinks per week). However, the MK survey also includes questions about experiences of addiction like 'Do you get shaky if you don't have alcohol?' (Q64/68) or 'Do you think your smoking has made you sick?' (Q77/86). The desire to quit smoking is also taken into account by asking 'Do you want to quit smoking?' (Q74), 'Why do you want to quit?' (Q75), and 'In the last year, have you tried to quit or reduce the amount you smoke?' (Q76). These supplementary questions help to shift the focus away from simple descriptive statistics to examining the lived experiences of addiction, however briefly.

The first question in *Your experiences* asks participants to select which Indigenous programmes and services that they participate in, providing a list of common examples with particular health, wellbeing and/or cultural aims (e.g. The Indigenous Marathon Project, Traditional Owner groups, quit smoking programmes). It also asks which government or other support services are available in the communities where individuals live, such as a local store, school, police department, or Aboriginal medical service, among others. The follow-up question asks if any of these services are controlled by local Aboriginal and/or Torres Strait Islander people.

Apart from gathering data about what resources people have access to in different parts of Australia, these questions are aimed at understanding whether Indigenous people in those areas have access to and/or control over culturally-safe spaces. Given that there is a large amount of variation in what percentage of local populations are Indigenous in Australia, it may be important to find out to what extent local power structures reflect this, if at all. The following two sub-sections in *Your experiences* build on the above point to ask participants about their experiences of discrimination and racism in everyday life and in health care. There is an emerging body of literature in Australia over the past decade which emphasises the significant negative impact that experiences of racism have on the health and wellbeing of Indigenous peoples (see Paradies et al., 2008 for an introduction) (also discussed in Chapters 4, 6 and 8).

The last sub-section *Worries in the family and community* addresses recent negative events which participants may have experienced such as a death in the family, domestic violence, and children being taken away, among others (Q101). It also asks about issues present in the community such as alcohol abuse, racism, and people fighting, among others. The cumulative effect of major adverse life events and exposure to social dysfunction can have a significant negative impact on individual health and wellbeing for Indigenous Australians

(Zubrick et al., 2010). This is related to the concept of *toxic stress*, which arose from studies of the life-long physical and psychological impacts of adverse experiences in childhood (for comprehensive overviews, see Bucci et al., 2016, and Shonkoff et al., 2012). American paediatrician Jack Shonkoff and his colleagues argued that toxic stress is the result of 'strong, frequent, or prolonged activation of the body's stress response systems' which can lead to 'disruption of brain circuitry and other organ and metabolic systems during sensitive developmental periods' (Shonkoff et al., 2012: e236, also see Lapp et al., 2019). This can affect learning and behaviour from childhood through adulthood and may have a causal relationship to stress-related chronic illnesses (Bucci et al., 2016, Lapp et al., 2019, Shonkoff et al., 2012: e236). This has been referred to as *allostatic load* in studies with Indigenous Australians, which accumulates across the lifespan and can lead to a range of metabolic, cardiovascular, and psychological disorders (see Ketheesan et al., 2020, Radford et al., 2017, Sarnyai et al., 2015).

Question 103 at the top of the *Family support and connection* section includes the prompt 'In my family…' and lists nine sub-questions, including:

- We get on together and cope in the hard times.
- We celebrate special days/events.
- We talk with each other about the things that matter.
- We are always there for each other.
- We manage money well.
- We have common interests.
- People are accepted for who they are.
- We have good support from mob.
- We have family knowledge and traditions that we pass on to our children.

The responses for these sub-questions are formatted as a 4-point Likert scale: Not at all, a little bit, a fair bit, a lot. The option 'Unsure' is also included. The last two sub-sections of the survey address two of the most prominent Australian Government policies to have

disrupted intergenerational cultural connection and wellbeing: the removal of Aboriginal people from their traditional homelands (*Missions, stations, and reserves*), and the theft of children from their families and Country (*Stolen Generations*).

2.4. Research questions

The methods outlined above address different aspects of the Mayi Kuwayu Study and its survey, and the different kinds of data which were available to be integrated into this thesis. Participant observation allowed me to understand how the day-to-day running of MK was structured and how the survey was refined through constant negotiation between the various stakeholders, particularly during the focus groups. Through the interviews I was able to identify each key individual's role within MK, understand their underlying motivations (at least as presented in this context), and learn more about the purpose and potential impact of MK on the wider Indigenous health narrative. Utilising MK's digital archive allowed me to weave together a more complete picture of the practical processes involved in running this large-scale research project. This helped me understand how localised, qualitative concepts of Indigenous cultures may be transformed into national-level quantitative metrics.

Using my Indigenist research approach together with these methods led me to ask: *How does the Mayi Kuwayu Study provide a blueprint for understanding cultural determinants of health for Indigenous Australians?*

There are clear links between this question and the changing landscape of Indigenous health research in Australia as described in Chapter 1. The Indigenous health narrative increasingly acknowledges the importance of culture for the wellbeing of Indigenous peoples and thus the need for cultural determinants of health to be identified at the

population level. MK is the first large-scale research endeavour which has sought to identify these cultural determinants. By examining their methodology and methods, this thesis aims to discover how the framing of MK, as both an epidemiological and Indigenous-directed enterprise, provides a blueprint for understanding how culture influences Indigenous health and wellbeing.

This thesis ethnographically explores four key dimensions of the development of the Mayi Kuwayu Study survey and how the researchers conceptualised these cultural determinants through their epidemiological framework:

1. The initial development of the culture concept by the MK researchers
2. The culture concept as defined by the community focus groups
3. The development of the cultural measures used in the survey
4. The potential impact of MK findings in Australia and internationally

Understanding how culture is defined by different groups and its importance for human health is where medical anthropology can bring together epidemiological and anthropological epistemologies.

Chapter outlines

Subsequent chapters of the thesis address different aspects of the baseline survey's development, and the underlying historical, political, and social elements which influenced its design. Following this methodology and methods chapter, Chapter 3 presents the perspectives of the Mayi Kuwayu Study researchers on the representation of culture in MK. This includes an analysis of the positioning of MK within social epidemiology and what this implies about the way culture is understood by the researchers. The chapter then critiques MK's conceptual model of the cultural determinants of health, placing this within the context of the MK researchers' perspectives. This leads on to an exploration of how

Indigeneity manifests in the Mayi Kuwayu Study and how this has influenced its operationalisation of culture. Finally, this chapter proposes that MK strategically engages the culture concept to re-orient the Indigenous health narrative in accordance with an Indigenous worldview.

Building on these discussions, Chapter 4 provides an overview of the community consultations that were undertaken by the MK researchers between 2015 and 2017. Of the 28 focus groups that took place at 12 locations over this period, the emphasis in this chapter is on the eight focus groups I observed during my fieldwork in Australia in 2017. This discussion elaborates on the Indigenous health experience in Australia, and how the focus group process itself led to a particular kind of knowledge and meaning-making which could be used by the researchers to inform the survey.

Chapter 5 presents a more detailed examination of the MK survey, and how specific cultural indicators within the survey were developed from the first 'proof-of-concept' study in 2014 to the baseline survey released in 2018. It relates the interpersonal negotiations which took place between the researchers and MK's other stakeholders and investigates the effect these had on what questions were left in (and out) of the survey. This was a survey designed to be *for* Indigenous people, and this motivation had clear and precise effects on the researchers' decision-making processes.

Chapter 6 presents a qualitative thematic analysis of the focus group discussions and the baseline survey to determine how the survey reflects the community feedback. This was vital to comprehend how culture as a lived experience may be transformed into quantitative metrics. While aspects of the subjective experience may be lost, what is gained by operationalising culture through the survey is the ability to represent Indigenous realities in ways which are powerful in the Indigenous health narrative.

Chapter 7 builds on the findings of previous chapters to discuss the potential of MK to change Indigenous health norms in Australia, and its implications for the perceptions of Indigenous cultures in the public health domain. The future-thinking of the researchers is presented alongside excerpts from focus groups to envision the impact MK may have in Indigenous communities, on the field of epidemiology, in health policy, and on the global stage. Chapter 8 offers a discussion which brings together the conclusions of previous chapters to address the thesis question and outline the thesis' most important findings and how they contribute towards existing literature.

Chapter 3 — Culture and Epidemiology

The Mayi Kuwayu Study is first and foremost an epidemiological endeavour. As a discipline, epidemiology is interested in quantifying patterns of health and disease and their determinants within a population. My objective for this chapter is to explore how it is practiced by the MK researchers with respect to Indigenous cultural concepts. The chapter begins by giving an overview of the ways in which Indigenous cultures are understood by the researchers, including an examination of MK's conceptual model. This leads on to a discussion of how the researchers think MK fits within the field of epidemiology and the implications of this for the ways in which Indigenous cultural knowledges are framed by their survey. The Indigeneity of particular researchers from MK and their impact on MK's mobilisation of the culture concept are also considered. Finally, I propose that MK strategically uses the culture concept to influence the content and direction of the Indigenous health narrative in Australia.

3.1. Culture concepts in epidemiology

As the Mayi Kuwayu Study's lead researcher, Ray Lovett was the first person I wanted to talk to about how MK began. Though I had known Ray since 2014 and had been in correspondence with him since October 2016 to collect data for my thesis, it wasn't until I was in Australia in April 2017 that I was able to sit down with him and get his account of how MK started. My first interview with him was conducted on Thursday Island, known locally as TI or Waibene, its traditional Kaurareg name. Accompanied by Elsie Seriat, a former resident of Thursday Island, Ray and I were there to conduct a focus group session with members of a local exercise group (see Chapter 4 for details of this focus group). In the afternoon after the focus group we walked back to our accommodation for a break

and I took the opportunity to ask him some of the questions that I had been storing up for some time.

> SB: So Ray, I just wanted to ask you about how the idea and the concept for the survey came about?
>
> RL: It's probably a few things that contributed to it. So the first kind of thinking about it came from my PhD work, where I was looking at… Part of my thesis was around acculturation and enculturation. And so, the enculturation bit got me to thinking about how people learn about their culture. So that's kinda where the idea started, and for me that was personally important because, you know, how was I meant to learn about my Aboriginal culture? And then I was kinda reading lots of stuff, but I, you know, because I am an epi[demiology] person I couldn't find much stuff that actually looked at quantitative associations and all that sort of stuff. And then I'd also been reading about, well, if we do have the same level of education as non-Indigenous people and same employment, even in employment levels, there was still some form of gap in health outcomes. So I became really interested in what that was. And that kinda got me to thinking, well, particularly in the south-east of Australia where cultural stuff is, you know, has had the greatest impact or loss of that stuff… is that something to do with that stuff we can't account for in health outcomes? […]
>
> So it kinda grew from there, and the Lowitja stuff came along, and there was a real keen sense that we needed to investigate things. Now, there wasn't… lots of people have issue around quantifying things. So there was discussion about that at the Lowitja forums where all this was being talked about. And I just went back to my epidemiology training, and I've always found it's much easier to engage with policy people if you're able to give them, you know, this piece of evidence in inverted commas that shows an association between if you do this, this is what effect it has. And so, I really wanted to be able to kind of do that. So that's where the survey came into being.
>
> — Interview with Ray Lovett, 6 May 2017, Thursday Island, QLD.

In this first interview Ray discussed how the idea for the survey and its focus on culture came from his doctoral thesis *Mob and country: A role for identity in alcohol screening for Indigenous*

Australians living in the ACT and region (Lovett, 2013), and in particular, the concept of enculturation. Terms such as enculturation have been heavily utilised in psychology and public health literature to explain within-group variability of various psychological and social conditions (Rudmin, 2009, Waldram, 2009, Weinreich, 2009). Enculturation has been described as the extent to which individuals learn about and identify with their heritage culture, including whether they 'feel a sense of pride in their cultural heritage, and participate in traditional cultural activities' (Zimmerman et al., 1996: 296).

The anthropological critique of enculturation is based on the assumption that it is an involuntary, unconsciously accepted process (Herskovits, 1973). As an aspect of cultural relativism, enculturation discounts individual agency and independent thought in favour of total acceptance and practice of cultural norms (Kanarek, 2013). However, the concept of enculturation, particularly in identity formation during childhood, has not been extensively studied in non-Western groups by anthropologists (Poole, 1994). Instead it has been the literature from psychology, public health and education which has investigated the concept in the context of Indigenous lived experiences, linking greater enculturation to positive health and social outcomes (Bals et al., 2011, Currie et al., 2011, Whitbeck et al., 2004, Whitbeck et al., 2001, Yoder et al., 2006, Zimmerman et al., 1994). These studies suggested that enculturation leads to greater resilience for Indigenous peoples, and that this can be reinforced by people actively seeking and engaging in cultural activities. This contradicts the anthropological assumption above by arguing for Indigenous agency in engagement with culture.

Culture 'features' and 'patterns' are terms commonly used in psychology to map the ways in which culture appears to operate in society (Adams and Markus, 2004). In his PhD thesis, Ray argued that Indigenous culture patterns have been modified as a result of the exchange of cultural features between Indigenous and non-Indigenous groups since

colonisation. He argued that the ways in which Aboriginal people identify, as well as Aboriginal patterns of land use and movement across the country, have been fundamentally disrupted by European settlement. Ray reasoned then that alcohol, tobacco, and drugs are used by some Aboriginal people as dysfunctional coping mechanisms to deal with the various traumas resulting from the disruption of these culture patterns (Lovett, 2013).

Ray's use of these terms reflects the general use in epidemiology of standardised or modified psychological measures. For example, Ray used a modified version of the Vancouver Index of Acculturation (Paulhus, 2013) and the Kessler Psychological Distress Scale (K-10) (Kessler et al., 2002) to measure 'acculturative stress' in his thesis (Lovett, 2013). The Vancouver Index of Acculturation was initially developed with first- and second-generation Chinese undergraduate students living in North America (Ryder et al., 2000). The Index measures both enculturation in the 'heritage' or former ancestral culture, and acculturation in the current 'mainstream', dominant culture in which an individual now lives. This instrument has since been used for other ethnic groups internationally, but was modified in Ray's thesis to replace the term 'heritage' with 'Aboriginal' in the heritage subscale and the word 'mainstream' with 'Australian' in the dominant culture subscale (Lovett, 2013: 72).

The conceptualisation of culture using psychological theories with associated measurement norms is conventional in the practice of epidemiology. This is in contrast to the way culture is often referred to by anthropologists to describe specific and localised human traditions (Wagner, 2016: 1). From an anthropological perspective, understanding culture through the lens of psychology may be problematic. For example, there may be a greater emphasis on identifying and categorising normative, universalised practices and behaviours in order to group individuals, while potentially ignoring more complex, less tangible

phenomena. Furthermore, this measurement may lead to the representation of such practices as key indicators of culture and may not be able to account for trends in new practices. When each new version of the MK survey is developed, the researchers will be reluctant to modify its questions in order to maintain consistency and comparability across the data over time (R Lovett 2018, personal communication, 10 January).

Given the epidemiology or public health background of the majority of MK's researchers, it is expected that they would use their disciplines' norms in developing MK. The process of enculturation in particular, as highlighted in the above interview with Ray Lovett, underpins the ideology of MK and its focus on Indigenous identities and participation in cultural activities. The following section investigates this premise further by analysing MK's conceptual model.

The Mayi Kuwayu Study conceptual model

Conceptual models in epidemiology map hypothetical influences on, or causes of, population health outcomes. These models 'involve setting the bounds around a research problem', and underpin the development of research questions and methods, guide analysis, and aid in the interpretation of research data (Diez Roux, 2012: 42). Conceptual models often focus on explaining particular 'causal factors', and come in different forms (Diez Roux, 2012). A major critique of conceptual models by researchers who focus on health disparities is that such models create false dichotomies in health aetiology given their characterisation of social versus biological factors, environmental versus genetic influences, individual versus population-level factors, or behavioural versus stress-related processes (Diez Roux, 2012: 53). Furthermore, a classic (though contested) anthropological critique is that epidemiology is fundamentally based on scientific positivism and the assumption that there is an objective truth which can be observed and

measured (e.g. Fenton and Charsley, 2000: 406, Rubenstein, 1984, and see Inhorn, 1995: 286-287, Trostle, 2005 for a counter engagement) (for an Indigenous critique of this issue in anthropology, see Chapter 2).

I was able to identify only one epidemiological conceptual model in the literature which sought to map cultural determinants of health at the population level for Indigenous peoples (see below for a discussion of the model by Daniel et al., 2011). MK is unique in Australia because of its focus on culture and in seeking to develop cultural indicators of Indigenous health and wellbeing on a national level. Cultural indicators are the questions in the survey that will be used in statistical analyses to represent an individuals' attachment to or participation in their Indigenous culture/s (i.e. enculturation). Because of its unique focus, investigating the theory behind the development of these indicators was critical to my understanding of where MK's survey fit within the field of epidemiology, and the implications it would have for future research on Indigenous culture and health internationally.

Early on in the development of MK, its researchers developed a conceptual model to represent the ways in which MK frames culture and its impact on Indigenous health and wellbeing (Lovett, 2017a: Slide 8) (see Figure 6). It has featured in their research proposals, funding proposals, and public presentations I attended in Australia and Canada in 2017 and 2018. The model itself emphasises the influence of both the immediate and broader environment (compositional and contextual), as well as an individual's own characteristics (including experiences and culture) in the development of their physical and mental health (Lovett, 2017b: 18).

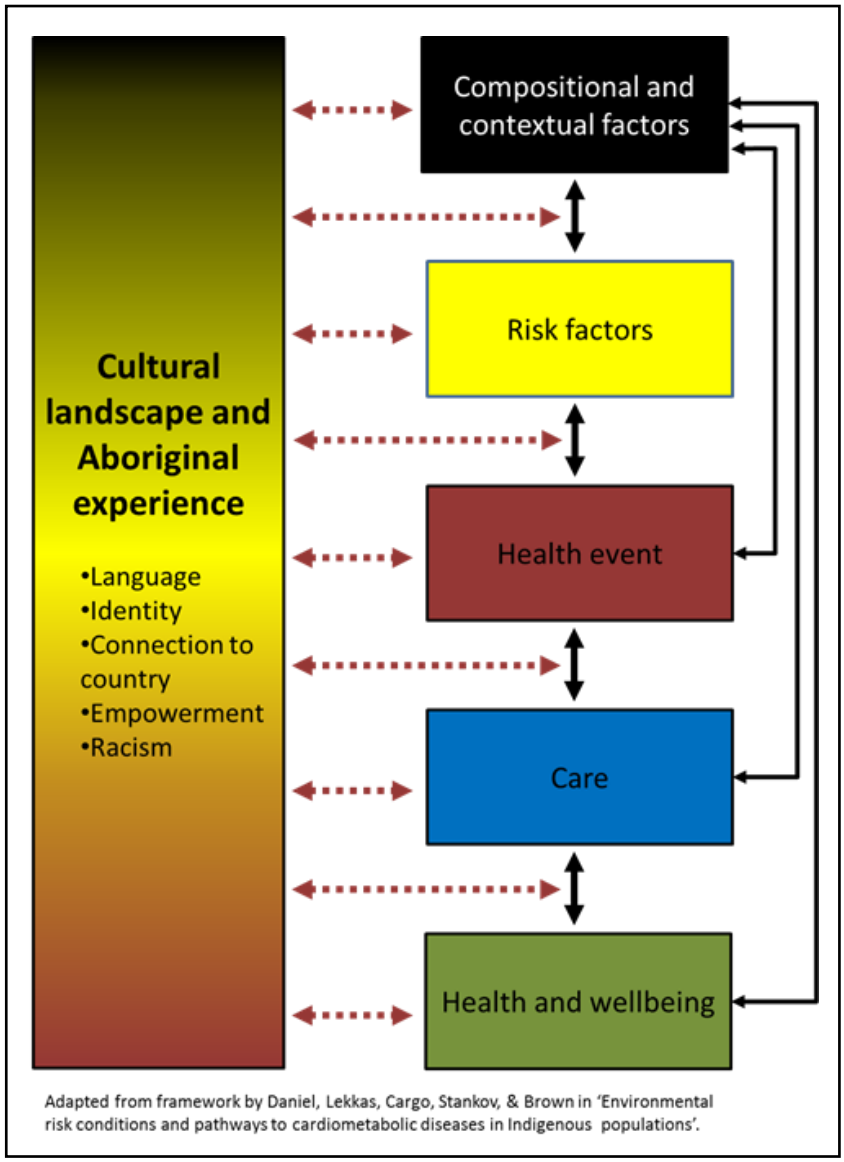


Figure 6. Mayi Kuwayu Study conceptual model (Lovett, 2017a: Slide 8)

Some aspects of enculturation (e.g. language, identity, connection to Country, empowerment) and one aspect of acculturation (e.g. racism) appear to be represented in the left hand column of the figure. As outlined in Chapter 1, a number of key cultural determinants of Indigenous health were later identified by the MK researchers in a comprehensive literature review (see Salmon et al., 2018). Some of those overlap with the aspects included here such as language, connection to Country, identity, and self-determination. An emerging body of literature has also begun to detail the profound effects which experiences of racism have on the Indigenous lived experience, including

health (see the work of Paradies, 2006, 2007, 2016, Paradies et al., 2008, and Zubrick et al., 2010).

At the time, MK's research proposals stated that the conceptual model was informed by limited findings about the health of Aboriginal children in Australia (Eades et al., 2008, Zubrick et al., 2005) and advice from the early focus groups they had conducted (Mayi Kuwayu Study, 2016). They also go into some detail about how they have adapted the model from two existing bioecological frameworks (Mayi Kuwayu Study, 2016). The first is Bronfenbrenner's Bioecological Model of Human Development (Bronfenbrenner and Morris, 2006), which has been used predominately in studies about child development in developmental psychology (Tudge et al., 2009) and public health (Eriksson et al., 2018). The second framework is the model developed by Daniel et al. (2011) in their study of environmental risk conditions and pathways to cardiometabolic diseases in Indigenous communities.

The Bioecological Model of Human Development details 'particular forms of interaction between organism and environment, called *proximal processes*, that operate over time and are posited as the primary mechanisms producing human development' (Bronfenbrenner and Morris, 2006: 795, emphasis in original). This Model suggests that human growth takes place in a reciprocal relationship with the surrounding environment within five broad structures: Microsystems (interactions of the individual with the immediate environment), mesosystems (interactions between settings containing the individual), exosystems (interactions between settings that do not contain the individual), macrosystems (pattern between micro, meso, and exosystems characterising a particular culture) and chronosystems (the environment as a historical element) (Bronfenbrenner and Morris, 2006). However, these structures do not appear to be directly represented by MK's conceptual model.

The work of Daniel et al. (2011) on the other hand seems to be clearly reflected in MK's conceptual model, and is referred to directly in the model by the MK researchers (see Figure 6). Daniel and his colleagues suggested that the context or properties of an environment (e.g. physical, built, social) along with its composition or collective attributes of people in a place (e.g. income, education, unemployment) lead to environmental risk conditions which can influence an individual's susceptibility to disease (Daniel et al., 2011). The model developed by Daniel et al. (2011: 333) (Figure 7) is an example of a directed acyclic graph which is a visual representation of the relationships between different variables, incorporating the direction of effect between each variable (Barrett, 2020). There are a number of similarities between Figure 7 and MK's conceptual model, including the influence of the cultural landscape, the role of macro-structural factors, and the impact of risk on experiences of health.

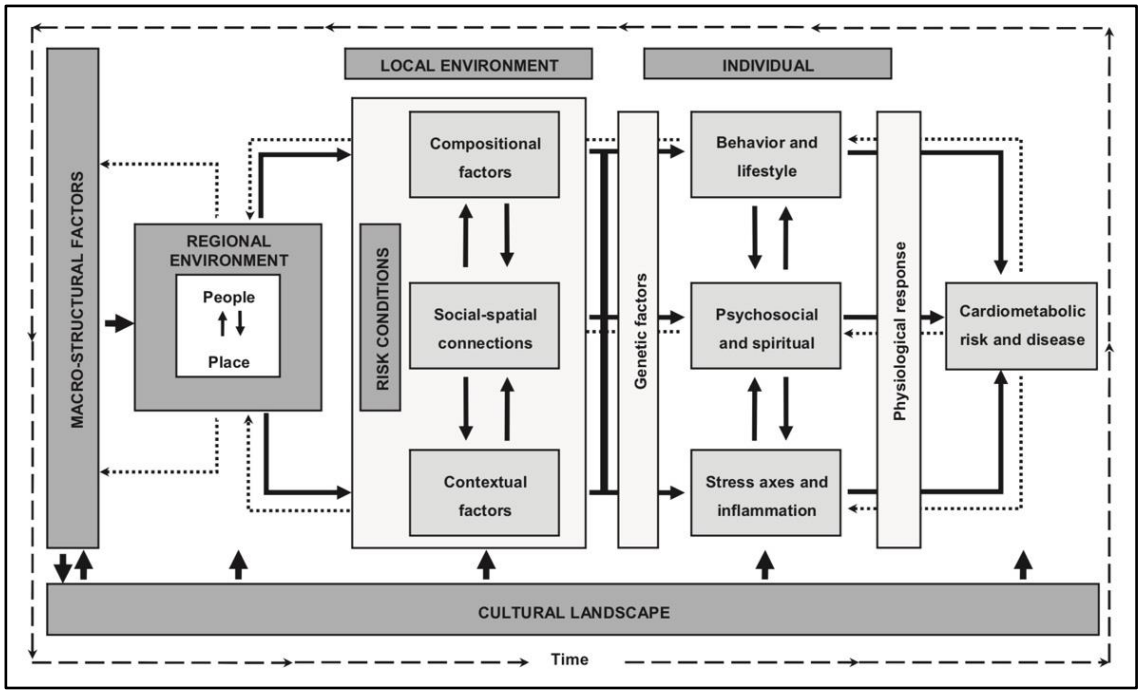


Figure 7. Framing multilevel influences of environmental factors on Indigenous cardiometabolic status and recursive relations (Daniel et al., 2011: 333, Figure 2)

During my fieldwork the influence of MK's conceptual model on the day-to-day development of the survey and the perspectives of the researchers was completely

ambiguous. No one referred to the conceptual model when discussing the development of the survey — except Ray in his conference presentations — and the majority of my participants did not know about the model in any detail when I asked them about it during our interviews (see below). This is despite the statement from their research proposal that 'This model will structure data collection and inform analyses relating to the outcomes of interest, in keeping with the emerging recognition of the importance of conceptual models in statistical analyses relating to life-course epidemiology' (Mayi Kuwayu Study, 2016: 6), and its use in subsequent proposals and presentations.

This may reflect the fact that the conceptual model was developed specifically for a 2016 NHMRC funding proposal (as discussed by Katie Thurber below). Further, there may be some methodological issues with the fact that the majority of the research informing the conceptual model is based on studies of children and adolescents, whereas MK only recruits adults aged 16 years and older. This has never been explicitly addressed in MK documents which discuss the conceptual model.

During interviews I specifically asked the researchers and some of the professional staff about the conceptual model to discover what role it played in the development of the survey. I showed them a print-out of the conceptual model (Figure 6) and asked them what they thought it was trying to convey, without referring to the underlying bioecological frameworks. Their responses generally reflected their position within the hierarchy of MK. The administrative staff who did not have a role in constructing the survey, but who had seen the model before, said that they found the diagram visually confusing, but generally agreed with the idea that culture influences all aspects of an Indigenous person's life. They often viewed the role of Indigenous culture in terms of their personal experiences, primarily through family histories for Indigenous participants. The two staff members I asked who were non-Indigenous referred to their professional

experiences of the importance of culture to Indigenous peoples and acknowledged that they could not speak to the reliability of the conceptual model because of their non-Indigenous heritage. The researchers who were not core research team members expressed a lack of knowledge or understanding about the conceptual model and were not involved in its development.

The researchers who were most involved at the initial stages of developing the survey had the greatest knowledge about the model. They cautioned that it was only a tool or a guideline for thinking about the influence of Indigenous cultures and other factors on health outcomes. One of these researchers was Emily Banks who is a CI in MK. Emily is a non-Indigenous Australian who has decades of experience in the field of epidemiology. Her main career focus has been on developing large-scale cohort studies, including the *Million Women Study* in the UK, and the *45 and Up Study* (Sax Institute, 2018a) and the *Study of Environment on Aboriginal Resilience and Child Health* (SEARCH) (Sax Institute, 2018b) in Australia. She supported Ray from the beginning in developing the epidemiological frameworks of MK and is his supervisor at the National Centre for Epidemiology and Public Health (NCEPH) at ANU. I had the opportunity to interview her when I was in Canberra, and as she is one of the key researchers in MK, I was eager to hear her thoughts about the conceptual model.

> SB: So speaking of models, but going also back to the theory, this is something you've already seen before. It's the conceptual model for the survey. And I just wanted to get your thoughts on this. Because, as far as I understand this conceptual model is the guidelines around how the survey questions and areas have been designed.
>
> EB: So the first thing I would say is I would be quite careful of the anthropologists' lens there. So I actually think that that was a way… this is a kind of, a useful tool to think about those things. I would not say that if we came up with something that didn't agree with that we'd go 'Right that doesn't fit in the

> model, chuck it out'. So I'd actually say that the relationship between the conceptual model and what is put into practice… it's not as tight as people would generally have to have in other things.
>
> So, and you can see there's lots of arrows going backwards and forwards. And I remember at the time when Ray and I were putting something like this together, we had multiple different models and some of them were sort of circles going out and some of them were… but this is sort of, a model that we would see as helpful but when you think about that 'All models are wrong, some are useful', if there was a point at which it wasn't helpful, I don't think we'd find that particularly problematic. And for example, we did this in the context of having to write an NHMRC grant. So it was… we were trying hard to get something that would be useful.
>
> And it's also, I think, one of the other things is that this is a communication tool, is to say we think about all these things together. But for example, and I don't even know why, we don't have any arrows going from risk factors to health… or actually we don't have anything going from risk factors to care. Now I would think you could quite sensibly have an arrow going from risk factors to care. So I don't… I think this is useful and I've very happy to talk a bit more about what it means to me, but I also think that you could have exactly the same conceptual model put in front of different people and they'd have a different way of interpreting it as well.
>
> — Interview with Emily Banks, 29 May 2017, Canberra, ACT.

Katie Thurber, a non-Indigenous American working as a Postdoctoral Fellow with MK, was also involved in the initial phases of its development. When I asked her about the conceptual model she said:

> We put together that model for the purposes of a National Health and Medical Research Council funding application, which is generally a bio-medical focused funding agency. I don't think the model is perfect, and it isn't intended to suit all research conducted using the MK data resource. That conceptual model is one way to convey some of the ideas we had about the study, within an epidemiological framework. This conceptual model may not suit all researchers

> from all disciplines, but it is an example of one conceptual model that can be applied to the study.
>
> — Interview with Katie Thurber, 22 November 2017, Canberra, ACT.

It has long been argued that conceptual models which integrate biological and social factors across the life course should be widely used in longitudinal epidemiological studies (Ben-Shlomo and Kuh, 2002). In public health this integrative approach is known as complex systems (Diez Roux, 2012: 53), and is increasingly being utilised to understand a wide variety of biosocial conditions, from obesity (Galea et al., 2010), to mental health (Langellier et al., 2018), and even sports injuries (Bittencourt et al., 2016, Hulme et al., 2019). Once MK begins to collect longitudinal data, the researchers will be able to undertake a life course approach to understand causal relationships between the various cultural, health, and other factors included in their survey.

The life course approach was developed in the 1990s and is now widely used across the field of social epidemiology (Galea and Link 2013: 843). This approach 'includes studies of the biological, behavioural, and psychosocial pathways that operate across an individual's life course, as well as across generations, to influence the development of chronic diseases' (Ben-Shlomo and Kuh 2002: 285). In the context of MK, this approach would also be able to identify the influence cultural engagement has on these pathways, and vice-versa, across the life course for Indigenous Australians. This is where developing a conceptual model may be important for identifying and testing potential pathways and causal directions.

However, in the context of MK, my ethnographic data suggested that even when a conceptual model has been developed, it is not fundamental to research design. This contradicts Diez Roux's (2012: 42) assertion above that such models are fundamental to the development of research questions and methods. Given the loose interpretation of MK's conceptual model as a guide by the researchers, I remained unsure of how the

researchers planned to define and measure Indigenous cultural concepts and their impact on health and wellbeing within their survey, and what they were basing these relationships on, if not their conceptual model.

Cultural domains used in the Mayi Kuwayu Study

According to the original research proposal, the Mayi Kuwayu Study's survey aimed to measure what the researchers described as five key cultural domains (modified from Mayi Kuwayu Study, 2016: 7):

1. *Identity and cultural knowledge exchange*
   There is evidence to suggest that people who identify as belonging to an Aboriginal group and have a positive Aboriginal identity are less likely to experience mental health issues, have lower suicide rates, and fare better on socio-economic indicators (Dockery, 2011). How Indigenous Australians receive knowledge about their heritage has a strong impact on identity formation.
2. *Connection to Country and family*
   The pre-eminent factor in Indigenous Australian identity is connection to and the relationship with Country and family. Limited evidence indicates that stronger connection to Country and participation in on-Country activities is associated with improved mental health (Dockery, 2011), wellbeing, and reduced cardiovascular disease risk factors for Indigenous peoples (Burgess et al., 2008, Chandler et al., 2003).
3. *Aboriginal and Torres Strait Islander languages*
   Evidence from a Canadian study found that speaking an Indigenous language is an important cultural protective factor for mental health and suicide (Chandler and Lalonde, 1998). The second National Indigenous Languages Survey, although not representative, suggested that nearly all Indigenous Australian languages are in decline and that language use was associated with improved levels of health and wellbeing (Marmion et al., 2014). However, the full picture is not known.
4. *Community cohesion, connection, and self-efficacy*
   The bonds within Indigenous Australian communities and the broader Australian community may influence health behaviours, although this is a relatively new research area (Reilly et al., 2008). While the Indigenous Australian population reports distress levels three times higher than the general population (ABS, 2013), evidence suggests that psychosocial stress is moderated by self-esteem, social support, and mastery (Pearlin et al.,

1981). Mastery includes problem solving and control over events. It bears similarities to constructs such as self-efficacy (Bandura, 1986) and sense of cohesion (Antonovsky, 1987), which are clustered around the concept of perceived control. These may have relevance, given the loss of control over lands and social structures since the European invasion. Those experiencing racism are also more likely to report higher levels of psychological distress and lower levels of engagement within their own community and the broader community.

5. *Governance, decision making, community engagement, and empowerment*
   Empowerment through engagement in civic organisations enhances individual competence and self-esteem which increases perceptions of personal control. This perception can directly improve health outcomes (Wallerstein, 1992), and can also include connectedness with other people and participation in groups and communities who wish to gain power to bring about change (Zimmerman and Rappaport, 1988). In a Canadian study with First Nations communities, the presence of cultural factors related to organisational involvement and management (health services and schools) within communities were found to contribute significantly to reductions in youth mental health issues and suicide (Chandler et al., 2003). The relationship between wellbeing outcomes (particularly psychological distress) and environmental factors, including employment and educational attainment, may be moderated by these factors of self-efficacy and empowerment through involvement in local community organisations (Marmot and Wilkinson, 2005).

During my follow-up fieldwork from October to November 2018, I found that these domains had been modified according to the findings of the literature review mentioned above (Salmon et al., 2018) and a re-evaluation of the feedback from the focus groups. According to MK's protocol published in June 2018 (Jones et al., 2018b: Table 2.), the key cultural domains that were now investigated by MK were:

1. Country and connection to Country
2. Indigenous beliefs and knowledge
3. Cultural expression
4. Self-determination and leadership
5. Language
6. Family, kinship, and community
7. Identity

It is unclear from these documents why the domains were reformulated, but they do generally reflect the domains identified by the literature review by Salmon and others (2018) which were connection to Country, cultural beliefs and knowledge, language, family, kinship and community, expression and cultural continuity, and self-determination and leadership. When I asked Ray Lovett, Emily Banks, and Katie Thurber about these changes during my follow-up interviews, they said that it had happened gradually through the long negotiation process of finalising the survey and that there was no major event or encounter that had pushed the changes along.

This is congruent with observations I made during my fieldwork. Modifications to the survey were often made very gradually through processes of constant negotiation, in person and electronically (see Chapter 5). Further, these changes were often made and then all but forgotten about, with the only record of changes being contained within older survey drafts. When I asked the researchers during our interviews about retrospective changes to the survey, they had difficulty remembering what had happened or why — such was the pace of the survey's development. Thus, being able to triangulate the various sources of data for my research, including documents from the digital archive, interviews, and observations of meetings became essential to my understanding of when and how changes to the survey occurred over time.

Later chapters will examine how these newly determined domains correspond with the Indigenous community feedback from the focus groups (Chapter 4) and the final baseline survey (Chapter 5). In the following section I explore how MK fits within the field of epidemiology and how this positioning has influenced the researchers' views on the utility of the culture concept in their survey.

3.2. Epidemiology and the Indigenous experience

The Mayi Kuwayu Study's focus on cultural determinants of health, and its use of a conceptual model make it unusual in the field of epidemiology. In light of this, I wanted to understand how MK fits within the broad discipline of epidemiology from the researchers' perspectives. Further, I wanted to understand how this positioning would influence the researchers' interpretations of Indigenous Australian experiences. During my time in Canberra I observed that one of the key relationships amongst my interview participants was between Ray Lovett and Emily Banks. Due to her experience and position within the NCEPH, Emily occupied a supervisory role over MK, and Ray and the other ANU-based researchers often consulted her about the design of the survey. I asked her about how MK fit within the field of epidemiology during our first interview:

> SB: Do you think the MK Study fits within epidemiology?
>
> EB: I don't see there's any way in which it wouldn't. […] I would see it as squarely fitting within epidemiology. And I think epidemiology — I mean really epidemiology is like, it's a word like anthropology. It's a pretty broad thing. […]
>
> SB: Well, the reason I asked the question is because in anthropology there's a lot of debate around culture and what it means. And for the MK Study to, basically, measure aspects of culture — that in itself is a very controversial idea for anthropology.
>
> EB: Yeah. Well, I think what I would say is that epidemiology has a long history of pragmatism. […] If you work from first principles you can come up with a million different solutions, but it's only really by looking at what works on the ground that you actually get something that gives you a firm thing to build on and to guide what you do in the future. […] I think that the epidemiological frame is really… it's actually not about theory. Well, the theoretical framework is that it's about empiricism. And that it's usually about quantitative measures. […]

> There's a fantastic Nobel Prize winning economist. The first woman to win the Nobel Prize in economics. And she came up with this law… let me find it… I think it's called Ostrom's law. And anyway, her law states that if something works in practice then you can find a theory that it will work for. So it's the opposite way around. So I think often in anthropology there's this thing where you've got to create this theoretical framework. And whether something fits into your theoretical framework or not. And then you proceed. And epidemiology on the other hand, you know you could argue it's about you don't have to ask why. […]
>
> But what we're generally trying to do is categorise people into exposure levels. Low, medium, and high. And we know that if you ask people how much they drink they will underestimate. Or some will underestimate, and some will overestimate. But in general, you'd be able to estimate people who are low, medium, and high, knowing there's some error there. And you'll be able to look at it in relation to outcomes. […] So the idea of going out there and saying 'Right we want to measure culture. How are we going to measure culture? Let's do some things that give us a valid measure of general low, medium, and high exposure to racism'. That's absolutely squarely in epidemiology.
>
> — Interview with Emily Banks, 29 May 2017, Canberra, ACT.

Emily argued that quantitative measurement is imperfect but useful in the sense that it allows for the categorisation of individuals into low, medium, or high exposure levels, and these levels of exposure can then be related to outcomes. She then stated that this was one of the concepts that they applied to culture in MK. Ray Lovett also mentioned this to me in our conversations, as did Katie Thurber. According to them, categorising culture into exposure levels allows for some imperfection in the measurement of cultural factors, while retaining its usefulness for analysis.

An example of this low-medium-high categorisation appeared in the report of the 'proof of concept' pilot study conducted by the MK researchers between 2014 and 2016 with several Aboriginal communities in the Murray Local Land Services (MLLS) region (n = 163 participants) (see Chapter 5 for details). The cultural indictors measured in the pilot

focused on connection to Country and caring for Country activities, such as spending time on Country, finding and/or preparing foods, and sharing cultural knowledge (Lovett et al., 2017). Figure 8 is an example of one of these questions:

c. How often have you done the following in the last 12 months on the country you live on now?	Never	Once or twice	A few times	Quite a few times	All the time
Protecting country: Sacred sites, animals, totems, other important sites	○	○	○	○	○
Ceremony on-country	○	○	○	○	○
Making artworks: Painting, weaving, carving	○	○	○	○	○
Using country: Food, medicine, hunting, fishing	○	○	○	○	○
Burning country: Cleaning up country, fire work	○	○	○	○	○
Other on-country activities	○	○	○	○	○
Land management activities (*IPA, Ranger programs*)	○	○	○	○	○

Figure 8. Question 6c from MLLS questionnaire (Lovett et al., 2017: 42)

Responses for the cultural indicators in this pilot survey were limited to between five and seven factors (e.g. Never, Once or twice, A few times, Quite a few times, All the time). The exposure levels the researchers had referred to above were only used in the reporting of these indicators, such as 'The results indicate that there is a small/moderate amount of caring for country activity currently being engaged in across the region: current rates of caring for country activities are moderate to low (≈20%)' (Lovett et al., 2017: 3). This mirrored the way in which some of the health indicators were reported, as in this example: 'Almost half (48.4%) had poor to moderate levels of overall life satisfaction (a common measure of wellbeing), and 51.6% reported excellent life satisfaction (scores of 8 or more out of a possible 10)' (Lovett et al., 2017: 10).

The report of the pilot study did not describe what the various thresholds were for low, medium, and high cultural exposure, perhaps due to the small sample size of the pilot and lack of previous data on the validity and reliability of the cultural indicators used. Validity and reliability are standard ways of determining the value of a survey instrument in epidemiology. Validity describes the extent to which a metric accurately represents the

real-world phenomena it aims to measure, and reliability relates to the consistency of measurement instruments over time, across items, and across participants (Price et al., 2015). Therefore, for MK's metrics to be valid, they needed to accurately reflect the cultural dimensions they were designed to measure, and to be reliable, they needed to be consistent over time, across items, and across participants.

Katie Thurber argued that MK fits more specifically into social epidemiology:

> SB: OK. Do you think that the methodology for the study fits within the methodology of epidemiology?
>
> KT: Ah yes and no. I think it probably fits within social epidemiology. In general epidemiology tends to be focused on identifying risk factors for disease, and generally tends to be very bio-medically focused. And the point of this study is not to be that. There's certainly some epidemiology that's focused on social-cultural and environmental determinants. So it's not incongruent with epidemiology but, it's doing things a bit differently. So I guess it does still sit within epi, the way we're going about this.
>
> But the goal was to create a study that is not constrained to one discipline. So I suppose we're doing an epidemiological survey, but hoping that the data from the survey could be used across disciplines. We are coming from the standpoint of people who conduct epidemiological analyses, and so we know what the data need to look like for that, and what the questionnaire needs to look like accordingly.
>
> — Interview with Katie Thurber, 22 November 2017, Canberra, ACT.

The idea that MK is an example of social epidemiology also resonated with Ray Lovett. I asked him one afternoon why he referred to himself as a social epidemiologist and not a cultural epidemiologist, given that the focus of MK was culture. He replied, 'Culture is social, so I'm a social epidemiologist' (R Lovett 2018, personal communication, 10 January). However, agreeing with Katie's assertion that MK would contribute to multiple disciplines, Anna Olsen, another of MK's CIs, thought that the findings of MK would also

have a lot to contribute to cultural epidemiology. Anna is a non-Indigenous Australian who works as a senior lecturer at the Research School of Public Health at ANU. She came to MK as one of the few researchers with a background in qualitative research methods. Anna thought the Indigenous leadership of MK and the way culture was being conceptualised within the survey would provide new perspectives for the field of cultural epidemiology.

> SB: Could you also tell me more about how you've been digging into the concept of culture? Because I've had some discussions with Ray about this as well, so I'd be interested to hear what you've been talking about.
>
> AO: Well, you know Ray's very much the lead. So a lot of the conversations we have are me, kind of, talking about different things that I've read […] a lot of the stuff I've come across is looking at the intersection of culture and health as it helps us to understand distribution of health and illness, as well as understanding peoples' interactions with health systems. So talking about… so the most recent conversations Ray and I have had are about cultural epi. […] I think Ray… there's a lot Ray can contribute to that field because the bits that I've read, there's not much in the way of Indigenous voices in there, and I think he… both him and his experience as a researcher, as well as this project, could potentially add quite a bit to that space.
>
> — Interview with Anna Olsen, 8 January 2018, Canberra, ACT.

However, as introduced in Chapter 1, cultural epidemiology focuses on localised concepts of health and their interaction within a specific cultural context (for an overview of the field, see Weiss, 2001, 2018). This is not the aim of MK, which seeks instead to measure broad cultural concepts which would be applicable across the diversity of Indigenous cultures in Australia. While the results of MK may indicate areas where more contextualised research would yield important information, at this stage, it seems that MK fits more clearly within the realm of social epidemiology.

One of MK's AIs had another take on how MK fit within the discipline of epidemiology. Maggie Walter, a Palawa woman and Professor of Sociology at the University of Tasmania, provided some advice to the researchers based at the ANU in the initial stages of developing the survey. She also gave the primary researchers feedback about MK's research protocol and later survey drafts. I had not had the opportunity to meet Maggie in person while I was in Australia, but was able to interview her via Skype from Oxford.

> SB: Do you think the Mayi Kuwayu Study or survey fits into the field of epidemiology?
>
> MW: Yes it does. And ah… well, it doesn't fit into the field of epidemiology — it stretches its boundaries, as they should well be stretched. So epidemiology is one of the big sinner disciplines. Nearly all of them are sinner disciplines, but epidemiology is particularly so, because at least with anthropology you know there has to be some sort of recognition that anthropology is one gaze that is filtered through a different gaze. Whereas epidemiology tends to set itself up as because it's about stats and about health, and you know blood flow and things, it is being objective. But of course nothing's objective about statistics or data. They're all human artefacts. […]
>
> SB: Can you tell me about how you describe the MK as stretching the boundaries of epidemiology? […]
>
> MW: With providing a different set of data. So they're providing new variables and um… and new ways of actually framing/conceptualising those variables. And so, that it just breaks the paradigm a bit of this sort of established trope of what Indigenous health data should be.
>
> — Interview with Maggie Walter, 5 March 2018, via Skype.

Maggie's description of the 'established trope of what Indigenous health data should be' relates to her previous work which critiqued the context and presentation of Indigenous Australian statistics.

> The numerical format of these statistics and their seemingly neutral presentation, however, elide their social, cultural, and racial dimensions. In a seemingly unbroken circle, dominant social norms, values, and racial understandings determine statistical construction and interpretations, which then shape perceptions of data needs and purpose, which then determine statistical construction and interpretation, and so on. Just as important is that the accepted persona of statistics on Indigenous people operates to conceal what is excluded: the culture, interests, perspectives, and alternative narratives of those they purport to represent — Indigenous peoples… Current Australian practices in regard to the collection of data on Indigenous people are the cloned descendants of the data imperatives of colonisation. In what I refer to as the deficit data/problematic people (DD/PP) correlation, processes of enumeration have long been used to correlate the highly observable societal Aboriginal and Torres Strait Islander inequality with the concept of racial unfitness. (Walter, 2016: 80-82)

As discussed in Chapter 1, epidemiology brings its own cultural lens to the study of human health. American epidemiologist Nancy Krieger put forward that 'data are not simply "observed"… data are not a "given"' (2011: 17), 'meaningful observation is, at some level, theory-laden: what we "see" depends in part on what our ideas are about what we expect to see and what assumptions underlie the methods used to "observe" the data' (2011: 24). What the researchers — in partnership with various Indigenous organisations and communities — decide should be 'observed' and *how* this can be observed is what will be 'seen' in the results of MK. Examining Indigenous cultural concepts through the framework of epidemiology may 'stretch the boundaries of epidemiology', but it does not represent a value-neutral representation of the influence of Indigenous culture on health and wellbeing. The methods and materials used for the Mayi Kuwayu Study design bring with them their own epistemological assumptions.

There were similar concerns raised about the exploration of Indigenous cultural elements within the framework of epidemiology at the annual CIs and Partners Meeting on 25 October 2017. Some of the attendees discussed issues of cultural essentialism and the need

to take care when using the survey method for understanding Indigenous cultures. Cultural essentialism has been defined as 'all attempts to explain cultural variations from the inherent, essential profile of the actors involved' (Leerssen, 2006: 34). While it is not the case that the MK researchers themselves were trying to distinguish between different Indigenous cultures through their survey, the data may be interpreted by others as distinguishing between those with culture (i.e. the 'real' Indigenous people) and those without it.

Despite their cohesive motivations, I observed some minor tensions between the researchers around how MK could quantitatively represent Indigenous cultures on a national scale without risking cultural essentialism. During the CIs and Partners meeting, it was clear that the main researchers involved in the day-to-day design of the survey were acutely aware of the complexities involved in identifying particular cultural elements to be measured. Though the issue of cultural essentialism remained unresolved on the day, Ray Lovett continued to think about how this related to the fundamental purpose of MK. In one of our interviews he confirmed that the risk of cultural essentialism was mostly in how their data would be interpreted by others and argued that the Mayi Kuwayu Study Governance Committee would be able to mediate some of this risk through their research approval process.

One of the major contributors to the discussion about culture at the meeting was Janet Smylie. Janet is a Cree-Métis woman, medical doctor, public health researcher, and lecturer at the Dalla Lana School of Public Health at the University of Toronto and St. Michael's Hospital in Toronto, Canada. Like Emily Banks, Janet was brought onto MK as one of ten CIs when the research proposal was first being drafted. Her experience developing surveys for Indigenous peoples, particularly in the development of *Our Health Counts* in the Canadian cities of Hamilton and Toronto, gave her some advisory authority within MK.

During the meeting, Janet played a significant role in the conversation, having input both as a researcher and as a cultural mediator. I was able to interview Janet during her visit to Canberra, and was particularly interested in getting her viewpoint as a researcher and as an Indigenous person on whether epidemiology has a cultural bias.

> SB: If I could just ask you to expand on something you mentioned, which was you were really aware of this use of the non-Indigenous tools in the survey and how they're doing things. When I've spoken to other people, other epidemiologists, they say 'Oh it's just a tool'. They don't think of it as having a particular cultural lens. And in anthropology we're always asking about who are you, and whether the methods that you are using have a context. I was wondering if you thought that epidemiology itself has a particular cultural context, or do you think it's something that, as they have said, it's just a tool to be used, and it's about who picks up the tool?
>
> JS: Oh I think epidemiology has a huge — like the classic clinical epidemiology — has a huge presumptive set of Eurocentric, rational, assumptions. And that the problem is in their training clinical epidemiologists have very little social theory. So they actually believe in objectivity. So I would say that disciplinary wise, like social epidemiology, like actually bring social theory to epidemiology… then you start situating the tools. So you can pull out a tool from epidemiology, like a survey, and you can move it from a clin[ical]-epi context where it's a got a whole set of assumptions around 'There is a truth, an objective truth and we're trying to find it'. And you can pull it and move it to Indigenous community. Like one or… but I guess it's still… then it might actually be seen like not so clever, right. Cause its essentialist.
>
> […] people make assumptions that Indigenous people didn't track things over time. So I say that one of the things that we've talked about in Canada is that we think our Indigenous midwives were the longitudinal cohort carriers in our communities. Cause they actually had birthed the babies and then they saw them develop over time, and they actually knew the kin-lines of those babies. So they know a life-course. And so, I think that our databases might have been story-banks, though I think that's also a myth that it was all oral. So that's getting debunked. We actually did write things down. Like we have winter counts and other things that were written.

> So I don't like it when Indigenous scholars, say from education or social work, say counting is colonised, because we've always had to count and track things and I think we've done it in sophisticated ways. And I think we've done it in community and population-based ways. […] So yeah, I think that to me it's a tool, but you need to be aware. And tools transform. So yes the whole process could be — it's dangerous process when we take these tools, cause they're colonial tools, right. But we're clever and we're adaptive. […] So is this survey tool… like people are getting a bit excited because the topic is culture and health. So it's a tool for promoting that conversation.
>
> — Interview with Janet Smylie, 26 October 2017, Canberra, ACT.

Janet believed surveys may be a useful tool for Indigenous health research if used appropriately and said that longitudinal data was also collected by Indigenous people before colonialism. She talked about the Red River cart, a symbol of the Métis people, as an example of how Indigenous people are able to adapt Western tools to suit their own needs:

> So my people use something called a Red River cart. And it was based on a Scottish cart. So we didn't have carts before the Europeans came. But it's actually a symbol of Métis people. And I know actually within my family lines we travelled with that as we were getting dislocated. It was different, so again I'm not a… there's better historians than I certainly… but the classic settler thing was a wagon with four wheels. But carts you could move easier. And we adapted them because we didn't have blacksmiths. So we took the metal axles and changed them over to wood and leather. […] But the other thing we did was we popped the wheels off so they could go across the river. So that's… so clin-epi [clinical epidemiology] has a huge assumptive theoretical paradigm for sure. And all of epi does I guess. And then you can take a piece of that, like survey research, and you can move it and you could adapt it, right. But it's still a cart, it's still a wheel. You can pop the wheels off and float it across the river. But surveys are still reductive.
>
> — Interview with Janet Smylie, 26 October 2017, Canberra, ACT.

Putting these various perspectives together highlights not only the complexities of situating MK within the field of epidemiology, but also perhaps some internal communication issues between the researchers about what exactly MK and the survey represent. During my follow-up interviews I asked all of my interviewees whether MK was at risk of essentialising culture. Ray Lovett said that it always was, but that it was important to start somewhere. This was a sentiment that was shared by all of the participants I did further interviews with. It was also clear that the survey is understood to be doing many different things by different people, and that these varying perspectives are masked by the seemingly unified object of the survey.

The complex question of whether MK was able to reliably represent Indigenous cultural elements within an epidemiological framework was sometimes in doubt. During the follow-up interviews I asked those with experience in epidemiology if there were issues in representing Indigenous cultural concepts through an epidemiological lens. All of these participants agreed that there was, but that the extensive consultation process which included Indigenous people from across Australia going through drafts of the survey and providing feedback mitigated some of these issues. They argued that through this process they were able to gain the insight of people on whether these questions applied to them. Moreover, as a number of the researchers working on developing the survey were Indigenous, their Indigeneity was seen to be a mediating factor in how representative the cultural elements of the survey would be of Indigenous lived experiences. The following section examines this aspect more closely and suggests that Indigeneity was fundamental to the Mayi Kuwayu Study research process.

3.3. The role of Indigeneity in the Mayi Kuwayu Study

When interviewing my participants I wanted to find out how the Indigenous governance of the Mayi Kuwayu Study influenced the design of the survey, and how this made it different from other national surveys with Indigenous Australians, like the NATSISS. Many of the researchers spoke about the importance of Indigenous leadership for MK, and how this would change the power balance in broader conceptualisations of Indigenous culture, health, and wellbeing in Australia:

> what I have really seen over those years is the transformational power of having a very large scale study that gives you insights into a population. […] the idea is to create resources that will give voice, and give a window to a population, and actually let their stories and their experiences be told and let their experiences count and guide what happens in the future.
>
> So the idea was to create a collaborative, large-scale cohort of Aboriginal and Torres Strait Islander people, and to have that as a community-governed resource. So sort of getting away from words like 'community consultation' and 'community engagement' but actually community-governed and community-owned. And also to have that particularly addressing some of the deficits in knowledge, which Ray's particularly interested in, which is the role of culture in health.
>
> — Interview with Emily Banks, 29 May 2017, Canberra, ACT.
>
> I think its [Indigenous governance of MK] critical. I think it has ensured that things are conducted in a way that reflects the wishes of communities who are being represented in the study. I think it wouldn't be possible to have conducted this study and to have the community support that we have if the governance arrangements weren't in place from the beginning. I can't imagine the study having attracted the support it has without that. And we can't undertake this study if we don't have community support.
>
> — Interview with Katie Thurber, 22 November 2017, Canberra, ACT.

> I feel very confident there's going to be some really big differences between MK and other large national, or large-scale surveys that are out there. In no particular order, the fact that this is Indigenous-led and developed makes a really big difference. So I think it makes a big difference in terms of the content. So the… just deciding what's important to go in there, how you word it, the order, is… makes a really big difference in terms of data quality and peoples' experiences of filling it out. So that's going to be a big difference. And also, people's participation, I think, will be potentially much higher than usual, because it's not a Government survey. It's an Indigenous-led survey, and knowing that the data is going to, you know, improving health, to collecting knowledge and information, to… the work… data that's not going to be turned around and re-labelled as yet another story about everything that's wrong in Indigenous communities.
>
> — Interview with Anna Olsen, 8 January 2018, Canberra, ACT.

> I think it's a ground-breaking study, and I'm very strongly supportive. And part of the work that I do is aimed around having more Indigenous control of what data are collected about us, and about our… our aspirations and interests being prioritised in what data are collected.
>
> — Interview with Maggie Walter, 5 March 2018, via Skype.

While I was in Australia I observed how the Indigenous leadership and control of MK operated on a day-to-day basis. Much of the orchestration of this leadership came from Ray Lovett as the lead researcher. Although MK is a relational project, it was clear that Ray acted in the role of the charismatic leader who made MK work. Aspects of charismatic leadership which have been found to operate across cultural contexts describe outstanding leaders as having foresight, being encouraging and motivational, communicative, trustworthy, dynamic, positive, and building people's confidence (Den Hartog et al., 1999). To the best of my knowledge there has not been any academic research done on charismatic Indigenous Australian leadership. There are a few scholarly discussions of Indigenous Australian leadership in the literature, but they are fairly contextualised: within the arts (Evans and Sinclair, 2016), women in education (Fitzgerald, 2006) and the media

(Ryan, 2016), and men in the Port Keats region (now more commonly known as Wadeye) in the NT (Ivory, 2009).

The common theme arising from accounts of historical and contemporary Indigenous Australian leadership is resistance, confronting difficult issues, 'saying the unsayable' (Lillian Holt in Sinclair, 2004: 15) and 'walking between two worlds' (Fitzgerald, 2006). However, in doing so, Indigenous leaders are often personally and professionally challenged by non-Indigenous individuals and structures as they 'are asked, and often inappropriately expected, to have levels of cultural expertise and authority that may or may not be the case, as well as be the embodied representation of all things Indigenous' (Evans and Sinclair, 2016: 472) (also discussed in Chapter 2). They must also 'look after' and be accountable to other Indigenous people, whether it is their families, their communities or the groups of people they are leading (Australian Indigenous Governance Institute, 2018, Ivory, 2009: 28, Ryan, 2016: 31-32).

Stemming from more traditional forms of leadership, modern Indigenous leadership in Australia is seen as a collective undertaking, where organisations rather than individuals represent and consult the wider community before making decisions or taking action (Australian Indigenous Governance Institute, 2018). This is in contrast to the style of leadership undertaken within the Australian Government, where individual elected representatives make decisions in parliament on behalf of their constituents. The conclusions from the extant literature about Indigenous Australian leadership characteristics corresponds well with my ethnographic data from MK. Ray was often described by his colleagues in ways which align with cross-cultural understandings of charismatic leaders (after Den Hartog et al., 1999):

> what I have found with each of the other studies I've been involved in is it usually requires the people… it requires leadership and vision, and it requires champions.

> It requires people who believe in it. And it also requires a certain amount of self-sacrifice in that it requires people who are willing to make efforts that then lead to a much greater collaborative capacity. […]
>
> So I think that the enterprise of Mayi Kuwayu is it is a huge team effort. And it requires a certain level of basic hard work. And so, when I look at what Ray's putting into that, and really how much that is a team approach and how much that he's doing that is really going to give back to the community and will be a really… something immensely useful for years to come.
>
> — Interview with Emily Banks, 29 May 2017, Canberra, ACT.
>
> I know the way Ray operates and because I worked for him before, I know the way he approaches things. I think he really has the community's best interests absolutely at heart in the way that he's very principled about ensuring that there's Aboriginal control and leadership of the work. And so I think he's sort of, quite a powerhouse in this space, and is leading something that is actually coming back from our community as a value that's been identified by our communities themselves.
>
> — Interview with Ruth Gilbert, 16 November 2017, Canberra, ACT.

Apart from aiming to be an example of good practice when it comes to conducting research with Indigenous Australians, Ray was continually aware of his responsibility as an Indigenous person to conduct research which benefitted the community in a culturally-appropriate manner. He also saw MK as a means for connecting with his own identity.

> And you see it with other people as well who either question their identity or have lots of uncertainty [getting involved in Indigenous research]. And then you see other people who are really strong in their identity and how that makes them feel. You can see how that makes them feel, and what not. So you know it's kinda searching for that same sort of stuff. So for me in my work, generally, it's a part of that because for me it's really reinforcing for my own identity that I work with Aboriginal people on issues important to them. And so, that for me is really nice for my identity. And then, going through a journey of really exploring my own identity. So asking my grandmother about our family history, being really involved

> with our southern Native Title processes. So my work has been related to that personal journey as well. And it's all gone together.
>
> — Interview with Ray Lovett, 6 May 2017, Thursday Island, QLD.

Janet Smylie also spoke about the importance of occupying the roles of researcher and Indigenous person in the design of research about Indigenous health.

> So it's always… there's a high bar I think when we try to develop health research tools that are meaningful and relevant to Indigenous community. I think as an Indigenous woman who is also trained as an epidemiologist and health researcher, I want to have the best of both worlds for the community. And then if I travel or visit other Indigenous nations I want them to have that too.
>
> — Interview with Janet Smylie, 26 October 2017, Canberra, ACT.

It is evident from these testimonies that part of the way MK's survey aims to understand the cultural determinants of Indigenous health is to have Indigenous researchers taking control as the interpreters of the data from the bottom-up and top-down. The importance of this was highlighted by Mark Wenitong, a Kabi Kabi man from southern QLD, public health medical advisor for the Apunipima Cape York Health Council, and CI in MK:

> SB: What impact do you think having Indigenous governance and researchers on the survey has had?
>
> MW: OK. My honest opinion is that if it hadn't been done by Indigenous people I wouldn't have taken any notice of it whatsoever. And that's not because I don't think non-Indigenous researchers can't document things well. I think it's more around contextualisation, if… and… particularly contextual analysis, and front-end framing as well. Knowing what actually is, probably, important to Aboriginal people from the start. This is often quite different to the mainstream 'great Australian dream' type approach that values Western material issues. So needs to be framed socio-culturally properly. […]

> The other thing, I guess, is that thinking through the approach and processes. So if you're… you know, if you are going to do this kind of research and you're approaching Aboriginal communities for interviews and a whole lot of other things, they're much more likely to get involved, in a real way, if it's an Aboriginal team that's running it. And that they know the people. You know, they have some kind of a relationship. Or know of them. And sometimes that's through family as opposed to reputation, and academia, and you know, professionalism. It's just like, 'Yeah no we trust… we like his family. They're OK. We can trust them. Let's work with them'. Not sure if I can add anything at this stage, but this is in the context of a shared, very deep old culture, and contemporary mistrust, particularly of researchers. As, to be honest, research hasn't so far given us the health gains proportionate to the investment. And our communities are aware little has changed. So the relational part is more than 'We are friends', but, what is *not* needed to be said with Aboriginal and Torres Strait Islander research teams. […]
>
> So it's more around just relaxing people and so they understand, actually we are trying to get your stuff, not what you want us to hear. We really do value you as a cultural Aboriginal person and your Aboriginality. We want to know more about you want to express that. About how… you know. So those kind of things I think are important from a governance and historical perspective. That is, that previous framing from policy programme and research has seen culture as a deficit, hence, our people know how to frame issues that keep the interviewer/researcher/government happy. But then we have missed the key issues for our peoples' wellbeing. So it's vital we have Aboriginal and Torres Strait Islander researchers who our people will share culture with. But for me, yeah, I think this is the kind of research you can't do to Aboriginal people, you just gotta do with them.
>
> — Interview with Mark Wenitong, 25 January 2018, via telephone.

Indigeneity is evidently a powerful factor in this research and has effects not just for those participating in the survey, but also for MK itself to be able to say that it represents the reality of Indigenous health and wellbeing in Australia. Ray Lovett as MK's leader, consulting with and including other Indigenous leaders, organisations, and communities in developing the survey seems to me to provide a compelling backstory for MK. Its focus

on Indigenous culture rails against the homogenisation of Indigenous Australians by current national statistics, and their ignorance of 'what really matters' to Indigenous people.

It was implied by a number of the researchers I interviewed that the findings of MK's survey will not only benefit the end-users but will also become a powerful tool in communicating the lived experiences of Indigenous Australians to (the overwhelmingly non-Indigenous) policy-makers (see Chapter 7). In so far as statistics may be called the 'language' of policy-makers, turning culture into numbers — in the hands of Indigenous people — may lead to better communication between Indigenous and non-Indigenous stakeholders. The next section will elaborate further on my proposal that using culture in this way has been a strategy for MK to promote positive change in the Indigenous health narrative.

3.4. Culture as strategy

There was a real sense from the beginning of its development that the Mayi Kuwayu Study and its survey could act as political tools in negotiations with the Federal Government, State/Territory governments, and other local authorities to promote the interests of Indigenous communities. This may be linked to the concept of strategic essentialism, first proposed by Indian postcolonial philosopher Gayatri Chakravorty Spivak. Strategic essentialism enables one to 'carve out a representative essentialist position' in order to 'do politics according to the old rules', and remain aware of the dangers of universalism (Spivak, 1990: 45).

In his paper *Beyond Black and White: Essentialism, hybridity and Indigeneity*, Paradies (2006) discussed the strategic essentialism of Indigeneity in Australia through the idea of pan-

Aboriginality, which is at once inclusive and exclusive, allowing individuals with Indigenous heritage to claim their Indigeneity, but also to be held up to imaginary stereotypes of what an Indigenous person can be (also discussed in Chapter 2). He critiqued the essentialist implications of Indigeneity in Australia but acknowledged how useful the pan-Indigenous identity concept has been for political mobilisation, and as a form of resistance against ongoing colonialism. Likewise, in the context of this thesis 'culture' might be read as a masterword (Spivak, 2009: 4), used by MK to strategically essentialise and mobilise an Indigenous worldview within the data-as-power landscape. As discussed earlier in this chapter, the researchers were very much aware of the risk of cultural essentialism, but like Spivak and Paradies, recognised it as both powerful and necessary.

The previous sections have highlighted the framing of MK within social epidemiology, and the use of the survey as representing Indigenous interests. Indigenous leadership of the project brings together knowledge and legitimacy in the survey's development, thereby encouraging community buy-in. This section will lead on from this discussion to present the ways in which MK aims to use the survey to contradict existing dialogues around the measurement of Indigenous health and wellbeing through providing strengths-based, Indigenous-governed data.

Ray Lovett sat on the Indigenous Advisory Committee for the ABS. In one of our interviews he spoke about his concerns over the way Indigenous health and wellbeing were being conceptualised at the national level, and the power dynamics at play between Australian Government departments in the collection of these data.

> SB: And then what about the meeting you had today? […] talking about the NATSISS? […] how was that?

RL: Ah… it's quite interesting going to those kinds of meetings, cause they structure what… how they make decisions is very different to us. So I think I was probably one of two, three, Aboriginal people from across the whole country. So they had the screens from every ABS office in the country. So from Melbourne, Brisbane, Perth, Darwin… ah…

SB: Like in the movies…

RL: Yeah. Yeah like in an incident room or some national security thing. Um… and their starting basis was 'We've run a test — a proof of concept. It's 10 minutes over. It must be reduced by that 10 minutes'. And that's it. That's where you start. And they had highlighted a whole bunch of questions that they thought that either people didn't respond to very well, or there were problems with the validity of the data. There's absolutely no discussion about wording, that there might be problems with the wording. […]

SB: Oh OK. So they didn't really provide an explanation. They were just like, 'These are the questions'?

RL: Yep 'These are the questions that didn't work so well, because lots of people couldn't answer them. So we'll cut them'. […] And that's what they did for every, every one. They wanted to exclude the questions from non-remote areas on some of the cultural variables. Yeah. But at the same time I'm really torn in those kinds of meetings, because that's exactly what this [Mayi Kuwayu] Study's about. And my, kind of, first question in all of that kind of stuff is 'Should the ABS be the institution that actually holds our cultural data?' […]

So I raised that in the initial steering group meeting. I'm on the steering group. And, I don't know, that got ignored. Because policy makers want the data. So ABS serves their client. PM&C [Department of the Prime Minister and Cabinet] pays five million dollars. So they serve the client. Yep. So, my point was, 'Are not your clients Aboriginal and Torres Strait Islander people?' And they couldn't answer that question. […]

SB: […] But it seems odd that they would… Is that something that you plan to look into further or just drop it?

RL: No I'm not doing that. Well I have absolutely no power in the process. I'm just an advisor — external advisor. Our views are… you can see very clearly, weighted less in the negotiation. So PM&C says what they want. Department of Health says what they want. And because those two fund this stuff, that carries much more weight.

— Interview with Ray Lovett, 6 February 2018, Canberra, ACT.

Maggie Walter also expressed frustration at the way the Australian Government currently uses their data to frame Indigenous health.

MW: The ABS health survey, I've had some input… well no I've attempted to have some input into that. I haven't been successful. Which… and that just rolls on its merry way with the same set of questions being repeated year, after year, after year. I had been involved in actually going to the ABS and trying to persuade them to change. But nah, they weren't very interested. They thought that inter-survey consistency was more important than… they didn't want to disrupt that. And so I did point out to them that if you ask a rubbish question for 20 years in a row it still a rubbish question. You've just got 20 years of rubbish data. So that…

SB: Can I ask what sort of things you would like to change about the ABS survey?

MW: Ah it needs to focus on strengths. It also needs to focus on Aboriginal understandings of health. It also needs to have… focus in on Aboriginal lifeworlds. So the health data needs to be collected in the context of the social-cultural, and other positioning, and… that surround the way Aboriginal people live their lives in Australia. Both from our own perspective and also the lifeworld in which we're forced to live as a colonised minority. So if you just collect smoking rates, but you don't do anything about whether the person is living in a community, whether it be urban or… and whether that person is able to maintain good connections, whether that person is… how they're situated in relation to their schooling, how the parent… all of those things.

If all of those things are completely not there, then you got one descriptive stat that explains nothing. It just describes. So it describes high levels of smoking. And we already know that, so… and it's not by accident. So it's carefully worked out so the focus… if you've only got those data, then the focus has to be on the

> individual Aboriginal person or their family. So it completely takes any life off the social-structural embeddedness of that disadvantage, and it focuses all in on the person. Why are they choosing to smoke? Yeah. What is it about them that makes them make the wrong decision? The implication always being it's something to do with their Aboriginality.
>
> — Interview with Maggie Walter, 5 March 2018, via Skype.

In contrast to the Australian Government's approach, Emily Banks emphasised that one of the important goals for MK was to provide reliable, positive information for Indigenous communities:

> So one of the things I think is most troubling about Aboriginal health research is how infrequently good news gets back to the community. So for example, Aboriginal cardiovascular mortality has dropped, death rates have dropped by about 41% from 1997 to 2010. So that's… we'd be almost halved by that. But nobody knows about that. It's not fed back. […]
>
> So I would see it [the Mayi Kuwayu survey] as having the potential to render visible and amenable to understanding things that are currently invisible. And you're not able to apply that quantitative lens to… I've often really thought that it would be great if we could replace the word 'research' with 'understanding'. Because quite often people say… first of all they'll say… it's the first thing to go in some budgets, like 'Oh we got rid of the research thing, we didn't have enough'. But if you said… well you can say 'Oh we won't bother doing research on that', but you'd be hard pressed to say, 'Oh we won't bother understanding that'.
>
> — Interview with Emily Banks, 29 May 2017, Canberra, ACT.

The introductory chapter highlighted significant issues with the ways in which Indigenous data has been collected and analysed by the Australian Government. Both Ray's and Maggie's experiences as government advisors was that their expertise and suggestions to improve ABS surveys were not taken into account by non-Indigenous government representatives. MK, in contrast, promotes an Indigenous worldview, and aims to address

the lack of explanatory data Maggie described above. I suggest that MK uses culture as a strategy, not only to represent Indigenous perspectives, but also as a form of power against the behemoth which is the Australian Government. Ray's thought about whether the ABS should hold Indigenous cultural data is indicative of these underlying motivations. Indigenous-led epidemiological conceptions of culture challenge the positivistic notion of an objective reality by restoring the subjective into the very tools of data collection.

From my perspective this is what is implied by MK's conceptual model. The bioecological models of health which informed the model and use of the survey tool align with epidemiological norms. While the extent to which these epistemologies reflected Indigenous perspectives was never explicitly discussed by my participants, it was evident that the Indigeneity of the researchers played a significant role in authorising and legitimising MK's framing. By focusing on culture, MK acknowledges the complex systems which inform the Indigenous experience, and the need for Indigenous researchers as interpreters of epidemiological data. This appeared to me to feed directly into the power of MK to alter the current deficit discourse in the Indigenous health narrative.

The following chapter details the focus groups organised by the MK researchers, and delves into how Indigenous community members, in conversation with the researchers, discussed culture and its relationship to health and wellbeing. The focus groups contributed in important ways to MK's representation of key aspects of culture. They played an important social, cultural, and political role within MK, legitimising the study's claims to be representative of the diversity of Indigenous experiences and were a form of collective consensus-building in refining the survey's metrics. The chapter centres on my observations during eight of these focus groups and describes what happens when culture is transformed from a lived experience into research data.

Chapter 4 — Culture and Community

The focus groups conducted by the Mayi Kuwayu Study researchers were one of the most important research processes undertaken for the development of the survey. With each focus group, the survey itself became more refined and more reflective of the collective experience of Indigeneity in Australia. This process was crucial for the survey's ability to define and measure key dimensions of Indigenous identities and cultures. These discussions about culture and wellbeing also held great value in and of themselves for the participants and the researchers alike. Within each conversation, there was a torrent of knowledge and emotion which at once gave all of us — as Indigenous people — catharsis, remembrance, sorrow, joy, pain, and hope. Hearing their stories, personal and historical, left the researchers and myself with a great sense of the potential of this study to generate a national understanding of what really matters for Indigenous communities.

This chapter focuses on the format of the focus groups and highlights major cultural themes which arose from those I observed. It details which focus groups were conducted where, what the process was, some of what was discussed, and what I observed when I was present (see Chapter 6 for further details on themes). The purpose of this chapter is to reflect on the Indigenous experience in Australia, and to provide context for my evaluation of how MK conceptualised cultural determinants of health through its survey. The focus groups touched upon a number of the ideas introduced in previous chapters, including the ways in which culture is transformed from conceptual into operational definitions (Chapter 1), and how MK achieved 'representativeness' through these community consultations (Chapter 3).

The Mayi Kuwayu Study researchers conducted 28 focus groups between 2015 and 2017 at 12 locations across Australia, with 197 participants in total (see Appendix 5 for full details).

These groups were organised by Jan Chapman in collaboration with local Indigenous community organisations which volunteered to participate (see below). I attended eight of these focus groups in 2017 to collect participant observation data. This included observing how the researchers conducted the focus groups to understand how this process influenced which questions were or were not incorporated into MK's survey. Figure 9 shows the locations where the focus groups were held, with the red dots representing focus groups I attended, and the black dots representing those I did not attend. As stated in Chapter 1, the focus groups were not intended to be representative of all Indigenous Australian cultural groups. Many of the focus groups included participants whose Indigenous identity was not tied to the local area, and several participants identified with multiple Indigenous groups and/or locations.

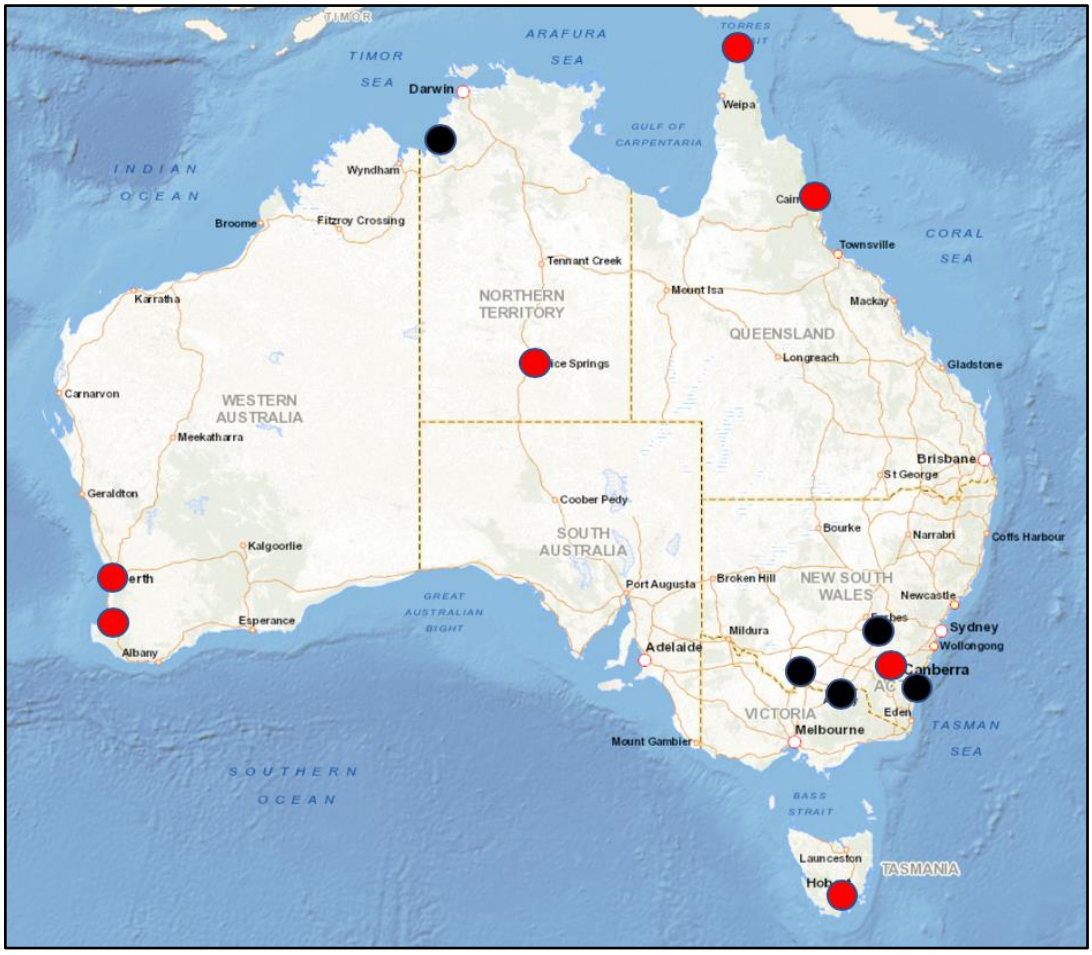


Figure 9. Locations of focus groups (based on Geoscience Australia material; Commonwealth of Australia, 2020b)

From the perspective of the MK researchers the purpose of the focus groups was to determine what the most important dimensions of Aboriginal and Torres Strait Islander cultures were for health and wellbeing at a national level. This could in turn be used to design the survey's cultural indicators. They also wanted to ensure that the other metrics included in the survey would be important and relevant at the community level. The researchers aimed to conduct their focus groups across a range of urban, regional, and remote locations to reflect the diversity of Indigenous experiences and understanding of English (the language used by the survey) (see below and Chapter 7 for my reflections on the use of English by MK).

While this was achieved to some degree, the researchers wished they had more time and funding to organise additional focus groups. Ray in particular wanted to gather perspectives on culture from younger Indigenous people, and to sample more urban areas where the majority of Indigenous Australians (79%) live (ABS, 2017). Nevertheless, the researchers were confident that they had achieved what they referred to as 'data saturation' when it came to understanding the key aspects of Indigenous cultures which influenced health and wellbeing for their survey.

4.1. Building focus group relationships

The Mayi Kuwayu Study utilised an opt-in policy for the focus groups, where Indigenous community organisations contacted MK if they wanted to hold a focus group in their area. Advertising and promoting MK was the first step towards accomplishing this. As discussed in Chapter 1, during the development of the survey Ray and his staff were involved in advertising MK at academic and professional conferences, on radio and television shows, and online. On the four occasions I went with them to conferences, the MK staff set up a small stall in the foyer with a large stand-alone banner advertising MK.

They had information brochures for delegates to take, and a sign-up sheet where those who were interested in MK could write down their contact details to receive the study's newsletter. At all of these conferences, Ray would give a presentation about MK either in a special session or as a keynote, and delegates would always come up to him to ask further questions. During the presentations I observed, Ray would mention that MK was looking for community organisations to partner with, and that funding would be provided to help organisations to facilitate focus groups (see below). Another way in which Indigenous community organisations became aware of MK was through MK's stakeholder networks. These included State-based Aboriginal health councils and the professional networks of the MK investigators themselves. *[Sensitive information removed]*

Once an organisation volunteered to facilitate a focus group, the researchers provided them with information about MK and their focus group requirements. MK also offered each organisation five thousand Australian dollars as compensation for hosting them. Organisations could then opt-in to participate. The researchers requested that six to eight participants be recruited for each focus group. There was no set number of focus groups

that the researchers wanted to conduct, as they were more interested in achieving data saturation, as mentioned above. Ray said that after a certain point the focus groups discussed the same topics as those held before them, and that was when the researchers knew that they had reached saturation. This is consistent with my experience observing the focus groups over time, as there was a large amount of repetition across the focus groups in the cultural themes discussed.

Individuals who participated in the focus groups all had strong ties to the local organisation facilitating the sessions. Most were living in the local area, except for the focus groups conducted at conferences, or where participants had travelled to the site for other business. Most of the participants were female, and for those who disclosed it, most were middle-aged (35–55 years old) (the full reported age range was from 16 to 78 years old) (R Lovett 2018, personal communication, 9 January). Speaking from my experience of the focus groups I attended, their individual occupations were very much dependant on the type of organisation involved in facilitating the focus group. For example, at the health service focus groups held in Bunbury, all of the participants were part-time or full-time employees of the organisation. At the health cooking group held in Canberra, many of the participants were part of a re-integration programme for former inmates from a local prison. Several had brought family members along for the meal provided. At the conference in Perth, all of the participants were in some way engaged in the field of Indigenous health, either as employees of Indigenous health organisations or departments, or as university students.

On a few occasions, organisations would express an initial interest in MK but for unknown reasons they did not follow through with facilitating a focus group. During my first period of fieldwork Ray mentioned that a focus group was being organised in the north of Western Australia, at Broome or in the Kimberley region, but it was never

finalised. Ray said that they did not have anyone on the MK team with strong connections there, and so this may have been why the local organisations did not pursue it.

On one occasion a focus group was arranged but did not go ahead on the day. The attendees, who were employees of the organisation facilitating the focus group, were told by their employers that they were required to attend and were not given any information about MK beforehand. The organisation was having significant management issues at the time. Their senior Indigenous management had recently resigned, and the organisation was currently overseen by a few non-Indigenous executives. The employees we met were concerned about being taken away from other work commitments to participate in the focus group and were in clear distress about their current situation in the organisation. Ray made the decision that it would not be ethical to continue with the focus group, and so we left. All of the other focus groups I attended did not have such issues and proceeded according to plan.

What this occasion illustrated — which was true for all the focus groups — was that how the sessions proceeded, at least initially, was very much dependent on how much information had been provided to participants by the organisation in advance. Participants often arrived at the focus groups without knowing much about MK or why they were asked to attend by their affiliated organisation. The researcher/s would discuss MK with everyone before the focus group began, in addition to providing information and consent forms for participants to read and sign. However, I had the sense that sometimes participants did not fully understand the purpose of the focus group until the end of the process.

During one of our interviews Ray confirmed that some focus groups did not understand that the main purpose of the survey was to determine the connections between Indigeneity

and wellbeing. This was apparent when I would ask the focus groups two questions of my own before everyone left at the end of the session:

- Why do you think other Aboriginal or Torres Strait Islander people would want to participate in the focus groups?
- Why do you think the researchers are running the focus groups?

In one of the Bunbury focus groups, one participant replied, 'I don't think any of us knew what this was about before we came here' and another said, 'We got a calendar invite'. In the Cairns focus group, it was evident that one participant did not completely comprehend the intentions of MK:

> But what's the ultimate purpose? Like, what does — like, you want them to help put together something? A set of questions. For what purpose though? What's the purpose of the survey and who's going to help? And what's it going to be used for?
>
> — Focus group participant, 4 May 2017, Cairns, QLD.

This is an example of how my questions at the end gave the groups an opportunity to reflect, collect their thoughts out loud, and to seek a de-briefing from the researchers. This was not something I had intended when I formulated the questions, but the effect was to elicit an honest and interesting conversation about what people thought about their participation in the focus groups.

> SB: […] why do you think — why researchers like Ray are running the focus groups?
>
> Participant: Why?
>
> SB: Yep.
>
> Participant: I think to… for ways… sharing different information from different group and getting it together. And it might be same information from us looking

> at it different angle, and… I think a more holistic approach on making it better for communities instead of coming in a concrete survey that's put out because of the Government, and it's all written in jargon words and it goes out to community and then they look at the form and go like, 'How do I answer that?' You know? Things like this. But they come in, find out if it's OK with the community, alter and change it so it suits each community's language and understanding of how to answer a question instead of it coming in as a solid print and coming in and the questions don't even meet the community's criteria and things like that. So it's good that this survey's going around and is open for discussion and alterations.
>
> — Focus group participant with Sarah Bourke, 5 May 2017, Thursday Island, QLD.

> SB: Why do you think the study researchers are doing these focus groups? […] Why do you think Jan and Ray over at the other table want to do these focus groups for the survey? […]
>
> Participant 1: I guess a lot of study goes towards developing policies as well, and practices within organisations and the Government. So researchers are there to feed that information through that hopefully they will, you know, implement policies and practices that would be beneficial to Aboriginal and Torres Strait Islander people.
>
> Participant 2: I think that you know that you're getting it from actual real people you've witnessed. It's not like ticking boxes and anybody could have done it. So this information you're actually with Aboriginal people asking for their input and then whether what you do with it is another thing.
>
> — Focus group participants with Sarah Bourke, 26 April 2017, Bunbury, WA.

The process for the focus groups always followed the same pattern. First the researchers would arrive at the location and set the room up with information and consent forms for the participants. All of the focus groups were led by Ray when possible, or by Jan if Ray was not available or if the focus group was with a women's group. In most cases, both Ray

and Jan were there to conduct the focus group. In a few instances other members of the MK team were included, though I was not present on these occasions.

Once the participants had arrived and were seated around a table, in a circle of chairs, or on the floor, the lead researcher would give a verbal explanation of the information and consent forms, and request that everyone complete them. If I was present, I would then do the same. The MK researcher would then confirm that everyone was happy for the focus group to be recorded and turn the audio recorder on. Sometimes focus groups were not recorded, or the audio recording failed (see examples below). All of the focus groups were conducted in English, and the participants almost always spoke English when responding to the researchers' questions and in conversations with each other.

There were only a few occasions when an Indigenous language word was used to describe a cultural concept to the researchers (see *Thursday Island* below for examples) but these were then explained to the researchers by the participants using English. For three of the focus groups for which transcripts are available, the participants often spoke to each other in an Aboriginal language during the discussion and then related their response to the researchers in English. A translator was not recruited for any of these focus groups, and the discussions from the recordings have not been translated into English by MK since the focus groups were held. I believe this reflects the underlying ideology of MK which aimed to collect generalised and comparable information about Indigenous cultures. The researchers were not intent on collecting context-specific information about culture for the development of the survey. The implications of this for how MK is able to represent cultural determinants of health will be discussed further in Chapter 6.

During the focus groups, the MK researcher would begin the discussion by asking the group 'Can you tell me about the important things that you think make up Aboriginal and Torres Strait Islander culture here?' and facilitate the discussion from there. The

discussions typically lasted an hour, although some would go on longer depending on the level of engagement. Once the discussion came to an end, the researcher would then turn off the audio recorder and hand out drafts of the survey for everyone to complete and give feedback on. This would then take another hour or so. If I was present, it was at this point that I would ask my two questions mentioned above. Following this, the researchers would collect all the forms, answer any further questions from the participants, and then leave.

At a later stage, Jan would write a brief summary of what was discussed during the focus groups and send it to the relevant organisation for their records. This was accompanied by a brochure based on the paper produced by Salmon and colleagues (2018) reviewing the literature on Indigenous cultural determinants of health and wellbeing (R Lovett 2020, personal communication, 14 April) (see Chapter 1). It is not known, either by the researchers or myself, whether this information was in fact passed on to the focus group participants by the organisation. I discussed this at the time with one of the researchers, and they said that they did not have the resources to return to every group and ensure that the feedback reached all of the participants.

Further, it seemed that MK's relationship with some of the organisations was fairly tenuous as a result of a lessening in engagement following the focus groups. On four occasions the researchers themselves returned to the area to give the results back to the community and to discuss the study further (Deniliquin, Albury, Cairns, national Indigenous health conference) (R Lovett 2020, personal communication, 14 April). All of these sites (except Cairns), in addition to Thursday Island and Bunbury, have since become community research sites for MK. Alyson Wright is a non-Indigenous Australian, who at the time of my fieldwork was undertaking a Masters of Applied Epidemiology at the ANU under the supervision of Ray Lovett. The aim of Alyson's current PhD project will be to engage with Indigenous communities around Alice Springs and assess whether MK's

survey questions and feedback from the focus groups are representative of wider perspectives in the local area.

Summary of other focus groups

There were a number of focus groups I did not observe, either because they were before my involvement with MK, were held while I was based in Oxford, or for financial reasons. These focus groups were held in Albury, Alice Springs, Canberra, Cowra, Deniliquin, Ulladulla, and Wadeye. Some of these locations are in regional country towns within driving distance of Canberra, and so a hire car was used by the researchers to get there. As Canberra is an urban area and the institutional home of MK at ANU, facilitating focus groups there did not involve extensive travel for the researchers. Wadeye is a remote location which is expensive and time-consuming to reach, and so Ray was the only researcher to travel there. Consequently, this was the only focus group where a researcher was present for more than a day to engage with participants.

The Deniliquin focus groups were conducted very early on in the development of MK, and so they were not recorded and detailed feedback was not collected by the researchers at the time. I was told by Ray that the Wadeye focus group was much less formal than the others, where he simply wrote down what people said on a whiteboard without any recording or other notes collected. According to Ray and Jan, the remaining focus groups were similar to those I had observed. Transcripts were available for four of these sessions, and are therefore included in my qualitative analyses presented in Chapter 6.

4.2. Focus group observations

Bunbury — 26 April 2017

Ray, Jan, and I left our Airbnb accommodation in Perth early in the morning to drive two hours south to the major country town of Bunbury. Of the 30,000 residents in the Bunbury area, 3.5% identify as Aboriginal or Torres Strait Islander, which is slightly higher than the WA average of 3.1% (ABS, 2016b). This focus group was organised with employees from a large health service operating in the area. This organisation serves around 4,000 Indigenous clients in the region and is the largest Aboriginal Controlled Community Health Organisation in WA. It aims to provide holistic and culturally sensitive health services for its clients, many of whom are from one of the 14 Noongar language groups local to the south-west of WA (South West Aboriginal Land and Sea Council, 2020). The word *noongar* itself means 'a person of the south-west of Western Australia' (South West Aboriginal Land and Sea Council, 2020).

We arrived before noon at a local community club, which was the venue the health service had chosen for the session. The building was closed when we arrived, and so we waited in the carpark for Ray and Jan's contact to arrive. When they did, they said they expected 20 people to attend the session. This surprised Ray and Jan who were only expecting the six to eight participants that they had requested for all focus groups. The side entrance of the building was unlocked and we were led straight into a large room at the back of the club. There were tables and chairs packed up along the sides of the room. Ray and Jan decided to set up two different tables with chairs around them so that the large group could be split, with each of the researchers in charge of one focus group.

When the health service employees began to arrive they started to congregate at Jan's table. I decided to sit with them, as this was Jan's first time leading a focus group. I wanted to observe how she would facilitate it and felt that we were in a similar situation given that this was first focus group I would observe. The health service organiser and some of the focus group participants explained to us that after this session they were holding their monthly staff meeting in the same place. This meant that following MK's session, the attendants would be remaining at the club for the rest of the day. There was a sense that this would be a long day for them, and both Ray and Jan seemed disconcerted that the participants may not be able to invest a lot of energy in the focus group.

The participants arrived gradually, and once the table had eight people around it Jan introduced herself, me, and then went through MK's information and consent forms with everyone (see a photo of the group in Figure 10). I did the same for my forms. Once this was complete, Jan asked me to turn on the recorder, and she began to lead the discussion. Ray had reminded her when we were waiting in the carpark beforehand to let the group discuss things amongst themselves without interruption. She did not follow Ray's advice strictly, perhaps because of nerves or because she was eager to get responses from the group. I also had to resist the urge to ask further questions during the discussion. While Jan was interested in gathering key words about culture, I was curious to find out why people thought certain aspects of culture were more important than others. However, this was not the goal of the focus group, nor the goal of my research. So I continued silently to observe the group interaction.



Figure 10. Focus group participants with Jan Chapman (centre), Bunbury, WA

I was given the impression that the group was quite focused and willing to answer Jan's questions. They seemed to be comfortable speaking about themselves and their personal experiences. As staff members of the same organisation they were clearly familiar with one another. The group appeared to me to be quite young on average, with almost all under 40 years of age. Some of the youngest members of the group did not contribute to the discussion at all, which I interpreted as a nervousness about speaking up within this relatively intimate setting. I also believe that these younger participants they may have been reluctant to share their experiences of culture. As I observed in several groups, when the discussion focused on particular aspects of culture, younger people often remained quiet and deferred to the older participants. This is a common cultural protocol in Indigenous communities. It is often the case that older people, including elders, are designated as the custodians of cultural knowledge and are empowered by their position in their communities to talk about culture to outsiders.

I believe that in many cases the younger people felt disconnected from the more traditional aspects of culture, and therefore lacked confidence in discussing culture within the focus group setting. This feeling is referred to by Indigenous people as *shame*, and describes a sense of inadequacy and low self-worth in social settings leading to an unwillingness to participate in social interactions (Louth, 2012: 2). Shame is a result of Indigenous peoples internalising negative ideas that non-Indigenous society have of Indigenous people (Stoneham et al., 2014: 7). This causes younger Indigenous people in particular to avoid sharing their opinions for fear of appearing uneducated, stupid, or not stereotypically 'Indigenous' (Louth, 2012: 2-3).

Most of the participants' cultural identities were not tied specifically to the Bunbury area, but were from surrounding regions. A sense of connection to culture and Country persisted for some despite living away from their homelands.

> Even with Country, for myself — like you said — I go back for funerals and stuff. But I've been down here for six or so years and I'm connected wherever I go. It doesn't matter that I'm originally from Kalgoorlie. I probably don't like going back there anymore because the people passed and I don't have that connection there anymore. I don't feel like that's — yes, I know that's where I'm from and that's where I was born and some family are there, but I don't know. I feel like Bunbury's my home. I feel as long as I'm — I love to go to the beach and as long as I'm out in nature… I've gone up to Alice Springs, I feel a connection there. So wherever culture is, that's where I've got a connection.
>
> — Focus group participant, 26 April 2017, Bunbury, WA.

After the discussion about culture concluded, Jan instructed everyone to fill out the survey and to give feedback on it. There was very little verbal feedback about the structure of the survey or the wording of questions. The survey took most of the participants a long time to fill out, some taking more than an hour to complete it. Once everyone had finished with the survey I asked the group my two questions. As mentioned above, my questions

seemed to trigger a debriefing between the participants and Jan as the researcher. One person was concerned about what the survey would be used for and by whom, and Jan provided her perspective in response:

> Participant: I suppose it's just mixed emotions, because I'm saying you can have hope that this does stuff I suppose… but with Government and Aboriginal people, I don't know. I just feel like they're not heard, or, even though they try to put their points across or whatever, we're still in the same situation we were from way back. I don't know… like, how many more surveys do you want to do to actually have something put in place that's working and when it works, they take it and yeah.

> JC: But this is not owned by Government, not funded by Government — that would be a different feature again. Like, we're funded by NHMRC […] they are funded by Government, but we don't have that title with us. What they pay attention to and what they don't pay attention to is really out of everyone's control, but it will be out there. And as much as we're still in the same position we were ages ago, people are more aware that Indigenous people have chronic disease. Indigenous are low on the wage scale. They're starting to know. Doesn't mean they're knowledgeable, just that they're starting to know. Anything makes a difference and hopefully this'll make a big difference.

The focus group ended soon afterwards. The researchers and I packed up our equipment and left to get a late lunch at the shopping centre in the middle of town. Ray and Jan began to reflect on the focus groups with each other over lunch and on the drive back to Perth that afternoon. This is an example of an occasion where I used respect to listen but not take observational notes on what they were saying (see Chapter 2). My reflection on the day was that so much rich information was delivered during the focus group, but that there was much which was left unsaid about the their local, lived experiences of culture, health and wellbeing. As an anthropologist, I itched to delve more deeply into the concepts they brought up. One participant mentioned during the discussion that Bunbury was a good place to live, but this was not picked up by Jan, and thus left out of what the

researchers collected as 'data'. This was something I observed time and again across the focus groups. What counted as data in this setting was very much dependant on the researchers' interest (including my own) and had a direct impact on how the survey was constructed (see Chapter 6 for an in-depth discussion).

Cairns — 4 May 2017

This focus group was organised at a local university campus with Indigenous academic and professional staff members. Ray and I were accompanied by Elsie Seriat, who was our contact for the Thursday Island focus group scheduled for the following day. We flew from Canberra together, and arrived at the Cairns airport at 1 p.m. We then took a taxi straight to the university campus. We went inside one of the campus buildings, walking past a central atrium and café with displays of Aboriginal art, and went upstairs where we were met by Ray's contact. We were shown into a meeting room and proceeded to set up the boardroom-style table inside with information and consent forms. *[Sensitive information removed from this paragraph]*

We were told several people had been invited to the workshop but only three arrived on the day, including the organiser. Once everyone had completed the consent forms, Ray turned on the audio recorder and began the discussion. The participants in the group were immediately engaged in talking about culture.

> RL: So if you could tell me about the important things that you think make up your Aboriginal or Torres Strait Islander culture, what are those things?

> Participant 1: Family. […] Well, I was brought up — so obviously, I have a European father, but we were brought up with my mother's culture and from a young age. And it's always… but even though my father's European, he's sort of drummed it into us too that family always comes first, and you've always got to be responsible for your family. But that's always been from my mother's culture within Torres Strait. My grandparents… I don't know. You've just got to be there to look after your family. It's like an expectation, and so, when I see it not being done I get very frustrated […]
>
> Participant 2: Family is important but for me, I was raised in a dysfunctional family and with all the dysfunction comes the struggle right throughout your entire life. […] But even though we were still — a lot of the family were dysfunctional; we were still close and connected.
>
> Participant 1: And I think that those social issues affects everybody in some way, shape or form. It's the same. […]
>
> Participant 2: Yeah, when we go back to colonisation, you know? Like, wounding of the spirit. Like, most of our people have wounds. Deep spiritual wounds, especially the Stolen Generation people. Because I'm of mixed blood — English, Scottish surname — so I sort of call myself fruit salad. And Aboriginal. It's all mixed.
>
> *LAUGHTER*
>
> […]
>
> Participant 3: But I think it's that relationship, isn't it? And the obligations you have and commitments you have with — as you say — being responsible. And it's all about passing on that knowledge. Cultural knowledge, but just some bible knowledge, I guess, and taking care of passing on that information. Passing on cultural information.

A sense of having lost culture and the impact this has had on younger people was another theme from the workshop:

> Participant 3: Our kids are really confident. They're educated. They're moving in different directions. They have a good understanding of Western systems as well as still maintain their Aboriginal and Torres Strait Islander identity and culture. So I think sometimes we just see what we see because of our jobs, but I think there's a whole new generation coming through that are really carrying on the traditions and the culture. […]
>
> Participant 1: I don't know. They're just — you teach them the cultural stuff, but the way society is and moves with non-Indigenous, it seems our culture and our responsibilities and everything we've tried to teach and learn seems a very small part of their Western world. And it's just taking over, and they just don't seem to get how important those cultural things are and how important it is to maintain it. I just see a lot of it getting lost.

While the participants were filling out the surveys Ray explicitly asked the group about the survey questions to gather their perspectives on how questions in the survey should be framed:

> RL: So thinking about how we might ask about these things then… So how do you think we might ask about family responsibilities, family connection, and these sorts of things? How would we ask about that, say, in a survey sense? Or how would we ask people?
>
> Participant 1: See, I look at — I think there's a few different ways to be asking, because it depends on the level of education of the people you're asking, the language you use and how… what's the words you're actually using. And then it depends on where in this country have you come from, because my work experience is in mixing with people from around the country. They all speak differently — and I'm talking the black fellas. And I don't know so I really can't define that as one good way to be asking everybody. I don't know.
>
> Participant 2: I think like, sharing your stories and you know. Because out of the stories, you can get information from those stories that they tell because most people like to tell stories. You know, about their own life. And if they've given you permission to get those stories, it would be good to get stories.
>
> Participant 1: Yeah.

> Participant 2: Because when we were doing research in Yarrabah it's mostly the people's stories that we were collecting. That they were telling us what impact the family living programme had on them in the community. And not only that they were saying, but we also can see the evidence of it, you know, in their lives. What they were doing and what they were saying was true. […]
>
> Participant 1: I work with the Aged Care as well as people with a disability as well as mental health. The mental health is specifically Aboriginal and Torres Strait Islander. I also manage a shelter for domestic violence up in the north. And they're mainly Indigenous. And this is a non-Indigenous organisation I work for, but in this region they have a very high number of Indigenous clients that are the ones with the disability. They were put in institutions many years ago and then brought out when they closed the institutions down.
>
> So we've got a lot of Europeans giving us tools and surveys and questions to use on these clients and its like — no way. There's absolutely no way I'm going to use these tools. And what I tell all of my staff is, yep, 'Look at that tool. What's the type of thing they're trying to draw?' And that's the important thing. What are you trying to do? What's the type of information? And then I tell them all, 'Put that thing aside and just yarn'. It's the conversation and how you draw the information out. […] because it's really hard to define what is it about your culture that you really value. You ask that of someone that's got the… you know, it's just like 'Oh, well I don't really know'. So I struggle with defining particular questions to get maybe variety.

This conversation highlights a major issue with the survey method as a tool in Indigenous research, and particularly research which focuses on culture. The focus group participants said that the answers people would give in the survey lacked context, and that it would have been better for participants to be able to share their family stories. Alongside this is the perception of survey or other quantitative measures as Western tools, as one of the participants suggested above. While MK has been developed by Indigenous people, and has incorporated Indigenous perspectives throughout the development process, it still utilises what is perceived to be a non-Indigenous method of doing research. MK's survey does not ask about those personal stories, and for the vast majority of participants, it will

not be administered in person. As much as it captures general data on Indigenous culture, health, and wellbeing, there is much that it does not (see Chapter 6 for further details).

> Participant 2: If they're telling you a story, they might tell you, 'The other day we went out to the bush to look for some bush food'. And when they tell that story, there's more to it than looking for bush food. They're going back into their ancestral lands where the ancestors used to hunt. And so there's things that go on inside that bush, you know. They listen for different callings of different birds if they go, like the Torres Strait pigeon. Or pig or whatever. And then they're reconnecting back into the land and with most Indigenous people there is a strong connection to the land.
>
> Because when I go back to Western Australia where I was born in Broome, I feel a sense of peace just walking in the places where I used to walk and swim and fish. And it's a new peace come over me and makes me feel good to be home. And in Western Australia, they call that good *liyan* you know? Good feeling. It's a good feeling to be home, and that's what… if those feelings… if you really listen to this story, you'll get those things coming out in the story.

Once the discussion was concluded, the participants began to fill out the survey and provide feedback to Ray. One of the issues that came up was that many of the questions would not be relevant to Torres Strait Islanders, and that the survey should be modified to include them more explicitly. Ray took this on board and the focus group concluded soon after.

Thursday Island — 6 May 2017

The day after the focus group in Cairns, Ray, Elsie, and I flew north from Cairns on a small plane to Horn Island in the Torres Straits. We caught the bus from the airport to the well-used ferry which operated between Horn and Thursday Island (Figure 11). Elsie said goodbye to us at the pier to go home with her family who were waiting for her at the dock. She had grown up on Thursday Island, but her family was Wagadagum (Migi Buai) from Mabuiag Island, and Kaurareg from the Kaiwalagal Archipelago in the Torres Straits.



Figure 11. Ferry dock on Thursday Island with a view towards Horn Island

Thursday Island has been the main organisational hub of the Queensland Government in the Torres Strait Islands since the late 1800s. It is far from the biggest island in the Straits, with an area of just 3.5km^2, but is the most densely populated with 2,939 residents, most of whom identify as Aboriginal or Torres Strait Islander (n= 2,020, 68.2%) (ABS, 2016c) (ABS statistics do not distinguish between Aboriginal and Torres Strait Islander peoples). Ray and I rolled our suitcases along the boardwalk and the road which ran parallel for the

short five minute walk to our accommodation at the Jardine Motel. We relaxed for the rest of the afternoon at the Motel and went for a walk up the hill which overlooked the small island and sea beyond before retiring for the evening.

The following morning Ray and I got ready early and went to get a coffee from the local takeaway shop before meeting Elsie outside a local youth centre on the main street at 8 a.m. This focus group was organised by Elsie, with two elders and members of a local exercise group. *[Sensitive information removed]*

Ray had worked the previous evening to update the survey draft to integrate comments from the Cairns focus group, specifically including 'Torres Strait Islander' alongside 'Aboriginal' where it appeared in the text. We set up inside the one-roomed building at a large table with the usual forms, and Ray printed off the latest version of the survey. The focus group participants began to arrive shortly after. A total of six individuals were present, ranging in age from 25 to 62 years old, including three female members and one male member of the exercise group, and two male elders (see Figure 12).



Figure 12. Thursday Island focus group participants including Elsie Seriat (3rd from the left) and Ray Lovett (3rd from the right) (One participant chose not to be photographed)

Once our introductions were complete, Ray turned on the audio recorder and began the discussion. The elders in the group led the conversation, with the younger people deferring to them. As stated above, this practice aligns with cultural protocols common to many Indigenous groups and occurred in almost all of the sessions I observed. The elders spoke in particular of the more traditional concepts of Torres Strait Islander culture and wellbeing.

> RL: Important things that make up particularly Torres Strait islander culture, what kind of things would you say make the…?
>
> Participant 1: About a culture?
>
> RL: Yeah. What's important?
>
> Participant 1: Well, I think first of all, our Lore. L-O-R-E. Because it's actually based on the heart of our identity, each of our clan groups across the region has *kod* — K-O-D. […] It's a place where your heart, your discussion is made about the whole wellbeing of your community. […] And so hear dialogues. You know, the actual activities that you participate in from a survival perspective where the

> winds, the environment, the seas, because you find there that you're one with those. You're one with your environment. You identify yourself with the sea and the air, so I think that one of the main things of who we are is knowing our bloodlines, blood types of those… your community.
>
> […] I suppose the three tiers that we look at. Our physical connection, and then you have the two most important that is not seen is your emotional connection and your spiritual, which is number one important factor because all of our belief system and our connectivity bases on spirituality. That's why in the Torres Strait, we accept the Christianity because it aligned itself in the same way that our mind-set or thinking, we do our worship. But it's an everyday thing because we breathe and live our culture. We don't come Sunday and then worship our culture on Sunday. It's every day. […] So I think that what I said before, our important factor for Torres Strait islanders is actually really recognise our identity to our Island and our culture. The rest is actually like an island mat. You just weave it together, you know, because that's who you are.

Identity was a strong theme in this focus group and was discussed in relation to the physical environment of the Torres Straits, including animal totems, and more generally. The elders spoke powerfully about cultural identity and seemed to regard it as an opportunity to teach the younger people in the group, including Ray and myself.

> Participant 1: Because I think that's where, especially now when we live in this — you're a generation that travels between the tradition and the contemporary, and you do that all the time. And it's important not to lose your authenticity of who you are. You make — because in English, we struggle to speak perfect English. There's no such thing as perfect English, but we struggle to do that. And yet, in the language that was God given, for you, me. It's part of our identity, but you are weighing out of the two. You can move into the two different worlds and you're still comfortable, and I think that's the most powerful stuff from an elder looking at a young person, is to see them.
>
> The elder only limited now, but the next runner, you know, like the marathon. It's long and that's what our culture's all about. It's actually relating to this. It's about the endurance. It's not a short race and you find that when we just do bursts, you become worn as a sprinter. When the thing finishes, we live in a fast world now.

Fast changing environment and influenced by many cultures. And that's where we stand because we — with our Aboriginal brothers and sisters — identify that we are the longest surviving society in the world, and therefore we have a coat hanger, or a coat hook we can hang our identity on. It's not something that doesn't fit anyway, but it's as a place. And where's that place? It's in you. You're cut of that. That song. You cut it and dance. When the celebration finishes, you're still there, you know?

RL: [Addressing the younger members of the group] What about you guys?

Participant 2: He summed it up.

Participant 3: Yeah, he did. But as a young person listening to Uncle [name] talk, it is stuff that's not really spoken about now. When you talk about the winds, that's something that — good way, that's the first time I've heard it, but wow. My grandma was Torres Strait Islander but didn't really speak much of her culture, So we didn't really practise a lot of that. And my Dad's non-Indigenous. So that's actually the first time that I've heard of that one. Wow. You are impressing.

Participant 1: And you guys live in a very important time, because — whether for me, with an East and West knit, and then I'm the product of that both. That's why it makes me stronger that I can actually stand in a contemporary forum, no matter what colour they are, what culture they are. I'm able to converse with them, because I know who I am.

Participant 3: Wow.

Participant 1: And what strengthens me now and strengthens you lot is that connection with you, that in our language, we say [*language word*], meaning 'weave' in the eastern island. [*Language word*] — weave, in the western island. That's you totally weave together. You make that identity more strong because it's alive. It's not an archive thing. You can't actually hang it in an archive because you live it. You breathe it. Every morning you get up, the wind touches your face, you're happy because you have your senses. You smile, and just reminding you that well, you're not alone. So it's more than just a fate. More than I can preach from a pulpit to say the faith you own, because you know, we are just in this natural body. We need to feel, because our senses — we're governed by our senses. So when that senses, when the wind it touches you or when you look at the sea, you

know, something stirs within us. You can't explain but know because you am me and I am you. That's it.

Younger members of the group expressed a feeling of disconnection from culture and identity, and had similar concerns for their children:

Participant 4: For me, my journey back to the Torres Strait after living in Mackay my whole life was for that. For that connection and knowing family and the connection to culture because it wasn't something that we grew up a lot with. Living away from home and my Dad being one of the youngest in his family, there wasn't something that was very well practised. I think he really, as a whole family unit, the… So yeah, that was part of coming home and being fortunate enough to have married into another Island family that's very culturally linked has really strengthened my understanding and my connection to the culture. So yeah, it's been something that I try very hard to make sure my kids are more aware of who they are and what is culture and not that you're from TI. That's now where you're from. This is where your Dad's family is from. This is where your Mum's family's from and all that sort of stuff. So I think it's very important.

And like I said, if you don't have that identity, then you're lost in the world. If you don't — if you just identify as a Torres Strait Islander, you know tick the box, but you don't have that within you, you don't have that centring or that knowledge of what that actually means to you, I think that's — you do get lost in the world that is full steam ahead. Social media. You're looking at what every — you know, like you said, the kids these days are seeing what everybody else in the world are doing. America, people down south, what they can do here, there, and everywhere. And if you don't have that centre ground at home in your community, where you know where you belong and who you are and what you want to do with your life, you can very easily get drawn out into a world that is very disillusioning.

Another story shared in the group explained how Indigenous people can support each other to achieve more in their lives:

Participant 1: That's where you break old barriers. You break anything that you know. I remember when I was a kid growing up. I was a good sportsman, but I

> was a short distance runner. […] When it come for high jump, I'm lining up there too to high jump. And they look at me and they called me short man. 'Hey, shorty, how come you come here?' And I thought well, I've got to stretch my own limitation too. I can jump but I didn't make it to their heights but I participated in all the other heights coming up, and what I did was I pushed them forward, to go higher than what they — because they all of a sudden said — thinking now, physically, 'This short fellow can jump probably higher than us'. So they now, they take it up to the next level of rung. I can't go but they can go. But who wins? We all win, you know.
>
> Participant 2: That's it.
>
> Participant 1: Because we'll be the champion coming from that class or that mob. But that's what we are. We're here to push one another. The ability, not in a bad way, but proper because you, me, in our lifetime I believe, we will never really go to the highest of what we can do. We're going to need others to push us to keep on going.

After the discussion the participants began filling out the surveys. I asked my two questions, and again, felt that they acted to debrief the group. One point raised was that it would be beneficial if there were a feedback form for focus group participants to fill out about how the session went from their perspectives. I thought that this was a valuable suggestion, as the feedback often only went one way, with the researchers providing a summary report of the main points from the discussion long after the focus groups were held. To my knowledge this kind of participant feedback was not collected from any of the focus groups following this one.

This discussion about culture and identity on Thursday Island was very inspiring for me, and for Ray when we reflected on it. He would often mention this focus group later in conversations with the other MK researchers and partners as an example of the important knowledge that was gained from the focus group process. As Indigenous researchers it was moments like these that made us feel good about the work we were doing. It validated not

only the work itself, but also our personal identities in the research space (see Ray's perspective in Chapter 3). An environment was created in this focus group which made everyone feel like they were valued and that they were a part of something larger which would help Indigenous cultures survive and thrive in the future (see Chapter 7 for further discussion).

Alice Springs — 12 May 2017

This focus group was conducted with members of a women's group at a council building in Alice Springs. This group are prominent in the local area for addressing issues to do with family and domestic violence, and work to educate Aboriginal men and women about non-violence both locally and online. Jan and I had flown to Alice Springs from Canberra the day before and went to the council building early in the morning to meet her contact there. This focus group was organised by a non-Indigenous female member of the council staff, who had driven to some of the town camps surrounding Alice Springs to collect participants for the session. Three women participated in the focus group, including one who worked for the council and two elders (see Figure 13).



Figure 13. Alice Springs focus group with Jan Chapman (right)

We gathered in a small meeting room which had a whiteboard, some chairs, and large, brightly coloured cushions piled in the corner. All but one of the women chose to use the cushions on the floor, and so Jan and I joined them on the ground, forming a loose circle. The women requested that the woman who organised the session remain in the room for the focus group. This was something I knew was a point of contention for the MK researchers. The researchers only wanted Indigenous people to participate in the focus groups, though in some cases non-Indigenous facilitators had been allowed to be present, but not to contribute to the discussion.

After the usual introductions Jan wanted to begin the discussion, but because she did not have the audio recorder with her, she decided to try and record the conversation on her phone. During the session the non-Indigenous organiser acted as a kind of secondary facilitator alongside Jan, helping to draw more descriptive answers from the participants for whom English was a third or fourth language. It took some time for the women to become comfortable in the discussion, and from my perspective, it took some time for Jan get used to the brief responses the women first provided. This extract from the start of the

focus group discussion illustrates these interpersonal dynamics alongside the key dimensions of culture brought up by the women.

> JC: So we're here today to talk about culture, to find out what cultural things are important to you, to you and your wellbeing. You know, so we'll be able to get it there, but I'll take notes but, what to you is important in culture? […]
>
> Participant 1: Culture for me is respecting our elders. By means of that is that they are our first teachers. They're our guidance. They're our backbone of our family.
>
> JC: That's good. Thank you. Some pre…
>
> Participant 2: Are you going to ask us a question?
>
> JC: No. This is still going to be — you can talk whenever you want. Previous groups have said language or connection to Country.
>
> Organiser: There'd be lots wouldn't there.
>
> Participant 1: Yeah. I always start with elders because they're our teachers and they're sort of, like you said, help us connect back into Country. They teach us knowledge, history, storylines, songlines.
>
> Participant 2: Laws.
>
> Participant 3: Caring and sharing with family.
>
> Participant 1: And it's also that family kinship connection that keeps us strong in a way.
>
> Participant 3: Listening to our grandmothers and mother and all our Aunties talking about history and dreamtime.
>
> Participant 2: Dreamtime stories. Stories. Songs.
>
> Participant 3: What is right and wrong for women. Their teachings. Indigenous women, Law, culture. Law and culture.

Participant 1: And it's that respect with men's Law and women's Law.

Participant 2: Ceremony too is strong. Keep it strong.

Participant 3: Spiritual and…

Participant 1: And it's healing too.

Participant 3: Spiritual healings. Coming of age to be a young woman. And which a man to have for husband. Your straight skin name. […]

Participant 2: Skin group. Marry the right skin group.

Ceremony was a particularly important aspect of culture for the group.

Participant 1: Dancing is like… there's few ceremony dancing. You've got the dancing, there's healing dancing, women's get together. It's like a strong healing culture with the men's — I don't know what they do but they do their own part. We don't sort of want to know about, but they still do their ceremony and dancing there.

Participant 3: It's like a taboo you know? You go or can't go to the men turnout and the men can't go to the women's.

Participant 1: And our ceremonies, you get healing ceremonies, dancing and then you can get connection to family ceremony, connection to land ceremonies. There's all — there's one big part, it's called ceremonies but there's different parts of dance, like the ceremonies, they've got the men's and the women's and you've also got the healing. You've got teaching the young ones dancing ceremonies. You've got young woman healing ceremonies, like kids that are coming out of primary school going into high school, but they do that on communities.

Participant 3: Smoking ceremonies. Baby.

Participant 1: With smoking ceremonies they also can use that as a healing ceremony, smoking healing ceremony or a smoking healing — like to get the bad spirit out of the house or something. You can also have a smoking ceremony for babies and it's — when they do that, they smoke in the babies to make their

> insides and their bones and their blood strong and it sort of helps them with their thinking ability as they're growing up. That's if the alcohol doesn't come in and step in their way. Yeah.
>
> Organiser: So smoking is used through a whole lot of different points of life.

The importance of elders for maintaining connections to Country and history were clearly stated:

> Participant 1: And I remember, I don't know if they do it today, but me when I was growing up — only about maybe 4 or 5 years old — I remember having a Sorry Ceremony where all the old elders would just sit down and sing their sorrows away and it was kind of healing kind of tone. And I don't think they'd have that anymore but it'd be good. It frustrates me because as a young mum and a young person wanting to have… build the rest of the young people — bring back the respect in themselves and respect our elders because they're the one who give us the guidance. I mean it's from… whether it's from the stars to the footprints of the animals.

After the discussion Jan handed out the survey forms to be completed, and she and the organiser went to help the two older women to complete their forms. As in the previous groups, it took a long time for people to complete the forms. Once the session concluded, the women went to eat the lunch provided for them, and Jan and I said goodbye and left to get our own lunch and walk around the town.

Jan in particular felt that culture was very strong in the NT. She had lived in the NT when she was younger and told me that doing focus groups here helped her feel good about her own Indigeneity. However, she also reflected on how much culture had been lost in other parts of Australia, and how this was represented in other focus groups which spoke about this loss. This was a thought-provoking focus group for me to observe, as many of the topics raised were those typically associated with 'traditional' Aboriginal culture. As one of the participants stated, some of these practices had not been undertaken in a long time,

and yet many were still a significant part of their daily lives and informed the ways in which they saw themselves as individuals, family, and community members.

Canberra — 14 November 2017

This focus group was organised by a local health service with attendees from their weekly healthy cooking group. It was a coincidence that I went to observe this focus group. I was at the MK office at ANU in the morning to work in their designated student room when I ran into Jan. She told me that she was leaving soon to run the session. Jan and I drove from the ANU and arrived at the health service just after 11 a.m. We waited in the car for the focus group facilitator to meet us, and once they arrived, we walked to an external building nearby which was often used by the service as an art room or general meeting space.

The facilitator told us that the building was owned by the ACT Government, and that the Government had not invested any money in improving the building since it was built around 20 years ago. I remembered this building from when I was a teenager participating in a YWCA event over a decade ago and agreed that nothing had changed. The organiser said that the health service were going to pay to have it refitted with IKEA products, and to renovate the out-dated and dysfunctional kitchen and bathroom facilities. She advised us not to use the bathroom there as the toilet flush would come back up and that the public toilet nearby was usually full of discarded, used needles.

[Sensitive information and figure removed]

The healthy cooking group included three other staff members from the health service as well as participants. There were around ten people in the room, but only a few contributed to the discussion. The organiser told us that some of the participants were required to attend the cooking group as a condition of their jail parole, while others came for the social benefit or just to have a meal. She also told us to expect a low level of literacy from some members of the group, and that they may need assistance reading and filling out forms. Participation in the cooking was not compulsory for the attendees, and I observed that it was the staff members who did the majority of the food preparation and cooking. Most of the people who attended the session had been collected by the health service staff from their homes in Canberra, or from a small town nearby called Queanbeyan on the ACT/NSW border.

There was a large table in the centre of the room which everyone gathered around. Jan gave her introduction and MK's forms for everyone to fill out, and I did the same. When this was completed, Jan used her phone to record the discussion and placed it in the middle of the table. However, Jan later realised that the recording did not work. Jan took dot-point notes of the cultural themes brought up during the discussion, as both researchers did for all the focus groups.

There was a conversation in the group about whether Indigenous people from other places feel at home or welcome in Canberra. Canberra is a very multicultural place, particularly within the Indigenous community. While it is situated in Ngunnawal and Ngambri Country, it has always been a meeting place for Aboriginal people — even the word *canberra* means 'meeting place' in the Ngunnawal language. Canberra was often a site for huge events called corroborees. A corroboree is a celebration, typically involving dancing and singing ceremonies, which brings together different family groups. The word 'corroboree' is widely used by Indigenous Australians today, though it is an Anglicisation

of the Dharuk word *garaabara* (a type of dance), and was used by early British colonists (*Collins English Dictionary*, 2012). In modern times, Indigenous people from around Australia migrate to Canberra for work, usually in connection with the Australian Public Service whose head offices are all located in the capital. My impression from the focus group discussion was that some of the participants felt disconnected from the wider Indigenous community in Canberra because of its diversity.

One older member of the group said that he had a healthy relationship with Country. Others mentioned the importance of feeling connected to Indigenous history, not just in the Canberra region, but also events that had happened in other places. One example of the strong connection between history and Country given was the Gurindji Strike or Wave Hill Walk-Off. In 1966, Vincent Lingiari led 200 Indigenous stockmen, domestic workers and others in a strike at Wave Hill, a cattle station in Kalkarindji in the NT, to protest the acquisition of their traditional lands by White Australian pastoralists and the financial exploitation of their labour (National Museum of Australia, 2019). Similar themes to the other focus groups were also brought up here including family, traditional Lore/Law, language, and education. One participant also mentioned the importance of Indigenous values, like participation in community, and maintaining balance within oneself and one's life.

There was also an exchange about ill health and food availability in Canberra. The participants talked about how their addiction to certain to foods high in fat, salt, and sugar stemmed from the types of food given as rations on the missions that their parents, grandparents, and other family were exposed to. This was also a finding in my Master's thesis which focused on the social construction of obesity for Indigenous Australians (Bourke, 2015). Foods which were given as rations such as sugar, tea, flour, and other starchy, salty, and fatty foods are now thought of as a way to connect people to their

childhood, parents, and ancestors (Fredericks, 2013, Foley, 2005: 26, Thompson et al., 2000: 733). As a contrast, the group spoke about bushfoods and how they were not only healthier, but represented an understanding of and connection to Country, where the knowledge of how to prepare the food and survive off the land was an important aspect of culture.

From my perspective, this focus group was less organised than the others I had observed, and the majority of people present did not contribute to the conversation. After the discussion, when Jan handed out the surveys, it was evident that some people were uncomfortable with filling out the surveys, perhaps because it took a long time to do, or because they were having trouble reading and understanding it. Jan and the health service staff members were on hand to help people who wanted assistance to fill out the forms. However, there may have been an element of shame which played out in this group too, leading to people not complete part of their forms. Jan told me later on that only five of the ten forms she had handed out had been fully completed, and this is the number reflected in Appendix 5.

Bunbury (Women's group) — 27 November 2017

Ray, Jan, and I drove from our accommodation in Perth to Bunbury to conduct a focus group with a local women's group. We arrived at the location mid-morning, which appeared to be a residential house that had been converted into small offices with a large meeting room in the back. We walked around the back of the building where there were young children playing in the backyard outside. A group of women were sitting inside the meeting room around a table, and we later learned that this was their regular, monthly catch-up. As this was a women's group, Ray left us to attend a meeting with the health service that had hosted the previous focus groups. Indigenous cultural protocols often

dictate that women talk to women, and men talk to men. Jan and I sat down at the table with the group and proceeded to introduce ourselves and our research. Once the consent process was completed, Jan began the discussion. Jan used an audio recorder, but she told me later that the recording failed.

The discussion was dominated by the two older women in the group. The conversation was often interrupted by children running into the room looking for attention from their mothers and Aunties. The group asked one of the youngest women to take the children outside and to mind them in the backyard. Jan again tended to direct the conversation, rather than letting it develop naturally as Ray did. She also asked about themes that the participants did not mention initially to prompt responses.

In discussing culture, one of the older women commented that 'We make it strong'. I took this to mean that cultural elements were actively maintained and promoted within the local community. However, they acknowledged that there were gaps in cultural practice, particularly for young people, who could not for many reasons be taken out onto Country. Another issue when they were out on Country was hunting, as non-Indigenous locals would call the local government council complaining about animal cruelty. Furthermore, access to Country was being blocked by non-Indigenous landowners and for conservation. Restrictions were placed on where people could camp and for how long, with three months being the maximum time Aboriginal people were allowed to remain in the bushland.

The women mentioned a number of groups — elder's, women's, men's, youth — that focused on supporting people's social and emotional wellbeing. Noongar language was also being taught to primary school children, but they told us that this was not across all the schools in Bunbury. According to the women, Noongar used to be taught more widely, but that there were complaints made about it by non-Indigenous students and

parents. This was despite the fact that the schools continued to teach Chinese and Italian, and the women told us that this was probably due to racism against Indigenous peoples within the school's governing body. One of the women informed us that a Chinese woman teaches the Noongar classes, and the rest of the group expressed regret that she probably knew more Noongar language than most of the Noongar locals.

The women were interested in and knowledgeable about traditional food and medicines. They mentioned quandongs being macerated to make jam, and nuts being used to make jewellery. A nut or seed was mentioned by one of the women that could be chewed to relieve joint pain. However, the women spoke out about the problems with some people not sharing their traditional knowledges with others. This seemed to be representative of underlying tensions between family groups in the area, which existed alongside the desire to protect the knowledge from being exploited by others, including non-Indigenous people. I again felt that it was unfortunate that this local cultural knowledge was not being incorporated into MK and the survey. As discussed in Chapter 7, while some focus group participants saw the potential of MK to raise awareness of the importance of culture for Indigenous wellbeing, the ability of MK to document local knowledge and experiences was severely limited by its epidemiological framework.

Once the discussion was finished, Jan handed out the surveys for everyone to complete. Again, there was some frustration in the group about how long the survey took to fill out. I saw that some of the women worked together to fill out their surveys, asking each other questions and reading some of it out loud to gather opinions. The duration was also affected by the children being present and lunch arriving. Because of this some women left the table early and did not complete their forms.

Perth — 28 November 2017

Ray, Jan, and I flew from Canberra to Perth to attend a national Indigenous health conference. The conference is held annually and brings together a range of professionals and students together to engage in topics related to Indigenous health and wellbeing. Ray and Jan were scheduled in during one of the conference sessions to hold focus groups with conference attendees, and had a stall promoting MK in the main foyer throughout the conference. The room they were allocated for the session was large, and the researchers did not know how many people would attend. Ray and Jan decided to set up eight tables, each of which could accommodate nine people, with the MK information and consent forms (see Figure 14 below for an example). *[Sensitive information removed from this paragraph]*



Figure 14. Table set up for a focus group, Perth, WA

I decided to sit at one of the tables so I could observe how one of these groups worked throughout the session. Every table was supplied with pens and butcher's paper in order to write down the aspects of culture that were important to them. There were no recordings made from the session, as it would not have been possible to isolate the conversation from each table with so many speaking at once in the room.

Once delegates began to settle down at the tables, Ray introduced himself and MK using a microphone to amplify his voice and a projector screen at the front of the room to display his presentation (as shown in Figure 14). He informed the attendees that Indigenous voices would be privileged in these focus groups, though non-Indigenous people were welcome to sit and listen. This was in contrast to what he had told me before people had come into the room, which was that he would ask non-Indigenous people to move to the back of the room or to leave the session if there was not enough space for the Indigenous

attendees to participate. This was in line with the general protocol the researchers had applied for every focus group to ensure that Indigenous people felt comfortable talking about themselves and their culture without the input of non-Indigenous people.

The table I observed throughout this session included seven women and one man, all of whom seemed to be under 35 years old. I was encouraged by this as I wanted to observe what the dynamic would be amongst a group of young Indigenous people, which as stated above and in Chapter 6, were under-represented across the focus groups. In other groups I had observed, older members tended to dominate the conversation. Without needing to defer to elders, everyone around this table contributed to the conversation. One of the women took charge of the scribing, and their discussion began. It seemed to me that writing their thoughts on the large butcher's paper helped to focus the discussion, and they all watched while key words were being written down. It was also apparent that they were all familiar with this kind of brainstorming process. The people around the table were university students studying health sciences, or were individuals who worked in Indigenous health organisations.

A number of cultural themes came up during their discussion. None of the participants shared a personal story during this part of the task, as others had done in previous focus groups I attended. Instead, cultural concepts were described in generalised ways using keywords. This was almost exactly the same way the researchers themselves had taken notes during other sessions. Below are some of the expressions I wrote down which the participants used to describe keywords:

> *On language:* 'Language is our knowledge. Our power to express ourselves'
>
> *On life and death:* 'When an elder passes away, their spirit is always with you'

> *On Indigenous society and collectivism:* 'One person's achievement is everyone's achievement'
>
> '[It's] an equality thing. But that's not the right word for it. Everyone has value. And everyone can take something and give something'
>
> 'Kinship — that's what that is'

The scribe continued to write down the groups contributions until she reached the bottom of the butcher's paper. As she did not want to use another sheet, she began to wrap up the discussion. Figure 15 is a photo of what this group wrote down and captures common themes which were recorded by other focus groups in the room. With the task completed, the group I was observing began to relax and discuss other presentations from the conference. One of the participants talked about his experience of a traditional healing session which was run in the small room around the corner by an Aboriginal practitioner. He was told by the practitioner that he had a second heart in his stomach, and that there was sadness in his lower back. The participant thought that made sense because he did not live on Country. Traditional Aboriginal healing services have begun to become more accessible to the public through the incorporation of practitioners (e.g. ANTAC, 2020), and through partnerships with mainstream health care providers (see Burnie, 2019).

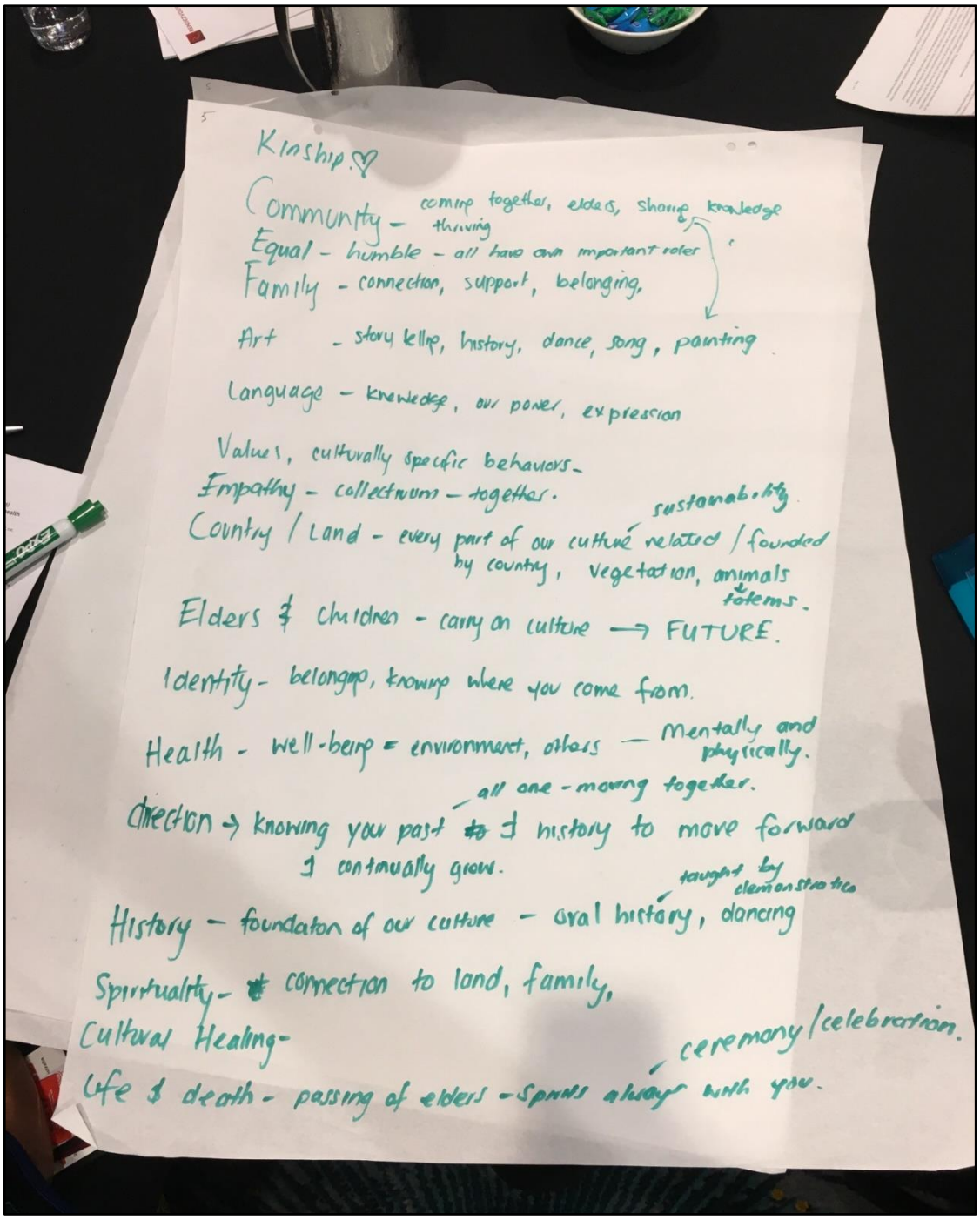


Figure 15. Butcher's paper from Table 5, Perth, WA

Ray then asked representatives from each of the focus groups to present their findings to the room. Once this was completed, he reiterated that there were common connections between many of the focus groups MK had conducted. Jan then walked around the tables and handed out copies of the survey for attendees to complete. Ray told the attendees that

the survey would take around 40 minutes to complete, but that it may take less or more time depending on the individual.

When the participants began to fill out the surveys, some discussed the meaning of certain questions between themselves. In Figure 16 below, the two participants on the left can be seen talking to each other about the first page of the survey. The woman next to them can be seen looking at the form being completed by the participant on her left. Three of the four participants on the right are looking and listening to the couple on the left talk.



Figure 16. Table 5 participants filling out the MK survey, Perth, WA

This kind of informal collaboration in filling out the survey was not uncommon during the focus groups. There was a conversation about this during one of the MK team meetings I observed. The researchers agreed that this kind of collaboration was likely to happen between members of a household when people received the survey in the mail out. As most of the questions in the survey were not considered by the researchers to be

'sensitive', they thought that it would not have a significant impact on the way individuals answered the majority of the survey.

The survey used at the conference was the same one that was used for the women's group in Bunbury the day before, as Ray had not had enough time to alter it before the conference session. As I was sitting at their table during the session, some of the participants asked me to confirm what some of the questions meant (see discussion on positionality in Chapter 2). As Ray and Jan were busy doing this very thing at other tables, I decided to answer them given that I had been through the survey enough times before with the researchers to be able to provide appropriate guidance. A few of the participants on the table were distracted part way through completing the survey and stopped filling out the form and left early. Again, there was frustration around the table about how long the survey took to complete.

Risdon Cove — 9 December 2017

This focus group was organised by a state-wide Aboriginal organisation and was held at a cultural centre in Risdon Cove. Jan and I had flown from Canberra to Hobart the night before and drove from our hotel in Hobart to Risdon Cove early in the morning to conduct the focus group. From the outside the centre looked relatively new, well maintained and resourced, and was set in a secluded piece of land. Both Jan and I felt that this place was peaceful. *[Sensitive information removed from this paragraph]*

We were met by the organiser outside and were led to one of the two buildings on site, where it looked like a community workshop was being held. Jan and I were asked to set up

in a large back room. We positioned some of the chairs into a circle and waited for participants to arrive. Two men arrived early and sat talking to Jan for around 20 minutes. However, they said they were unsettled by having to stay seated and waiting indoors, as they preferred to be moving around and to be outside. One of the men suggested we set up outside, but Jan told him we needed to stay in the room for the audio recording and to ensure the group would not be disturbed. Eventually others arrived, but they were unsure why they were asked to come meet us. One person said that they were told by the organiser to go to the room for an optional session about culture as a part of the community workshop being run next door.

Jan explained to them why we were asked to be there and told them about the Mayi Kuwayu Study. She then asked if they were happy to be a part the focus group. This initiated an intense discussion in the group about what the goal of the survey was, who would have access to the data, and who would be on the data governance panel. They were concerned that it would be 'just academics' and not people from the community who practiced culture. The implication here was that Indigenous academics do not practice culture, and therefore should not represent the interests of all Indigenous people in this context. A prominent Aboriginal academic was mentioned as the sort of person that should not be on the governing body for MK. Jan answered their questions and after this discussion, eight people agreed to participate in the focus group. Jan began the usual procedure of gaining consent, which I did as well, and then she started the discussion. Jan pulled out her phone to record the conversation, but she later told me that it did not work.

The participants told us that there were a number of cultural revival practices which had been established recently at Risdon Cove. Risdon Cove was the site of a massacre of the Mumirimina people on 3 May 1804 (Tasmanian Aboriginal Centre, 2019). A land grant for Risdon Cove was granted to Aboriginal people in 1995 by the Tasmanian Government

through the Aboriginal Lands Act 'for the benefit of all Aboriginal persons and in the interests of reconciliation with the broader Tasmanian community' (Tasmanian Govenment, 2019: Section 18.2). This Act established an Aboriginal Land Council of Tasmania, formed of elected Aboriginal representatives from eight regions, to administrate the use and management of the 13 land grants provided across the state. However, the Act did not give the Council the power to control access to the land, or its use by the Government to construct roads, drains, sewers, and waterways.

The same men who had arrived early told us they were actively involved in the maintenance and reintroduction of traditional knowledges and practices around Risdon Cove, including kangaroo hunting. A key part of this was teaching culture to their young children, which seemed to be an avenue for the adults to bond with their culture and maintain it. Their revival achievements in recent times were clearly a real source of cultural pride, and the adults were keen to pass their knowledge on to their children. One participant said 'Culture helps me feel my place in the world'.

The group also told us that protecting their culture and cultural practices was a 'constant battle', which placed significant stress on their communities. The pressure of having to protect the land from the Tasmanian Government and industry had a negative impact on the health and wellbeing of local Aboriginal people. They told us this drew focus and energy away from undertaking positive projects like self-determination.

Another issue which was discussed in the group related to the official identification of Aboriginality in Tasmania. It was a significant concern for these participants, who said that non-Indigenous people were falsely identifying as Aboriginal in Tasmania. One participant said 'It doesn't feel good'. Part of the issue seemed to be that the Government was permitting people to officially identify as Aboriginal without the knowledge or consent of

established Tasmanian Aboriginal organisations. As one of the participants described it, 'Identity is a part of culture. And now the Government's giving it away'.

I knew this to be a major debate in Tasmania from the work I did for my undergraduate honours project on the repatriation of Indigenous Australian remains from the UK (Bourke, 2012). Books are still being published which erroneously claim that Aboriginal Tasmanians are extinct (see *Sapiens: A Brief History of Humankind* by Yuval Noah Harari (2015: 310) for a prominent example). The fact that Tasmanian Aboriginal people are now being properly recognised by the Tasmanian Government has been due to the tireless advocacy of the community. To have this identity undermined and exploited by non-Indigenous people has clearly had a negative impact.

Once the discussion was concluded, Jan handed out the surveys for everyone to complete. Several of the participants left early or part way through completing them. One of the participants said that she had intentionally left some questions unanswered as she felt uncomfortable providing that information, even anonymously. After the rest of the group finished, Jan and I collected our things and drove back to Hobart.

This focus group was an example of how discussions about culture led participants to talk about painful experiences, either from the past or the present. From my perspective, this was tied closely to the desire of the community to fight against injustice, and to advocate for acknowledgement by Australian governments of the ongoing and intergenerational traumas endured by Indigenous peoples. The Makarrata Commission called for in the *Uluru Statement from the Heart* (First Nations National Constitutional Convention, 2017) delivered earlier that year was just one example of how such an acknowledgement could help to heal Indigenous communities and work towards reconciliation between Indigenous and non-Indigenous Australians.

This chapter presented an overview of the content and processes which characterised the focus groups conducted by the Mayi Kuwayu Study researchers, including detailed descriptions of the eight focus groups I attended during my time in Australia. There were many cultural concepts which were common across the focus groups including the importance of maintaining connections to family, to Country, to language, and engaging in activities such as ceremonies, storytelling, hunting, and the collection and use of bush foods and medicines. There were also several barriers to engaging with culture that the focus groups discussed such as the ongoing impact of colonisation, and interference from non-Indigenous individuals and groups, including government authorities and industry (see Chapter 6 for a detailed analysis of the focus group content).

Across every focus group I observed, all participants agreed that self-determination was necessary to improve the health and wellbeing of Indigenous peoples. Fundamental to this was the ability to practice and develop culture in all its forms. Many of the groups said that it was younger people who most needed encouragement to work against the destructive forces brought about by colonisation. When it became clear to the participants that MK was an Indigenous-led and governed initiative, they were generous in sharing their knowledge and passion for improving the outlook of their communities. As much as the focus groups worked to validate MK, they also worked to validate the researchers themselves as Indigenous people in the research space. MK was always meant to be more than just another survey about Indigenous health. It was intended to be mechanism for change, and to support the movement towards self-determination.

The following chapter turns to an examination of the survey itself. It looks back at the pilot studies which informed the survey's evolution, and explores the practical and theoretical development of some of the key cultural indicators created and used by MK. Like the focus groups, this undertaking was as much a reflection of the researchers

themselves as it was a reflection of the ways in which this national study evolved over time. By delving into the details of how culture becomes numbers, the integration of Indigenous perspectives into this epidemiological instrument will be revealed.

Chapter 5 — Culture and Question

Israeli American sociologist Aaron Antonovsky (1996) used the metaphor of a river to describe the health/disease continuum in which all people 'swim'. As he phrased it, 'we are all, always, in the dangerous river of life. The twin question is: How dangerous is our river? How well can we swim?' (Antonovsky, 1996: 14). Health risks and disease are cast as dangers in the river, while the swimmer themselves is imbued with a 'sense of coherence' which they may use to cope with these dangers (Antonovsky, 1996: 15-18). Following Antonovsky's metaphor, we may interpret culture as a skill, resource, or strength which Indigenous people may draw on to help navigate the river.

From the beginning, MK's survey sought to represent the relationships between Indigenous peoples and their cultures within a salutogenic framework (after Antonovsky, 1979) (Chapter 1), in effect, attempting to 'map' the river and account for the resources of those who swim in it. It was the outcome of four years of planning, consultations, negotiations, and trial runs between MK's researchers, partners, and focus group participants. Thus, the survey or 'map' developed gradually within this web of collaborative relationships and interactions between its various stakeholders. To communicate the complexity of these interactions which occurred across time and space as well as between different individuals and groups, I have organised the ethnographic data presented here into what I determined to be three key phases during the survey's development.

The initial phase encompassed two 'proof-of-concept' projects undertaken by the MK researchers. The first project led to the creation of the earliest version of the survey, which was designed in collaboration with a number of organisations from 2014–2015 and was piloted in 2016 with Indigenous community members living in the Murray-Darling region

of NSW and VIC. A second proof-of-concept project was undertaken in 2017 in partnership with the Central Lands Council (CLC) in the NT, to measure the potential benefits of their Indigenous community Ranger programme in facilitating caring for Country activities and promoting wellbeing for Rangers. This project compared a sample of CLC Rangers attending a training programme near the Ross River in the NT, with a sample of non-Rangers living in and around Alice Springs, NT. These pilots served to establish the character of MK's survey as one which was specifically aimed at understanding the relationships between key aspects of Indigenous Australian cultures, and health and wellbeing outcomes.

The second phase considered here was the refining of the survey by the MK researchers from 2016 to 2018. I draw from data collected during interviews with the primary people involved and observations of MK team meetings to describe and analyse the process. I have also incorporated key information obtained from MK's digital archive, including feedback received by the researchers from external investigators and Indigenous health experts who were consulted about the structure and content of the survey. In analysing these conversations I learned about the politics of whose opinions mattered and when. This section touches on the ways in which the Indigeneity or non-Indigeneity of various individuals influenced the refinement of the survey, developing this theme further from Chapter 3.

The third phase I relate here explores the ways in which particular questions in the survey evolved from the first draft piloted in 2016 until the final version used in the 2018 baseline survey. I chose to focus on the questions from the *Cultural knowledge and practice* (CK&P) section of the survey (Q25 & 26), which provide a representative example of the methods used by the MK researchers to refine the rest of the survey. This particular section also touches upon the wider issue highlighted in Chapter 4 of how localised cultural

knowledges and practices may be generalised and meaningfully measured in a national survey (see also Chapter 6).

5.1. Testing the culture and wellbeing relationship

As detailed in the introductory chapter of this thesis, qualitative and mixed-methods research conducted over the last two decades from Australia, New Zealand, Canada, and the United States, strongly supports the positive relationship between culture, health, and wellbeing for Indigenous peoples (see Bourke and Wright et al., 2018, and Salmon et al., 2018 for reviews of this literature). The Mayi Kuwayu Study is the first large-scale cohort study in Australia to quantitatively examine this relationship. In the early stages of developing MK, before it even had a name, its researchers needed to demonstrate that this connection could be measured and analysed in way which was meaningful and useful for epidemiologists, public health researchers, and the Indigenous communities who took part. A pilot questionnaire was therefore created and tested, laying the foundation for what was to become the Mayi Kuwayu Study. The following section examines the development of this pilot, and draws out the processes, metrics, and findings which set the course for later versions of the MK survey.

Proof of concept 1: The *Connection to Country* project

The first iteration of MK's survey began in 2014 as a part of the *Connection to Country* project, established by the Murray Local Land Services (MLLS) in partnership with the University of Canberra, ANU, AIATSIS, the University of Sydney, and local Aboriginal communities in the MLLS region (Lovett et al., 2017). The MLLS administers regional country towns along the Murray and Edward–Kolety river systems, including Corowa, Moama, Deniliquin, Tocumwal, Holbrook, as well as the city of Albury next to the

Victorian border (NSW Murray Local Land Services, 2019b). The MLLS acknowledges and maintains relationships with a number of Aboriginal groups in the region, including the Monaro, Muthi Muthi, Barapa Barapa, Wamba/Wemba, Bangerang, Wiradjuri, and Yorta Yorta peoples (NSW Murray Local Land Services, 2019a).

An initial questionnaire was designed by the MK researchers in consultation with local Aboriginal community groups and individuals to gain a better understanding of the connection to Country that Aboriginal people experienced in the area (see Chapters 1 and 4 for an overview of connection to Country). The questionnaire also aimed to review what future cultural activities the participants would like to be involved in, such as caring for the environment, recognising local Aboriginal history, ceremonies, traditional skills, arts, and gathering bush foods and medicines (Lovett et al., 2017: 22-23). Further, it asked about barriers to engaging in any of these activities, like events being on at the wrong time, participants not having free time, affordability, refusal of permission from landowners, and not knowing who to talk to, among other reasons (Lovett et al., 2017: 26-27). While this pilot was conducted before my DPhil began, it was a significant moment for MK. Therefore, I incorporated questions about it into my interviews and conversations with the researchers involved, asking them to reflect on how it influenced their research processes and later drafts of the survey.

Ray Lovett and Jan Chapman were the two main MK researchers involved in developing this questionnaire. This was a process which began after ethics approval was received in September 2014 and concluded in October 2015. Once the consultations were complete and the questionnaire developed in February 2016, five community-based researchers were trained by Ray and Jan to recruit participants using what the MK researchers called a 'purposive sampling strategy' (Lovett et al., 2017: 9). This is an epidemiological method which can provide a representative sample of the population of interest by utilising expert

knowledge to recruit individuals (Battaglia, 2008). This method allowed the community-based researchers to use the membership databases from their organisations to find potential participants to contact, in addition to recruiting people they knew to complete the questionnaire. *[Sensitive information removed from this paragraph]*

When I discussed this pilot with Ray he told me that one of the community-based researchers had to pull out of the programme due to other work commitments, and that he and Jan had to step in to undertake recruitment in that area (R Lovett 2018, personal communication, 9 January). Ray also said that the surveys which he and Jan had administered were not as complete as the surveys collected by the community-based researchers. This demonstrates the importance of having individuals who are embedded within the local Indigenous context involved in face-to-face recruitment (International Indigenous Cohort Collaborative, 2020: 28). Community-based researchers are now an integral part of MK's recruitment strategy in some areas of northern QLD and the NT. However, at the time the details of the recruitment process were not included in the official report on the *Connection to Country* project, nor the role Ray and Jan played in recruiting participants themselves in lieu of a community-based researcher.

Paper-based questionnaires were provided to participants to complete, and they were given the choice to be assisted by a researcher or not. The questionnaire included 40 questions, with sub-questions, and took participants between 20 minutes to one hour to complete

(for full details, see Lovett et al., 2017). The questionnaire asked about a number of Indigenous cultural factors, including:

- Questions about the local community where they lived, with a separate section asking specifically about the Indigenous community
- Indigenous cultural identification and history
- Cultural knowledges and practices
- Connection to Country
- Caring for Country, including what activities they would like to be involved in
- Barriers to connecting with Country or caring for Country
- Aboriginal and Torres Strait Islander language use

It also included general questions about health and social and emotional wellbeing, such as:

- Self-assessed health (Excellent, Very good, Good, Fair, Poor)
- Kessler Psychological Distress Scale (Kessler-5)
- Overall life satisfaction and personal achievements
- Health conditions and behaviours (e.g. alcohol consumption, smoking)
- Experiences of racism
- Involvement in community organisation and activities, including the Indigenous community and its leadership
- Family situation and history (including Stolen Generations)
- Socio-demographic factors (gender, sexual orientation, post code, date of birth, relationship status, household composition, education, employment, income, and experiences of financial hardship)

Of the 163 people (94 females, 59 males) who completed the questionnaire, 142 identified as Aboriginal, two identified as Torres Strait Islander, and three identified as both Aboriginal and Torres Strait Islander (Lovett et al., 2017: 11). Two thirds of the respondents said that they lived on their Country, and the vast majority (83%; n=130) agreed that it was important to care for their Country (Lovett et al., 2017: 12-15). According to the survey results, being on Country could be both a positive and negative experience for Indigenous people:

> 67% (n=97/145) reported that they often to always felt happy, 67% (n=101/151) reported that they often to always felt proud, and 47% (n=68/146) said they often to always felt like they had achieved something. However, some participants reported that they often to always felt sad (21%, n=31/148) or worried (30%, n=43/142) when they were on country in the past year (Lovett et al., 2017: 18).

About two-thirds of participants (66%; n=96) had important environmental concerns for the Country where they lived, including issues with water sources, soil, feral pests, weeds, plants, decrease in native wildlife and vegetation, climate change, and other environmental problems (Lovett et al., 2017: 21-22). In terms of wanting to care for the Country they were living on, between 83% to 93% of all participants wanted to be more involved with cultural activities like caring for the natural environment, recognising local Indigenous history, practicing cultural activities such as ceremonies, arts, traditional skills, and learning about how to collect and use bush foods and medicines (Lovett et al., 2017: 23).

While the number of participants in the *Connection to Country* project was small, the results did support the concept that there is a quantifiable and positive relationship between key aspects of Indigenous culture and wellbeing. As the final report from the project stated (Lovett et al., 2017: 28):

> With the exception of experience of racism, the results were consistent with a general pattern that more positive or frequent experience of feeling part of the community, belonging to mob, speaking language, having higher levels of formal education, and engaging in caring for country were associated with better health and wellbeing. … The associations were significant in the following cases:
>
> - Time spent on country (proportion of life) was significantly associated with better physical health and higher life satisfaction.
>
> - Knowing who mob is was significantly associated with better physical health, lower psychological distress, and higher life satisfaction.

- Visiting mob's country and living on mob's country: those who visited more frequently or who lived on their mob's country were significantly more likely to have low psychological distress and high life satisfaction.

The questionnaire developed as a part of this early project formed the bones of MK's baseline survey released in October 2018. By comparing these results to later drafts of the survey and drawing from conversations I had with the MK researchers about the nature of the survey, it was clear that these early findings influenced how the survey was structured overall. Ray and Jan consistently emphasised that these results reflected what they knew themselves about the importance of culture and identity for Indigenous peoples. The questions asking about identity and time spent living on or visiting Country, and language use, have always been placed right at the beginning of the survey This indicates that these are the most important questions to be answered by participants, and also demonstrates the researchers' desire for the participants to feel that the survey is *for* them (see Chapters 6 and 7).

Proof of concept 2: The CLC Rangers project

The success of the first pilot prompted the formation of a second proof-of-concept project in the NT in 2017. At this point, the survey had already been trialled in a number of focus groups. For this pilot a new section was added to provide an assessment of the CLC Community Ranger programme specifically, and its benefits for the cultural engagement and wellbeing of the Rangers. Indigenous Ranger projects have been operating across Australia since 2007, providing employment for Indigenous people to undertake land and sea management activities (National Indigenous Australians Agency, 2019). Funded by the Australian Government these projects seek to 'support Indigenous people to combine traditional knowledge with conservation training to protect and manage their land, sea, and culture' (National Indigenous Australians Agency, 2019).

This pilot was the result of an existing relationship that had been established between MK and the CLC by Alyson Wright. Alyson had previously worked for the CLC in Alice Springs. The CLC is one of many land councils in Australia who are funded by the Australian Government to employ Indigenous people in Ranger programmes. The CLC employs 90 Rangers in 11 Ranger groups across Central Australia to conduct land management activities, including maintaining cultural sites and resources (Central Land Council, 2019). Some of the Ranger groups also support cultural practices for the wider community by facilitating women's and men's cultural trips around Country, protecting sacred trees, managing rock art sites, and gathering materials for traditional medicines (Central Land Council, 2019).

In 2016, senior land management staff at the CLC were looking for a way to evaluate the impact of their Ranger programme on the social and physical wellbeing of its participants (A Wright 2019, personal communication, 4 June). Alyson suggested that they get in touch with Ray, who was interested in piloting the survey a second time. After discussing the possibilities, the CLC staff held a teleconference with the MK researchers and then met to plan how they might use MK's survey to evaluate the Ranger programme (A Wright 2019, personal communication, 4 June). As a result, they invited the researchers to work in partnership to further refine and test the survey during a focus group held in Alice Springs in February 2017. In May 2017, researchers from MK then attended the annual week-long Rangers' professional development camp at the Ross River Homestead in the NT to pilot the survey.

The Rangers attending the camp were from 11 different Ranger groups operating across Central Australia and had travelled to the Ross River Homestead from their homes in remote and very remote communities. The MK researchers set themselves up under a small marquee near the main meeting area and over the course of several days invited all

the Rangers attending to fill out the survey. I was not able to attend the camp for financial reasons at the time, and so I asked some of the researchers who did attend about their experiences during the interviews I conducted. One of these people was Alyson Wright, who was also interested in working with MK for her PhD. In describing her experiences administering the survey to the Rangers, she said that there was a good level of engagement with the MK survey, but that it was not seen as a priority by the Rangers who were more interested in catching up with others that they had not seen for a long time.

Of the estimated 80 Rangers who attended the camp, 43 (26 males, 17 females) completed the survey (Jones et al., 2018a: 1480), some with help from the researchers. Alyson emphasised that this face-to-face interaction was important because a few of the participants had low levels of English literacy and numeracy (A Wright 2019, personal communication, 4 June). This interaction also allowed the researchers to test the survey's internal validity, or face validity, by gauging people's reactions to questions in the survey and making sure that the participants interpreted the questions in the same way that the researchers did (A Wright 2019, personal communication, 4 June).

> I think in the process of developing the survey, you can't just rely on 'Oh yes people answered it because I put it in front of their face, and they ticked the boxes'. I think the process of going through a survey face-to-face and getting people to answer it gives the research team a much richer experience and understanding of what questions work and what don't work, and what can be challenging for specific communities. I think when you're trying to do something nationally, across a really diverse group of people, and languages, and constructs of what culture and wellbeing are, there's some challenges in how you make the questions fit across those. So I think that whole experience was really valuable for the research team.
>
> — Interview with Alyson Wright, 31 January 2018, Canberra, ACT.

To evaluate the impact of participation in the Ranger programme, people who had never been employed through the Ranger programme were also recruited between May and November 2017 to complete the survey by a community-based Indigenous researcher living in Alice Springs. This researcher was able to recruit 160 (50 males, 110 females) non-Rangers who lived in remote or very remote communities near Alice Springs to form a control group for the CLC Ranger group (Jones et al., 2018a: 1480).

According to MK's final report, there was a statistically significant, positive connection between being a Ranger and reporting very high life satisfaction (Jones et al., 2018a: 1485). This was the case even after accounting for other possible influences on life satisfaction such as education, financial status, employment, existing health conditions, and risk factors (Jones et al., 2018a: 1485). There was also a significant association between being a Ranger and high perceived family wellbeing (PR = 1.69, 95% CI: 1.29, 2.20), which remained significant after individually adjusting for education, employment, financial status, the presence of health conditions such as heart disease and diabetes, and health risk factors such as smoking and high blood pressure. Being a Ranger also had a positive but non-significant association with 'very good' self-reported health (PR = 1.33, 95% CI: 0.94, 1.88) (Jones et al., 2018a).

The researchers found no relationship between being a Ranger and lower stress levels (defined as scoring low to moderate psychological distress on the Kessler 5 scale) , which the authors could not account for within the limitations of their project (Jones et al., 2018a: 1486). The researchers warned that the purpose of this project was simply to provide a proof-of-concept for the association between participation in the Ranger programme and health and wellbeing factors, but that it did not have the statistical power to comment on potential causal pathways (Jones et al., 2018a: 1488). Nevertheless, the researchers suggested that the higher levels of life satisfaction and family wellbeing

experienced by the Rangers may be due to their greater participation in caring for Country activities, in addition to the promotion and transfer of cultural knowledge and skills as part of their work (Jones et al., 2018a: 1487-1488).

Alyson described one particular event from the researcher's trip to Ross River which may have important implications for data collected by the final survey:

> there was a circumstance where I was looking at the survey and I'm like 'It's got here your height and your weight', and Ray's like 'Yeah, you know, for BMI'. And I said 'I get that. But do you think people are going to know off the top of their head, at the Ranger camp, their height and their weight?', and he's like 'Yeah'. 'I don't think they will', and he's like 'What do you mean?' I'm like 'Well why would they?' you know. So then there was this last-minute rush in Alice Springs to Kmart to get a measuring tape and some scales — which of course we didn't use at the Ranger camp. I think [the questions about height and weight] they're still in the survey, because obviously they [the researchers] still want to try and work out how to make those things work, but at the Ranger camp maybe two people responded to the height and weight out there.
>
> — Interview with Alyson Wright, 31 January 2018, Canberra, ACT.

It is unknown whether the lack of knowledge about height and weight in the Ranger group relates to individual beliefs or not. The importance placed on height, weight, and BMI as a measure of physical health and risk for chronic conditions such as obesity, type II diabetes, and cardiovascular disease, is well established in the biomedical literature. In general, this highlights one of the major limitations of MK and the survey at this point in time. Epidemiological measures, in particular those used in national surveys, by their very nature lack contextualisation. In reporting their findings, researchers draw instead on the epistemologies from which these measures originated — in this case the biomedical model. While MK is making a number of efforts to design and interpret their survey from a strengths-based, Indigenous perspective, the survey still relies on a Western

epidemiological framework. Therefore, in some respects their measures and the findings which result may not reflect Indigenous epistemologies of health.

It may be that height and weight are not thought to be important things to keep track of by some Indigenous people. While it is yet to be determined what proportion of the first cohort of participants in MK answered these questions in the survey, it is interesting to consider whether being overweight or obese is believed to be an indication of ill-health by Indigenous peoples, as it is in the general population. My Master's thesis which examined the social construction of obesity for Indigenous Australians demonstrated that the dietary behaviours which contribute to obesity may also support social wellbeing (Bourke, 2015). For example, from an Indigenous perspective sharing fast-food with the family is seen as a protective factor for health within the community and family social systems (Thompson and Gifford, 2000: 1464). The act of preparing or sharing 'family food' is viewed as promoting individual connections to family, to the community, to Country, and to the past (Thompson and Gifford, 2000: 1463-1464). This is consistent with anthropological conceptions of commensality (Fischler, 2011). The act of sharing food and eating together forges and strengthens intimate social bonds beyond just addressing an individual's nutritional needs (Fischler, 2011: 533-534).

Furthermore, there is evidence to suggest that the reference groups for BMI measures should not be used as a guide for Indigenous Australians. It has been emphasised by the WHO in their expert committee report that BMI statistics are largely based on North American and European reference samples (WHO, 1995). A study of Indigenous Australians living in remote areas of the NT supports the notion that Indigenous populations can vary anthropomorphically from Caucasian populations, and that using a Caucasian reference group may be problematic (Wang et al., 2000). From a sample of over 2,800 Indigenous Australians, Li and McDermott (2010) found that BMI was not an

accurate predictor of cardio-metabolic risk, as the optimal BMI cut-offs for their sample were well below the WHO recommended guides, where BMIs above 23 for Indigenous men and 25 for Indigenous women were equivalent to the WHO's obese category (BMI = >30).

In a follow-up discussion with Ray Lovett in April 2020, I learned that the outcomes of the MK pilot undertaken with the CLC Rangers in the NT have already been used to successfully advocate for more government funding to expand the Indigenous Rangers programme nationally, setting up branches of the programme in more areas (R Lovett 2020, personal communication, 14 April). The MK researchers are also working closely with the Yarrabah Leadership Forum to roll out the survey for the Aboriginal community in Yarrabah, QLD. The goal of this partnership is to assist the community in understanding their cultural determinants of health and to monitor the impact of programmes aimed at improving cultural wellbeing over time (R Lovett 2020, personal communication, 14 April).

Administering the survey to larger samples of people than that of the focus groups allowed for further validation of the survey measures. In undertaking the CLC proof-of-concept project, in addition to the pilot conducted in the Murray-Darling region, the researchers were able to demonstrate that the survey could provide interesting and useful results for community stakeholders. Moreover, these projects helped to establish the survey as a tool that was developed in collaboration with community groups and organisations. This is a dimension of MK which has often been publicised by the researchers, both as a way to demonstrate the representative nature of their survey, and as a declaration about the way in which health research with Indigenous peoples should be conducted. However, the details of how the survey came to be refined over the course of these consultations has not been detailed anywhere else at the time of completing this thesis. The rest of this chapter

therefore aims to provide an ethnographic account of these details by examining the processes and relationships which governed the development of the survey from 2016 to 2018, when the final baseline survey was released.

5.2. Refining the survey questions

The process of refining the survey from its first to its final version involved extensive revisions and consultations between the researchers and partners, including the testing of survey drafts during the focus groups (see Chapter 4 for details of the focus groups), and the two proof-of-concept pilots outlined above. Beginning with the first draft developed for the *Connection to Country* project in 2016, the concepts and questions included in the survey have been scrutinised and tested with each new focus group and core research team meeting. Feedback on the survey was also sought out periodically from MK's other CIs, AIs, and community partners who did not have regular input into MK at the time of my fieldwork.

> SB: What was your experience going through the survey?
>
> MW: […] I think, you know to be honest, at first, I thought 'Wow this is really pretty simple'. You know, the questions were very, very simple. And then the more I read them and the more I thought about them, the more I thought 'Damn this is good', you know. This is… cause it kinda takes out all of that assumption, communication stuff that usually you are asking around surveys to Aboriginal people. And particularly to the remote mob, who may not have a great education background. So they might not respond well to big, tricky, sophisticated questions. But, you know, if you've spent much time on Country it's pretty easy question. And it's pretty direct, and there's little room for misinterpretation. To be honest my initial thought was 'Why the hell haven't we done this before?' Surely somebody's asked these basic questions. But no. Apparently not. […]
>
> So from a broad perspective, this is kinda the stuff that Aboriginal people have been saying culturally for a long, long time in health. That these particular issues

> — time you spend on Country, and knowing your identity, knowing who your mob is, being able to speak language — those kind of things, older people have always said to us that's the kind of thing that brings you healing and improves your sense of wellbeing.
>
> — Interview with Mark Wenitong, 25 January 2018, over the phone.

Mark Wenitong's impression of the survey's simplicity reflects two major aspects of the survey development process outlined previously. First, that the survey has been designed to address those important aspects of culture that have a major impact on Indigenous health which other national health surveys have left out. Secondly, that the nature of the questions and the language which has been used has been painstakingly reviewed and revised many times by the core research team.

I observed the core research team discussing the survey in meetings on a number of occasions in Canberra in 2017 and 2018. The primary people involved were Ray Lovett, Jan Chapman, and Katie Thurber, with other members of the research or administrative teams occasionally present to contribute to the discussions. One of the primary objectives of the survey refining process was to reduce the number of questions asked by the survey so that it took the majority of participants 20–25 minutes to complete. Ray explained to me that this was based on the accepted view in epidemiology that participants begin to experience survey fatigue after this point. Survey or respondent fatigue occurs when the concentration and motivation of participants to answer survey questions begins to decline over time, resulting in poorer quality data (Ben-Nun, 2008). This is a phenomenon I observed during all of the focus groups I attended, when the survey often took participants more than 40 minutes to complete.

However, the desire to cut down the survey length was in constant tension with the researchers' wishes to keep as many questions as possible in the survey. As a person who

was external to the survey refining process, Alyson Wright had made a similar observation about the researchers' fixation on reducing the time it took to complete the survey, and was critical about its results:

> There is always this thing with this team about 'How do we make it shorter?' I think there is a tension here in this type of research. I agree sometimes that when you're doing a 'Yes', 'No', tick a box thing, you don't want to spend hours and hours on it. But if you're passionate about something, which is what came through in some of the interviews we were doing out at the Ranger's camp, people are happy to talk for a very long time. Sometimes, if it's a more free-flowing conversation, you know, there's not so much the restriction in that it needs only take 20 minutes to complete. I question the notion that for it to be good it needs to be short.
>
> The problem when you're collecting quantitative data is that you need so much of it. So of course, there is this bias towards a short, quick interview because you have to, you know, you have to do another 20,000 of them to get the number that you need. So you don't want it to take forever because of just the amount of ones you've got to get through. Yeah. So I don't know. I don't know if there's ever going to be a proper balance between what's considered 'short enough' and what's considered also 'robust enough'.
>
> — Interview with Alyson Wright, 31 January 2018, Canberra, ACT.

An overarching logic for selecting questions for the survey was discussed during the annual CIs and Partners meeting at ANU on 25 October 2017. Emily Banks led a conversation within the group about what questions the survey should be asking to be of most benefit to current and future researchers. She said that part of the critical role of this steering group was to 'future-proof' the survey, and to factor in both traditional (e.g. smoking) and novel (e.g. racism) causal factors in order to satisfy multiple models of research inquiry.

Completion reliability was key to the process, but Emily also argued that people would be generous with their time if they understood why it was being done. This was something that Jan had told me on a number of occasions. Even when it took a long time, the focus group participants would almost always complete the survey. The discussions from the team meetings led to the drafting of a survey development protocol (Mayi Kuwayu Study, 2017c: 2) which outlined the research goals of MK, and the priorities of the baseline survey:

> The Mayi Kuwayu baseline survey will prioritise for inclusion questionnaire items that:
> 1. Address one or more of the key research questions (developed by the Mayi Kuwayu Steering Committee) [comprised of the CIs and partners].
> 2. Have been shown to be valid and/or reliable in the Aboriginal and Torres Strait Islander population.
> 3. Have been developed or adapted through the Mayi Kuwayu community consultation process (and are therefore acceptable and relevant to the study population).
> 4. Are brief.
> 5. Minimise free text.
> 6. Are considered important and likely to provide new information by the Mayi Kuwayu Steering Committee and the Community and Technical Panel.

The principles which have governed the wording and selection of questions in the survey, as well as governing the prioritisation of future research questions and data analyses, are based on including items which (Mayi Kuwayu Study, 2017c: 2):

- Are relevant across contexts, and that capture information about context
- Enable strength-based responses and analysis
- Understand, are supportive and inclusive, particularly for those navigating cultural discontinuity

However, this protocol has not been published by the MK team and when I contacted a member of the team for an updated version in 2019, I was informed that a newer draft had not been produced and that the old draft may or may not reflect the procedure followed in

the final stages of the survey development. Furthermore, the 'Community and Technical Panel' was never formalised, but rather consisted of various external Indigenous health experts who did not have a current position with MK, and Indigenous members of MK's staff. While both of these processes were thought to be important for the development of MK at the time they were conceived, they remained unresolved. At the time of submitting this thesis the researchers were in the process of completing a paper for publication outlining the methodology they used for selecting questions for the baseline survey.

The main reason for the delay in publishing research protocols was the limited number of administrative and research staff working on MK during its development. There were only six full-time staff working on MK at the time of my fieldwork, compared to the 30+ staff who now work with the study and related projects (R Lovett, personal communication, 23 April 2019). Each member of the MK team occupied multiple roles, and given the increasing momentum of the survey's development, time restrictions for delivering the survey, and financial pressures placed on MK, non-essential tasks were either delayed or not completed at all. It seemed to me that Ray and Jan both took on the equivalent of two or three full-time jobs. Ray in particular as the lead researcher was not only the main person in charge of developing the survey and running the focus groups, but spent a significant portion of his time travelling to attend meetings with various organisational representatives to garner support for MK. He was also regularly presenting at conferences, was the main contact for radio and TV shows to advertise MK, and regularly travelled internationally to learn from and collaborate with the leads of other indigenous health studies.

During my time in Australia I observed the negotiation process that occurred between the researchers in deciding what were the most relevant or important questions to ask.

> It was always tightening it, tightening the survey so that it was succinct. You would ask a question, and you could come at that one question from like, ten sub-questions. But in the end you realised a couple of strong questions in there would give a lot of answers. Reduction kept happening throughout the whole process.
>
> — Interview with Jan Chapman, 31 January 2018, Canberra, ACT.

The process for cutting or refining questions often followed a pattern, as Jan indicated above. Smaller changes, like the phrasing of a question or their order as a result of focus group feedback would be undertaken by Ray directly, or by Katie Thurber with any changes overseen by Ray. Ray's influence over the whole process was clear, both as the MK lead but also as an experienced Indigenous researcher. His leadership style was directive, but the decision-making process was always shared.

> SB: Do you think the survey as it is now reflects the feedback that you've got from focus groups? Or do you think it's a combination of feedback and also Ray's influence, or the other researchers?
>
> JC: The survey, as it is now, has been developed and directed by many influences, from the focus groups, the Mayi Kuwayu team, and from Ray. Because he knows what he wants… what direction to take. And being the researcher he is, he knows by asking one specific question it may well answer many others. Or it might create another track to go down. I queried some of the questions, but now realise they need to be in there, actually, to get the answers that need to come through. So his knowledge as a researcher is always going to be a major influence. Always.
>
> SB: So he kind of gets the final say on things?
>
> JC: No, he gives up the final say. He will open it to others to discuss, but he will often come up with the first idea to start the ball rolling. So certain things he'll have the final say in the sense that it's a set of questions that have to be there. They can't come out, as they are base questions. But he doesn't stand over any decision making — he discusses and listens. So yes, he'll open it up if he sees that it could be something else […] He shares the decisions.

— Interview with Jan Chapman, 31 January 2018, Canberra, ACT.

Larger changes in particular, like the removal or addition of questions or sections, would happen after feedback was sought from other MK investigators and associates every six months or so. The latest draft of the survey would be emailed out to the MK partners along with an Excel spreadsheet listing the questions and instructions for the reviewers to comment on. They were asked to rank the questions as 'A', 'B', or 'C', according to their perceived importance (K Thurber 2018, personal communication, 23 January):

A: High priority; should be included in the baseline questionnaire if space allows

B: Low priority; important but not critical

C: Should not be included

Their feedback would then be collated and members of the core research team in Canberra would meet to discuss the feedback and make decisions on what changes should be made. I observed a number of these meetings in 2017 and 2018 to understand this collaborative process. Firstly, questions which had been ranked as 'C' by one or more of the reviewers would be discussed in order, followed by items listed as 'B' and 'A'. Often it would take several meetings to get through all the feedback. When each question was discussed, the conversation between the researchers was free flowing, though one person — often Katie Thurber — would keep the group on track and progressing quickly, making notes directly onto the survey draft on her laptop.

Below are some examples of the exchanges that would occur in relation to specific questions, which I summarised in my field journal as follows:

Mayi Kuwayu Study team meeting — 1 February 2018

Attendees: Ray Lovett (RL), Katie Thurber (KT), Jill Guthrie (JG), Jan Chapman (JC), and Alyson Wright (AW).

For the question 'What is the big family name(s) you belong to?' one of the reviewers asked about what the family names question is for and what it will be used for. They suggested changing the beginning of the question to 'Do you know…'

RL: It's really a kinship question.

JG: [In its current wording] Does make me think I can or I can't name them.

RL: People have felt quite good about identifying them. Y/N responses limit people. Need to be able to express that.

AW: Maybe not as personal if it isn't face-to-face?

KT: Is the purpose of the survey to make people feel empowered or to ask questions we're going to analyse?

RL/JC: Asking this question has never been a problem in focus groups.

KT: We won't be analysing by family names — it's hard to analyse.

JC: We should keep it because it's important for people to fill out.

KT: Come back to the question later?

The group decides to skip this question and only look at questions in this meeting that have been ranked 'B' by multiple reviewers.

Mayi Kuwayu Study team meeting — 9 February 2018

Attendees: Ray Lovett (RL), Katie Thurber (KT), Jan Chapman (JC) and Alyson Wright (AW).

The group began discussing one reviewer's feedback that there were too many questions at the beginning of the survey asking about identity and Country. The discussion also follows on from the conversation they had last week about the family names question.

RL: Let's start with [reviewer's] comments — Family names.

KT: Put 'mob' first? Most people would know it.

RL: No this doesn't seem to matter. Central Australian groups didn't know 'mob'.

JC: I don't like the word 'mob'. Don't use it much.

RL: Could try switching it in the [20,000 mailout] pilot.

KT: Want to make sure that you're doing the best for most people.

RL: [Current wording] may bias answers towards regional/urban people.

AW: Mob means smaller groups and families in the NT.

JC: What about skin names?

RL: People might like answering it.

KT: But we probably won't analyse it.

RL: But we have to balance with people wanting to participate.

KT: If this [question about family names] is asked just to have participants share, it wouldn't be useful.

RL: May look too much like ABS questionnaire otherwise.

KT/RL: Asking about clan/skin name — we might want to know if people do know this.

KT: What about family name?

RL: Knowing it demonstrates kinship connections.

KT: [Reviewer] says that we should only ask sentinel questions.

RL: 'Are you Indigenous?' is a sentinel question — implies that there is no need for all the rest.

KT: So ignore her comments?

RL: Yes.

There are a couple of points to pick up on from the two discussions above. The first concerns the inclusion of questions in the survey which may not be useful for current research objectives. As pointed out by both Ray and Jan, the question about participants' family name promotes engagement and provides an avenue for participants to express their pride in their identity. Some Indigenous Australians identify themselves with a family name, or surname, alongside or in place of traditional cultural group names. The larger size of Indigenous families and their increased mobility across Australia mean that belonging to one of the big-name groups (e.g. Brown, Jedda, Lovett, Mills) can help identify you to others. The inclusion of this question also seemed to tie into the researchers' wish to distinguish this survey from the ones administered through the ABS.

The second point is the prioritisation or de-prioritisation of feedback from the reviewers. In the example above, Ray disagrees with one reviewer's comments that there may be too many questions at the beginning of the survey asking about identity. Playing into this from my perspective is the role of the Indigeneity or non-Indigeneity of the researchers and the reviewers. I had a conversation with Ray about this and asked if the Indigeneity of the reviewers influenced the researchers' decision-making process about what feedback was incorporated and what was ignored, particularly in relation to the cultural indicators. He confirmed that this was a factor, and that the feedback from non-Indigenous reviewers

may not be heeded if it conflicted with what Ray and Jan believed should be in the survey (R Lovett 2018, personal communication, 10 February). This was the case in the exchange above where the reviewer was a non-Indigenous person.

This instance demonstrates one of the ways in which the Indigenous researchers in MK exercised their power over how the survey was constructed. Their Indigeneity and experience were drawn upon as expert knowledge to mediate and direct the ways in which feedback from others would be incorporated. This was certainly the case during the focus groups when non-Indigenous people contributed to the discussion about culture. For example, at the Perth conference there was one table at the back of the room occupied by three non-Indigenous health workers. They participated in the butcher's paper activity and discussion, but their responses were never integrated into MK having been discarded later by Ray and Jan. Given that the purposes of the focus groups was to collect Indigenous perspectives on culture, their decision to exclude data from non-Indigenous attendees is appropriate. It is possible to then to see why the feedback from non-Indigenous reviewers about cultural measures used in the survey was similarly ignored when it conflicted with their lived experience as Indigenous people, and the knowledge gained through conducting the various focus groups.

This power dynamic also operated in a different way when expert Indigenous reviewers expressed a strong viewpoint during the survey refining process. For example, in earlier versions of the survey there was a relatively long section about gambling, while in the final version it was reduced to two questions. This was mainly due to the input of Maggie Walter who argued that too many questions focusing on negative behaviours may reinforce the deficit discourse (R Lovett 2019, personal communication, 23 April). Terry Dunbar, a Larrakia, Warumungu, and Iwaidja woman and CI with MK, also spoke about the gambling questions in our interview. She said that while participation in gambling may

be interpreted as a negative behaviour in research, within certain social contexts it actually reinforces social wellbeing for Indigenous peoples.

> There are Indigenous social clubs as well as the general social club, and a lot of the older women in the Northern Territory they play a lot of bingo. But I can tell you that if you were to go to one of those you'd be laughing your head off nearly all night. Except for when the bingo's being read out — you can hear a penny drop then. But as soon as you have a little break, they all get rude all these old girls! And they talk about their husbands, they talk about all these things. And then some of the men, because you have a few men that go, they go 'Oh no' and just walk away. But they have a good time. So it's a real social gathering when they do things like that. And that for me — I'd put that under wellbeing.
>
> — Interview with Terry Dunbar, 9 November 2018, Canberra, ACT.

While the overall structure of the survey aims to support strengths-based research about the positive contribution cultural factors have on Indigenous health and wellbeing, negative behaviours and experiences also have a significant impact. It is only by accounting for these factors within the survey that the protective role of culture can be determined, and for alternative interpretations, like Terry Dunbar described above, to be tested. In Chapter 1, the Lowitja roundtable report emphasised the need for 'safe spaces' where negative experiences in Indigenous communities could be discussed with respect (Lowitja Institute, 2014: 2). MK may be interpreted then as forming one of these safe spaces, where the tensions between culture and colonisation which form Indigenous realities may be interpreted. The future direction of MK and the researchers hopes for its impact on Indigenous health narratives will be discussed further in Chapter 7.

5.3. The evolution of a question

In order to demonstrate how questions in the survey changed over the course of the refinement process, this section focuses on how one question has developed since the first

pilot with the MLLS in 2016 up until MK's 2018 baseline survey. I have chosen to review the section *Cultural knowledge and practices* (CK&P) from the various survey drafts because it is a matrix question which has been included in every version, and is representative of the ways in which other major questions in the survey were modified. I focus my analyses on those drafts which correspond with focus groups I attended or were discussed in team meetings I observed.

The 2016 MLLS pilot report includes a copy of the 40-item questionnaire they administered to the participants. From this survey, the question about CK&P appeared as follows:

4. 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 ways.	**No**	**A little……A lot** **① ② ③ ④ ⑤ ⑥ ⑦**	**Unsure**
Do you know how to find, and or prepare foods (e.g. hunting and gathering)?	○	○ ○ ○ ○ ○ ○ ○	○
Do you know about finding, preparing and using traditional medicines?	○	○ ○ ○ ○ ○ ○ ○	○
Do you know about special words for your relations e.g. Aunty? (shows how you are related to others)	○	○ ○ ○ ○ ○ ○ ○	○
Do you know your mob's lore?	○	○ ○ ○ ○ ○ ○ ○	○
Do you know about special places?	○	○ ○ ○ ○ ○ ○ ○	○
Do you know about important ceremony?	○	○ ○ ○ ○ ○ ○ ○	○
Do you know how to perform special dance/s?	○	○ ○ ○ ○ ○ ○ ○	○
Do you know about designs (symbols and shapes) used in your mob's art?	○	○ ○ ○ ○ ○ ○ ○	○
Do you know about your mob's traditional music/instruments/songs?	○	○ ○ ○ ○ ○ ○ ○	○
Do people in your community share cultural knowledge?	○	○ ○ ○ ○ ○ ○ ○	○
Do you listen to traditional/cultural songs?	○	○ ○ ○ ○ ○ ○ ○	○
Do you listen to/have knowledge of cultural stories?	○	○ ○ ○ ○ ○ ○ ○	○

Figure 17. CK&P question from the 2016 MLLS questionnaire (Lovett et al., 2017: 39)

The way the question has been phrased in this first draft is of particular interest because it highlights several complex issues which Indigenous Australians have to deal with on a daily basis. In the question heading there is a phrase telling participants not to compare

themselves 'to previous generations or others'. These words implicitly refer to the cultural loss that has been experienced by Indigenous people across Australia over successive generations since colonisation (Chapter 1). It also touches upon pervasive White Australian views of Indigenous authenticity, which can be internalised by Indigenous people who feel like they are 'not Aboriginal enough' if they do not have traditional cultural knowledge or practices (discussed in Chapter 2).

The CK&P question counters this deficit discourse by reinforcing a strengths-based message about culture at the top of the left-hand column: '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 ways'. Nevertheless, the word 'traditional' is still used for some of the responses like 'traditional medicines', 'traditional music', and 'traditional songs'.

For the format of the responses, a 7-point Likert scale was used to allow participants to rate the degree to which they agree with a statement, though as an ordinal measure, the intervals between values are not necessarily equal. For example, if a respondent selects 7 for 'Do you know your mob's lore?' this cannot be interpreted to mean that they have seven times more knowledge than a respondent who selects the value 1. One typical characteristic of the 7-point Likert scale is that only the extreme values at 1 and 7 are labelled in surveys. This means that participants must ascribe their own interpretations to what values 2 to 6 represent, as do the researchers when interpreting these data. In the MLLS report, the researchers chose to group values together into three categories: 'a little' (values 1 and 2), 'somewhat' (values 3, 4, and 5), and 'a lot' (values 6 and 7) (Lovett et al., 2017: 15). This categorisation reflects MK's aim to analyse the survey results according to low, medium, and high exposure rates which Emily Banks mentioned in our interview described in Chapter 3.

This categorisation into exposure rates may be problematic, as it draws on epidemiological epistemologies to interpret complex Indigenous experiences. However, by the time I attended my first focus group with the MK research team in Bunbury on 26 April 2017, the 7-point Likert scale had been replaced by four columns which could be more clearly interpreted by both the participants and researchers (Mayi Kuwayu Study, 2017a: 3) (as in Figure 18). In the title bar on the left the researchers provided an explanation for participants about how the different categories should be interpreted:

These are things that Aboriginal people have said are important to their culture, but not all Aboriginal people do these things, and that doesn't make you more or less Aboriginal. Please select whether you do the following things: not at all (none), a little bit (a few days in the year), a fair bit (a few weeks in the year), or a lot (a few months in the year).	**Not at all**	**A little bit**	**A fair bit**	**A lot**
I spend time learning about my Aboriginal culture, such as its history, traditions, and customs.	◯	◯	◯	◯
I make Aboriginal artworks (e.g. painting, weaving, carving).	◯	◯	◯	◯
I participate in Aboriginal practices of food preparation (e.g. bush meats, dampers, Johnny cakes).	◯	◯	◯	◯
I participate in Aboriginal cultural practices involving music/dance (traditional or modern).	◯	◯	◯	◯
I have received Aboriginal healing methods (e.g. traditional healers, bush medicine).	◯	◯	◯	◯
I spend time on country (e.g. living in homeland, travelling through country).	◯	◯	◯	◯
I care for country (e.g. burning grass, cleaning up country, fire work, conservation, regeneration).	◯	◯	◯	◯
I use country and land (e.g. for bush tucker, bush medicine, hunting, fishing).	◯	◯	◯	◯
I protect country (e.g. sacred sites, animals, totems).	◯	◯	◯	◯
I participate in ceremony (e.g. smoking ceremony, cleansing, Corroboree).	◯	◯	◯	◯
I attend/participate in Aboriginal community meetings.	◯	◯	◯	◯
I participate in social engagements that are related to Aboriginal people (e.g. NAIDOC Week, Sorry Day events, Knockout).	◯	◯	◯	◯
I respect the teachings of Elders.	◯	◯	◯	◯
I spend time learning about issues facing Aboriginal people today.	◯	◯	◯	◯
I am aware of what country I belong to and I acknowledge where I am from.	◯	◯	◯	◯
I feel I belong to land in a specific area associated with my people.	◯	◯	◯	◯
I have strong kinship links/family links.	◯	◯	◯	◯
I participate in Aboriginal cultural activities (e.g. Men's and Women's business, burials).	◯	◯	◯	◯
I feel I contribute to my community (e.g. spending time with Elders, going to community events).	◯	◯	◯	◯
My community accepts me as a part of the Aboriginal community.	◯	◯	◯	◯
I practice respect for Elders.	◯	◯	◯	◯

Figure 18. CK&P question from the Bunbury focus group on 26 April 2017 (Mayi Kuwayu Study, 2017a: 3)

In this draft the CK&P question has been placed at the end of a sub-section titled *Culture and Identity*. Items in the survey were not numbered as before, though the location of this question remained in the first third of the survey. This has always been a consistent strategy used by the researchers for two purposes. This first was to ensure that the participants' first impression of the survey was that it is primarily about culture, thereby distinguishing it from other national surveys administered by the ABS, such as the NATSISS (R Lovett 2018, personal communication, 30 January). Secondly, it was placed at the beginning so that participants would not be experiencing survey fatigue when filling out this portion of the survey. If questions in this section were consistently left unanswered by participants, the researchers could more reliably assume that there was something wrong with either the phrasing or content of the question (R Lovett 2018, personal communication, 30 January). Feedback from the focus groups also suggested that questions about culture should be placed at the beginning of the survey (R Lovett 2018, personal communication, 30 January).

There are 21 sub-questions in the Bunbury survey, compared to the 12 sub-questions used in the MLLS questionnaire for the CK&P section. Some of the questions can be related to those in the MLLS version, but most are new and include more specific questions about the variety of ways in which people practice their connection to Country. The message given in the heading was changed to 'These are things that Aboriginal people have said are important to their culture, but not all Aboriginal people do these things, and that doesn't make you more or less Aboriginal'. This still reinforces a strengths-based message, and more directly challenges the authenticity discourse. Further, the word 'traditional' and its implications have all but been removed, suggesting that the researchers modified this section so that it could be also applied to contemporary cultural practices and forms.

After the Bunbury focus group Ray replaced some of the references to 'Aboriginal' with 'Aboriginal/Torres Strait Islander' in the survey. This was particularly important at the time, as the focus groups in Cairns in north QLD and on Thursday Island in the Torres Straits were due to be held on 4 May and 6 May, respectively. He also made changes to the formatting of the CK&P question to become its own sub-section within the survey for the first time, and changed the sub-title to 'How much time do you spend doing the following things'. The section was further modified to include the questions about disconnection from culture and cultural revival activities (Figure 19).

	Not at all	**A little bit**	**A fair bit**	**A lot**
Have you ever felt disconnected from your Aboriginal or Torres Strait culture?	◯	◯	◯	◯
Have you been involved in any of these cultural revival activities: not at all (none), a little bit (a few days in the year), a fair bit (a few weeks in the year), or a lot (a few months in the year).	**Not at all**	**A little bit**	**A fair bit**	**A lot**
Learning Aboriginal words and language	◯	◯	◯	◯
Learning dance/s	◯	◯	◯	◯
Learning/participating in a cultural ceremony	◯	◯	◯	◯
Learning/making art or music	◯	◯	◯	◯
Learning/using bush medicine/healing methods	◯	◯	◯	◯
Learning about your mobs culture and history	◯	◯	◯	◯
Learning about caring for country	◯	◯	◯	◯
Learning to live off the land (bush foods)	◯	◯	◯	◯
Learning about kinship systems	◯	◯	◯	◯

Figure 19. Additional questions in the CK&P section from the Cairns focus group on 4 May 2017 (Mayi Kuwayu Study, 2017b: 4)

The inclusion of these questions was the result of an ongoing conversation between the researchers about how they could measure cultural disconnection, as well as accounting for cultural revitalisation activities in the survey. The results of the MLLS pilot clearly demonstrated that the participants wanted to be more involved in cultural and caring for Country activities (89–99% of participants living on their Country, and 68–98% of participants not living on their Country) (Lovett et al., 2017: 23-24). Literature published in Australia and Canada has also provided evidence that cultural revitalisation or renewal

promotes cultural belonging, and can help to mediate or reverse the effects of intergenerational trauma resulting from colonisation (Aboriginal and Torres Strait Islander Healing Foundation Development Team, 2009, Ayunerak et al., 2014, Fonda, 2009, Goudreau et al., 2008, McCalman et al., 2009).

By the time I returned to Australia in October 2017 to observe more focus groups, the CK&P section had been modified further. For the focus group conducted in Canberra on 14 November 2017, it was formatted as follows:

Cultural knowledge and practice: These are things that Aboriginal and Torres Strait Islander people have said are important to their culture, but not all Aboriginal and Torres Strait Islander people do these things, and that doesn't make you more or less Aboriginal/Torres Strait Islander.

How much time do you spend…	**Not at all**	**A little bit**	**A fair bit**	**A lot**
With someone in your community that has cultural knowledge (elder, knowledge holder)	◯	◯	◯	◯
Doing cultural ceremony and Law	◯	◯	◯	◯
Caring for country	◯	◯	◯	◯
On country	◯	◯	◯	◯
Hunting for bush tucker	◯	◯	◯	◯
Learning language, culture, Law, kinship, and respect	◯	◯	◯	◯
Making art, music, and paintings	◯	◯	◯	◯
Passing on cultural knowledge	◯	◯	◯	◯
Participating in social events related to Aboriginal and/or Torres Strait Islander people (e.g. NAIDOC week, Sorry Day events)	◯	◯	◯	◯
Contributing to my community (e.g. participating in community meetings, organising events, volunteering, healing, being on committees or boards)	◯	◯	◯	◯
Receiving Aboriginal/Torres Strait Islander healing methods (e.g. traditional healers, bush medicine)	◯	◯	◯	◯

Have you ever felt disconnected from Aboriginal and Torres Strait Islander culture?	◯ Not at all ◯ A little bit ◯ A fair bit ◯ A lot ◯ Unsure

<u>If you have ever felt disconnected</u>, have you ever done any of these to reconnect? *Skip if you answered 'not at all' above.*	**Not at all**	**A little bit**	**A fair bit**	**A lot**	**Want to but can't**
Cultural ceremony (dancing and singing)	◯	◯	◯	◯	◯
Caring for country	◯	◯	◯	◯	◯
Research family history	◯	◯	◯	◯	◯
Hunting or bush tucker	◯	◯	◯	◯	◯
Learning language, culture and kinship	◯	◯	◯	◯	◯
Art, music or painting	◯	◯	◯	◯	◯
Bush medicine/healing methods	◯	◯	◯	◯	◯
Other: _____	◯	◯	◯	◯	◯

Figure 20. CK&P section from Canberra focus group on 14 November 2017 (Mayi Kuwayu Study, 2017f: 4-5)

This is a much more streamlined version of the main question with just eleven sub-questions. The phrasing of the sub-questions also changed, becoming more generalised and less personal. There were discussions amongst the researchers at the time about using this section to capture cultural capital. Cultural capital is a well-known concept in the social sciences, stemming from French sociologist, anthropologist, and philosopher Pierre Bourdieu's work on social capital in the 1970s and 80s (for a summary of this theoretical work, see Bourdieu, 1986). The researchers used the Bourdieuian concept of cultural capital to facilitate a discussion about culture. The way they spoke about cultural capital most closely aligned with what Bourdieu described as the 'embodied state' which exists through accumulated dispositions of the mind and body (1986: 282-284). However, rather than being tied to economic capital through material or symbolic gain for the individual, as Bourdieu proposed, in this conversation it was described in a way which brought collective social gain and harmony to the group. Further, it is not a scarce resource to be hoarded (after Bourdieu, 1986: 284), but rather freely transmitted socially by Indigenous people, both individually and collectively.

During the annual CIs and Partners Meeting on 25 October 2017, cultural capital was brought up in relation to teenage pregnancy and whether this was an important issue to be captured by the survey. Jill Guthrie, a Wiradjuri woman and CI with MK, said that having cultural capital was a positive thing as it meant that young mothers had the cultural and financial support around them to raise children. Janet Smylie responded to this, emphasising the role of cultural capital and its transmission in maintaining family relationships. Ray Lovett picked up on the conversation, saying that while the survey measures social capital, it needed to be unpacked further as a concept to make sure the survey addressed the most relevant aspects.

Janet Smylie stressed in the discussion that you cannot know who has cultural capital by looking at them. Terry Dunbar then told a story about the different ways cultural capital can operate for Indigenous people. She said that 20 years ago in the NT health services if an Aboriginal person died at the health clinic retribution for their death would be sought by their relations. Now she said there was a sense of forgiveness by Aboriginal people. She told the story of a young man who died at a clinic because he had not received treatment in time. Terry said she was angry about the situation, but that she then attended a cultural meeting where everyone came together to discuss and resolve it. She said that was cultural capital working through the group at the time, and Janet replied that this was an example of collective cultural capital.

There seemed to be an agreement amongst the Indigenous members of the meeting that cultural capital is a concept which can describe a variety of experiences, but that these experiences should not be separated into individual versus collective cultural capital for Indigenous peoples. Janet said that it was important to recognise that cultural capital is a concept which underpins community behaviour, though the ways in which it operates can be under-valued and over-categorised. Jill said 'We are the sum of several cultures', and that these should not be considered individually without understanding their place within the whole. Unfortunately this conversation had to be cut short, as there were other items of business to be discussed at the meeting. However, it is clear that the conversation was continued by the researchers working on the survey draft. Figure 21 is an example of how these discussions were recorded in Microsoft Word as a comment on a draft of the survey.

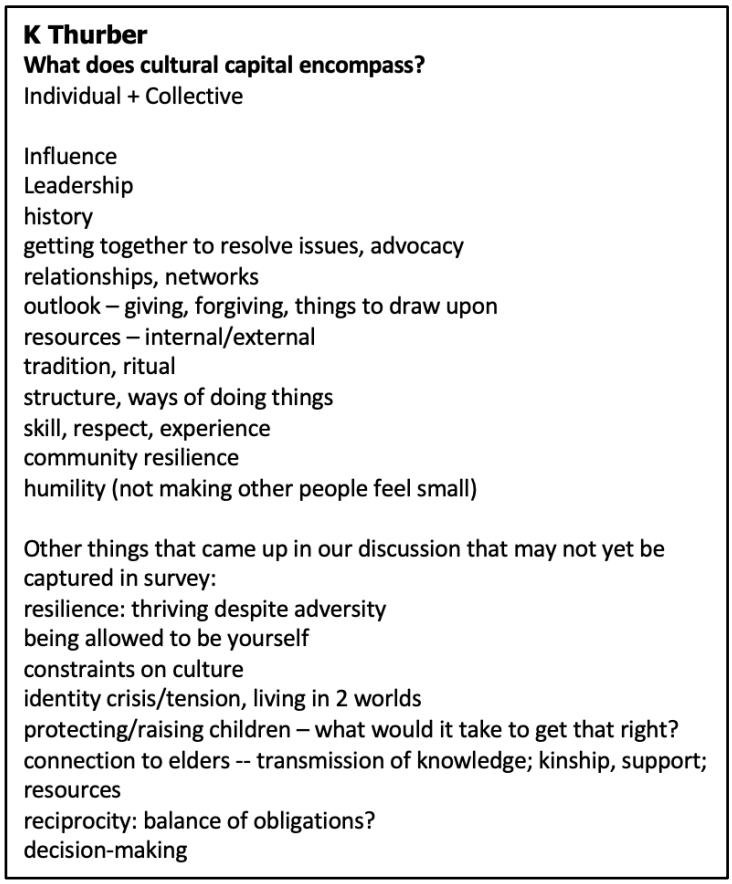


Figure 21. Comment by Katie Thurber from a survey draft dated 30 October 2017 (Mayi Kuwayu Study, 2017e: 5)

In a later draft from 6 November, most of these points had been crossed out, because after having reviewed questions in the survey, the researchers decided that these aspects were already addressed in some form (Mayi Kuwayu Study, 2017d: 4). The points remaining were:

- History
- Outlook – giving, forgiving, things to draw upon
- Resources – internal/external
- Skill, experience
- Protecting/raising children – what would it take to get that right?

The additional questions from the CK&P section in the 14 November draft also more directly address feelings of disconnection with culture and ask whether certain activities

such as caring for Country or researching family history are undertaken in order to reconnect (as in Figure 20). Nevertheless, while both sub-sections in this version are shorter than previous drafts, the content it captures remains the same with the exception of asking specifically about involvement in food preparation practices, protecting Country, respect for elders, and learning about issues affecting Indigenous Australians today.

The same version of the survey was then used for the second Bunbury workshop I attended on 27 November 2017 with the women's group. One focus group participant had a query about the use of the word 'Law' instead of 'Lore' in the second sub-question. Jan explained that they had used other forms of the word before, but that some participants in previous focus groups had wanted it spelled that way because it was 'as good as White man's law'. This sentiment is reflected in the story about the two sides of a coin representing the equal value of Torres Strait Islander Lore and Australian law told by one of the participants in the Thursday Island focus group (see Chapter 6).

The question was also used for the conference session conducted in Perth the day after the Bunbury session. There was no discussion about this section in the focus group I observed, however, following the conference the CK&P section was modified by the researchers to include a column on the right-hand side with the label 'Want to but can't'. Including this response option may collect the same kind of data as two sections included in the original MLLS questionnaire which asked about whether people would like to be involved in caring for Country activities, as well as the barriers they faced in accessing Country and practicing cultural activities.

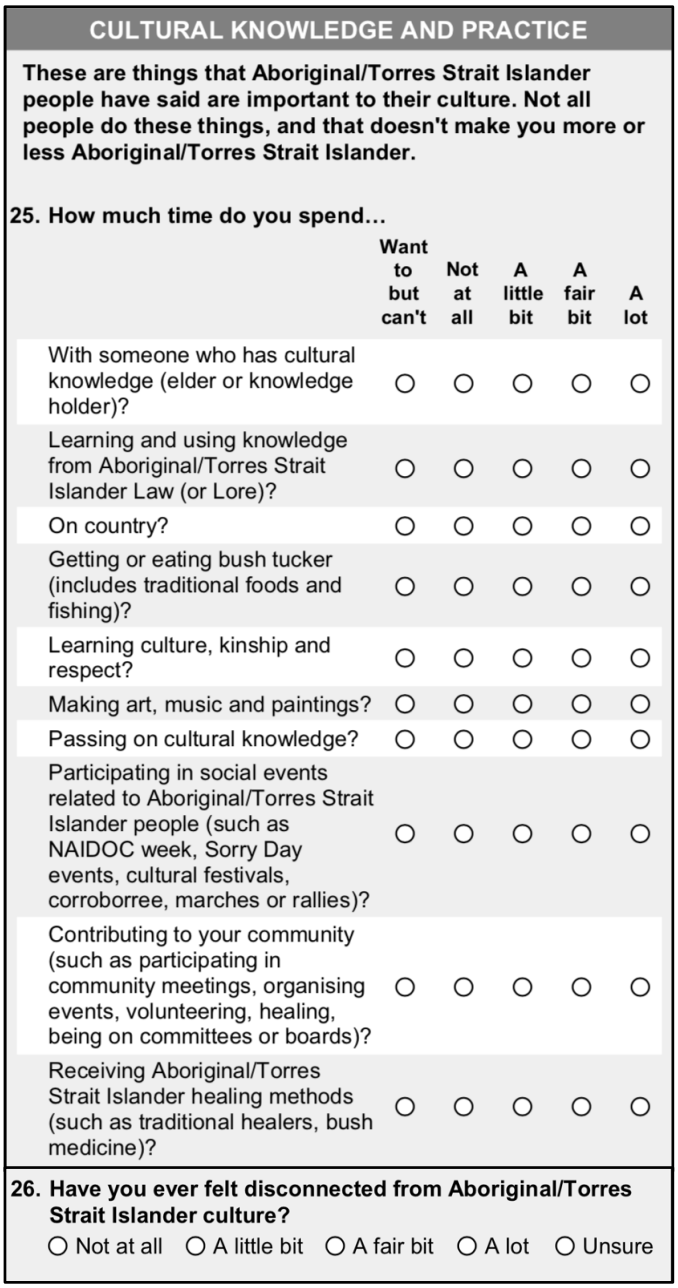
Part of the first sub-question was also changed to 'With someone who has cultural knowledge (elder, knowledge holder)', removing the phrase 'in your community'. This change acknowledges the frequent movement of Indigenous peoples across cultural borders in Australia, and that while they may not be currently living in their community,

they are still able to learn from knowledge keepers around them. The CK&P section of the survey then remained as it was for the final focus group I observed at Risdon Cove on 9 December 2017.

After the focus group consultation process had been completed, the refining of the survey continued with occasional feedback sought from external experts, other MK investigators who were not involved on a day-to-day basis, and Indigenous staff members as discussed in section 5.2. The feedback from these individuals about the CK&P question was minor, but consisted of comments like:

- The order of the response columns might need to be adjusted as someone might answer 'Not at all' as well as 'Want to but can't'.
- The sub-questions seemed to have a bias towards those living in remote areas.
- The phrasing of 'Doing cultural ceremony and Law' is incorrect as people don't 'do' Law, but rather practice and learn from Law. Also that Law and ceremony were related but different constructs, and perhaps shouldn't be bundled together.
- Need to add 'gathering' to the 'hunting for bush tucker' sub-question.
- Could add a question about 'having a yarn with someone who has cultural knowledge'.
- Should include 'sporting carnivals' as an added example for the Aboriginal/Torres Strait Islander social events sub-question.

The MK researchers also decided to remove the list of activities they associated with reconnecting with culture, because in their words, 'With these questions removed, we can't say whether participation in activities was in order to reconnect, but we can look at disconnection in relation to extent of participation; and longitudinal data will provide more insight on this' (Mayi Kuwayu Study, 2018b). By examining the final version of the CK&P question in Figure 22, we can see that it takes into account some, but not all of this feedback.



CULTURAL KNOWLEDGE AND PRACTICE

These are things that Aboriginal/Torres Strait Islander people have said are important to their culture. Not all people do these things, and that doesn't make you more or less Aboriginal/Torres Strait Islander.

25. How much time do you spend…

	Want to but can't	Not at all	A little bit	A fair bit	A lot
With someone who has cultural knowledge (elder or knowledge holder)?	○	○	○	○	○
Learning and using knowledge from Aboriginal/Torres Strait Islander Law (or Lore)?	○	○	○	○	○
On country?	○	○	○	○	○
Getting or eating bush tucker (includes traditional foods and fishing)?	○	○	○	○	○
Learning culture, kinship and respect?	○	○	○	○	○
Making art, music and paintings?	○	○	○	○	○
Passing on cultural knowledge?	○	○	○	○	○
Participating in social events related to Aboriginal/Torres Strait Islander people (such as NAIDOC week, Sorry Day events, cultural festivals, corroborree, marches or rallies)?	○	○	○	○	○
Contributing to your community (such as participating in community meetings, organising events, volunteering, healing, being on committees or boards)?	○	○	○	○	○
Receiving Aboriginal/Torres Strait Islander healing methods (such as traditional healers, bush medicine)?	○	○	○	○	○

26. Have you ever felt disconnected from Aboriginal/Torres Strait Islander culture?

○ Not at all ○ A little bit ○ A fair bit ○ A lot ○ Unsure

Figure 22. CK&P section from the MK baseline survey (Mayi Kuwayu Study, 2018a: 3)

By following the development of the CK&P section from its first iteration in the MLLS questionnaire to the final version as it appears in the baseline survey, it is possible to draw out both the processes by which questions in the survey were refined over time, as well as the contexts in which these changes were made. Further, we can deduce what aspects of cultural engagement are considered important and kept in the survey, compared to those considered to be less important, at least in the short term, and removed. Once a decision

was made by the researchers, they quickly moved on to the next phase of the survey, with the details of specific changes to the survey only vaguely remembered or forgotten. This is a particular kind of memory bias which I encountered as a meta-researcher. It was easier for me to study what was left in, and to ask the researchers about this, but not what was left out of the survey.

The main lesson learned from this analysis of the evolution of the CK&P section relates to cultural revitalisation. As stated above, the results from both the MLLS pilot (Lovett et al., 2017: 23) and the literature (Aboriginal and Torres Strait Islander Healing Foundation Development Team, 2009, Ayunerak et al., 2014, Fonda, 2009, Goudreau et al., 2008, McCalman et al., 2009) demonstrate that cultural revitalisation is of interest to Indigenous peoples and important for wellbeing. Cultural revival activities were also mentioned in several of the focus groups as contributing to wellbeing and reinforcing identity (Chapter 4). Nevertheless, these questions were removed from the final version of the survey. This demonstrates that the survey does not, at this stage, account for the full breadth of the Indigenous lived experience. To return to the metaphor used at the start of this chapter — the Mayi Kuwayu Study cannot map the whole river. But that does not mean the map we have is not useful and valuable.

The next chapter will seek to explore this further by analysing the themes brought up across the focus groups and compare these to the themes represented by the different sections of the baseline survey. By examining this intersection, it can be determined how the survey reflects the focus group feedback, and what impact the nature of the survey tool may have on interpretations of its results.

Chapter 6 — Culture and Meaning

In seeking to define the cultural determinants of Indigenous health, the Mayi Kuwayu Study researchers relied on the focus group process to refine their survey metrics and build consensus around what the most important aspects of culture were for health and wellbeing. This process was complex and drawn-out, leading to an ethnographic ambiguity around how the discussions from the focus groups influenced the minute design of the survey. From what I observed, the focus groups formed a rich cultural resource from which the MK researchers could draw major themes for their survey. However, there was comparatively little feedback given during the focus groups on the survey questions themselves. Instead, it was the researchers who determined to a large extent how the questions were worded, in what order they were presented, and what was included or excluded for the final version.

Of course, this was based on their own observations of almost 200 focus group participants completing the survey, and of reading through their responses and taking note of which questions were completed and which were not. While I could not directly observe this process, throughout my fieldwork I gathered its artefacts. This included the series of draft surveys, observing the research team meetings where parts of the survey were discussed and refined, and by asking the researchers directly about the refining process during interviews. Nevertheless, on my return to Oxford I still felt a lack of understanding about exactly what influence the themes brought up during the focus groups had on the structure of the baseline survey, and their influence over how MK conceptualises cultural determinants of Indigenous health. Therefore, I decided that I needed to conduct my own analysis of the focus group data alongside an analysis of the survey itself to gain a better hold on *what* and *who* the survey represented.

This chapter presents my detailed thematic analysis of the focus group data introduced in Chapter 4 and thematic analysis of questions from MK's baseline survey, following on from Chapter 5. Here, I compare the focus group data directly with the content of the survey to ascertain what information was incorporated into the survey, and the reasons why. This investigation yields important information about how qualitative research methods feed into the development of quantitative tools, and the various factors which can influence this process. Furthermore, by applying an anthropological and Indigenist perspective to these findings, the wider social, political, and cultural implications of MK for the future of Indigenous health in Australia may be ascertained.

6.1. Building a culture framework

During the focus group process I was struck by how similar the discussions about culture and wellbeing were across the sessions. Based on my observations I determined that this commonality reflected the generalised nature of the Mayi Kuwayu Study itself. The researchers introduced MK to the participants as a national survey where the same questions would be asked of many different groups of Indigenous people. Furthermore, the primary question they asked the group to discuss — 'Can you tell me about the important things that you think make up Aboriginal and Torres Strait Islander culture here?' — primed the participants to provide general responses, albeit with some locational specificity.

Feeding into this was the focus group format. The settings of the focus groups I observed varied slightly in their formality, though MK's research process remained consistent. The most casual setting, from my perspective, was the Bunbury women's group. The women and their children were already present in the room when we arrived, and the focus group took place during their regular monthly meeting. The most formal setting was the Cairns

focus group, where participants met us in a meeting room at the university, though this was a setting which was familiar to them as university employees. The combination of the information and consent form processes and the use of an audio recorder differentiated these focus groups from everyday conversations about culture which may take place between family members or friends. As a result, they may have moderated what they said or how they expressed themselves to conform to the formalised process. Further, the vast majority of the participants had not met the researchers (or myself) before the focus groups, and as far as I'm aware, have not met them since.

The formal nature of the focus group process was an ethical requirement that MK needed to meet in order to conduct their research. It was a method which was both convenient and effective for the researchers to collect information about key aspects of Indigenous Australian cultures and to get community feedback on the questions and format of the survey. The process itself was also important for validating the themes and questions within the survey from the researchers' perspective. The sessions led by the MK researchers aligns with what American education researchers Katrina Rodriquez, Jana Schwartz, Maria Lahman, and Monica Geist (2011) referred to as 'culturally responsive focus groups'. This type of focus group relies upon the shared identities and experiences of the researchers and participants to create a comfortable and affirming environment which encourages 'authentic sharing' in the co-construction of knowledge (Rodriguez et al., 2011: 403-404).

To reach my own understanding of the general themes which came out of these discussions I conducted a thematic analysis of the focus group data. This was an important task, firstly to comprehend the findings of the researchers in comparison with my own analyses, and secondly to understand more thoroughly what is lost (and found) through the transformation of qualitative concepts into quantitative metrics.

My analysis identified six key themes which emerged from the focus group discussions about culture: *Identity*, *Country*, *Language*, *Lore/Law and protocols*, *Cultural activities*, and *Wellbeing*. Crucially, these ethnographic data definitively contradict assertions by some anthropologists that the culture concept is an anthropological invention (see Wagner 2016) or that it is something externally defined and imposed on indigenous peoples by governments (Rapport 2014: 128). As stated in the introductory chapter, what has been missing from these anthropological narratives about culture are the unfiltered perspectives of Indigenous people themselves. In the following section I discuss each of the cultural themes in turn, drawing on the ethnographic record and my observations to explore their importance and meaning. A detailed summary of each theme and related descriptive phrases can be found in Appendix 3.

6.2. Key themes

Identity

Concepts of identity and the politics of identity was a strong theme across all of the focus groups. In the Thursday Island focus group, identity was seen to be the foundation which allows Indigenous people to connect with others and Country. As introduced in Chapter 1, Indigenous identities in Australia are both complex and highly contested as a result of colonisation and the ongoing struggle for Indigenous self-determination in the face of White Australian hegemony. In the absence of a direct connection to Country, language, or social and cultural history, it is family which remains at the heart of what defines Indigenous identities.

Family was mentioned by all of the focus groups as being a key aspect of Indigenous cultures and identities. Family relationships are a key influence on Indigenous wellbeing,

and it is the maintenance of these relationships which drives much of Indigenous social life (Bourke and Edwards, 1994). As identified in the Thursday Island group and Alice Springs women's group discussed in Chapter 4, it is family connections which are the key to knowing one's place within the world. The concept of family for Indigenous people can also extend beyond blood relations, particularly now that many individuals and families have become displaced from their traditional homelands over time.

> Participant 1: The hardest thing is you grow up and you're taught that this person's your Aunty and that person is your Uncle. And then you realise at the end of the day when you grow older, that Uncle [name] is not actually my blood Uncle but I've called him Uncle for so many years.
>
> Participant 2: That's right. Whereas lots of people question you, though, because before — back in the day you probably never questioned how am I related.
>
> Participant 3: Yeah.
>
> Participant 2: But now people go 'So how are you related to him?'
>
> Participant 1: Oh, that's my kids for me. 'So Mum, how exactly am I related to this person?' I said, 'Because you call such-and-such Aunty.' 'Yeah, but exactly how am I related?' So I have to stop and think, and I had a really good question that my daughter asked me and I just said — it was about one of her friends, 'Are we related?' and I'm like 'Yeah, his grandmother's arm match and your grandmother's arm match'. So we just left it at that. But two different arm match all together.
>
> *LAUGHTER*
>
> Participant 2: It's just respect. Common respect. Yeah.
>
> Participant 1: […] I just — for [name] — she was the oldest in the group and stuff and only two weeks ago, I pulled her aside and I said, 'Is it OK if I can call you Aunty?' and her face just went all teary. 'Because I just mean to respect you and feel that even though we're not family, I see you as an elder and I just want to

> call you Aunty'. And she's like 'Yeah, that's fine' and just gave me a big hug, and just [said] 'You never know, I may be your grandmother'.
>
> — Focus group participants, 6 May 2017, Thursday Island, QLD.

Under the theme of identity, there are a number of sub-themes I identified during my analysis (Figure 23). Family was the most prominent, but this was interwoven with descriptions of kinship, community, history, and the nature of Indigeneity itself. More specific features of identity such as totems were raised, as was the potential of social media to connect and re-connect with family members who no longer live nearby.

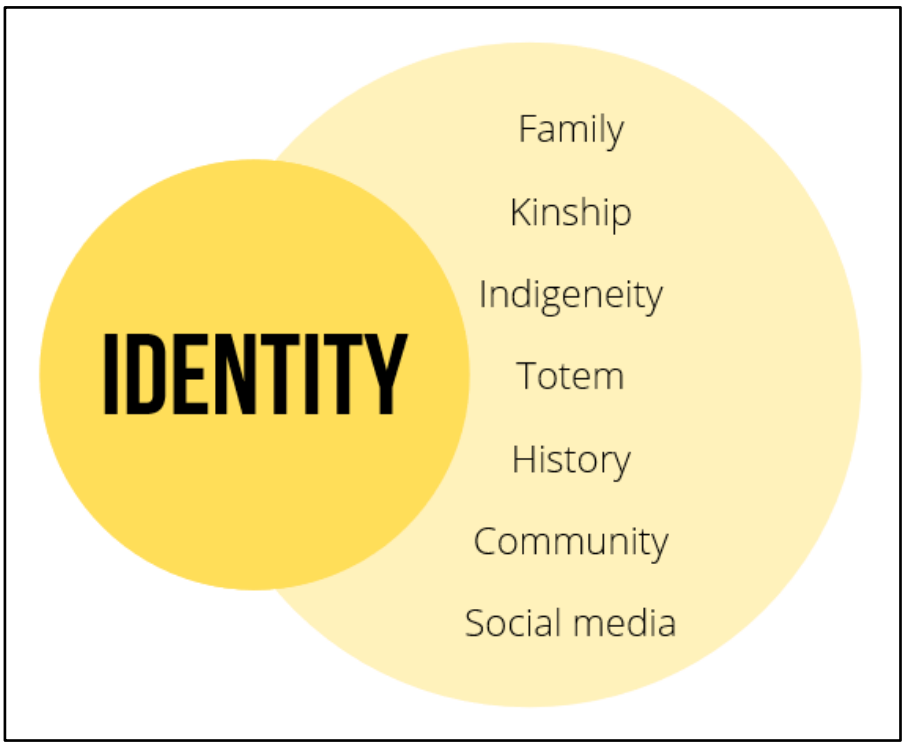


Figure 23. Identity sub-themes from analysis of the MK focus group data

My interpretation of the ethnographic data is that Indigenous identity incorporates both past and present manifestations and practices of identity which are both embodied by and transcend the individual to connect relatives across time and space. To be Indigenous is to be connected, and the maintenance of this connection through culture is what sustains a holistic sense of self for Indigenous people.

Country

The importance of Country was mentioned in all of the focus groups included in my analysis. It is a concept which encompasses a whole sense of wellbeing and identity, through the fundamental physical and spiritual relationship that an Indigenous person experiences with their traditional homelands, often described as connection to Country (Ganesharajah, 2009, Kingsley et al., 2009, Trzepacz et al., 2014). Thus, a person's lived experience may be intimately connected to their traditional homelands:

> country represents another aspect of the individual, similar to spirituality/religion, in that it contributes to the definition of self, and assists in answering the questions of 'who am I?', 'where do I belong?', and 'why am I here?' (Bishop et al., 2012: 36).

The ways in which Country was described by the focus groups mirror the ways in which people tend to speak about interpersonal relationships (see Figure 24). Living on Country, visiting Country, or being away from Country, were all said to be important factors which influenced the embodiment and practice of culture. Physical elements of the environment including significant sites and animals were also incorporated into the experience of Country for the focus group participants.

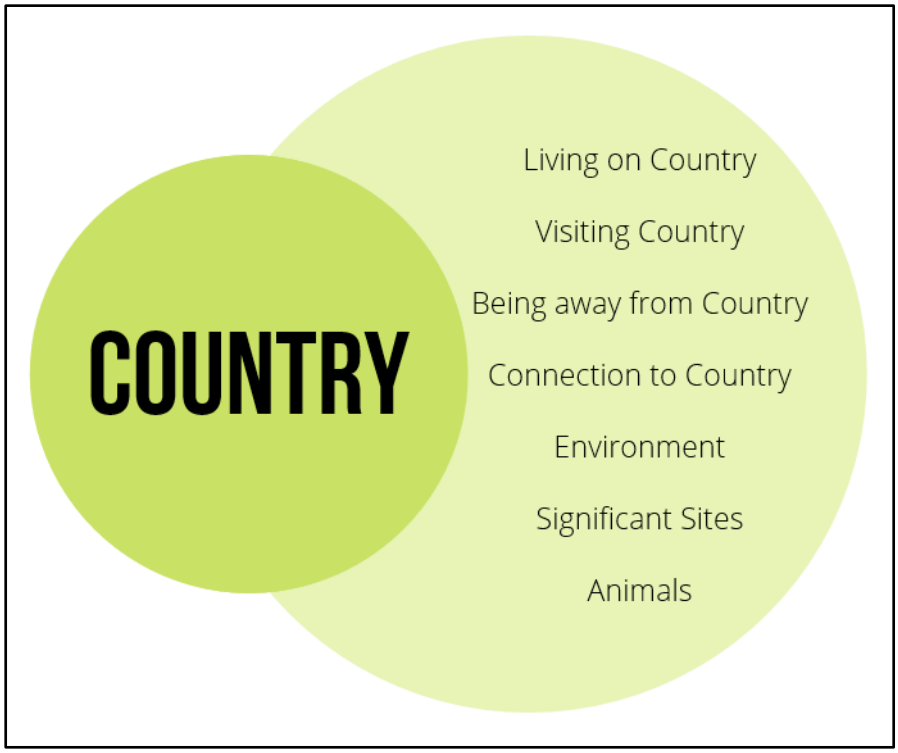


Figure 24. Country sub-themes from analysis of MK focus group data

One of the elders in the Thursday Island group related his identity and wellbeing to the environment of the Torres Straits, including the wind and seas (Chapter 4). In the Cairns focus group, one of the participants spoke about the importance of knowing Country:

> I'm just thinking we talked a lot about connection to Country and that, but I think it's actually about knowing your Country more. When we go up on Country, it's about taking the kids through the landscape, talking to them about special significant sites and what happened and showing them the fish traps and ground ovens and all those sorts of things. So sharing that understanding is not just having a connection to your land but actually understanding their lands is really important.
>
> — Focus group participant, 4 May 2017, Cairns, QLD.

In the absence of connection to Country, the majority of the participants spoke about feeling as though a part of them was missing, or that their health was not as good as it could be because they were away from Country. The participant in the Perth focus group who had visited the traditional healer and was told that there was sadness in his lower back

thought that it was a result of his absence from Country (Chapter 4). One of the Alice Springs participants described this absence as having a negative effect on both people and the environment:

> In the old days, women had to walk around all the hills and come in — walk around the Country, talk about the Country — and seeing in same time, walk along. Just see that Country come alive with food and with all animals that we hunt for. You're bringing those out when you're singing that story around more, for that particular animal that you want.
>
> Looking at today, it's not happening. You see, some Country just try — doesn't look too good on the Country. Not going back and teaching and not singing the song or not learning about the Country. You just say, 'You lose your — you're not only losing your culture, you're losing your Country as well. The land that you belong to.'
>
> — Focus group participant, 7 February 2017, Alice Springs, NT.

This sense of loss of Country is a major source of heartache for Indigenous Australians. As a result of colonisation, either control over Country was taken away from many groups, or people themselves were taken away from Country, often permanently. This disrupted people's direct connection to the land, as well as their social, cultural, and spiritual connections for them and their descendants. This has led to feelings of having lost a key part of identity for those taken away from Country. All of the above descriptions align with the existing literature about connection to Country for Indigenous Australians and its fundamental relationship to health and wellbeing (Ganesharajah, 2009, Kingsley et al., 2009, Trzepacz et al., 2014). Promoting re/connection to Country, for example through caring for Country activities, may have a substantial positive effect on Indigenous health and wellbeing outcomes at the local and population levels (Kingsley et al., 2009: 297).

Language

2019 was the International Year of Indigenous Languages. Before colonisation, it is estimated that more than 250 Indigenous languages were spoken in Australia, including 800 dialectal varieties (AIATSIS, 2019). Approximately 100 of these are still spoken in varying degrees today, but only 13 of these languages are being taught in schools to children (AIATSIS, 2019). There is already quantitative evidence which suggests that there is a positive correlation between the sustainability of Indigenous land, language, and culture, and subjective emotional wellbeing for Indigenous Australians (Biddle and Swee, 2012). The testimonies collected during MK's focus groups generally supports this correlation, however the complexities inherent in a modern Indigenous identity — including the wide-spread loss of language — may complicate this association.

Language was mentioned as an important aspect of culture in 14 of the focus groups analysed, and included discussions about Indigenous Australian languages, Creoles, and English. In the Bunbury women's group they spoke about how the Noongar language was being taught to school-aged children, but also expressed a frustration that it was not taught more comprehensively, or by an Aboriginal person. A loss of language affected some of the participants in the Cairns focus group as well, who said that they felt that language facilitated a stronger connection to their Indigenous identity. The loss of language was seen to have a negative impact on people, including causing young people to misbehave:

> Participant 1: Like, I wish I would've listened to my grandparents when they were speaking the language, because we were told you're not allowed to speak the language in the schools, but the grandparents used to speak it. And I regret that I didn't spend time to learn enough, because language is a key part of identity and a lot of young people don't have that identity. And that's why they just are running amok today. […]

> Participant 2: But for me, I know when we all come together, well that just — that really nice English just goes out the door. But it just happens. You don't even think about it. And then when you walk back into your job or you're surrounded by non-Indigenous, you just automatically slip back into really good English. […] You just flow between the two, but as soon as you're a mob together, you just go for it.
>
> Participant 1: It just connects you. Yeah.
>
> Participant 2: And it feels good, you know. And so, for someone that's not getting any of that in their life, there's got to be an impact.
>
> — Focus group participants, 4 May 2017, Cairns, QLD.

Nevertheless, one of the participants in a focus group in Bunbury was quick to point out that language use was not essential to their Indigeneity:

> I guess it would be good to learn your language but it won't make you any more Aboriginal than what you are and I think that that's something that's important for people to remember. Is that it's about what's inside your spirit, not about what you know and it would be nice to feel that connection, but it doesn't make you any more of what you are.
>
> — Focus group participant, 26 April 2017, Bunbury, WA.

This brings to the foreground the differences between Indigeneity, identity, and culture as experienced by Indigenous peoples. Indigeneity is about being Aboriginal or Torres Strait Islander by descent, and as pointed out in the Bunbury focus group, particular cultural practices including the use of Indigenous languages does not determine your Indigeneity. But the use of language can contribute to a person's sense of an Indigenous identity and reinforce their practice of culture (see Marmion et al., 2014). I believe that there are few Indigenous Australians who would not wish to learn their ancestral languages or those of other groups. However, given the widespread, systematic suppression of Indigenous

languages since colonisation, it is extremely difficult for individuals to learn or maintain their language cross-generationally when English continues to dominate every aspect of Indigenous lives.

Nevertheless, working against this hegemony is a sense of hope and an increase in the visibility and pride for Indigenous cultures across Australian society. A number of the participants in the Cowra focus group had gained formal certifications in Wiradjuri language, and spoke about other individuals who were teaching Wiradjuri to community members and school children in the region:

> Participant 1: There's a lady called [name] […] She's – she's a really good speaker of Wiradjuri language and she comes to school and she teaches me language at lunch times during the term and then I share that with the kids.
>
> Participant 2: Right. Yeah, I'm going into the public school next month with [name] to teach the kids language. […]
>
> Participant 1: I just think language, when you speak it, it's like […] I don't know. It's like a song when you're… when you're speaking it. It's real rhythmical, the language.
>
> Participant 2: It is, yeah.
>
> Participant 3: Well, at our language group they've got… they're doing the… the singing in the language too. There's one lady in Dubbo […] She does a Welcome [to Country] in song. And aww… she is just so good.
>
> Participant 1: You can't… you just… that feeling you get when you hear people speaking it. I don't know, can't describe it but that's one of the positives. I think that would… that's growing — language and sharing.
>
> — Focus group participants, 18 April 2017, Cowra, NSW.

These quotations suggest that language could be one of the best vehicles for Indigenous people to re/connect with their identity and Country. While a lack of historical information and local speakers may be a barrier for some people to learn their ancestral language/s, there is a growing movement in Australia to record Indigenous languages and embed them within the education and health care systems.

Technology offers the ability to move beyond local contexts. For example, in 2019 the Australian Literacy and Numeracy Foundation won an international innovation award and funding from the Google.org challenge to develop an app called the *Living Language First Platform* (Australian Literacy and Numeracy Foundation, 2019). This app, which allows Indigenous language learners and speakers to record and share language digitally, is a promising resource which would be able to connect Indigenous people interested in learning their traditional or local Indigenous languages with living speakers, regardless of age, education, or location. Given that MK will be longitudinal, it will become possible to measure the general social and wellbeing impacts of such language revival activities over time.

Lore/Law and protocols

Lore/Law and protocols govern both the transmission of culture between individuals and groups as well as codes of behaviour in social situations. They regulate more traditional aspects of culture such as ceremonies, songlines, storylines, and who can be the custodians of certain kinds of knowledge and places. Songlines, also known as 'Dreaming tracks' or 'strings', are navigational records of the Indigenous landscape passed down in songs, stories, and dances (Williams, 2015: 19). Lore/Law and protocols also relate to the general beliefs and values which Indigenous peoples share.

It is common practice for Australian educational organisations to refer to the Lore/Law and protocols of Indigenous peoples as a part of their commitment to respecting Indigenous communities (AIATSIS, 2018, Oxfam Australia, 2015). However, these resources often do not go into much detail about these concepts, and there is curiously little information available online discussing in depth the importance of Lore/Law and protocols to Indigenous groups, especially from Indigenous authors (for notable exceptions, see Callaghan and Gordon, 2014, and Janke, 2007). This could be for a number of reasons, including the specificity of Lore/Law and protocols, to particular groups and knowledge protections under Customary Law giving certain Lore/Law and protocols secret or sacred status. Secret and sacred knowledge is protected under Customary Law and is only known and shared between designated individuals and used for a particular purpose (Sentina et al., 2018: 10).

The scarcity of information available about one of the most significant aspects of Indigenous culture highlights the lack of attention that has been paid to Indigenous perspectives in academia, the media, and by the Australian Government to date. The importance of Lore was discussed specifically in the Thursday Island focus group. One of the elders in this group told a story about the differences and similarities between Australian law and Torres Strait Islander Lore, which came up in relation to a Native Title claim by the local community in the 1990s:

> Participant 1: In the 90s Justice French came here to talk about Native Title, and obviously, the Islanders here talked about the land and the sea. And the Justice says, 'Oh, you can't have the sea because we're here for the land.' And we're saying that 'We're not like our Aboriginal brothers. Our island and sea, meaning that all reef, is part and parcel. It's not that high water mark'. But the law says the high-water mark is actually anything below the high-water mark it belongs to the State or belonged to the Government. 'Everything on top of the high-water mark, it'd be yours'. And we're saying, 'But if the rising seas coming up'…

> Participant 3: We're getting less and less.
>
> Participant 1: You know, we're getting lesser and lesser of our identity. So we're talking about that L-O-R-E and L-A-W. And Justice French said 'Well, at the moment, you have to deal with L-A-W.' And I remember one of the elders. I think it was Uncle [name], when he stood up he said 'Can I just explain to you about L-A-W and L-O-R-E Justice French?' And he said 'Yeah, go ahead, Mr [name].' And Mr [name] says 'Have you got two dollars?' And straightway Justice French think 'Oh typical black fella — he wants money', you know?
>
> And he said 'No, a two-dollar coin.' But I don't think the Judge had two dollars but someone else gave him two dollars. And he said 'This one two dollars. The value is two dollars.' And the Justice said 'Yeah.' And he said, 'If I flick it up and it lands on tail, is the value still two dollars?' And he said 'Yes.' And he said 'Well, that's what L-A-W and L-O-R-E. It doesn't matter where that coin lands, the value is the same'. So the value system of our Lore is same as the value system of law. Which is very true. It was so simple that it was… blown out every excuses that people have that you can't get them two together.
>
> — Focus group participants, 6 May 2017, Thursday Island, QLD.

The way the focus groups discussed Lore/Law and protocols related to current and ancestral family relationships, including the role of elders as the key custodians of knowledge in the community (see Figure 25). My analysis found that while there was a strong focus on traditional concepts, the participants also emphasised how these traditions were embedded in, and represented by, modern social relationships and practices. These traditions provide a script for how to behave in difficult situations such as the death of relatives, as well as in the celebration of new life. Thus, Lore/Law and protocols seems to create a scaffold for the acknowledgement of Indigenous identities, connection to Country, and languages, and incorporates both traditional and modern practices. Lore/Law and protocols are also related to Indigenous forms of leadership and

governance, which is another aspect of Indigenous lives which is considerably under-researched (see Chapter 3).

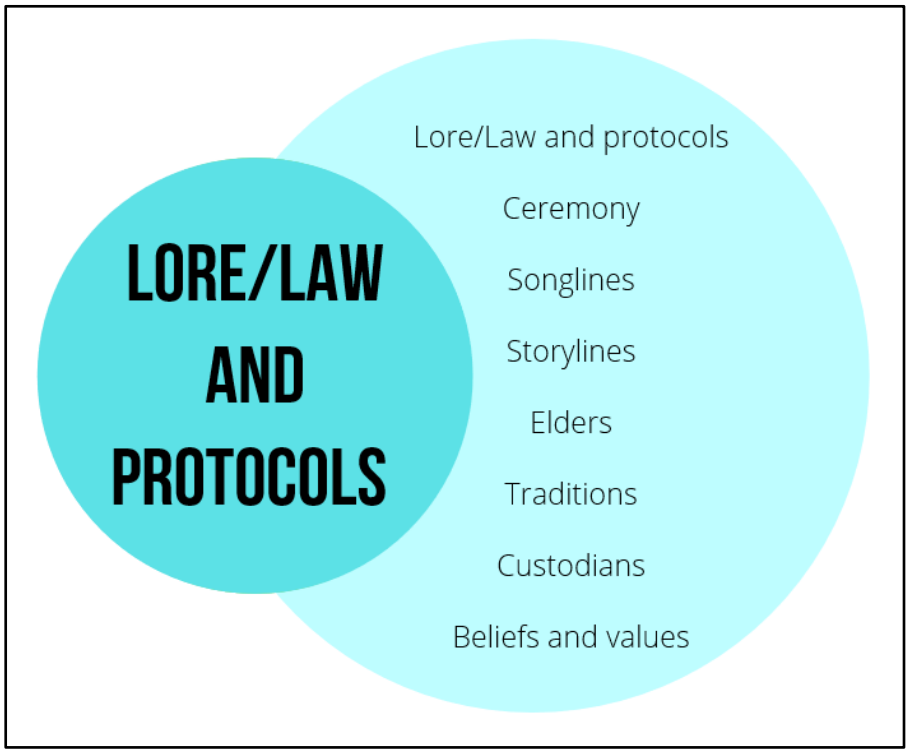


Figure 25. Lore/Law and protocols sub-themes from analysis of MK focus group data

Cultural activities

There were a number of activities cited across the focus groups as being part of culture. In my analysis I grouped these activities into 17 sub-categories (Figure 26). The specific activities which were mentioned in eight or more of the focus groups were traditional foods, hunting, storytelling, and dancing. As a modern form of the traditional practice of corroboree, large festivals are a very popular avenue for Indigenous people to practice and share cultural activities. These festivals often incorporate ceremonial, dance, and musical events, and provide a strong foundation for intra- and inter-cultural transmission and connectivity between Indigenous individuals and groups (Salmon et al., 2018: 51, Phipps, 2016).

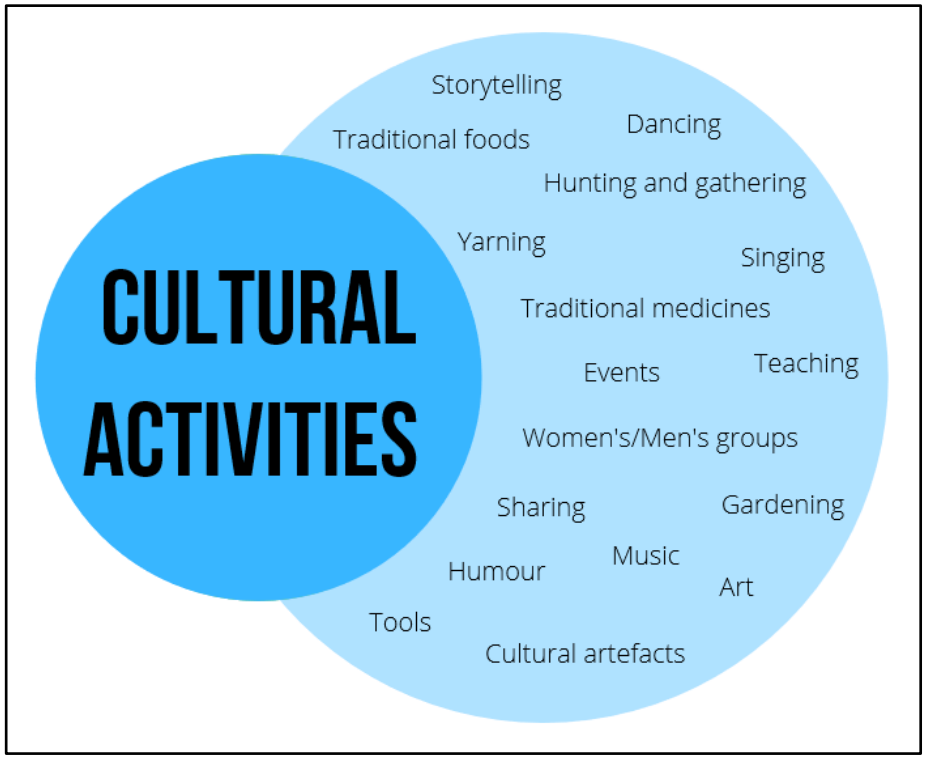


Figure 26. Cultural activities sub-themes from analysis of MK focus group data

One prominent example is the Laura Dance and Cultural Festival, which is held every two years at a traditional meeting place on QLD's Cape York Peninsula, and is a celebration of Indigenous identities, cultures, and wellbeing (see Henry, 2000, Phipps and Slater, 2010, Slater, 2010). As one of the participants in the Cairns focus group said, such festivals are more than just places to join in on cultural activities:

> Participant 1: Laura Festival is on this year and that would be good experience, if you're writing about Aboriginal and Torres Strait Islander wellness, because it will be wellness. It includes all of the cultures coming down together and doing their dances and sharing their stories.
>
> Participant 2: But it's that opportunity where they all can meet up again, not just share their cultures.
>
> Participant 1: But families connecting.
>
> Participant 2: But it's their opportunity where they come together again. We took up 60–70 clients that last festival. And these are people with significant

> disabilities, mental health, kids that are in out-of-home care. From Brisbane all the way up from our different regions. All staff volunteered their time. I cooked for everybody all we can. There was about 130 of us, and these people were able to find their mob from whichever community during the festival. And they reconnected, and it was just awesome, especially with these kids […] it's just all about culture and wellbeing.
>
> — Focus group participants, 4 May 2017, Cairns, OLD.

As detailed in Chapter 4, one of the participants in the Cairns focus group spoke about the importance of traditional or bush foods for connecting with Country, the ancestors and to facilitate storytelling. However, the Bunbury groups spoke about how the practice of cultural activities was being threatened by local government policies, landowners, and non-Indigenous individuals who were blocking or restricting access to Country. Participants in one of the Canberra focus groups also spoke about the impact of environmental disturbance on traditional food sources which make people healthier:

> JC: So if people ate more traditional foods? Be better?
>
> Participant 1: Yeah.
>
> JC: But… yeah, they don't.
>
> Participant 1: Too hard to find now.
>
> Participant 2: Yeah.
>
> Participant 1: All the kangaroos, they running away, and emus are hiding away too with the kangaroos. Yeah, too hard to find them […]
>
> Participant 3: It might have been our meat that cleaned out all the old people that… not old people, the people that used to get kangaroo in summertime, wintertime, anytime. And they had to cook for people living with kangaroo meat and that's what we call a kangaroo. And cutting up a really fat kangaroo and emu and it's good for people. It's like oily inside, I mean the really nice fat one.

— Focus group participants with Jan Chapman, 25 May 2017, Canberra, ACT.

Cultural activities are perhaps the most tangible feature of Indigenous cultures from a non-Indigenous perspective, and as such have been vigorously recorded since European contact by explorers, historians, anthropologists, and others. From the Indigenous perspectives represented within the focus groups, it was evident that cultural activities bring people together in a way that actively facilitates the other key elements of culture identified in my analysis (i.e. Identity, Country, Language, Lore/Law and protocols, and Wellbeing). These activities are material (traditional foods, medicines, art, tools, artefacts), performative (yarning, storytelling, dancing, singing, music, teaching, hunting and gathering, gardening, sharing, humour) and collective (women's and men's groups, events), and transmitted inter- and intra-generationally within and across cultural groups.

Wellbeing

It is apparent from the discussions above that wellbeing is a key aspect of the lived experience of culture and is expressed in a variety of ways. One of the participants in the Cairns focus group used the phrase 'cultural wellbeing' to describe what she thought was most important to her life, and what she tried to focus on with Indigenous clients from her work in aged care, disability, and mental health.

> And so for me, that cultural wellbeing the biggest, the most ultimate thing is being able to go home at some time — in some way, shape, or form — which is what we've actually done with our clients that nobody ever bothered to do. And the Government wouldn't fund it and things like that, but we found a way to do it. And the difference it's made in those people's lives is significant. It's just phenomenal. The difference once they've been able to go back to their Country, sit on that dirt, and be surrounded by the people they haven't seen for many years. And I think that's the biggest thing for me is that cultural wellbeing.

— Focus group participant, 4 May 2017, Cairns, QLD.

One of the Cairns focus group participants who had relocated to Canberra for work described their wellbeing as being intricately tied to the wellbeing of their family and their Christian beliefs, which facilitated their connection to culture.

> It is really… for me, having a belief is vitally important because having a belief is able to lift me up out of poverty and help me to grow and develop as a human being. Not only grow and develop myself but also to contribute back into society where people are struggling. That's why family wellbeing is important for me. Vitally important. […]
>
> I went a couple of months ago to APY [Aṉangu Pitjantjatjara Yankunytjatjara] lands around Mimili. And it was really strange cause I was probably five months away from home now, and I walked into the Church and I just felt this feeling of belonging. But they was speaking in language — the service — but I guess I could feel the presence and just the cultural sense that I belong here. It doesn't matter you don't speak the language, but we're one people. And I just broke down. I was emotional. Like, an emotional wreck. And just to know that when I — after the trip I come back to Canberra, I went straight to look for Church and just went there. And that's where I found my healing and for my family years and stuff, is just to go there. And so in a sense, that's what I value. Religion and identity, language, what we're just talking about — culture.
>
> — Focus group participant, 4 May 2017, Cairns, QLD.

These sentiments were echoed by another participant in the Cairns focus group, who spoke about how their Christianity had transformed into a closer connection with their Indigenous spirituality:

> I actually changed from 'I knew there was a God' and I had that there, but I actually left that there and I went to more of a spiritual world. And for me, that's stayed with me because I've had so much of that, and I thrive on knowing I'll just talk directly to my ancestors […]. So I find I have that stronger than the God and the Church but it doesn't mean I don't believe in that.
>
> — Focus group participant, 4 May 2017, Cairns, QLD.

It is interesting to note too that it was the researchers conducting the focus groups — Jan Chapman and Ray Lovett — who used the term 'wellbeing' the most during the discussions to explain what the survey was about, and what they wanted to hear from the participants. Outside of the focus groups, many of the CIs and other stakeholders I interviewed — particularly the Indigenous interviewees — spoke about the importance of wellbeing to them as well as for the survey (discussed further in Chapter 7). What seemed to dominate the focus group discussions around wellbeing was the importance of finding a balance or harmony with their culture and identity, which would enable their sense of loss to be healed and an inner strength to emerge from within (see Figure 27).

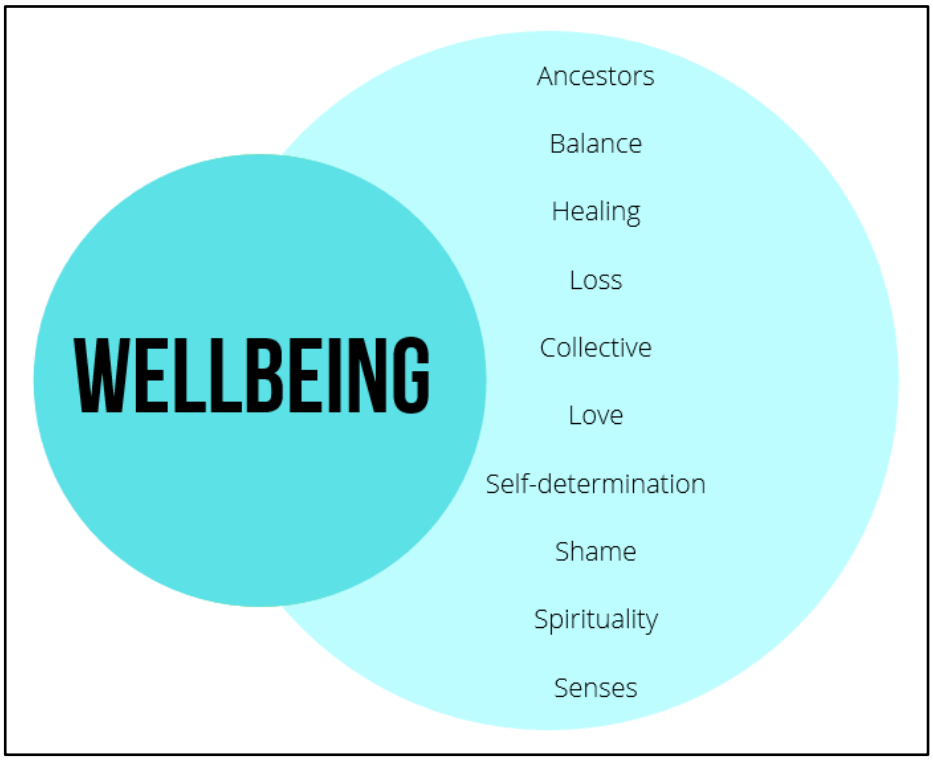


Figure 27. Wellbeing sub-themes from analysis of MK focus group data

6.3. Extrinsic influences

This section will provide a discussion and analysis of the extrinsic influences brought up by the focus group participants, which included both structural and socio-behavioural

elements. According to the focus groups, the presence of these extrinsic influences, which are both direct and indirect results of colonisation, function to disrupt and disturb the practice of Indigenous cultures today. Thus, this section begins with a brief overview of how the participants conceptualised colonisation and its impact on their communities.

Colonisation

The importance placed on the ongoing effects of colonisation by the focus group participants aligned with international research which argues that colonisation should be considered a direct determinant of health inequalities experienced by Indigenous peoples (Fayed et al., 2018, King et al., 2009, Reading and Wien, 2009: 22) (see Chapter 1 for a historical overview of colonisation in Australia). Colonisation was discussed by the participants in a variety of ways. This included descriptions of the repercussions of historical events, embodied experiences of physical or mental stress, accounts of disrupted identities and disconnection with culture, and contemporary relationships with Australian governments (Figure 28).

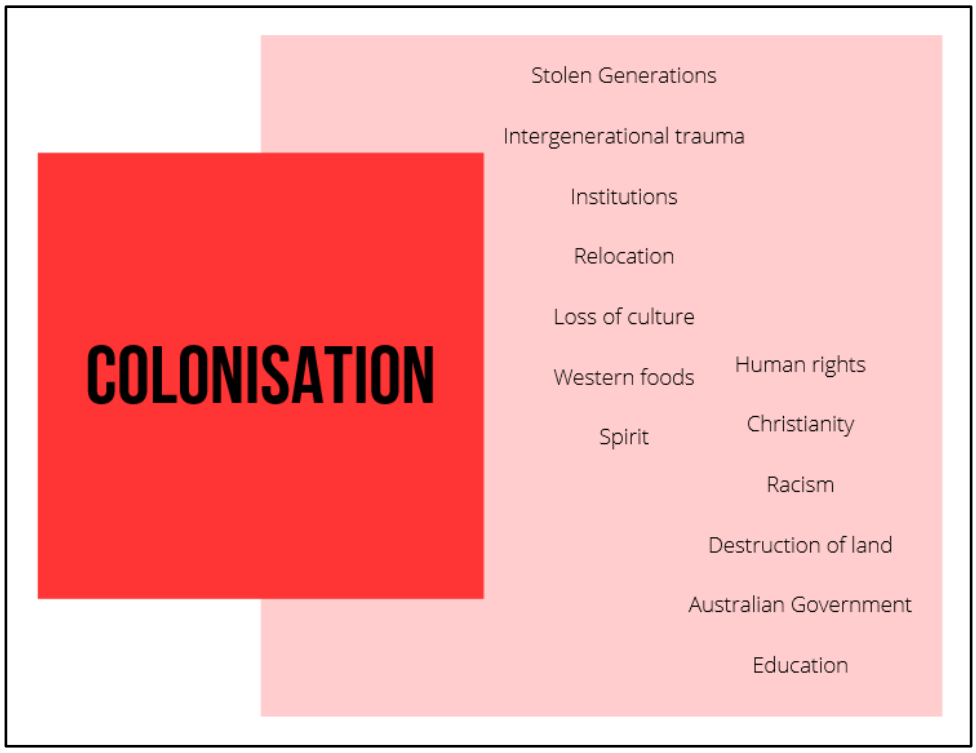


Figure 28. Colonisation sub-themes from analysis of MK focus group data

It was the accepted view that colonisation, while grounded in historical relationships between Indigenous and non-Indigenous people, was an ever-present reality which Indigenous people today were forced to deal with constantly in almost every sphere of their lives. Given that there is a lot that could be said about the Indigenous experience of colonisation in this section, I have chosen to concentrate on the two aspects of it which were discussed most often by the participants.

Historical events such as the forced relocation of cultural groups away from their traditional homelands and onto stations and missions, in addition to the Stolen Generations, had a significant and universally negative impact on connection to culture and identity for almost all Indigenous peoples. The intergenerational trauma resulting from these events was seen by focus group participants to be the primary cause of the social dysfunction experienced by Indigenous families and communities today. Further, the participants said that the Australian Government was now implementing child protection

policies which reinforced this trauma, effectively creating new Stolen Generations by removing children from their parents and communities and putting them into foster homes (for similar perspectives, see Douglas and Walsh, 2013, Fernandes, 2018, Funston and Herring, 2016).

> RL: So with the people not knowing even who their mob are and all that sort of stuff, is the Stolen Generation a big thing over here or around this area? Was it… does that play into that some of that sort of stuff as well?
>
> Participant: Oh yeah. Yeah, there's still — like I was saying — it's not generational resentment or that. It's just that how do you find your niche in life if you don't know where you've come from because if they've taken you from up north and brought you down to the south, I mean… and then you've gone on to marry a Noongar woman from here and she's got cultural ties to the Country. But where are you?
>
> And a lot of them never, ever got over that, where they actually fit in life. Some of them tried to go back and see who… but by then, mothers and fathers had passed or there was only Uncles and Aunties to try and bring them up to speed with what happened after they were taken. So there's still generational hurt there for a lot of people around, I suppose… like my Dad's age, [name]'s age. And we've heard stories of it. My grandmother had some of her children taken off her and put into missions and that because they thought that she couldn't look after them. And they come out not the same, you know? Yeah.
>
> But that was quite a hurtful, because then once you're dysfunctional that kind of carries down in the generations. They never are able to kind of get back into society and adapt. So yeah, that's an ongoing thing. It's like a merry-go-round process unfortunately, for some families that has had this happen to them. It goes right down. And it's still right here right now because of their parents covering up their hurt with alcohol. So their parents done it and now their children have done it and it's got right to the grandkids now. So that's really sad. […] So it's alive and well.
>
> But it's happening again now with the generations now. It's not alcohol. It's the drugs. The little kids are getting taken away from their parents. They're put into

> foster homes and things like that. And it's not good for them to be taken away from their parents. They should all go away, as a family, to a dry-out retreat and let them get the help that they need. There has to be another way.
>
> — Focus group participant with Ray Lovett, 26 April 2017, Bunbury, WA.

The power imbalance between Indigenous people and the Australian Government today is a clear continuation of the colonial relationships of the past. Rather than the explicitly racist and assimilationist policies practised before, what defines the dynamic now is the implicit, structural discrimination and violence perpetrated by the Government under the guise of working in the best interests of Indigenous peoples. One of the participants in the Ulladulla focus group described this dynamic from their perspective as a member of the local Aboriginal land council:

> Participant 1: There's a bloke in Central Coast, [name]. […] He writes about passive discrimination. And it is happening constantly. They're making decisions that are effecting us severely, which affects us economically, socially, culturally, the whole lot. But they have *their* law behind it to say that we can make that decision because our law says that. […] So that gives you — it makes it hard for you in my job to keep going because you're constantly getting kicked in the guts. You talk about mental health problems and pressure and stuff like that, and you go home, and you want to leave it at the door, but it doesn't. It comes with you because you've got a community that you're trying to help.
>
> — Focus group participant, 19 February 2017, Ulladulla, NSW.

These participants gave an example about how Fisheries NSW, a subsidiary of the NSW Department of Primary Industries, would not allow Aboriginal people to access some local lakes and beaches for cultural activities like fishing and cooking because they were classified as protected areas.

> Participant 1: We — us three — had a meeting with Fisheries, and we had a big discussion on traditional things that we used to do when we were kids. When we

were kids, you know? Around the lakes or around The Rocks area. You'd light a fire and cook some of the shellfish […]. You can't do that today.

Participant 2: Yeah, it's crap.

Participant 1: This is what we told the Fisheries, didn't we? We said 'We can't go around the lake down there and light a fire and go and collect these bimbillas [a type of shellfish] and make a damper there in the fire. We'd get into trouble.' But this is where… in a case of where a lot of the culture gets stopped because we can't do the traditional things. We can't just go and gather pipis and bring pipis home and have a feed. […] And in my day as a kid we could go and get some pipis and make a fire on the beach and cook them there and then and have a feed on the spot. You can't do that. You can't even take them off the beach and bring them home.

Participant 3: On that note, we're planning a NAIDOC day in Ulladulla, and we want to do the traditional food. As Uncle [name] was saying, they just wanted the beach. We have actually had to apply to the Fish — I think it's the Fishery Department or whoever — to take these for a celebratory reason. And we have to give a time and we have to actually have the names of the people who will be diving for seafood.

Participant 2: […] Our culture has been suppressed through Government policies. […] The more time goes on, the more policies that are implemented to prevent us from celebrating our own cultures.

— Focus group participants, 19 February 2017, Ulladulla, NSW.

The above quotations are representative of how the focus group participants described their experiences of colonisation, and the fundamental impact it had on all aspects of culture, their health, and their wellbeing. One of the Cairns participants described it as a 'wounding of the spirit' which many Indigenous people carry with them throughout their lives (Chapter 4). It is the sad reality that the key intrinsic aspects of culture discussed above must often be contextualised by the experience of colonisation.

Health conditions and behaviours

It is well-known and documented statistically that Indigenous Australians experience illness and disease in greater numbers and at higher severity than the rest of the population in Australia. Current statistics indicate that chronic diseases contribute to 64% of total disease burden, and 70% of the health gap between Indigenous and non-Indigenous Australians (AIHW, 2016: viii). Participants from the Ranger focus group emphasised that the burden of physical conditions can lead to social and mental health issues, which in turn lead to negative health behaviours. In these situations it is often family members who play a key role in caring for their relations:

> Participant 1: I've got a couple in my group now that have had heart problems. That have been sent away to be dealt with, like, seriously — from surgeons. And they were right on the point of losing their job, because of their health and so I just jumped in between, I said, 'No'. I said, 'This is physical — we've got to now think about the mental now. If this person loses his job right here, today, because others think he can't do it — what's it going to do to his brain now? He going straight to the Bottle-O [liquor store], or something, you know?' And that thing is just… there's just going to be nothing positive and it's just going to wear that person down and…
>
> Participant 2: Bring out the anger and whatnot.
>
> Participant 1: And yeah, it takes a whole different, ugly turn you know? But then, when there are people that can stand in, step up and stick up for people in that situation… it's… you can see their own drive starting to come back. […]
>
> Participant 2: You're not looking after yourself, you're looking after all your family members.
>
> — Focus group participants, 7 February 2017, Alice Springs, NT.

Several focus groups emphasised the overabundance of poor-quality food in communities and how this further contributed to the chronic disease burden.

> Participant 1: Have you ever seen that doco, the Sugar? It's called the Sugar Story. They play on the lands, they done the Sugar Story. John Tregenza ran it.
>
> JC: Oh, yeah. […]
>
> Participant 1: And that's where they first got all their [film] shots. They had all coats, all right, all the sweet stuff.
>
> Participant 2: No good, no healthy food.
>
> Participant 1: And then they noticed that people were getting bigger and bigger.
>
> Participant 2: Fatten us, all the meat, and all that fat and all that rubbish cooking in same oil. Hot chips and all like that. Yeah. They don't clean up thing when they've… Not fresh enough you know. Yeah, they just put it in the same place, the same oil.
>
> Participant 1 and 2: Take away. Fats, yeah.
>
> JC: So it's making a lot of people… are sick?
>
> Participant 3: [It's] Rubbish.
>
> — Focus group participants with Jan Chapman, 26 May 2017, Canberra, ACT.

The participants above refer to *That Sugar Film* (Gameau, 2015), which became Australia's highest earning cinema documentary, raising awareness about the impact of excessive sugar consumption on health (That Sugar Movement, 2020). A major concern for participants in the Thursday Island and Cairns groups was that the consumption of unhealthy foods was becoming tied to culture in the Torres Straits. Kentucky Fried Chicken (KFC), among other fast foods can be purchased in Cairns or Brisbane before

people catch their flight to Horn Island. Family members will often request that their relations and friends bring them these foods when travelling.

> Participant 1: That's the modern day *bala* [brother]. I'll give you an esky of fish, you bring back KFC. […]
>
> *LAUGHTER*
>
> Participant 2: It is very funny. Oh my gosh. But travelling from here to the mainland, I think one of the funniest things… coming — when you come back up and you see all the stripy bags on the plane. Class it as 'Torres Strait Islander's suitcases'.
>
> *LAUGHTER*
>
> Participant 3: KFC and Hungry Jacks. Sushi.
>
> Participant 2: And the stripy bags.
>
> — Focus group participants, 6 May 2017, Thursday Island, QLD.

> Participant 1: Someone who set up KFC in the Torres Strait will make a mint.
>
> Participant 2: Oh, they did do that fried chicken up there. Island chicken. Island Rooster. I don't think it hit the mark though, because they were still taking up KFC. […]
>
> Participant 3: Cultural thing.
>
> Participant 2: It's become cultural.
>
> Participant 1: Hopefully it won't be.
>
> — Focus group participants, 4 May 2017, Cairns, QLD.

Health conditions can also force people living in remote or regional areas to move away from Country for acute and long-term medical treatment in cities.

> JC: So most people in your community don't leave the Country? They live their whole life in the Country.
>
> Participant 1: Hmm, people go to boarding school. […] Some will move to Adelaide for medical reasons. Kidney dialysis, things like that.
>
> JC: But in this room of seven visitors, four have diabetes. So is that how much it's prevalent in your community?
>
> Participant 1: That's why I'm living in Adelaide.
>
> Participant 2: Yeah.
>
> JC: Right. So most people have diabetes? Heart problems?
>
> Participant 2: Heart problems.
>
> Participant 1 and 2: Kidneys. […]
>
> Participant 1: And cancers never used to happen before and now there seems to be a lot of Anangu people with cancer.
>
> Participant 3: Blood cancer, you know. Lupus and all that there, yeah. Lupus. […] In my joints, all over.
>
> — Focus group participants with Jan Chapman, 26 May 2017, Canberra, ACT.

The health-care experiences of many of the participants were intricately tied to government funding structures. They often felt the effects of funding cuts and de-prioritisation of Indigenous-centred care by bureaucrats far removed from their communities. Some of the participants in the Ulladulla focus group spoke about how identifying as Aboriginal when accessing mainstream health care meant that they were told

that they had to travel to the hospital in Nowra for care because that was the only designated Aboriginal primary care facility on the south coast of NSW.

> Participant 1: We don't have any services in Ulladulla for Aboriginal people. Our closest one is the AMS [Aboriginal Medical Service] in Nowra. […] To get our people to specialist appointments, we have to physically take them to Nowra or Wollongong or wherever they be. We don't have any specialist Aboriginal services in Ulladulla and closing the gap is not widely known. One of our goals actually is to purchase a bus so we can load it up and take people up to appointments and all that, but [name] contacted AMS many years ago about the dental appointments and what — Friday afternoon or something?
>
> Participant 2: Yeah.
>
> Participant 3: They wouldn't do it, would they?
>
> Participant 2: They would give us half a day as long as it was Friday afternoon. Can you believe that? […]
>
> Participant 1: Yeah, because I've heard horror stories of people like — I think one of these was your stories about having an abscess and being in pain and ringing up in say, November. And they're 'OK, we'll fit you in in March'.
>
> Participant 3: Yeah, you make an appointment. Yeah. 8 months later, you might get in. That's shit. […]
>
> Participant 2: And they've cut the maternity services for the whole population. And the one that they came out with, which was the best one… if you're little — a woman — and you're about to have a baby, you've got to go to Nowra. 'If you're Aboriginal you've got to go to Nowra'. If it's your first baby, you've got to go to Nowra. If it's your fourth baby you've got to go to Nowra. […] because [name] in there, turned up at Milton Hospital and he had to fill out this form and they went 'Oh you're Aboriginal. She's got to go to Nowra.' And she's — he had to drive her in his own car to Nowra Hospital.
>
> — Focus group participants, 19 February 2017, Ulladulla, NSW.

Where longer-term treatment is needed, individuals may need to be away from their Country for long periods of time. One of the participants from the Bunbury focus groups spoke about how he would drive his sick father to visit Country to help him maintain his connection:

> I think something a bit personal that's going on within my own family — my Dad's currently going through dialysis and is learning self-dialysis in Perth so he's away from my Mum and other family. And what he's finding is helping a lot is I bring him down here on weekends. And him and his older brother go for drives through to Brookton or Pingelly over other weekends when I don't get him. And it's good for him to go back to where he grew up and what he knew and they can share stories together and I guess, trigger things that they may have forgotten over the years, as well. I think that's helping a lot with his health and his mental health […]. Dialysis is quite a big step to be taking, so yeah.
>
> — Focus group participant, 26 April 2017, Bunbury, WA.

The role of family members in supporting each other's connection to Country is evident. Thus, we are able to interpret health conditions and behaviours not only in terms of their physical, mental, or cultural dimensions, but also with regard to their social dimensions. Again, the ethnographic data emphasises the interconnectivity of Indigenous experiences, which has important implications for the measurement of health and wellbeing by MK (discussed further in section 6.4) (see Figure 29 for *Health conditions and behaviours* sub-themes).

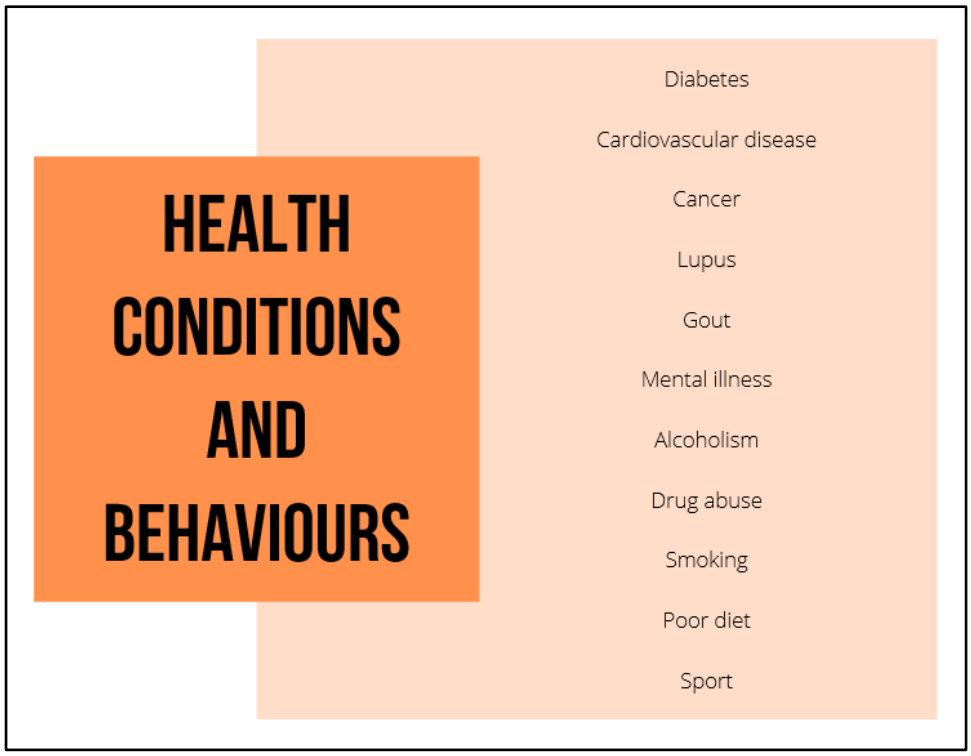


Figure 29. Health conditions and behaviours sub-themes from analysis of MK focus group data

The excerpts above also demonstrate that having to travel to receive health care is a significant logistical burden, which also functions to separate Indigenous people from their Country and families for the duration of their treatment. The negative impact that being away from Country has on many aspects of an Indigenous person's wellbeing has already been discussed above. But what is yet to be considered is whether these factors represent the Indigenous embodiment of structural violence through the mechanism of bureaucracy.

Structural violence was defined by American medical anthropologist Paul Farmer (2004: 307) as 'violence exerted systematically — that is, indirectly — by everyone who belongs to a certain social order'. Farmer (2004) argued that structural violence is a process which includes the erasure of historical context and the naturalisation of economic hierarchies and inequalities which have a direct impact on the health of individuals and groups. Structural violence operates through systems of power and functions to deny the needs of individuals. A major finding of my Master's thesis was that Indigenous obesity constituted

the embodiment of inequality and structural violence (see Bourke, 2015). Here we can see that, yet again, Australian bureaucracies harm Indigenous bodies even as they seek to help them.

Social dysfunction

Within many of the themes above, young people losing touch with their identities and culture was spoken about frequently by the focus groups. This cultural disconnection was seen to be the root cause of disrespectful behaviours towards their parents and elders in addition to negative coping strategies such as smoking, drinking alcohol and drug abuse. The participants said that families moving away from Country to live in the city compounded these issues further, along with disrupting the intergenerational transmission of cultural knowledge, including social protocols.

> Participant 1: I think a lot of kids… they become urbanised.
>
> RL: So you think that impacts negatively on culture?
>
> Participant 1: Oh, it impacts greatly. I was just saying to these fellows here about some of our people are going to the Perth area. From Country, you know. Get out of it. A lot of them are dying young. Different if you've been born there in those areas sort of thing, but if you come from Country like… A lot of those people have gotten sick and end up dying there. A lot of people die and buried in those areas and they shouldn't be.
>
> Participant 2: Yeah, move out and never go back home some of them.
>
> Participant 1: They don't take them home […]. The difference between Country and city life is that there's that big disconnection with culture. I think with AMSs and other Aboriginal organisations in Country areas and rural areas, we try as much as we can to get the young ones involved with learning about culture and respecting those boundaries. But most importantly, supporting and looking after our elders. Whether it be something as little as getting up and making a cup of tea

> for our elders, so they don't have to. They've done their dues and so they're looking after them. Whereas you go to the city… what I find nowadays that that respect's not there. That connection to culture's not there. They don't… a lot of them don't know who they are, where they belong, or where they come from.
>
> Participant 2: That's right, yep.
>
> Participant 1: And that comes in tail with not respecting their elders and getting up so they can sit down and not having them standing around sort of thing. And I think there's a huge difference between country life and that city [up]bringing, that there's that big massive disconnection in culture whether it be language, respect, and knowing where you belong and where you fit in the order of things. Especially knowing your family — family groups. You can, in the city, walk past someone and not even realise that you're related. Whereas in country life, you know… my parents, grandparents made a point of saying 'This is your Nan. That's your Pop. These are your Aunties. These are your Uncles'. And you showed your respect in certain ways and what not. There's a huge difference, I think.
>
> Participant 3: That's true.
>
> Participant 2: I think you get pulled up, if someone walked past you and you show disrespect. If one of mine walk past me I'll say 'Hey, come on.'
>
> Participant 3: But sometimes it's not their fault because when they've moved to the city. They've moved there just like… as young parents. And they go on to have a brood of six children and when their parents aren't there to explain the connection, they will walk straight past you. And you'll walk straight past them. It's so hard.
>
> — Focus group participants with Ray Lovett, 26 April 2017, Bunbury, WA.

Other dysfunctional social behaviours such as domestic violence and sexual abuse, and people going to jail were also said to be the result of cultural disconnection (see Figure 30). Because individuals no longer had important roles to play within cultural and community life they felt a profound sense of loss and lack of control or purpose in their lives. Elders

were seen by all the focus groups as occupying a pivotal place in passing culture on to younger generations. However, even elders were seen to be neglecting their responsibilities at times:

> TI is a disconnected community when it comes to our Torres Strait Islander people and children and family units. I think it's a lot more disconnected. And so out there at the islands, you know, the families still have a very strong connection to culture and being able to hand down the cultural knowledge. But TI is losing that because of… well, how many pubs have we got on this island? And those sorts of things… pokies [electronic gambling machines]… drawing our elder people — Aunties, Uncles, mothers, fathers — away from a family unit and not being able to concentrate a lot on passing over the culture. Because culture doesn't… it shouldn't have to be relied to be taught in the school. As part of our… who we are. It's from Aunties, you know. Uncles. That's where it's all passed down from. […] But TI itself, I think, is a community that really needs to work on how we improve.
>
> — Focus group participant, 6 May 2017, Thursday Island, QLD.

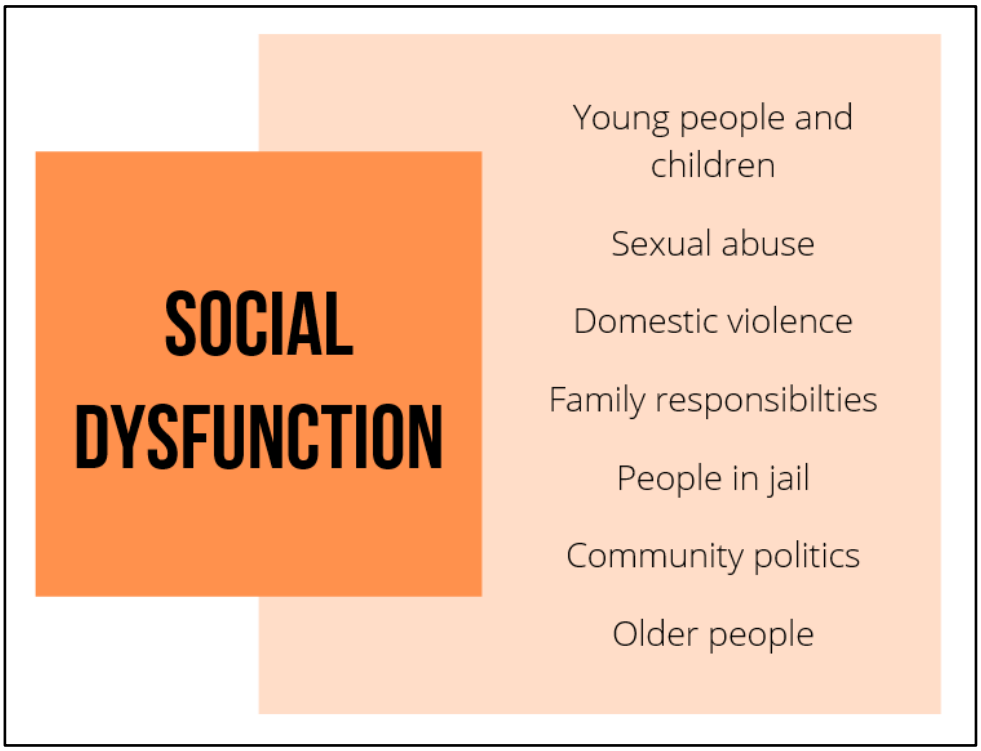


Figure 30. Social dysfunction sub-themes from analysis of MK focus group data

6.4. Key findings

It is evident from the above analysis that key intrinsic aspects of Indigenous Australian cultures such as identity, Country, language, Lore/Law and protocols, cultural activities, and concepts of wellbeing, are positively associated with physical, mental and social health, and reduced risk-taking behaviours. This is supported by findings from the international literature about Indigenous cultures in Australia, New Zealand, Canada, and the United States (see reviews by Bourke and Wright et al., 2018, and Salmon et al., 2018). However, the balance of these intrinsic cultural elements is heavily influenced by extrinsic elements which are both structural (e.g. colonisation) and socio-behavioural (e.g. health conditions, health behaviours, and social dysfunction). Figure 31 depicts these intrinsic and extrinsic elements.

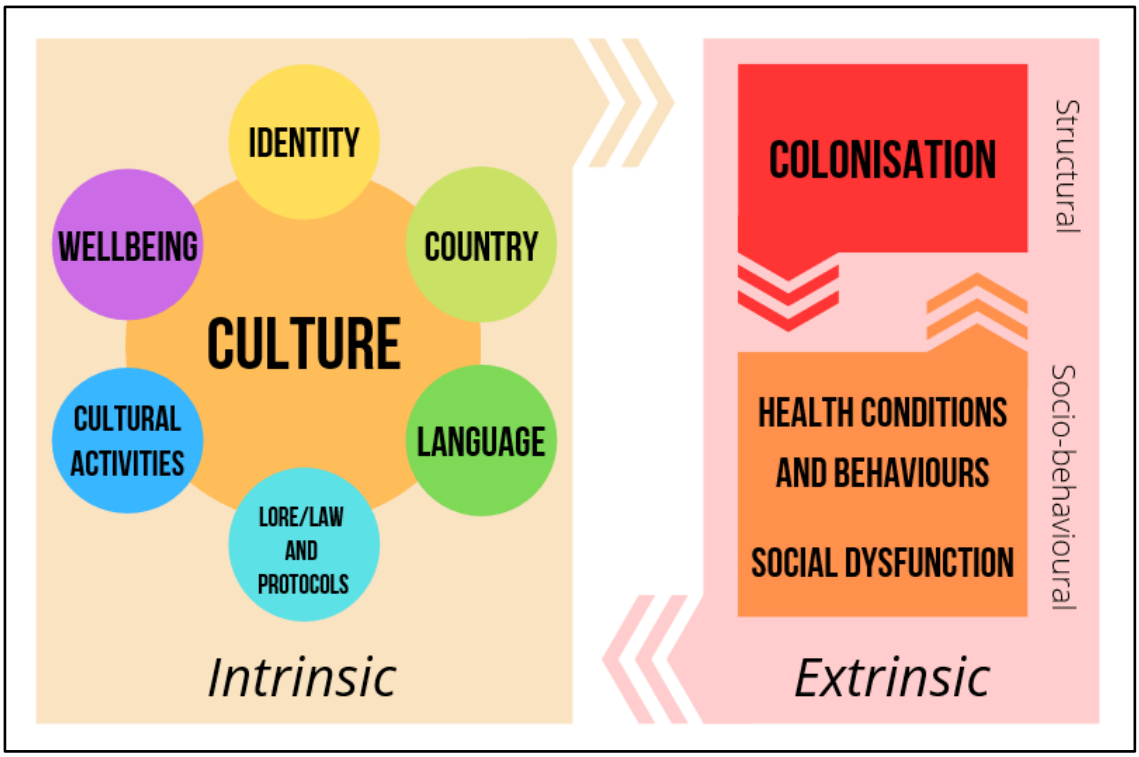


Figure 31. Key themes from analysis of the MK focus group data

The themes on the left of the diagramme are those key aspects of culture which the focus group participants described as being the most important. When they spoke about positive, holistic wellbeing, this suggested that a balance had been found across these cultural elements. This existed alongside family wellbeing and the maintenance of physical, emotional, and spiritual connections to Country. When the practice of intrinsic cultural elements was disrupted, feelings of loss, fear, and disconnection were the result. However, the participants also expressed a sense of hope and enthusiasm for cultural revival that was taking place in various forms.

The primary goal of MK's survey was to fill a void in the existing literature about Indigenous health and wellbeing. The results of the above analysis speak to the nature of both MK and the Indigenous lived experience in Australia, emphasising the importance of feeling connected to culture for wellbeing. The key cultural elements identified by MK's initial literature review (Salmon et al., 2018), those addressed by the survey (Jones et al., 2018b: 5), and those identified by the qualitative focus group analysis presented here (Figure 31) were very closely aligned (see Table 2 below).

Literature review (Salmon et al., 2018)	Themes from cultural practice and expression domain of the MK survey (Jones et al., 2018b: 5)	Key elements of Indigenous Australian cultures (Figure 31)
Connection to Country	Country and connection to Country	Country
Beliefs and knowledge	Indigenous beliefs and knowledge	Lore and protocols
Language	Language	Language
Family, kinship and community	Family, kinship and community	Identity
Cultural expression and continuity (including identity)	Cultural expression; Identity	Cultural activities
Self-determination and leadership	Self-determination and leadership	-
-	-	Wellbeing

Table 2. Key cultural elements for Indigenous Australians

There are only two differences between MK's cultural domains and those I identified from the focus groups. The first is the absence of detailed discussions about self-determination and leadership within the focus groups. Of all the focus group data I analysed 'self-determination' only appeared once (national Indigenous health conference table 7) and 'leader' or 'leadership' was mentioned twice in the Thursday Island focus group: once as 'genetic leadership' in reference to a father and daughter in the group who were leaders in the Thursday Island community, and once by the daughter describing herself as 'a young leader'.

I do not believe that this is due to an absence of a desire for self-determination or leadership within the communities the focus group participants came from — quite the opposite. Instead, I believe it was because discussing self-determination and leadership for Indigenous peoples can sometimes bring up negative experiences. In the Risdon Cove focus group, participants described protecting their culture as a 'constant battle' with non-Indigenous organisations and the Tasmanian Government, which had negative impact on

individual and community health and wellbeing (Chapter 4). In the Ulladulla focus group, participants spoke about how their ability to practice culture was limited because Fisheries NSW would not allow them to access some local lakes and beaches for cultural activities, like fishing and cooking, because they were classified as protected areas (see above).

The second difference is the inclusion of wellbeing in my analysis as a key element of culture, and not just as an outcome as identified by the MK researchers. It was evident that wellbeing and concerns about it underpinned other dimensions of culture. Knowing one's identity through family connections and connection to Country was seen to be the key to having a holistic sense of self and wellbeing for the focus group participants. One of the Cowra participants described the positive feelings they had when they heard people speaking and singing Wiradjuri. Some of the Cairns participants saw Indigenous cultural festivals as a place where wellness and wellbeing were celebrated and supported.

Wellbeing was mentioned frequently enough to be considered as an element of culture on its own. While this may have been due to the participants having been primed by the researchers to focus on wellbeing, the importance of finding balance or harmony discussed by the focus groups is reminiscent of the whole of life view of Indigenous health (NACCHO, 2011: 5-6, Salmon et al., 2018, Swan and Raphael, 1995). The wellbeing of Indigenous peoples has been described as a holistic combination and balance of physical, mental, spiritual, and cultural aspects of self in the context of environmental, political, social, and economic factors which influence wellbeing (Swan and Raphael, 1995, Colquhoun and Dockery, 2012). During one of the focus groups, two of the participants tied together wellbeing, culture, and the body, and suggested that the way forward for healthcare was to address cultural needs alongside those of the body:

> Participant 1: Without culture they'd be lost souls, all right. People would be very lost. There'd be a lot of small sickness wouldn't there.

> Participant 2: And I think the big picture about this one, that if our culture was ministered with my body, that's the right way to do that, you know.
>
> — Focus group participants, 25 May 2017, Canberra, ACT.

I would describe this viewpoint as an Indigenous philosophy of wellbeing, which is a common theme in the Indigenous health literature internationally. While this is an under-developed area of research in Australia, studies from Canada, the United States, and New Zealand, have begun to cultivate the subject. The Medicine Wheel, or Sacred Hoop, has been used across Canada and the United States to describe Indigenous philosophies of wellbeing for generations. As an example, the Anishinabek (Ojibway) term *mno bmaadis* encompasses the idea of 'living the good life' through achieving balance between the four directions — *Giiwednong* (North), *Waabnong* (East), *Zhaawnong* (South), and *Epngishmok* (West) — of the Medicine Wheel, representing the physical, emotional, mental, and spiritual elements of life (Wilson, 2003: 87). Māori in New Zealand also have a holistic philosophy of health where 'good health is seen as a balance between mental (*hinengaro*), physical (*tinana*), family/social (*whänau*), and spiritual (*wairua*) dimensions' (Durie, 2004: 1141, see also Durie, 1985).

The extrinsic elements presented on the right-hand side of Figure 31 are those influences which were identified by focus group participants as having a large impact on their culture and wellbeing. Colonisation was framed by the participants as the most important determinant of both individual and community health and wellbeing, and the other extrinsic factors were often described within this context. While all of the recorded focus groups discussed the negative impact of colonisation and other external factors on culture and wellbeing, none of the written feedback from the Perth focus groups included these factors. Given the specific, positive context in which the Perth sessions were conducted (detailed in Chapter 4), I interpret this as confirmation of the strong distinction in the

minds of Indigenous peoples between the intrinsic elements of culture and extrinsic influences which have an impact on the lived experience of culture, but are not part of it.

A surprising finding from my analyses of the focus group data was that anthropological vernacular such as 'kinship' and 'totem' were embedded in the participants' descriptions of these intimate connections. This seemed to me to be a result of the long established ties between anthropology and Indigenous Australians, most notably through that pillar of the anthropological canon, *Les structures élémentaires de la parenté* or *The elementary structures of kinship* by French social anthropologist Claude Lévi-Strauss (Lévi-Strauss, 1969). Perhaps like the use of the word 'tribe' discussed in Chapter 2, this represents a reclaiming of terms which have in past been used to Other Indigenous peoples (for a comprehensive overview and critique of anthropology's use of kinship, see Wilson, 2016).

Building on the ethnographic data presented above, the remainder of this chapter examines whether or not the questions included in the survey provide a fair representation of the focus group discussions about culture, and how this feedback influenced the researchers' decisions about what questions to include in or to exclude from the survey.

6.5. Comparative analysis with the baseline survey

From the beginning, the MK researchers have stated that the primary purpose of conducting the focus groups was to gather community-based perspectives about key elements of Indigenous cultures to incorporate in their survey. Therefore, one would expect that the questions included in the survey would be based on these focus group discussions. However, during my time in Australia observing the researchers refining the survey in their team meetings, I found that the perspectives of the researchers themselves

— in addition to the external feedback sought from the MK stakeholders — seemed to shape the structure of the survey more than the feedback gathered from the focus groups.

This section seeks to understand the ways in which either the focus groups or the researchers themselves determined what areas of Indigenous culture and wellbeing were included, or excluded, from the survey. An explanation of the methodology behind the survey question development has already been addressed in Chapters 2 and 5. The discussion here provides a critical analysis of the themes which the survey addresses in comparison with the themes arising from the focus group discussions presented above. Based on the six domains identified in their research protocol (Jones et al., 2018b: 5) (see Chapter 2), the questions in the baseline survey (Appendix 4) were grouped by the researchers into six sections:

- Identity, language, culture, and community
- About you
- Health
- Alcohol, smoking, and gambling
- Your experiences
- Family support and connection

The analysis below focuses on each of these sections in turn to provide a theoretical map of the mediation which took place between the focus group and stakeholder feedback by the researchers during the survey refinement process.

Identity, language, culture, and community (Q1–Q27)

This topic provides the first impression of the survey for participants. It has been carefully crafted by the researchers to give participants the sense that this survey is a way for them to express their Indigenous identities and perspectives. From my perspective, the *Identity,*

language, culture, and community section directly addresses the main goals of MK. Most of the questions included here have never been asked before in large-scale research in Australia, and this baseline survey will be the first time they are statistically validated. This section clearly touches upon all of the key aspects of culture identified by the focus groups (see Figure 31).

The sub-section *Language* reflects all of the feedback received from the focus groups, including how using languages makes respondents feel. The *Cultural knowledge and practice* sub-section also incorporates most of the cultural activities mentioned during the focus groups, with the exception of specific activities such as cooking traditional foods, storytelling, dancing, singing, women's and men's groups, gardening, and the use of humour. While storytelling, dancing, singing, and humour are aspects of certain responses to Q25 such as 'learning culture, kinship, and respect' or 'passing on cultural knowledge', among others, it is not stated explicitly. Certain aspects of Lore/Law and protocols are mentioned within particular questions (see Q12 and Q25), though they are not given their own section like the other intrinsic cultural factors. The aspects of identity which this section does not include are predominantly experiential, like the complexities of Indigenous identification highlighted during the focus groups. Further, the experience of being away from Country, as well as relationships to significant aspects of Country such as the environment, significant sites, and animals, have not been included.

The *Identity, language, culture, and community* section is a key example of how the MK survey does not (and perhaps cannot) address the more qualitative and individualised aspects of culture. This is an easy criticism for an anthropologist to make and I know that this was a struggle for the research team from the beginning. The challenges the researchers faced in quantifying cultural determinants of Indigenous health and wellbeing was discussed in Chapter 5.

About you (Q28–Q46)

This section of the survey asks the questions which participants may be more familiar with from other national surveys like the Census or the NATSISS. It includes questions about socio-demographic factors such as gender, date of birth, housing situation and living arrangements, height, weight, relationship status, employment, education, if they have ever been to prison or youth detention, financial situation, and sexuality.

The inclusion and phrasing of a few of these questions have been carefully crafted by the researchers to incorporate Indigenous perspectives. For example, the questions asking about the participant's financial situation (Q43 and Q44) needed to be revised many times as some of the participants in the focus groups were uncomfortable with answering direct questions about their annual income when it was trialled in an early phase of the survey's development (R Lovett 2017, personal communication, 1 November). The questions included in this section speak to the researchers' desire to collect data on standard socio-demographic factors, including social determinants of health, instead of addressing the key cultural elements brought up during the focus groups.

Health (Q47–Q59)

The questions in this section are divided into four sub-sections: *General health*, *Medications and health conditions*, *Mobility*, and *Health care*. Again, many of these items would be familiar to participants who have taken part in health surveys before. Some of the metrics included in the *Health* segment are already widely used for Indigenous Australian population health studies, such as self-rated health (AIHW, 2017) (Q47) and self-reported life satisfaction (Manning et al., 2015) (Q48). Another commonly used measure of psychological stress, the Kessler-5 (Kessler et al., 2002), has also been incorporated into the survey (Q50), with the

addition of three responses about feeling happy, sad, or pain following advice from MK's external reviewers.

Feedback from the focus groups about specific health conditions they experienced is addressed in the *Medications and health conditions* sub-section (Q51–53). However, the lived experience of these conditions, including their impact on connection to Country and culture, are not addressed by the survey. Therefore, the question of how many people become disconnected from their Country because they are forced to leave for medical care and what impact this has on their wellbeing cannot be directly answered by the survey. This was despite the fact that this issue was discussed in several of the focus groups (see section 6.3).

In earlier drafts, the *Health* section of the survey also included a question asking how many hours of sleep per day the participant got on average. The body of evidence that sleep deprivation has a significant negative impact on health and wellbeing has substantially increased in the last decade (Medic et al., 2017), and the benefits of good sleep are now widely promoted across the public health sector in the UK (National Health Service, 2018) and Australia (Sleep Health Foundation, 2019). When I asked Ray why this question was removed he said that the research team and the expert reviewers had decided it was not important enough to include (R Lovett 2018, personal communication, 30 January). Another reason he gave was that it was removed as a participation trade-off, given the premium placed on space in the baseline survey.

Alcohol, smoking, and gambling (Q60–Q91)

The trade-off between including important questions and maximising participation was often challenged in the development of the *Alcohol, smoking, and gambling* section. As discussed in Chapter 5, the gambling questions have been significantly reduced over the

course of the survey's refinement following concerns from MK associates that including them would produce data which contributes to the deficit discourse. Nevertheless, the alcohol and smoking questions have remained fairly prominent and consistent throughout the survey's development.

Ray's desire to tell a more contextualised story about Indigenous alcohol use and smoking was evident when I first met him in 2014. When I was undertaking my DPhil research with the MK team, he told me that nobody knew (or cared) that Indigenous smoking rates were falling significantly, because the statistics were only measuring incidence and were presented within a deficit discourse (R Lovett 2017, personal communication, 1 November). Including questions in the MK survey about participant experiences of alcohol, smoking, and gambling, may serve to contextualise health narratives in this area (see Chapter 5.2 for further discussion about the gambling questions).

Other health behaviours brought up by the focus groups, such as drug abuse and poor diet, have not been included in the survey. In early drafts there was a section about drug use, but this was removed because many focus group participants did not answer it. The researchers were also concerned that it would deter further participation in the survey, given the sensitive nature of drug use in Australia legally and socially, particularly by Indigenous people.

Your experiences (Q92–Q102)

This section of the survey has been divided into four parts: *Programmes and services, Discrimination/racism in everyday life, Discrimination/racism in health care*, and *Worries in the family and community*. Each addresses different aspects of what it is like for the participants to live in their local community. One of the participants in the Ulladulla focus group shared his experiences of racism which began when he was a child, and how now as an adult, he was

triggered by watching a movie about the issues an African American character faced when he wanted to marry a White woman:

> Because… and coming from this area all my ancestors and that come from. My Mum was born here, [and] a couple of our uncles. The fact that they all knew Mum, so when we come back here to live again in '48, they knew exactly who we were. But we… the trouble was then it wasn't so much the [White] kids as what it was the parents. They were the ones that would call you nigger, boong, and coon. I used to work for a couple of old guys out the back out here during the school holidays, and coming home of a Friday, they'd say the same thing every time. 'So what are you young coons going to do over the weekend?' I used to hate that. And what can a 13-year-old boy going to do with two adult men? They'd probably kill ya.
>
> But just like watching a show. There was a show on TV last night. It was a movie… American movie with the American Negro with a White lady. He was going to marry her. And to listen and see that — it was making me sick. Because it brought back all those… It just brought everything back. I said 'Look, I can't watch this. This is making me sick because it's bringing everything back to me.' And this is what happens with a lot of people. They'll tell you you're not a proper black fellow, but it still won't stop them from calling you a nigger, boong, and coon.
>
> — Focus group participant, 19 February 2017, Ulladulla, NSW.

Various forms of social dysfunction were brought up during the focus group discussions. However the issue which was spoken about the most often — young people misbehaving — has not been included in the survey. The focus groups themselves were skewed towards older participants, and so young people misbehaving was seen to be a major issue from their perspective. Had more young people participated in the focus groups without deferring to their elders during the discussions, other issues may have been raised or become more prominent in the ethnographic record. As highlighted in Chapter 4, this was

something the researchers wished they could have facilitated but were prevented from doing so due to time and financial restrictions.

Family support and connection (Q103–Q110)

The final section of the survey addresses family relationships, support and caring, forced relocation of cultural groups (referred to as 'tribe' and 'mob' in the survey) onto missions, stations, and reserves, and questions regarding the Stolen Generations and related intergenerational trauma. The importance of family and family support was brought up in all of the focus groups conducted by the MK researchers. Having a section dedicated to understanding the different forms of support family can offer is a valuable representation of the focus group feedback.

The positive framing of these questions reflects the ways in which family were spoken of during the focus groups. It may also be a strategy used by the researchers to balance out the negative topics addressed before (discrimination, racism, and worries) and after (forced relocation and the Stolen Generations) the *Caring* sub-section. If the purpose of this survey is to examine the most important social and cultural determinants of health for Indigenous Australians, than the inclusion of negative experiences should not be avoided. Colonisation and its ongoing effects, as outlined above, have significantly affected the lives of Indigenous Australians and will continue to do so for future generations. By confronting these issues head-on in the survey, their impact may begin to be accounted for.

This chapter has provided an in-depth analysis of the focus group discussions and survey sections, highlighting the ways in which the survey has been designed to address key determinants of Indigenous health and wellbeing. MK's survey does reflect the key cultural themes which arose from the focus group discussions illustrated by Figure 31. However,

my analysis pinpointed the inability of the survey instrument to capture some details of the lived experience of culture, health, and wellbeing, brought up by the focus group participants. While the constraints of the survey instrument, the desire to maximise participation, and the need to meet a deadline for development have already been acknowledged, what has not been addressed before is whether the creation of operational definitions of culture necessitates the exclusion of the lived experience of cultural elements.

It has been argued in the cross-cultural research literature that culture 'resists operational definition, not because it is a particularly intractable area of human affairs, but because the idea is tied to a particular context' (Tayeb, 1994: 431). American anthropologist Edward Fischer (2007: 207) stated that in translating lived experiences into metrics, we lose important subjective aspects of wellbeing. However, by fulfilling its purpose as a national-level instrument, the survey removes the need to specify cultural contexts. The focus groups provided conceptual, intersubjective definitions of the most important cultural factors. It was then up to the researchers to create operational definitions of these cultural factors which could be measured by the questions or variables included within the survey.

A key finding from Chapters 3 and 5 was that the Indigeneity of some of the researchers became a research tool to mediate between Indigenous concepts of culture, health, and wellbeing, and MK's epidemiological applications. Here in Chapter 6, we can see this dynamic at work again. The Indigenous researchers worked to interpret the focus group feedback into the language of the survey. As the discussion above indicated, this interpretation was not always complete, but it was representative of the collective input of all MK's stakeholders.

The following chapter details what has been gained through operationalising culture. Chapter 7 explores the substantial advantages of creating such a survey, drawing on

interviews conducted with the MK researchers and other stakeholders. It emphasises their hopes for the future of the survey and the influence it may wield over the framing of Indigenous health and wellbeing in Australia and internationally.

Chapter 7 — Culture and Hope

The researchers were always looking to the future of what the Mayi Kuwayu Study could be. This is a future in which Indigenous people are able to understand the role of culture in their lives and communities, and — crucially — have the resources to act on this knowledge to improve wellbeing. This is a future in which healthcare providers support Indigenous cultural practices and incorporate them as a part of the treatment plan. This is a future in which Indigenous people are in control of the research process and are able to use its tools to answer their health questions. This is a future in which Indigenous people own their data and decide how it is used, and by whom. This is a future in which policymakers incorporate Indigenous people into their decision-making and governance processes. Finally, this is a future in which Indigenous people around the world work together to achieve self-determination and decolonise Indigenous health narratives on a global scale.

This future-thinking was embedded within the ethnographic field from the very first time I met Ray and the MK team. Entwined with a deep sense of hope, this future represented the aspirations of all stakeholders who became involved with MK over time. Ironically, these hopes were only expressed explicitly during our interviews. Early on in my fieldwork I asked Ray why he thought his staff and the other researchers had joined MK, and he replied he did not know because he had never asked them. Yet, I knew from my interviews that these individuals had joined the team because they had thought about the potential of MK to change the future of Indigenous health in Australia and they had wanted to be a part of it. Much of this hope also had to do with Ray as a leader. As discussed in Chapter 3, Ray's leadership of MK is what drew a number of people to join. They trusted in his

integrity and the integrity of MK. In an Indigenous space, we would call this *doing things a good way*.

Indian-American anthropologist Arjun Appadurai (2004) wrote about the 'capacity to aspire' as a cultural capacity which is interwoven with future-thinking, allowing us to navigate the social world. The capacity to aspire 'nurtures' the ability of communities to 'debate, contest, inquire, and participate critically' in the social world, and vice versa (Appadurai, 2004: 70). Reflecting on those living in poverty in India, he argued that by encouraging the capacity to aspire through action and activism, it is possible to empower communities and strengthen their political and social voice (Appadurai, 2004: 63-64). I argue here that the capacity to aspire is what led to the creation of MK, and that it forms a powerful framework for increasing this capacity within Indigenous communities. This capacity is already part of the Indigenous lived experience, as evidenced by the resilience and resistance of Indigenous peoples since colonisation (see Chapters 1, 4, and 6). The MK researchers, as the instruments of this capacity, have facilitated a collective voice through the survey which recognises the vital role Indigenous identities and cultures have in promoting wellbeing.

Across the field of Indigenous health research in Australia and internationally, experts have called for a shift in power relations which puts Indigenous people in control of the research agenda from start to finish (Fogarty et al., 2018b, Kukutai and Taylor, 2016, Kukutai and Walter, 2015, Lovett, 2016, Morphy, 2016, Walter, 2018). When this happens, culture becomes the central pillar in a strengths-based research agenda (Chapters 1, 4, and 6).

> Deep down I have a hope, but the data have to speak for themselves. And I have to allow that… not allow that but facilitate that. You know that deep down hope is just from our concept testing of the survey [and] shows there's probably

> something to this. But yeah, at the end of the day, I think I mentioned today, it would be great if we're able to produce the killer stat that says identity affirmation, or cultural… focusing on building identity and culture is as powerful in achieving health outcomes as education.
>
> — Interview with Ray Lovett, 6 May 2017, Thursday Island, QLD.

This chapter attempts to integrate findings from earlier chapters, including the creation of evidence through data for policy development (Chapter 3), the role of Indigeneity in validating MK's methods and results (Chapters 3 and 5), the power of these data to work against the deficit discourse (Chapter 3), and the positive impact of culture on health (Chapters 4 and 5). By taking account of the wider societal context in which MK situates itself, connections can be made between the micro-structure of the survey and the macro-structure of the Indigenous health narrative in Australia.

The discussion to follow explores the researchers' aspirations for the potential impact of MK at four levels: impact in Indigenous Australian communities, impact on the field of epidemiology and Indigenous health research in Australia, impact on Australian public health policy, and impact on indigenous health research internationally. Drawing from interviews with the MK researchers and stakeholders and some of the focus group discussions, this chapter demonstrates how MK may help to transform the broader Indigenous health narrative to address the holistic needs and interests of Indigenous Australians by increasing the collective capacity to aspire.

7.1. Promoting culture in Indigenous communities

One of the main goals for the MK researchers was to create a resource which Indigenous communities could access and use to improve health by promoting engagement with culture (Mayi Kuwayu Study, 2016: 4). As detailed in Chapter 3, findings from public

health and education literature have made the connection between greater enculturation and positive health and social outcomes for Indigenous peoples, suggesting that enculturation increases individual and community resilience (Bals et al., 2011, Currie et al., 2011, Whitbeck et al., 2004, Whitbeck et al., 2001, Yoder et al., 2006, Zimmerman et al., 1994). In one of our interviews, Ray spoke about how important it was that Indigenous participants and communities felt that MK was *for* them.

> SB: The next question I had was, what are your hopes for the survey?
>
> RL: I really hope that it's undertaken by lots of people. I hope lots of people come to value what it's meant to mean. Like, I know it will probably never have the same meaning that it has for me personally and professionally. But I hope that if lots of people do the survey, and then we're able to provide that information back to communities, back to individuals, that it's… first and foremost it picks up and captures those very things that we talk about concerning Aboriginal identity, Torres Strait Islander identity, and that it is seen as something that's positive and reinforcing. But also at the same time providing information to show what that relationship between that identity… that connection is to wellbeing. That would be the most important thing.
>
> And then… part of me thinks that it's only when we start showing people that stuff, that's when people go 'Aha!' I mean, some of the focus groups like today's one [Thursday Island] was a really good one where people naturally came to that conclusion. […] So getting that buy-in, because it has the same meaning to those people that it has to me. That's really good.
>
> — Interview with Ray Lovett, 6 May 2017, Thursday Island, QLD.

The major theme underlying this excerpt from our interview is the relationship between Indigeneity and wellbeing. Within the deficit discourse, Indigeneity has been framed as a 'problem' and one which could only be solved through Indigenous people conforming to non-Indigenous norms (Fogarty et al., 2018a: xi, Gooda, 2011, Walter, 2018: 258). From an Indigenous standpoint within a strengths-based framework, Indigeneity and Indigenous

cultures have a positive impact on wellbeing, and this is what MK was designed to measure (see Chapter 1). As Ray mentioned above, community buy-in is a crucial aspect in achieving this.

Several of the focus group participants spoke about MK's potential in response to my follow-up questions at the end of the main discussion. Members of the Thursday Island group recognised the importance of participating in MK's focus group for 'preserving' their identity and keeping culture 'alive':

> SB: I just wanted to ask you guys, why do you think other Aboriginal or Torres Strait Islander people would want to participate in the focus groups? So think about your own reasons for coming or why you think other people might come.
>
> Participant 1: I suppose it just starts off with a general question you asked on the first page [of the survey]: 'What cultural things are important to you?' And I suppose we all talk about the same things. Saving our language, our culture, our cultural practices, our songs, our dance, and our stories. That's why we're all sitting around this table because we still want to keep that alive and not let it die off. Plus, we've probably all been around tables like this and discuss it, because we want to keep that alive and make sure that it is still alive seven years from now, and not be a culture that has died because of the Westernised way of living.
>
> SB: So for you, contributing that to the survey is important?
>
> Participant 1: Oh, the questions basically come back to that first question. Yeah. Because if it's not for those main things, you know, we're not who we are. Because then all of that reflects your individual options out of it.
>
> Participant 2: Yeah. I think I feel that our culture is dying out. We are losing culture and anything that we can do to try and bring it back and push it again for us, especially for the next generation coming through so that it isn't fizzled out, is a big — yeah, big thing.
>
> Participant 3: Like some saying tradition, dance, language is another. Campfire yarn, sharing, elders, yarn and talk, family, preserving our identity so it doesn't die

> out, and sharing all the things. Answers today to keep things a better understanding from different groups and different community and collecting that info too.
>
> — Focus group participants with Sarah Bourke, 6 May 2017, Thursday Island, QLD.

Elsie Seriat, who facilitated the focus group session on Thursday Island, talked about how MK could identify the ways in which culture was already being practised in the Torres Straits, and the areas where it could be revived or reinforced by elders in the community.

> SB: How do you think your culture has influenced the way that you live a healthy life?
>
> ES: So looking back, especially on the ways of living, it's really important and it has to be taught because it's not taught in our community of how our grandfathers and grandmothers used to live. And I think it's important that we learn that because it's not happening. Colonisation and all that stuff come through and we all go to the shops to buy food and that stuff because it's there. But how did they do it before? Obviously from the gardens and fishing and hunting and all that stuff. And if we could go back, and not necessarily live like that, but just practice all that stuff it'll mean that we can live longer and have a better life. And so I guess the cultural practices is really important but it's sad that it's not happening.
>
> How do we bring it back? I think what the ANU guys and Ray is doing is really important because it helps us to see where the holes are — how do we close that gap and stuff. So it's really important that we continue to teach, otherwise if we don't, it dies. Sad to say but it will. We'll lose our identity if we don't practice, and with what this research is all about is just making us realise on where we can improve or continue to practice. […]
>
> I'm just so excited to see the end results of it all. And then, like, especially the follow-up in three years' time or whatever of where we're sitting and stuff and how things are going. But I guess it's just more having the people aware, you know. Because in the focus group you talk about a lot of stuff and stuff that we want to bring back or stuff that we haven't been practicing and stuff. And I just

> hope that it makes people realise what's happening. Because in our focus group on TI that's what I was observing around the room is, like, the difference between the young people and the old people. The old people know all this stuff, but how do we teach, you know? Because they kept on referring back to the schools. But no it's not the schools. It's the house. Before they walk out that door you need to educate your kids, or whatever, your family about the importance of our culture and our identity and the ways of living. It's not the schools fault. So just being aware of it all and what's happening — really, really important for us Indigenous mob.
>
> — Interview with Elsie Seriat, 17 May 2017, Canberra, ACT.

Writing about the North American context from a psychological perspective, Laurence Kirmayer, Joseph Gone, and Joshua Moses (2014: 305) suggested that the saliency of culture for Indigenous peoples today was a result of the 'explicit assault on their cultures, languages, and traditions' and that 'respecting, restoring, and revitalizing culture seems like a very specific remedy'. The intergenerational transfer of knowledge is the most important way in which culture is shared and practised for Indigenous Australians. Above, Elsie emphasised the importance of elders taking responsibility for passing on this knowledge to younger generations. Indigenous people cannot rely on the school system to transmit this knowledge, as only 1.2% of the teaching workforce in Australia is Indigenous (More Aboriginal and Torres Strait Islander Teachers Initiative, 2014: 14). During our interview, Elsie spoke about how just observing the focus group on Thursday Island allowed her to learn more about her own culture, and that this would be a positive outcome for MK if it could teach other young Indigenous people about their identity.

> I guess it's going to be really interesting. Especially from being… I don't know… being a part of the focus group on TI and having to listen to, obviously, the elders in the group speak about culture and identity. How it's… what did they do… just I guess in the focus group I also learnt new things that I didn't know about my culture, my identity, and the winds and all these stuff that was mentioned there. Like, I was amazed. And then I thought that I'm one of thousands of other young

> Indigenous Torres Strait Islanders out there that don't know their identity and where they come from. And especially like, being away from home now… class myself as a girl from Thursday Island but I'm not from there. I'm from somewhere outside in Torres Strait. So I guess, like, having to listen to the elders speak it's really important. And this research, I think, will measure it all and the change. It's scary but exciting.
>
> — Interview with Elsie Seriat, 17 May 2017, Canberra, ACT.

This was a sentiment which seemed to resonate with many of the Indigenous people involved in MK. While I was in Canberra and interviewing MK's professional staff, Ruth Gilbert, who is a woman from the Wiradjuri Nation and was MK's Communications Officer at the time of my fieldwork, thought MK would help Indigenous people talk about the value of their culture more.

> SB: What do you think the impact of the survey will be?
>
> RG: In the first instance it will get people thinking and talking more openly about culture and hopefully you know, maybe wanting to invest more into revitalising culture. And just practising it. That's what I'm hoping. Just thinking about 'Oh, what am I doing this weekend? Maybe I can do…' I know that positive things like this can have such a strong impact in our communities. A while back, we were making artefacts on the weekend and getting my kids to make them too. Clapsticks, spears, and *boondis* [a hunting/fighting weapon]. They loved it. And I put the photos on Facebook and the next minute other people are like 'Oh that's great. I'm going to do this with my kids too'. Those little positive ripples go out.
>
> But also I think as the MK research results come out, it's going to be able to show more widely what culture means to people. And just get people more broadly, valuing its importance. Particularly the valuing of our first languages… I'm really concerned about our languages. Because languages are so precious and it's really hard to rebuild a language. And so it'll hopefully get young people thinking about — particularly those who do have strong language speakers and have these skills in their community — don't miss the opportunity to learn your languages if you've got those strong old people around you. Take the opportunity with both hands and don't let it go. It's so easy to lose and so hard to get it back. So

> hopefully the study will also get people thinking and talking about culture, because it'll go out to a lot of people.
>
> — Interview with Ruth Gilbert, 16 November 2017, Canberra, ACT.

Ruth's discussion of the importance of language accentuates a tension within MK. All aspects of MK have been undertaken in English, and yet the survey measures the impact that language use has on wellbeing (addressed by Q19–24 and Q92 in the baseline survey). By conducting the focus groups in English, were the researchers acknowledging the influence it has on Indigenous lives (including their own), or reinforcing its dominance? It is beyond the scope of this thesis to answer this question, but is important to acknowledge, especially as it relates to my own practices undertaking this research.

Janet Smylie gave another perspective on the topic of the relationship between Indigeneity and wellbeing at the community level. Drawing from her experience as a Cree-Métis woman and medical doctor in Canada, Janet discussed the importance of MK for promoting culture. She argued that culture should be recognised as a fundamental aspect of health by non-Indigenous doctors working with Indigenous patients and communities.

> SB: Who do you think will use the survey data and what for?
>
> JS: […] my primary audience is always Indigenous community partners, and the community governing and organisational stakeholders. And part of the excitement at the community level is hopefully… an idea could be that it would be used by the local and regional community and organisation partners, and the national, to promote funding for services and programmes. Because it's actually for individuals and families and communities. Like direct. To strengthen culture in all the ways that are important that have been articulated. That would be good. […]
>
> And I guess the other big piece is external to Indigenous community [are the] people that we share lands with. So maybe it will help physicians realise — well-intentioned physicians — that maybe the solution isn't seven more prescriptions. Or maybe that is required, but at the same time there's also asking people and

> reconnecting people to knowledge and practice and time on land so that's part of the treatment plan.
>
> — Interview with Janet Smylie, 26 October 2017, Canberra, ACT.

The above statements clearly support the potential of MK and its results to either explicitly or implicitly support the importance and practice of culture within Indigenous Australian communities. The focus group participants were encouraged by the fact that MK focused on culture, and the vital role culture has for Indigenous identities and ways of experiencing the world. MK was seen as a way to preserve this role, if not in a practical sense, at least as an approach which emphasises the importance of engaging with culture into the future for communities. The following section will continue to examine MK's impact on the field of epidemiology and health research in Australia.

7.2. A new direction for epidemiology

This section explores how the Mayi Kuwayu Study represents a new direction for epidemiology that seeks to work against the prevailing deficit discourse of Indigenous health data (see Chapter 1). In one of our interviews Ray mentioned that when he was promoting MK to government health bodies, with largely non-Indigenous audience members, the comment he got most often from them was that Indigenous culture was intangible and could not be measured. Maggie Walter elaborated on this in our interview, when she described MK as countering 'the epistemology of ignorance' of non-Indigenous health researchers.

> MW: It'll always be a struggle to explain to non-Indigenous researchers what these things [aspects of culture] mean [to Indigenous people]. There is the epistemology of ignorance. So that's the sort of Mills racial contract stuff, where it works very well in non-Indigenous researchers' favour to stay ignorant. Because if they don't stay ignorant then they have to change what they do, and they have to question

> what they do. So it's very hard. And it's very hard for them to actually… and it's not saying that they're deliberately doing that — sometimes they are — but mostly what they lack is they lack any cognitive foundation on which these ideas can land. So there's cognitive infrastructure there that allows them to make sense of it. So it's always a struggle to get them to understand, because they think they've got it and then it's gone. […]
>
> It's not just about writing models. You've gotta be able to interpret them, and you've got to decide what's important to put in a model. And unless you've got that… you're in that conceptual space, then you're just as likely to make a mess of things. […] And I've seen some very bad papers [written by non-Indigenous researchers] with those sorts of things saying 'We found this…' and then they don't add any more. They just say, 'We found this…' And you say 'Great — you've got to be able to explain it'.
>
> — Interview with Maggie Walter, 5 March 2018, via Skype.

In quantifying the cultural determinants of health, MK thus establishes a precedent for epidemiological research with Indigenous peoples which challenges both socio-political and disciplinary norms (see Chapter 3 for a discussion of these norms in epidemiology). Mark Wenitong articulated MK's possible impact on the medical sciences based on his work with the NHMRC:

> SB: What do you think the wider impact of the survey might be?
>
> MW: Um, I think it's going to be really interesting because, well you know, I've sat on NHMRC principal committees for about four trienniums with all the other medical scientists. And it is a bit of a step up, I think, for medical science itself to start thinking a little bit differently around culture, spirituality, and things like that, as opposed to just biomedical and psych[ological] kind of stuff. So I think there's a little bit of a challenge there. But the good thing is that most researchers, academics, and scientists will believe evidence. And it's kinda hard to miss the significance of some of those graphs, you know, that came from the pilot — that really does look like a dose response there. So… and depending on how you present it, and who presents it.

> What we have in this research team is a group of highly respected Aboriginal and Torres Strait Islander medical scientists, who understand hard data, presenting this to the medical scientific community and policy makers. I guess as well… presenting it that way is a way that is contextualised to the audience — both Aboriginal and Torres Strait Islander and the science community — so that people can understand it in context.
>
> — Interview with Mark Wenitong, 25 January 2018, over the phone.

The pilot study results Mark is referring to above are from the *Connection to Country* project run in partnership with the MLLS and others. As detailed in Chapter 5, this pilot provided evidence that practicing connection to Country was associated with positive health and wellbeing outcomes (Lovett et al., 2017: 28). The CLC Rangers' project also demonstrated this relationship. Being a ranger was significantly associated with very high life satisfaction and high family wellbeing, and had a positive but non-significant association with 'very good' general health (Jones et al., 2018a).

As discussed in Chapter 1, data have the power to both define and influence the Indigenous health narrative in Australia. Having Indigenous people in control of the production of this evidence using the tools of epidemiology means that Indigenous definitions of health and wellbeing may be communicated to those who are unfamiliar (or incapable) of conceptualising them otherwise. Katie Thurber reinforced this point in our interview. She said that the creation of numbers which represent the importance of culture for Indigenous health will become a way in which MK is able to communicate this to non-Indigenous governance structures.

> SB: So what do you think the wider impact of the survey will be?
>
> KT: In terms of research it will be the first time that we can quantify in numbers the breadth and the variety of cultural engagement, practice, belief, identity — a whole range of cultural factors. These are things that haven't been quantified. And

> we do know that as much as we can tell things in story, Government often requires numbers. And so, we really envision the role of MK as being a way to provide numbers that match the stories that people are telling. So that when we go to Government, we've got a stronger argument in terms that resonate with them — a combination of stories and numbers.
>
> — Interview with Katie Thurber, 22 November 2017, Canberra, ACT.

MK's ability to represent lived experiences has already been critiqued in Chapter 6. Katie's assertion that the 'combination of stories and numbers' will present a stronger case to government decision-makers refers to the work of other stakeholders who may use the data from MK to reinforce existing qualitative evidence. There has been a recognised need for Indigenous researchers to be at the helm of Indigenous-related data collection for at least the last 15 years in Australia (see Walter, 2005). However, Indigenous-directed research is still a rarity, particularly when it comes to epidemiological studies. While there are no doubt many reasons for this, what became obvious through my research with MK is the resistance of power-wielding government structures in Australia to incorporating Indigenous perspectives into existing projects, and to fund large-scale longitudinal data collection outside of their control.

This speaks to the ongoing legacy of the colonial mind-set (Smith, 1999: 25) and echoes the era of protectionism described in Chapter 1. Even now, the Australian Government appears reluctant to relinquish control over Indigenous health policy development and funding to Indigenous-directed organisations. This is perhaps because doing so would support Indigenous claims to sovereignty, and thereby undermine the Government's control over Indigenous lives. In Chapter 3, both Ray and Maggie shared their experiences of working with Federal Government health agencies as Indigenous health experts. Even when they were 'given a seat at the table' their input on the design and questions included in ABS health surveys was often ignored by Government representatives.

Thus, many of the research protocols used by MK may interpreted as a response to the sense of powerlessness that MK's Indigenous researchers have felt up to this point in time. These protocols include not accepting funding from Australian Government-run organisations, seeking ethics clearance from many different committees, conducting extensive community consultations, forging partnerships with Indigenous organisations, and operating within an IDS and IDG model. Taking these factors into consideration, it is clear that MK deliberately seeks to position itself in such a way that inherently challenges Australian colonial systems, and that this is what the focus group participants and other stakeholders consciously responded to. Given that the Indigenous experience in Australia is, in all ways, impacted by the ongoing effects of colonisation (Chapters 1 and 6), the creation of a tool of power such as MK which is controlled by Indigenous people represents a true decolonising and empowering force in Australia.

It remains to be known whether the data produced by MK will effectively subvert the deficit discourse through its data sovereignty and governance procedures. This is a question too complex to be addressed adequately here, but the findings from this thesis do support a positive outcome. It matters less that 'data is power' and that data can and has functioned to reinforce colonial representations of evidence in Australia. What is more important in the context explored by this thesis is that Indigenous people are *in control of the process* of producing said data, and therefore are able to generate power (however that is defined) for themselves (see section 7.4. for further discussion within the international context).

> The 'power of these data' should not be underestimated. The wider social and political acceptance of the validity of statistical analyses makes these techniques powerful purveyors of an Indigenous research agenda. From a political perspective, the results of such analyses are effective in influencing the influential. Such quantitative 'proof' is fundamental if Indigenous researchers and

> communities want to advance the case for much-needed social and political change. (Walter, 2005: 30)

The hegemonic power of data, which has so often been wielded by the Australian Government to misrepresent and mismanage Indigenous Australians, is now able to work for us to produce policy outcomes which will support Indigenous ontologies and concepts of wellbeing. The following section will focus on this potential for the development of future public health policy in Australia.

7.3. Health policy impact

During the Bunbury health service focus group, the participants said that they hoped the results of MK would help improve current health policies, and that having Indigenous people in charge of the research process made a big difference to their willingness to be part of it.

> SB: Why do you think the study researchers are doing these focus groups? […]
>
> Participant 1: I guess a lot of study goes towards developing policies as well and practices within organisations and the Government. So researchers are there to feed that information through that hopefully they will, you know, implement policies and practices that would be beneficial to Aboriginal and Torres Strait Islander people.
>
> Participant 2: I think that you know that you're getting it from actual real people you've witnessed. It's not like ticking boxes and anybody could have done it. So anybody's information. You're actually with Aboriginal people asking for their input and then whether what you do with it is another thing.
>
> — Focus group participants with Sarah Bourke, 26 April 2017, Bunbury, WA.

Several of the focus group participants spoke about how important it was that MK captured the views of 'real people'. I interpreted this as a frustration with the fact that a lot

of Indigenous health policy is developed either with no community input, or the input of community 'experts' — Indigenous and non-Indigenous — who may not represent everyone's experiences. This was an underlying concern for the MK researchers as well. Part of their justification for conducting so many focus groups around Australia was to have diverse community input into the development of the survey. While many of the practical aspects of refining the survey were undertaken by MK's epidemiologists, having the focus groups spread out over such a long period of time meant that community feedback could be incorporated into each draft of the survey (see Chapter 5).

Another aspect to consider is that because MK is providing a relatively well-funded, large-scale quantitative framework for documenting cultural determinants of health, community perspectives gathered through this process are more likely to have a direct impact on government policy responses. This was articulated by Mark Wenitong, who said that MK will create an evidence base that forces policy developers to address the holistic needs of Indigenous people, and not just their biomedical needs.

> SB: What you think is special about this survey?
>
> MW: […] So broadly speaking, we've [Indigenous people] kind of thought this way for a while but have had no evidence base for that in Western terms. So bringing this together is a fairly major thing from a policy perspective because in the past we'd say, you know, I've been working with a men's group in Cape York. And we'd put in a proposal to take the men back on to Country for two weeks, whatever, as part of the healing process. And most of these guys have been into jail. And so, we'd sort of say that would be healing. But, you know, basically the funding body would say 'So you wanna go camping for a couple of weeks and do a bit of fishing?' And you'd go 'Yeah, but in a therapeutic model'. And so, it was always seen with a bit of a grain of… you know, it was not taken seriously, most of this stuff. Furthermore, at the juncture of policy and poor health outcomes for Aboriginal and Torres Strait Islander people, using the cultural determinants potential to mitigate 'toxic stress' that is emerging as a major driver of our excess

> mortality from chronic diseases, via a therapeutic potential of supporting cultural programmes could be better developed. […]
>
> So I sit on a committee called IPAG [Implementation Plan Advisory Group] which is the implementation in Canberra for the National Aboriginal [and Torres Strait Islander] Health Plan. And so, the first thing I did was invite Ray, the CI, to come present for that… to that group, because that's the first Assistant Secretary, State and Territory governments are represented there, along with most of the people from the Department of Health who are involved in implementing the National Aboriginal [and Torres Strait Islander] Health Plan. So it's got some authority to it. But it's getting it to places like that, I think that's going to make even a bigger difference. So the broad… the more national stuff is going to be really interesting, because if we can continue to convince the policy makers at the highest level from the Minister down, this stuff can be just as important as if somebody's got risk factors for heart disease and documenting and monitoring that, and you know getting their own interventions in place, then we got a chance of getting into national policy. If it's in national policy, it can get funded in national strategies.
>
> — Interview with Mark Wenitong, 25 January 2018, over the phone.

Mark refers to the concept of toxic stress in this excerpt, discussed in Chapter 2. Mark anticipates that the results of MK will be able to establish the protective potential of culture against toxic stress and for reducing allostatic load across the lifespan (M Wenitong 2020, personal communication, 25 June). Mark's hope that MK would influence the NATSIHP was already in motion at the time this thesis was completed. On the Department of Health website, within the *National Aboriginal and Torres Strait Islander Health Plan 2013-2023*, the Mayi Kuwayu Study is mentioned as informing the cultural determinants of health aspect of the proposed Implementation Plan from 2022 (Department of Health, 2019) (see Chapter 1 for details of the NATSIHP). Lisa Strelein, a non-Indigenous Australian and CI with MK, agreed that the findings of MK would lend weight to the message that Indigenous people have been trying to get Australian

governments to listen to for decades. Her knowledge of government policy development and implementation guided MK's early development.

> SB: What do you think the wider impact of the survey will be?
>
> LS: […] One of the comments that Ray made right at the start is that it gives credibility [from a policy perspective] to what Indigenous people already know, and the science behind that intuitive knowledge. But also, it gives us more information about those connections. It's often hard in a policy environment to argue for cultural programmes and investment in cultural programmes. There's also often a misunderstanding about what cultural programmes actually deliver, or even what culture actually is. Culture is not just about songs and artistic expression of culture, although it is certainly inclusive of those things. But also, culture includes some of the things that the study tests around governance and the sense of control over your own destiny and connection to land.
>
> From a policy perspective it has always been hard for Indigenous people to argue that there is a reason to give land back other than because it's a nice thing to do. Or that there is a reason to invest in Indigenous governance other than the fact that people are demanding it. The study has the potential to make that connection between those amorphous rights-based arguments to make sure that people understand what the implications, and what the benefits are, of actually having those investments and then actually meeting those demands.
>
> — Interview with Lisa Strelein, 20 March 2018, Canberra, ACT.

The importance of MK for producing evidence in the form of quantitative data was first introduced in Chapter 1. As the work of Maggie Walter (2005, 2010) has highlighted, these data inform paradigms of 'truth' and 'knowledge' in the Australian policy environment reproducing their White/Western orientation. Both Lisa's and Mark's emphasis on evidence reflects their professional histories working with the Australian Government. How much of a relationship MK should have with Australian governing bodies was always a concern for the MK researchers, stakeholders, and focus group participants. The researchers were clear from the beginning that in order to effectively implement an IDS

and IDG model there could be no Government oversight of MK and its survey, and that ownership of its data would always rest with Indigenous communities. Ruth Gilbert referred to this during our interview:

> SB: Do you think it'll have an impact on Government policy, or even just the way the ABS does their stuff?
>
> RG: […] I think there needs to be far more of an understanding that Government don't own all that information. They don't own all the data. You know, Government shouldn't have to own everything. All those details about people's lives. Why not let leaders in Aboriginal and Torres Strait Islander health ask these questions of the people? And that information belongs for and with the people who provided the information. Rather than everything's under lock and key, under Government control. […]
>
> And even the early MK work done here so far, where they've worked with the CLC Rangers. That work already shows that working on Country has tangible, substantial personal benefits and community benefits in many ways. Mental health improvements. Rangers are an inspiration to other family members in community. It's a pride thing. Like, 'My uncles a ranger, he's out there caring for the Country. My mum's a ranger'. That's a really proud thing and so hopefully if the absolute positive impact of things like that are known, maybe then we could see an ongoing commitment from the current short-sighted Government approach to programmes like that.
>
> — Interview with Ruth Gilbert, 16 November 2017, Canberra, ACT.

These perspectives pick up on the theme of decolonising research as activism from Chapter 1. By maintaining autonomy from the Australian Government, MK is able to enact its Indigenous-directed agenda. However, there were a few points I observed during my fieldwork where this autonomy was unclear for community participants. For example, at the beginning of each focus group there was some discussion — almost always initiated by the researchers — to reassure the participants that MK and its data were not owned by the Government. In all but one focus group I observed this assurance was taken at face

value. For the focus group conducted in Risdon Cove there was a more in-depth discussion about this before the focus group officially began (Chapter 4).

Indigenous concerns about participating in Australian Government-owned initiatives has already been touched upon in this thesis (Chapters 3 and 4). In the Cowra focus group, participants said that they did not identify as Aboriginal or Torres Strait Islander in the Census because they were afraid of what the Government might do with their information. This is an anxiety shared by a number of my Aboriginal family members as well. It is possible that this fear of participating in formalised surveys had an impact on MK's baseline recruitment. In order to use the Medicare database of Indigenous clients, MK's survey had to be mailed out in Medicare-branded envelopes from the Department of Human Services, with a Government cover letter included with the survey materials inside. The researchers had hoped to be able to have an MK-branded envelope for the mail out, as it was thought that many people may see the Government envelope and immediately throw it out, or worse, think that the survey was a Government-run initiative. This was confirmed in a conversation I had with Ray in April 2020. He believed the Medicare branding had a huge impact on response rates, adding that the second most common reason people had called their hotline was because they were concerned that the survey was from the Government (R Lovett 2020, personal communication, 14 April).

The details of how results from MK would inform particular policies was never discussed in depth by the MK researchers with me. Our conversations about the potential of MK were in general terms, though more specific choices were made to address research priorities in the inclusion/exclusion of survey questions (see Chapters 5 and 6). Alyson Wright was interested in how MK's findings about culture would be translated into policy on a more practical level.

> I'm really interested in the development agendas that could be aligned with this study. It's not just a public health response. You know sometimes epidemiology just requires you to respond to public health threats — to immunise people, or to go out there and run a hand-washing campaign. But, when you're talking about culture, and you're talking about these kind of constructs, it's a development response that's required. It's not just a public health 'Oh yeah we can go and vaccinate people' you know? Put a needle into them and inject some culture. You just do that.
>
> I want to see how the research findings are translated and transform current policy and practices. For example, Mark Wenitong […] he talked about dose response. He suggested that the MK Study could look at things like dose response. So I was like 'Hmm… well what does that mean?' Does it mean how much language you can speak makes you healthier? Does it mean if you can say more words in language then you are healthier? This is interesting — how does an epidemiological concept transform into this kind of setting where everything is much more socially constructed? I'm interested in that.
>
> I think they do need to get traction within the medical sphere. So their methods need to be robust. It does need the epi because that's considered evidence if you sit in John Curtin School of Medical Research [at ANU], you know. I do think you need that hard data. But how it plays out in a policy sense that will be interesting. There are different land rights regimes across the country — whether it's Native Title, whether its land rights — they influence how much access you have to Country or whether you have decision-making over Country or rights for hunting. These are policies and legislation, where things don't move quickly or change quickly. So you know, if the survey finds that Country is really good for people, what does it mean for the people who will never be able to get back their land? Or don't know where their traditional lands are, you know? All questions for the future. But I find it really interesting. I find it fascinating, that kind of process of constructing the knowledge I guess.
>
> — Interview with Alyson Wright, 31 January 2018, Canberra, ACT.

Alyson's observations highlight the interplay between epidemiological evidence and medical evidence in the development of public health responses. Whether the right response is to 'inject some culture' depends on community interests and goals and how

these can work alongside the interests of public health bodies. She also makes a pertinent critique when she asks what happens to those people who have become disconnected from their Country.

The results from MK's pilot studies have already indicated that connection to Country is a key factor for Indigenous health, and this is reinforced by the discussions from the focus groups (Chapters 4 and 6). By looking at the influence that connection to Country has on health and wellbeing outcomes, MK will be able to find out whether a high standard of health and wellbeing is possible for Indigenous people who have been removed from Country as a result of colonisation. This has implications for international perspectives on indigenous health, as colonisation is an experience which all indigenous peoples have in common and must deal with in their everyday lives. The following section will look at the potential international impact of MK, with a particular focus on wider academic and scientific narratives about Indigeneity, knowledges, and cultures.

7.4. International impact and Indigenous Science

The Mayi Kuwayu Study is connected to a wider international movement by Indigenous-governed research communities who are actively resisting settler-colonial narratives, epistemologies, and structures. Having Indigenous people in charge of defining, collecting, and interpreting Indigenous health data is a key aspect of both MK and wider global narratives of decolonisation and research as activism. This thesis has already touched on one of the ways in which MK has engaged with these movements through their IDS/IDG protocol development (see Chapter 1). Looking towards the future, Ray was interested in sharing the knowledge gained during the development of MK's survey and database with other indigenous-governed cohort studies being developed in Canada and New Zealand.

In collaboration with these international networks, Ray helped to establish an International Indigenous Cohort Collective in 2018. I flew from Australia to Canada in February 2018 to attend the first face-to-face meeting of the International Indigenous Cohort Collaborative at the Toronto Council Fire Native Cultural Centre. At the meeting were several members of the MK team including Ray Lovett, Jan Chapman, Katie Thurber, Lachlan Russell, and Roxanne Jones, three researchers from the Canadian cohort study *Our Health Counts,* including Janet Smylie, and the lead researcher from a Māori cohort study on smoking in New Zealand called *Te Ara Auahi Kore* (TAKe) (He Kitenga, 2017). Together the Collaborative identified four objectives that they wanted to work towards (International Indigenous Cohort Collaborative, 2020: 9-10):

1. Foster an International Indigenous Cohort Collaborative of partners from Australia, Canada, and New Zealand.
2. Identify wise practices for community engagement in Indigenous cohort studies, through lived experience and the literature.
3. Facilitate the application and dissemination of these wise practices into ongoing community research study methods, health policies, programmes, services, and evaluations using an integrated Knowledge Translation (KT) approach.
4. Develop a comprehensive research proposal(s), informed by wise practices, the academic literature and the International Indigenous Cohort Collaborative. These would include:
    a. Establishing the International Indigenous Cohort Collaborative network.
    b. Creating an international Indigenous epidemiology/public health summer school.
    c. Organising an international Indigenous health gathering/conference.

The meeting enabled shared learning through the use of 'consensus building circles' which is based on Indigenous Canadian ways of knowing and doing (International Indigenous Cohort Collaborative, 2020: 15). According to Kahente Horn-Miller, a Kanienkehaka woman and Assistant Professor of Indigenous Studies at Carleton University in Ottawa, consensus decision making is a fundamental aspect of Indigenous governance in Canada.

> Consensus is a process of collaborative discussion that respects both the group and the individual. In consensus, the whole group makes decisions instead of a majority or minority rule. Consensus is not simply a process of finding the sum of individual viewpoints and tallying up the assents and dissents. The goal is to discern what the best decision is for the group and take into consideration the needs of the collective. Through consensus, each individual's concerns and ideas are considered. Every participant must have equal access to the process for it to be true consensus decision making. The group works with and adjusts a proposal until all can consent to its final form. (Horn-Miller, 2013: 116)

At the time I was not aware of what this practice was called, but could recognise that the format of the discussion differed in important ways from meetings I had attended in Western academic settings. For example, the meeting was opened by an Anishinaabe Knowledge Keeper with a prayer, smudge, and teaching. At times, knowledge sharing was facilitated by a talking feather which was passed around the table, allowing each person to contribute. It was only when I was given a draft of the report in February 2020 that I understood that consensus building circles are a fundamental aspect of Indigenous knowledge sharing relationships in the research setting in Canada.

The Collaborative meeting focused on identifying 'wise practices' for indigenous health cohort research internationally. During the opening circle, Janet Smylie observed that '"Cohort" is not an Indigenous word, but the concept — thinking about a group of people, not the individual, over time — has always been done by [Indigenous] communities' (International Indigenous Cohort Collaborative, 2020: 16). Wise practices is an approach to undertaking research with Indigenous peoples which has been developed in Canada over the last few decades. It is defined as 'locally-appropriate actions, tools, principles or decisions that contribute significantly to the development of sustainable and equitable social conditions' (Wesley-Esquimaux and Calliou, 2010: 19).

Unlike best practices, which tend to be universalised in research settings as a 'one-size fits all' approach and are not situated within a particular cultural context, wise practices are dynamic and responsive to local Indigenous cultural practices and social relationships (Wesley-Esquimaux and Calliou, 2010). Wise practices support Indigenous knowledge generation processes to promote knowledge translation (KT) within and between Indigenous communities (Smylie et al., 2004: 141, Figure 2) (shown in Figure 32).

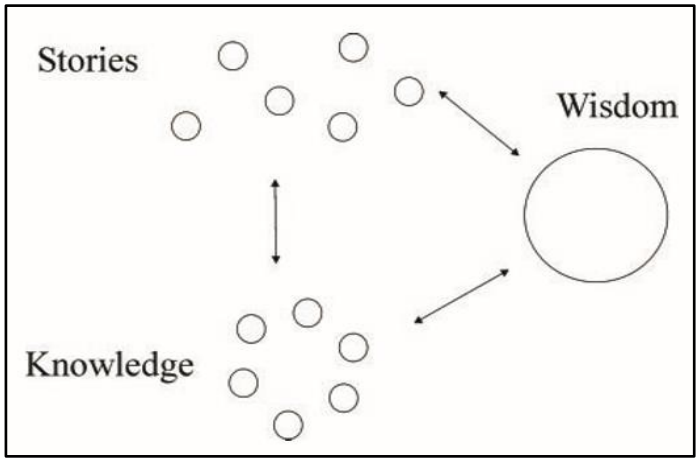


Figure 32. Indigenous knowledge generation process (Smylie et al., 2004: 141, Figure 2)

The methods used for Indigenous knowledge generation are 'participatory, communal and experiential, and reflective of local geography' (Smylie et al., 2004: 141).

> In Indigenous knowledge systems, generation of knowledge starts with 'stories' as the base units of knowledge; proceeds to 'knowledge', an integration of the values and processes described in the stories; and culminates in 'wisdom', an experiential distillation of knowledge. This process can be viewed as cyclical, as 'wisdom' keepers in turn generate new 'stories' as a way of disseminating what they know. (Smylie et al., 2004: 141)

Undertaking KT within the context of Indigenous cohort studies means ensuring that research can be translated into tangible benefits for local communities. During our interview, Janet Smylie reflected on her experiences measuring the cultural determinants of health for First Nations, Cree, and Métis peoples in Canada. She explained how scientific

approaches to understanding the world and collecting information about the world are an intrinsic part of Indigenous cultures and how Indigenous peoples have always related to each other and the environment.

> SB: What do you think the wider impact of the survey will be? Because you mentioned before it will flip the script on looking at the importance of culture for healing, rather than [exploring culture] as a side project you've mentioned in other surveys.
>
> JS: […] It could get people excited to talk about culture. […] Those things are all very empowering. Like the fact that because of the study I got to come here and then see people and build those relationships. So those are the ripple effects. And they're actually very Indigenous ripple effects. They're not side effects — they're *core* effects. They're core Indigenous effects that actually happen sometimes almost despite the science that we're trying to achieve. But can we actually get Indigenous ways of being, and promotion of Indigeneity in the way that we live it? And more space to be Indigenous in health sciences as a constructed-by-settler systems? […]
>
> And I think that it's an information age. And we're good at holding onto complex information systems. We had to survive, though I think the… when you're out on land there's always lots of information coming all the time. You have to be a bit attuned. But it's just as busy as Facebook. It's just more subtle. Yeah I think that information science is… Indigenous information scientists understand the parallels. So being on land would have been Indigenous information sciences. This is a different kind. To support Indigenous people to feel confident and competent and Indigenous in those spheres. And to see them as new ways of expressing and living and promoting thriving Indigenous communities is something that could be good.
>
> — Interview with Janet Smylie, 26 October 2017, Canberra, ACT.

Janet has made it clear here and elsewhere (Chapter 3) that Indigenous people already have scientific theories and have undertaken scientific practices as an inherent part of the

practice of culture. In the literature, this is referred to as either Traditional Knowledge, Indigenous Knowledge, or Indigenous Science.

> The processes of Indigenous Science parallel and at times intersect with those of Western Science. Observation is emphasized. Indigenous people carefully observed aspects of Nature such as plants, animals, weather, celestial events, natural structures, and ecologies of natural communities. They experimented with applications of their knowledge in the context of the environment or situation which was appropriate. There was no deliberate effort to decontext[ualize] experimentation by moving beyond observations. In an Indigenous context predication was not associated with the ability to control but primarily with gaining understanding of a natural process; for this reason science meant establishing relationships which led to establishing and maintaining harmony. Indigenous science intuits the desired results and then enters into specific relationships to accomplish its aims. It stressed direct subjective experience and close relationship to Nature. (Cajete, 1999: 84-85).

While it is beyond the scope of this thesis to explore this body of literature in detail, Indigenous Science has been documented by both Indigenous and non-Indigenous researchers and can work both with and against Western norms of science in Australia (for an indepth overview in the field of education, see Snively and Williams, 2016, and in ecosystems science, see Ens et al., 2015, and Weir, 2012). What is critical to the Indigenous health narrative, as Janet suggested above, is *who is in charge* of the science. This is perhaps the most important idea driving MK, and has been demonstrated in different ways, from various perspectives throughout the thesis.

In a recent follow-up discussion with Ray, I asked whether wise practices was something that would be incorporated into MK going forward. He said that 'wise practices' was a Canadian term and that it was not well understood in the Australian context (R Lovett 2020, personal communication, 14 April). Ray said that the MK researchers would soon be putting together a document outlining the need for 'good practices' in research with

Indigenous Australians. While this article had not been finalised at the time of submitting this thesis, the use of the term 'good' has already been used by Ray and his colleagues in reference to 'good data' for Indigenous health internationally (see Lovett et al., 2019). In this context 'good' conferred a sense of social justice within a human rights framework (see Chapter 1), working against the 'bad' data constructed by colonial powers, with IDS and IDG as the instruments of 'good' data practices (Lovett et al., 2019: 26). How these good practices will work with KT through MK remains to be seen.

This chapter has illustrated the many hopes of the MK researchers, stakeholders, and focus group participants for the future of MK. It focused on the potential effect it may have in communities, health research, and policy development at the local, national, and international levels. Such a shift in power would lead to greater self-determination for Indigenous Australians. The final chapter will bring together the major findings of this thesis to address the main thesis question.

Chapter 8 — Discussion

This thesis has explored the various ways in which the Mayi Kuwayu Study provides a blueprint for understanding cultural determinants of health for Indigenous Australians. By developing operational definitions of culture for their survey, the Mayi Kuwayu Study stands apart from its contemporaries such as the NATSISS and NATSIHS developed by the Australian Government. The introductory chapter of this thesis demonstrated how the focus on cultural determinants of health was born from the suppression of Indigenous ways of being and knowing since colonisation. To date, the majority of Indigenous health data has served to Other Indigenous peoples, producing a statistical Indigene as a focus for governmentality (Walter, 2010: 51). Culture has thus become a focal point for Indigenous resistance, resilience, and sovereignty in the Indigenous health narrative. By displacing the deficit discourse and putting culture and Indigeneity at the centre of its strengths-based research model, the Mayi Kuwayu Study emphasises *belonging*.

The thesis examined four key dimensions in the development of MK, addressing the initial development of the culture concept by the MK researchers (Chapter 3), Indigenous community experiences of culture and wellbeing (Chapter 4), the evolution of cultural metrics used in the survey (Chapter 5), and the potential impact of MK in Australia and internationally (Chapter 7). What emerged from these analyses called attention to topics much broader than the original scope of the thesis.

The most important finding of this thesis was that Indigeneity itself became a research tool within MK. Embedding Indigenous perspectives in the survey improved the ability of this epidemiological instrument to conceptualise and measure Indigenous definitions of health and wellbeing as grounded in culture. The second most important finding of this thesis was that MK has the potential to become an effective communication tool within and

between Indigenous communities, and between Indigenous groups and non-Indigenous health systems and government organisations, by identifying cultural determinants of health. The third most important finding builds on the first two to propose that MK has to the potential to decolonise the Indigenous health narrative by supporting the self-determination of Indigenous communities.

The fourth most important finding of the thesis was that MK was seen by focus group participants as a way of 'saving' culture for their communities. While this is an important aspiration, this thesis suggested that the ability of MK to achieve this in a practical sense is limited by its epidemiological framework. The fifth key finding was that the survey allowed for the diversity of Indigenous cultures to be captured within its framework, particularly in regards to the names of Indigenous groups and languages. The sixth important finding was that cultural determinants of health can be a valuable strengths-based analytical framework for large-scale epidemiological surveys.

These six key findings work in tandem to argue that MK forms the basis for a re-orientation of the Indigenous health narrative towards acknowledging the tangible and positive influence of culture for Indigenous Australians. These findings also offer meaningful contributions to major anthropological debates in the literature, which will be highlighted below.

This thesis represents a slice in time, as both MK and the Indigenous health narrative continue to change. The period it examined coincided with major changes in the socio-political relationship between Indigenous peoples and the Australian Government. Shortly following the start of my fieldwork in 2017, over 250 Indigenous representatives from across Australia came together to issue the *Uluru Statement from the Heart*. It called for an Indigenous voice to Parliament and a Makarrata Commission to advance reconciliation

between Indigenous and non-Indigenous Australians (First Nations National Constitutional Convention, 2017).

Also in 2017, growing political disillusionment with the failures of the Closing the Gap objectives a decade after its inception led the Federal Government to initiate a 'refresh' of the programme. This involved widespread consultations with Indigenous groups around Australia for the first time in the programme's history. In January 2020, the Prime Minister and his colleagues agreed to develop a *National Agreement on Closing the Gap* which would address three priority reforms, promising a true partnership with the Coalition of Aboriginal and Torres Strait Islander Peak Organisations.

Alongside these political changes, the Indigenous data sovereignty movement was gaining momentum in Australia and internationally. By the time I started my work with MK, its researchers were in the middle of a long process of developing their IDS and IDG principles, which have recently been finalised and published on their website (see Mayi Kuwayu Study, 2020). While the development of these protocols was outside the scope of my study, their presence reinforced MK's positioning as Indigenous led, owned, and operated. This, combined with the above-mentioned changes in the political landscape, has meant that the key findings of this thesis revealed that MK was very much of its time, and that these findings may be linked back to contemporary issues in the Indigenous health narrative. The rest of this chapter elaborates on the thesis' six most important findings based on the ethnographic data, and examines their implications for existing anthropological debates and underlying currents in the Indigenous health narrative. Each of these findings act as an umbrella for associated outcomes which are also incorporated.

Indigeneity as a research tool

Indigeneity was a research tool used by MK (and by myself) to embed Indigenous perspectives into its design, methods, and outcomes. Kovach (2009: 29) suggested that the 'fundamental epistemological difference between Western and Indigenous thought' would generate 'philosophical, ideological, and methodological conflicts for Indigenous researchers'. As outlined in Chapter 2, my positionality as an Indigenous researcher 'enacting hybridity' (after Narayan, 1993: 681) through an Indigenist research approach informed my data analyses and the conclusions I came to. As an example, for my thematic analysis of the focus group data and survey presented in Chapter 6, I drew on my experiences as an Indigenous person to interpret the participants' responses and to categorise them in a way which would be recognisable to other anthropologists and to other Indigenous people. This thesis therefore contributes to the anthropological literature drawing on Indigenous standpoint theory to analyse and critique our lived experiences (e.g. Medicine, 2001, Nakata, 1998, TallBear, 2014).

The Indigenist research agenda speaks to wider social dynamics within Australian society and directs scholarly attention towards issues of governmentality and power which are traditionally only framed from the 'top-down' in the social sciences, after Foucault (1978 [2001]) in particular (for an overview of this literature in the social sciences, see Bröckling, Krasmann, and Lemke, 2011, and in anthropology, see Inda, 2005). In sharing an Indigenous standpoint with my research participants, my focus was drawn towards understanding MK as a response to the construction of the statistical Indigene by Australian governments (Walter, 2010: 51) and as a site of power in its own right. This thesis is thus an ethnographic example of how data as power in the hands of Indigenous peoples challenges the centralised data model sustained through systems of

governmentality in Australia (for further discussion, see *Decolonising the Indigenous health narrative* below).

In the context of MK, some of the conflicts Kovach described above were surmounted by having Indigenous researchers in control of the epidemiological process. This positioning reinforced Indigenous authority and responsibility over the survey instrument, engendered trust for external Indigenous stakeholders, and was seen as a way of reclaiming data about Indigenous health from the Australian Government (Chapters 3, 5, and 7). Seeking Indigenous control over Indigenous outcomes in research is linked to a global movement of rights-based activism by indigenous communities, with a strengths-based approach identified as a key methodology supporting this objective (see Chapters 1, 2, and 7). This approach formed the foundations of a survey created to statistically validate a holistic model of Indigenous health and wellbeing (Chapters 3 and 6). Despite concerns about the Western/White bias of the epidemiological method and cultural essentialism, the Indigeneity of the researchers themselves, as well as the MK partners and the focus group participants, was viewed by the researchers as minimising these risks (Chapter 3).

Chapter 5 brought to light how much MK and its survey are also a reflection of the researchers themselves and demonstrated how the social dynamics between key Indigenous and non-Indigenous stakeholders influenced the survey design. The ethnographic data I collected suggested that the Indigeneity of some of the researchers played a strong role in determining which metrics were included in the survey and which were not. The collective input of so many Indigenous actors into the survey legitimised its metrics and MK's claims to be representative of the diversity of Indigenous experiences in Australia. This dynamic collaboration conformed to ideals of Indigenous leadership (Chapter 3) and of 'doing things a good way' (Chapter 7), establishing the ethical and cultural integrity of MK.

By creating operational definitions of culture, or indicators, MK and its survey may not be able to represent the full lived experience of cultural connection/disconnection for Indigenous peoples (Chapters 3, 4 and 6). This partly supports Fisher's (2007: 207) assertion that subjective aspects of wellbeing are lost in the translation of lived experiences into metrics. It must be acknowledged that such limitations may be an inevitable outcome of transforming conceptual definitions of culture into operational definitions of culture (see Chapters 1 and 6).

Yet, this does not mean that these operational definitions are not meaningful or useful. All of the researchers I interviewed agreed that that epidemiological research on cultural determinants had to begin somewhere. Janet Smylie's story about the Métis Red River cart was an analogy for how Indigenous people could adapt Western tools to suit their own needs (Chapter 3). Crucially, in my ethnographic data it was only the non-Indigenous people Ray said he interacted with who took issue with the idea of quantifying culture (Chapter 7). None of the focus groups I observed related any concerns with measuring cultural participation, beyond asserting that this should not be indicative of a person's Indigeneity (for an example, look under *Language* in Chapter 6). This counters the 'epistemology of ignorance' of non-Indigenous researchers who assume culture to be intangible, and therefore, do not attempt to account for it in their research on Indigenous health (see Chapter 7).

There were striking similarities between the cultural themes identified by my analysis of focus group data (Chapter 6), a review of the relevant literature (Salmon et al., 2018), and the themes identified by the MK researchers themselves (Jones et al., 2018b: 5) (see Table 2). This finding, in light of the support demonstrated by all of MK's Indigenous stakeholders, contradicts the idea that culture resists operational definition (Tayeb, 1994: 431). This may not be culture as we live it, but it is certainly culture as we see it.

Mayi Kuwayu Study as a communication tool

The second important finding was that MK has the potential to become an effective communication tool within and between Indigenous communities, and between Indigenous groups and non-Indigenous health systems and government organisations. The transformation of Indigenous perspectives on wellbeing into quantitative data generates a form of 'evidence' recognised by Western health systems (Chapters 1, 3, and 7).

The researchers hoped that the statistics generated from MK would empower local Indigenous communities by facilitating an understanding of the cultural practices and knowledges which influenced health and wellbeing in their area. A number of focus group participants described how MK would allow different communities to share knowledge about culture (Chapter 7). This was seen to be particularly important for younger people to learn about their identity.

The MK researchers anticipated that the data collected by the survey would be harnessed by Indigenous community groups to advocate for funding for cultural programmes from local governments and non-government organisations (Chapters 3 and 7). Janet Smylie and Mark Wenitong agreed that if evidence can be generated which demonstrated that culture has a positive effect on health outcomes, it would have a substantial impact on local and national health-care sectors, advocating for culture as a form of treatment (Chapter 7). The fact that the results of the CLC Ranger pilot have already been used in this way establishes the potential of MK for effecting real change (Chapter 5).

However, this thesis has also brought to light a number of structural issues and destructive rifts in the relationships between Indigenous peoples and Australian governing authorities. The introductory chapter outlined the record of failure of the Australian Government's Closing the Gap agenda over the last decade to incorporate Indigenous perspectives and

needs into its strategy. Currently there is no national oversight by Indigenous representatives on the design, implementation, and analysis of government statistics about Indigenous peoples (Lovett et al., 2019: 28). Their recent commitment to 'shared decision-making' on the Closing the Gap initiative (Prime Minister of Australia, 2020), while 'historic' (Turner, 2020), does not address the wider systemic issues which have resulted in embodied trauma for Indigenous peoples.

It was clear in my ethnographic work that Australian Government policies, officials and organisations continue to have a significant and often negative impact on Indigenous lives. Several groups spoke about how they were prevented or restricted from practising culture by local authorities (see examples from Risdon Cove in Chapter 4, and Bunbury and Ulladulla in Chapter 6). Therefore, while MK may be a powerful communication tool, whether non-Indigenous governing authorities will take heed is another matter.

Decolonising the Indigenous health narrative

The third important finding of this thesis was that MK works toward decolonising the Indigenous health narrative by supporting Indigenous self-determination within its epidemiological framework. This builds on the two findings presented above but could only be examined to a limited extent, given that it was not the focus of my ethnographic fieldwork. A number of the researchers I interviewed were critical of how government statistics have been used to date to stereotype Indigenous communities (Chapter 3). Ray Lovett, Maggie Walter, and Anna Olsen, described how much of Indigenous health research focused on 'problems' in Indigenous communities, aligning with the wider non-Indigenous perception of an 'Indigenous problem' in Australian society (Gooda, 2011: 9, 79). Despite expert recommendations spanning decades that Indigenous peoples be equal partners in developing health initiatives for Indigenous communities (for examples, see

Calma, 2005: Recommendations 2-4, House of Representatives Standing Committee on Aboriginal Affairs, 1979: iii, Human Rights and Equal Opportunity Commission, 1997: Chapter 26, Johnston, 1991: Recommendation 49, O'Mara, 2010), and repeated government 'commitments' to this effect, this partnership has never been enacted as promised.

My ethnographic data indicated that there is an ongoing colonial relationship between Indigenous peoples and the Australian Government, and that it has a universally negative impact on the wellbeing and potential of Indigenous communities. This adds to an international body of evidence which argues that colonisation contextualises almost all aspects of the Indigenous lived experience (Fayed et al., 2018, Griffiths et al., 2016, King et al., 2009, Lowitja Institute, 2014: 2, Paradies, 2016, Reading and Wien, 2009: 22, Sherwood, 2013) and is a direct determinant of health inequalities experienced by Indigenous peoples (Fayed et al., 2018, Griffiths et al., 2016, King et al., 2009, Reading and Wien, 2009: 22).

Participants in the Bunbury focus group spoke about how the continued removal of Indigenous children from their families into foster care was creating a new Stolen Generation (Chapter 6). In Ulladulla and Risdon Cove, focus group participants talked about how they were not included in decisions made by local governments over land and water access and use which had detrimental economic, social, and cultural impacts on their communities (Chapter 6). A particular issue raised in Tasmania was that the Government was allowing citizens to officially identify as Indigenous without any verification from Indigenous community organisations (Chapter 4). In the words of one participant: 'Identity is a part of culture. And now the Government's giving it away'. This is reminiscent of the assimilationist identification systems used in the past which Australian governments used to authorise who was Aboriginal and who was not (Chapter 1).

While this thesis did not seek to resolve how MK would change relationships between Indigenous communities and Australian governments, it did address how MK supports Indigenous self-determination within its epidemiological framework. This was linked to global narratives of decolonisation and research as activism, which was the foundation on which the international collaboration with Indigenous cohort studies in Canada and New Zealand was built (section 7.4). The finding that Indigeneity became embedded into MK through the application of Indigenous 'bias' as expertise and use of Indigeneity as a research tool provides a unique contribution to the anthropological literature on the enactment of expertise (for an overview of this literature, see Carr 2010). This enactment was evident in the ethnographic account of the International Indigenous Cohort Collaborative meeting, where Indigenous ways of knowing and doing were incorporated into the research process through consensus building circles, knowledge translation, and emphasis on wise practices. By incorporating Indigeneity with epidemiology, the MK researchers and their collaborators sought to 'reach across spaces' (see Chua and Mathur, 2018) to explore the potential of epidemiology for addressing Indigenous needs.

Anthropologists have long grappled with the need to decolonise the discipline while recognising that it is a project which will never be completed (Allen and Jobson, 2016: 139, Pels, 2018: 71). The Indigenous critique of anthropology (King, 1997, in Robben and Sluka, 2012: 207-209, Kovach, 2009, Medicine, 2001, Nakata, 2001, Smith, 1999, Westerman, 1969) is as pertinent today as it ever was, and many anthropologists from around the world have debated issues of decolonisation through their scholarship (for examples, see Allen and Jobson, 2016, Pels, 2018, Uddin, 2011, and White, 2019). This thesis demonstrates the positive contribution an anthropological perspective can make to the decolonising agenda, reflecting as it does on what is transformed when Indigenous

peoples are in control of the production of knowledge within the disciplines of anthropology and epidemiology.

By focusing on the strengths of Indigenous cultures and communities, and reinforcing forms of Indigenous governance and sovereignty through its research protocols, this thesis proposed that MK could be a decolonial — even anti-colonial — force in the Indigenous health landscape. If population statistics form the basis of a nation's self-concept and provide a mechanism for societal understandings, as suggested by Walter (2010: 45), then the new statistics generated by MK may help to transform Australia's self-concept from its very foundations. The results of this thesis indicate a positive change in these underlying socio-political currents, but cautions that the systems which have for so long oppressed Indigenous knowledges and peoples remain intact.

While the culture concept in anthropology has always been contested (see Chapter 1), it was clear in the ethnographic record that culture is a concrete reality for Indigenous Australians which informs all aspects of the lived experience — even in its absence. The focus group participants consistently said that culture helped them to feel their place within the world, providing them with a connection to their family, ancestors, and the environment (Chapter 4). When people experienced a disconnection from culture they felt lost in the world, and saw this disconnection as the root cause of physical, mental, and social ills in their communities (Chapters 4 and 6). These testimonies are consistent with the literature which describes culture as a protective factor for Indigenous health and wellbeing (Dudgeon et al., 2010, Salmon et al., 2018, Lowitja Institute, 2014).

Survey as 'saving culture'

The fourth important, but complex, finding of this thesis was that MK was seen by focus group participants as a way of 'saving' culture for their communities (Chapter 7). The

focus group participants, researchers, and stakeholders believed that recognising the importance of Indigenous cultures for wellbeing would lead to improvements in holistic health outcomes. These data support the proposition by Kirmayer, Gone, and Moses (2014: 305) that culture is often viewed by Indigenous people as a remedy for healing the wounds of historical trauma.

The thesis touched on a number of ways in which MK will contribute towards cultural understanding for communities. The first was through the focus groups (Chapter 4). While fewer than 200 people participated in these sessions, some of the participants felt that the discussions about culture would lead to a greater awareness and acknowledgement of cultural practices in their communities once MK's survey was released. The second avenue was through the two pilot tests of the survey, run in partnership with the MLLS in the Murray-Darling region and the CLC in the NT (see Chapter 5). Again, while a relatively small number of people participated (n = 366), MK led to a greater awareness amongst these stakeholders of the positive impact of culture on Indigenous health and wellbeing.

However, the ways in which MK may 'save' culture are limited. It may, as suggested above, make communities more aware of the positive influence culture has on wellbeing, and to some extent, be a record of the broad forms of culture (especially languages) being practiced locally (see *Survey as emphasising cultural diversity* below). However, MK was not designed to collect specific, contextualised information about culture and is not able to release identifying information about which individuals in a community are practising culture. While this may change in the future as the visibility of MK and its findings increase, for now, the ability for MK to 'save' culture is aspirational rather than practical.

Furthermore, there is a risk that by casting the cultural elements incorporated into the MK survey within the 'salvage paradigm' (Clifford, 1989), these elements may be misinterpreted as static measures of cultural authenticity (see discussion of cultural essentialism in Chapter

3). External researchers who used this approach would be repeating the mistakes of early anthropology in the creation of an 'ethnographic present' (Clifford, 1989: 73, Medicine 2001: 290), and as a consequence, undermine efforts towards cultural revitalisation and invention which may not conform to the newly established measures. However, as stated in Chapter 3, the Mayi Kuwayu Study Governance Committee would be able to mitigate some of these issues to ensure that MK's data will be interpreted by researchers with regard to historical and contextual factors, in line with an Indigenous worldview.

Survey as emphasising cultural diversity

Despite not addressing specific, localised experiences of culture, the survey does retain the ability to represent Indigenous cultural diversity. This finding offers an important contribution to the anthropological debate on culture. While many anthropologists have long been fixated on arriving at a universal definition of 'culture' (for the classic example, see Geertz, 1973), others in the discipline advocate for a 'love it or leave it' (Fox and King, 2020: 2) approach in favour of getting on with the business of doing anthropology (Fox and King, 2020: 1-5, Gupta and Ferguson, 1997). It can be argued that MK does just that. It did not need to arrive at a universal definition of culture in order to represent it in a way which would be meaningful and useful for Indigenous communities.

As stated a number of times throughout the thesis, MK is the first national survey in Australia to ask questions about important aspects of the Indigenous experience. This includes asking about how people identify as Indigenous by naming their tribe or mob, their family name, and their Country or Island (Q4, 5, and 7 respectively) which goes far beyond the Standard Indigenous Question (ABS, 2014) incorporated into most Australian Government surveys. Question 21 in the MK survey asks participants to list the Aboriginal or Torres Strait Islander languages or words they know, providing much more detailed

information than the language section of the NATSISS which only asks whether participants know an Aboriginal or Torres Strait language, and to what extent (Yes/Yes, some words only/No) (see ABS, 2016a: 36-38). Furthermore, because the information the participants provide will be linked to their geographical location, in addition to their culturally-relevant locations, these data will be able to be analysed at the local level.

Once MK has gathered longitudinal data it will be possible to examine how key cultural elements change over time, such as those included in the CK&P sub-section. The survey will be able to track the holistic impact of community-based wellbeing projects like those being developed in Yarrabah (Chapter 5), as well as large-scale programs such as the expansion of the Indigenous Rangers programme (Chapter 5), and cultural revival initiatives such as the *Living Language First Platform* (Australian Literacy and Numeracy Foundation, 2019) (Chapter 6). The MK researchers and partners plan to work with external researchers in the future to develop sub-studies to generate contextualised, qualitative data which may be compared to the MK data, providing further insights into the Indigenous lived experience in Australia (R Lovett 2020, personal communication, 14 April). It is also possible that new questions will be incorporated into future versions of the MK survey to address emerging forms of Indigenous cultural practices or to answer novel research questions which reflect changes in the wider Indigenous health narrative.

Cultural determinants as a novel research framework

The final key finding of this thesis was that cultural determinants offers a promising framework for large-scale research seeking to apply a strengths-based approach to the study of human health and wellbeing. The desired shift from social determinants of health to cultural determinants of health in the Indigenous health narrative (Chapter 1) mirrors a wider change across health research and practice away from a focus on risk factors and

towards a contextualised understanding of resilience (Panter-Brick, 2014: 432). In contrast to the ambiguity of the social determinants concept (Islam 2019), this thesis has demonstrated the care and caution used by the MK researchers in developing a national-level survey to understand cultural determinants of Indigenous health and wellbeing.

Expressed in Chapter 5 through Antonovsky's (1979) river metaphor of the health/disease continuum, MK used its epidemiological framework to map the river and those who swim in it from an Indigenous standpoint, bringing together notions of risk and resilience within a complex systems model. This thesis thus contributes towards a growing body of work in anthropology which aims to understand individual and community capacity, capability, and strength through the concept of resilience (see Panter-Brick 2014), or social cohesion and self-efficacy (see Henderson and Kowal, 2011), instead of treading down the well-worn paths of suffering and structural violence (e.g. Burbank, 2011, Sutton, 2009). As the framework of cultural determinants of health gains research momentum in Australia and elsewhere, anthropological perspectives can provide valuable insights into how concepts of culture and its influence on health outcomes translate across qualitative-quantitative methodologies, disciplinary divides, and between Indigenous and non-Indigenous worldviews.

The Mayi Kuwayu Study is a microcosm of the global movement towards Indigenous self-determination through research. Within this study the use of strengths-based and decolonising practices, like its IDS and IDG protocols, stands in stark contrast to the ways in which national health surveys administered by the Australian Government have sought to represent Indigenous Australians. The absence of culture in identified determinants of Indigenous health over the last 40 years since the first national Aboriginal health report in 1979 reflects the absence of Indigenous people themselves in the design, implementation, and analyses of these data. The fact that MK has now been funded by Australia's premier

health research foundation (NHMRC), and the leading Indigenous health research organisation (Lowitja Institute), speaks volumes in favour of the benefits it may provide both to science and for Indigenous self-determination in the health landscape.

At the time of completing this thesis, the COVID-19 pandemic has gripped the world, and it is not possible to understand the lasting impact it will have on all our futures. Below, I detail what was happening with MK from April to July 2020, and what the researchers aimed to achieve in these few months while they worked from their homes during the lockdown in Australia.

In April 2020 I spoke with Ray Lovett to learn about the short-term future of MK. In March, the researchers cancelled their scheduled community visits to conduct face-to-face recruitment, however the online survey was still available for people to complete and MK continued to be advertised through social media. The researchers aimed to shift their focus in the meantime to work on a backlog of papers to be published. One of the papers relevant to this thesis was an account of how they had developed the metrics used in their survey, and the rationale they applied. They hope to publish this article in the journal *Australian Aboriginal Studies* managed by AIATSIS in December 2020.

The MK researchers were also in the process of putting together an expert panel to redesign the survey in time for the second wave scheduled for early 2021. There will be both internal and external processes for reviewing the survey. The internal process involving the MK staff, some of the CIs, and community-based researchers, will review unusual responses to survey questions and the items which participants recruited by community-based researchers needed clarified. The external process will involve collaboration with MK's partners and other experts to examine questions which may be redundant and how they might address priority areas which are not currently covered by the survey.

Alongside these projects the MK researchers are working with *Thiitu Tharrmay* ('to share knowledge' in Ngiyampaa), ANU's Aboriginal Reference Group, to develop a new conceptual model of Indigenous experiences of trauma within a directed acyclic graph (see Chapter 3). They are discussing the 'cause and effect' relationships between experiences of historical trauma (e.g. Stolen Generations) and Indigenous contemporary trauma (e.g. racism) and how these interact with social determinants of health to impact wellbeing outcomes. Their drive to do this theoretical work came from preliminary analyses of MK's baseline data (n = 7,526) which revealed that around 57% of participants had experienced at least one form of historical trauma (R Lovett 2020, personal communication, 9 July). They also found that contemporary experiences of trauma such as discrimination and racism, which 85% of respondents had experienced, were very strong mediators for almost all wellbeing indicators used in the survey, often demonstrating a 'dose-response' relationship with negative outcomes (R Lovett 2020, personal communication, 9 July). As predicted in Chapter 3, developing conceptual models to describe and analyse MK's data has become an important task for the researchers.

This thesis is the only ethnographic exploration of the first national health survey in Australia to be developed and owned by Indigenous Australians. In applying an Indigenist research approach alongside anthropological theory and methods, I was able to use the meta-research concept to gain unique insights on the Mayi Kuwayu Study, and how Indigeneity itself could become a research strategy. This thesis is an ethnographic example of how Indigenous-controlled power may be generated through data, and an exploration of its potential to work against systems of governmentality by challenging the Australian Government's centralised data monopoly. Its major findings provide an important contribution towards literature on anthropological methodologies and decolonial theory from an Indigenous standpoint, as well as literature on the framing of culture in

epidemiological research from a medical anthropology perspective. Developing new ways of adapting scientific tools to address Indigenous-identified priorities means that health research can truly empower Indigenous communities and decolonise wider social narratives. By making cultures count, the ability to shape the future of Indigenous health is already in our hands.

Appendix 1. Interview Details

Name	Identification	Role	Affiliation	Date	Location
Alyson Wright	Non-Indigenous Australian	Research Officer	NCEPH, ANU	31/1/18	Canberra, ACT
				9/11/18	Phone
Anna Olsen	Non-Indigenous Australian	CI	NCEPH, ANU	8/1/18	Canberra, ACT
Catherine D'Este	Non-Indigenous Australian	CI	NCEPH, ANU	13/2/18	Canberra, ACT
Dawn Casey	Tagalaka, QLD	Community Partner	NACCHO	16/3/18	Skype
Elsie Seriat	Wagadagum (Migi Buai) from Mabuiag Island, and Kaurareg from Kaiwalagal Archipelago, Torres Strait Islands, QLD	Community Partner/Focus Group Facilitator	Indigenous Marathon Project	17/5/17	Canberra, ACT
Emily Banks	Non-Indigenous Australian	CI	NCEPH, ANU	29/5/17	Canberra, ACT
				25/10/18	
Jan Chapman	Taungurong, VIC	Programme Manager	NCEPH, ANU	26/5/17	Canberra, ACT
				31/1/18	
				25/10/18	
Janet Smylie	Cree-Méti, Canada	CI	Dalla Lana School of Public Health, University of Toronto, and St. Michael's Hospital	26/10/17	Canberra, ACT
Jill Guthrie	Wiradjuri, NSW	CI	Research School of Population	31/5/17	Canberra, ACT

			Health, ANU		
Katie Thurber	Non-Indigenous American	Postdoctoral Fellow	NCEPH, ANU	22/11/17	Canberra, ACT
				17/11/18	Phone
Lachlan Russell	Non-Indigenous Australian	Ethics Manager	NCEPH, ANU	30/5/17	Canberra, ACT
Lisa Strelein	Non-Indigenous Australian	CI	AIATSIS	20/3/18	Skype
				12/11/18	Canberra, ACT
Maggie Walter	Palawa, TAS	AI	University of Tasmania	5/3/18	Skype
Mark Wenitong	Kabi Kabi, QLD	CI	Apunipima Cape York Health Council	25/1/18	Phone
Mary Guthrie	Wiradjuri, NSW	Funding Partner	Lowitja Institute	25/2/18	Email
Maureen Davey	Non-Indigenous Australian	Community Partner	Tasmanian Aboriginal Corporation	7/2/18	Phone
Raymond (Ray) Lovett	Wongaibon, NSW	CI (Mayi Kuwayu Study Lead)	NCEPH, ANU	6/5/17	Thursday Island, QLD
				9/1/18	Canberra, ACT
				6/2/18	
				27/10/18	
Rochelle Jones	Munns and Alberts families, QLD	Administration Assistant	NCEPH, ANU	25/5/17	Canberra, ACT
Ruth Gilbert	Wiradjuri, NSW/ACT	Communications Officer	NCEPH, ANU	16/11/17	Canberra, ACT
Terry Dunbar	Larrakia, Warumungu, and Iwaidja, NT	CI	Yaitya Purruna, Indigenous Health Unit,	15/2/18	Phone

			University of Adelaide		
			NCEPH, ANU	9/11/18	Canberra, ACT
Tom Calma	Kungarakan and Iwaidja, NT	Mayi Kuwayu Study Ambassador	Tackling Indigenous Smoking	6/11/18	Canberra, ACT
Wei Du	Non-Indigenous Chinese	CI	NCEPH, ANU	26/5/17	Canberra, ACT

Appendix 2. Interview Question Guide

Mayi Kuwayu Study Researcher/Staff

1. Do you identify as Aboriginal and/or Torres Strait Islander?
2. What has been your role in developing the survey?
3. How does this survey compare to other health surveys in your experience?
    a. Do you think it fits into the field of epidemiology?
4. What do you think about MK's conceptual model?
    a. Do you agree with it?
    b. Do you think anything is missing?
5. What role do you think having Indigenous governance over the survey has played?
6. From your experience, how have the community consultations worked?
7. What do you think the wider impact of the survey will be?
8. Who do you think will use the survey data and what for?
9. Is there anything you would like to add to something you said before?
10. Do you have any questions for me?

Community/Funding Partner

1. What is your relationship to the MK Study?
    a. How is the organisation you represent supporting the survey?
2. How does MK differ from other health surveys you have been involved with?
3. What do you think of how the survey is being developed? (e.g. Aboriginal and Torres Strait Islander researchers, community consultation, participant ownership of data)
4. In what ways does the survey meet the goals of your organisation?
    a. Have there been any changes that you requested be made to the survey or its development?
5. How does your organisation plan to use the data produced by this survey?
6. Are there any concerns or issues from your organisation that you have discussed with the MK researchers?
7. Is there anything you would like to add to something you said before?
8. Do you have any questions for me?

Mayi Kuwayu Study Ambassador (Tom Calma)

1. What has been your involvement with the MK Study to date?
2. What does your ambassador role involve? Is it long-term?
3. Have you been involved with other surveys of Indigenous health?
4. How do you see MK as being different from these other surveys?
5. What is your perspective on the idea of measuring culture?
6. What role do you think having Indigenous governance over the survey has played?
7. What do you think the wider impact of the survey will be?
8. How do you see MK interacting with the *Closing the Gap* campaign?
9. What do you think is the future of Indigenous health research in Australia?
10. Is there anything you would like to add to something you said before?
11. Do you have any questions for me?

Appendix 3. Thematic Analysis of Focus Group Data

	Theme	Dimensions	Descriptions	Focus Groups
Culture	Identity	Family	Family support in times of need (e.g. when someone passes away) Family support Respect for family Family knowledge/stories/traditions being passed down Looking after family/being responsible Family roles and traditions behind it/ways they're carried out Your family are your friends – focus of socialisation Caring and sharing with family	Alice Springs 1, 2 Bunbury 1, 2 Cairns Canberra Cowra Perth 1–7 Thursday Island
		Kinship	Knowing where you belong/Where you came from/Knowledge of identity/Family heritage Knowing where you stand as a person/How you fit in with family members on Country Structure of the family (knowing extended family) Kinship, marriage, and structures Roles with associated responsibilities Knowing identity and where you come from/Who your tribe and mob are Where you're made/Your belonging Bloodlines/Skin names/Skins/Mob Connection/interconnectedness/Keeps us strong	Alice Springs 1, 2 Bunbury 1, 2 Perth 1, 2, 4–7 Thursday Island
		Indigeneity	Connecting with other Aboriginal people and cultures Recognising other Indigenous people and feeling connected to them Confirmation of Aboriginality — need for statutory declarations of Aboriginality, but people don't know who their mob are Keeping identities secret in Central Australia — potential barrier for the survey People don't identify in the Census because they were/are afraid of the Government and what they might do with the information Recognition of Aboriginality	Alice Springs 1 Bunbury 2 Cairns Cowra Perth 3
		Totem	Knowing what your totem is but never learning the importance of it Connects tribes/families across Australia	Alice Springs 1, 2 Bunbury 2

			Totems and totemic systems Marine life Got our totem from where we come from	Perth 1, 5, 7 Thursday Island
		History	Direction (knowing your past and history to move forward and continually grow — all moving together) Oral histories	Alice Springs 2 Perth 4, 5
		Community	Women — glue and strength	Alice Springs 2 Perth 2, 3, 5, 7
		Social media	Potential of Facebook for staying in touch	Bunbury 1
	Country	Living on Country	Building rapport with doctors who then move and so people have to travel to see them Being on Country/Drinking from their waterholes/Eating bush tucker builds peoples strength up Ownership of Country Lack of employment in remote communities It connects with our culture/tribal group Healthy living lifestyle	Alice Springs 1, 2 Bunbury 1 Perth 6, 7
		Visiting Country	Going back to Country/Going bush/Access to Country Being on Country Islands Some people only get back to Country for funerals Sense of peace when visiting Country Men go back to Country more because they go hunting Going out on Country/Getting away from town can recharge peoples' batteries/Charge their energy Camping	Alice Springs 1, 2 Bunbury 1, 2 Cairns Perth 1, 2, 4–6 Thursday Island
		Being away from Country	Relocation for health reasons (e.g. Alice Springs, Adelaide, or Melbourne hospitals) People in cities not having access to traditional foods and family time Lack of funds/time to reconnect when living in the city Older people not being able to go hunting or gathering because of health/Mobility issues	Bunbury 1 Canberra
		Connection to Country	Spirit-land-culture connection Connection to Country and sea Being one with the winds, environment, seas (identify yourself with the sea and the air) Connection to spirits/ancestors Connection to ancestral lands (including non-Indigenous heritage) Learning/Knowing about Country Respect for land, preserve culture and land Mother Earth provides all that we need Our Lore is the lore of the land and that's what makes us strong	Alice Springs 2 Cairns Perth 1, 3–5 Thursday Island
		Environment	Environmental changes limiting traditional food sources Being in nature	Alice Springs 1, 2 Bunbury 2

			Connection with the environment and land (sea, bush) The river Threat of feral animals and weeds to sacred sites and areas Seasonal cycles Sustainability Continuation and strength Stars Footprints of the animals Can't take items off the land otherwise the person will get sick	Cairns Canberra Cowra Perth 4, 5, 7
		Significant sites	Sacred sites Scar trees Boundary lines	Alice Springs 1 Bunbury 1 Cairns Canberra Cowra Perth 4 Ulladulla
		Animals	Animal knowledge Dog companionship Animal relationships Hearing/Seeing animals Visiting the platypus Animal spiritual dream or Country	Alice Springs 2 Bunbury 1, 2 Cairns Canberra Cowra Perth 7 Ulladulla
	Language	Aboriginal and Torres Strait Islander languages	Including creole Use of pidgin English Don't miss language if you've never had it Hearing and speaking language makes you feel good Use of Aboriginal English Cultural revival (re-learning language)	Alice Springs 1, 2 Bunbury 1 Bunbury 2 Cairns Canberra Cowra Perth 1, 2, 4, 6, 7 Thursday Island Ulladulla

		English	Knowledge of English as limiting or facilitating meetings/Getting things done in the community Rangers sometimes act as translators for meetings	Alice Springs 1
	Lore/Law and Protocols	Lore/Law and protocols	Family relationships Responsibility under Lore/Law (women, men, skin system, moiety) Customs Accountability and respect Cultural protocols and rites Lore and respect Not being allowed to follow protocols when someone dies Correctness of who is involved in ceremonies/who is the correct person to teach other people about an area/get their permission to go somewhere, or they can come with you to make sure Protocol for what to do when someone dies Body language Gendered knowledges What's right and wrong for women/men's law and women's law Taboo	Alice Springs 1, 2 Bunbury 1 Cairns Canberra Cowra Perth 1, 4, 6, 7 Thursday Island Ulladulla
		Ceremony	Women's/Men's ceremony Initiation Ritual Ceremonies and procedures Sacred practices Past, meaning Sorry business and cultural protocols around this Adversity through sorry business and pain Smoking ceremonies/For babies/When somebody dies/Welcoming someone/Coming of age Connection to family ceremony Healing ceremonies	Alice Springs 1, 2 Bunbury 1 Cairns Canberra Cowra Perth 5, 6
		Songlines	History Spirit	Alice Springs 2 Perth 6
		Storylines	Maintaining storylines Knowing your tribal storylines from both mothers and fathers	Alice Springs 1, 2 Bunbury 1 Perth 6
		Elders	Respect for elders	Alice Springs 1, 2

			Protocols for how to treat elders Protocols/Respect for elders Elders keeping the family together/Backbone of our family Learning from elders/Our first teachers/Our guidance Help us connect back to Country	Bunbury 1 Cairns Cowra Perth 1–5, 7 Thursday Island Ulladulla
		Traditions	Traditional conditions and knowledge of the systems and traditions	Cairns Perth 2, 3
		Custodians	Custodianship of history of your connections	Alice Springs 1, 2 Perth 6, 7 Thursday Island
		Beliefs and values	Worldview Values, culturally specific behaviours Equal/Humble Empathy Collectivism/Together	Perth 4, 5
	Cultural Activities	Traditional foods	Bush foods Honey ants Cooking Ground ovens Cooking island food Comfort from making and eating traditional foods and dishes Sharing food with family	Alice Springs 2 Bunbury 1 Cairns Canberra Perth 1, 4, 7 Thursday Island Ulladulla
		Hunting and Gathering	Seasonal Fishing/Including fish traps Gathering Guidance and counselling would happen when people are out hunting — people are free to open up Learning of culture from family happens when hunting Learning numbers when hunting and gathering Learning skills and seasons	Alice Springs 1, 2 Bunbury 1, 2 Cairns Canberra Perth 4 Thursday Island Ulladulla
		Storytelling	Stories Creation stories Dreaming Dreamtime story	Alice Springs 1, 2 Cairns Canberra Perth 1–7
		Dancing	Dance Expression Island dancing	Alice Springs 2 Canberra Cowra

[redacted]			Learning culture through dancing Ceremony dancing Healing dancing Corroboree	Thursday Island
		Yarning	Campfire yarn	Cairns Perth 4 Thursday Island
		Traditional medicines	Bush medicine Old ways Witch doctors	Alice Springs 1 Canberra Perth 4, 7 Ulladulla
		Singing	Songs that have been passed down	Alice Springs 1, 2 Canberra Perth 5 Thursday Island
		Teaching	Teaching our kids/Teaching the culture to the young ones Passing knowledge onto the younger generations/Passing on cultural knowledge Teaching and learning Sharing knowledge Keeping what knowledge we have	Alice Springs 1, 2 Bunbury 2 Cairns Canberra Cowra Perth 2, 5 Thursday Island Ulladulla
		Women's/men's groups	Women's business	Alice Springs 2 Bunbury 1
		Events	Cultural events/Festivals (e.g. NAIDOC, Laura Festival) Corroboree Celebration	Alice Springs 2 Cairns Cowra Perth 4, 5
		Gardening	Big thing in the Torres Strait	Cairns
		Sharing	Sharing with others Reciprocity	Alice Springs 1, 2 Perth 4
		Humour	Sense of humour (Koori)	Cowra
		Music	Drums	Cowra Perth 7 Thursday Island

		Art	Rock art Painting	Cowra Perth 1, 3–5, 7
		Tools		Perth 1
		Cultural artefacts	School paddle	Perth 4 Thursday Island
	Wellbeing	Ancestors	Ancestral strength	Perth 3
		Balance	Lack of modern work-life balance Harmony and balance Aligning belief system/balance Health-wellbeing = environment	Cairns Perth 3, 4, 7 Thursday Island
		Healing	Cultural healing Spiritual healings Smoking healing Witch doctors — learn from an early age and they look at people who are most connected to Country to do them stuff	Alice Springs 2 Perth 5, 7
		Loss		Perth 7
		Collective	Collective experience — shared hardships and success	Perth 7
		Love	Love for family/Country/Language	Perth 7
		Self-determination		Perth 7
		Shame		Thursday Island
		Spirituality	Spiritual connection/Wellbeing *Kod* Physical, emotional and spiritual connection Good *liyan*	Alice Springs 2 Cowra Perth 5, 7 Thursday Island
		Senses	Using your sense to connect with your culture	Thursday Island
Other Factors	Colonisation	Stolen Generations	People not coming back after being taken away	Bunbury 1 Cairns Canberra Cowra
		Intergenerational trauma	Knowledge passed down about what happened to parents/grandparents Older people tend to keep secrets about bad things that happened to them in the past	Bunbury 1 Cowra
		Institutions	Loss of language (Government restricting language use in institutions)	Bunbury 1
		Relocation	Resettlement from traditional/tribal areas Displacement from Country and losing family connections Not being able to visit Country or family for many years Disconnection from families	Bunbury 1, 2 Cairns

		Loss of culture	Cultures been taken away, or not practised so there's a sense of loss because you don't have that connection Indigenous culture not fitting in with Western world	Alice Springs 2 Bunbury 2 Cairns
		Western foods	Unhealthy foods present in community (e.g. in shops, takeaways) Introduction of KFC/Island Rooster leading to habits of unhealthy food sharing (e.g. people taking KFC on the plane to TI)	Cairns Canberra
		Spirit	Colonisation — wounding of the spirit Deep spiritual wounds Keeping secrets about bad things affects you spiritually	Cairns Cowra
		Human rights	Needs not being met — basic human needs including physical, spiritual, emotional, mental, cultural	Cairns
		Christianity	Conflict between Aboriginal culture and Christianity Christianity aligning with traditional Torres Strait Islander mind-set Colonisation and the influences of missionaries Adapting to Church doctrine meant letting go of language and traditional practices	Cairns Thursday Island
		Racism		Cowra
		Destruction of land	Appropriation of ancestral lands for tourism/Destruction of sites for development	Cairns
		Australian Government	Issue with representation — Government just talking to a few people about something affecting many Difficult to get funding for cultural programmes from local government Government restrictions on fishing prevents cultural expression/celebrations Government restrictions on land development and throwing up roadblocks for progress for Aboriginal organisation — goes on for years and affects peoples' wellbeing	Alice Springs 1 Canberra Ulladulla
		Education	Better educated young people	Alice Springs 2 Cairns Perth 4
	Health Conditions and Behaviours	Diabetes		Bunbury 2 Canberra
		Cardiovascular disease	Heart problems	Alice Springs 1 Canberra
		Cancer	Leukaemia	Canberra Thursday Island
		Lupus		Canberra
		Gout		Alice Springs 1
		Mental illness		Alice Springs 1
		Alcoholism	To deal with trauma Alcohol	Alice Springs 1, 2 Bunbury 1 Cairns

		Drug abuse	Especially with younger people Drugs	Alice Springs 1 Bunbury 1 Cairns
		Smoking		Alice Springs 1
		Poor diet		Alice Springs 1 Cairns Canberra Thursday Island
		Sport		Cowra
	Social Dysfunction	Young people and children	Being disrespected/Treated poorly by young people Lack of knowledge/respect by young people Young people not valuing culture enough when they're taught it Children being put into foster care Drug use Child abuse Boredom is an issue for younger people, especially children, so they go into town, smoke, drink Children who have to go away for high school get lonely/Homesick and end up running away back to their family/communities Kids ignore adults and play on their electronic device in the car/house, when this time was used before to talk about culture, etc. Lack of interest from younger people to learn from elders — has led elders to ask Rangers to have their storylines recorded before they die Culture has become a story to young people because they're not out there practising it Not listening because technology now has come in, too much computers, video games	Alice Springs 1, 2 Bunbury 1 Cairns Ulladulla
		Sexual abuse		Cairns
		Domestic violence	Domestic and family violence Threat of violence	Alice Springs 1, 2 Bunbury 1
		Family responsibilities	Shame and frustration when vulnerable family members are not being taken care of Family dysfunction leads to lifelong struggle	Cairns
		People in jail		Bunbury 1
		Community politics	Disagreements within communities about how things should happen	Alice Springs 1
		Older people	Pubs and pokies taking older people away from the home where learning used to occur — only have school to teach young people	Thursday Island

[This table has been modified to remove sensitive information]

Appendix 4. Mayi Kuwayu Study Baseline Survey

51145

Mayi Kuwayu The National Study of Aboriginal and Torres Strait Islander Wellbeing

Our Cultures Count

the Lowitja Institute Australia's National Institute for Aboriginal and Torres Strait Islander Health Research

MAYI KUWAYU: THE NATIONAL STUDY OF ABORIGINAL AND TORRES STRAIT ISLANDER WELLBEING

The Mayi Kuwayu Study is controlled by Aboriginal researchers at the Australian National University. In Ngiyampaa language, 'Mayi Kuwayu' means to follow Aboriginal people over time.

We want to understand how Aboriginal and Torres Strait Islander culture links to health and wellbeing. We have worked with many Aboriginal and Torres Strait Islander people and communities to make this survey.

We invite you to complete this survey to help us understand how culture links to health and wellbeing. So that we can follow your health over time, we ask you to fill out the Mayi Kuwayu survey every few years, and to have your Mayi Kuwayu survey connected to other health information about you.

To do this survey online, go to: **https://mkstudy.com.au/ To do this survey over the phone,** call: 1 800 531 600 (free call).

FILLING IN THE SURVEY

To help us read your answers, please write as clearly as possible using a BLACK or DARK BLUE pen.

Circles mean select **one** response only ○

Boxes mean **select all answers that apply** ☐

Fill in the whole circle or box. Do not tick. ● Yes ○ No

If you make a mistake, cross it out and fill in the correct circle or box. ✗ Yes ● No

A B C 1 2 3

For written responses, fill in the text box with numbers or CAPITAL letters. If you make a mistake, cross it out, and write the correct answer above or below.

~~I N C O R R E C T~~

CORRECT

I am age 16 years or older: ○ Yes ○ No *If you are less than 16 years, do not do this survey.*

Your full name:

Your home address:

Suburb/ Town: **State/ Territory:** **Postcode:**

Mailing address, if different to home address:

Suburb/ Town: **State/ Territory:** **Postcode:**

I agree to complete the Mayi Kuwayu baseline survey (this survey). ○ Yes ○ No

I agree to have my Mayi Kuwayu survey data connected to health records about me, including hospital records, cancer records, and death records. ○ Yes ○ No

I agree to be contacted by the Mayi Kuwayu Study in the future. ○ Yes ○ No

I prefer to be contacted by: ☐ Phone ☐ Email ☐ Mail

Your mobile phone number(s):

Your email address:

If we can't reach you, who can we contact to find out where you are?

Full name of contact person:

Phone number(s):

Email address:

SIGNATURE

I have been provided with information about the Mayi Kuwayu Study including how the Study will gather, store, use and disclose my information. I have been given contact details if I want to ask questions.

Date today: (day/month/year) / / 2 0 1

Signature:

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IDENTITY, LANGUAGE, CULTURE AND COMMUNITY

IDENTITY AND COUNTRY

1. I am:
○ Aboriginal ○ Torres Strait Islander
○ Both Aboriginal and Torres Strait Islander
○ Neither Aboriginal or Torres Strait Islander

If you are not Aboriginal/Torres Strait Islander, do not continue.

2. Are there any other ways (nationality, ethnicity) you identify?
○ No ○ Yes, describe:

3. What is Aboriginal/Torres Strait Islander culture for you?

4. Who are your tribe(s) or mob(s)?

○ Unsure

5. What big family name(s) do you belong to?
Name(s)

○ Don't want to answer ○ Unsure

6. Do you know your skin name(s)?
○ No ○ Yes ○ Don't have a skin name ○ Unsure

7. Where is your tribe's (mob's) country(s)/Island(s)? *The area your ancestors are from.*

○ Unsure

8. Do you currently live on your country/Island?
○ No ○ Yes ○ Unsure

9. How much of your life have you lived on your tribe's (mob's) country/Island? *This includes all country you follow.*
○ None ○ A little bit ○ A fair bit ○ A lot
○ All of my life ○ Unsure

10. If you don't live on your tribe's (mob's) country/Island, how often do you visit? *Skip this question if you currently live on your tribe's (mob's) country/Island.*
○ None ○ A little bit ○ A fair bit ○ A lot ○ Unsure

11. Whose country(s)/Island(s) are you connected to? *Select all that apply.*
☐ Mother's ☐ Father's ☐ Other country ○ None ○ Unsure

12. Do you have special cultural responsibilities for country(s) /Island(s)? *Select all that apply.*
☐ Yes, mother's side ☐ Yes, father's side
☐ Yes, for other country ○ No ○ Unsure

13. What is the name of the suburb, community, outstation, town or Island where you currently live?

14. Is where you live a town camp, reserve or mission?
○ Town camp ○ Reserve ○ Mission ○ None of these
○ Unsure

15. Do you know your totem(s)/dreaming?
○ No ○ Yes ○ Unsure ○ Don't have one

16. Do you feel pressure to meet cultural obligations?
○ Not at all ○ A little bit ○ A fair bit ○ A lot ○ Unsure

17. Do you feel torn between your culture and non-Indigenous culture?
○ Not at all ○ A little bit ○ A fair bit ○ A lot ○ Unsure

18. Are there places where you choose to not identify as Aboriginal/Torres Strait Islander? *Select all that apply.*
☐ Hospital ☐ My regular health provider ☐ Medicare
☐ School or Uni ☐ Work ☐ Centrelink ☐ Census
☐ With friends ☐ In my community ☐ Housing or real estate
☐ Other, explain:
○ No

LANGUAGE

19. What is your first language?
○ Aboriginal/Torres Strait Islander language
○ English ○ Other

20. Do you speak any Aboriginal/Torres Strait Islander words or languages (includes songs and singing)?
○ No ○ Yes, a little bit ○ Yes, a fair bit ○ Yes, a lot

21. What Aboriginal/Torres Strait Islander words or languages do you know? This includes if you know some words or songs.

1.
2.
3.
4.
5.
6.
7.

22. Who else in your family speaks (spoke) Aboriginal/Torres Strait Islander words or languages? *Select all that apply.*
☐ My partner or spouse ☐ My child(ren) ☐ My grandchild(ren)
☐ My parent(s) ☐ My grandparent(s) ☐ My sibling(s)
☐ My cousin(s) ☐ My Aunty(ies) or Uncle(s) ☐ Other family
○ No one in my family ○ Unsure

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23. Tell us about your Aboriginal/Torres Strait Islander words or language.

	Want to but can't	Not at all	A little bit	A fair bit	A lot	Unsure
I am confident in speaking words or language.	○	○	○	○	○	○
It is important that I use words or language.	○	○	○	○	○	○
I feel good when I use words or language.	○	○	○	○	○	○
I am learning words or language.	○	○	○	○	○	○
My family is interested in keeping language strong.	○	○	○	○	○	○
My community is interested in keeping language strong.	○	○	○	○	○	○

24. Do you want to speak more English?
○ No ○ Yes

CULTURAL KNOWLEDGE AND PRACTICE

These are things that Aboriginal/Torres Strait Islander people have said are important to their culture. Not all people do these things, and that doesn't make you more or less Aboriginal/Torres Strait Islander.

25. How much time do you spend…

	Want to but can't	Not at all	A little bit	A fair bit	A lot
With someone who has cultural knowledge (elder or knowledge holder)?	○	○	○	○	○
Learning and using knowledge from Aboriginal/Torres Strait Islander Law (or Lore)?	○	○	○	○	○
On country?	○	○	○	○	○
Getting or eating bush tucker (includes traditional foods and fishing)?	○	○	○	○	○
Learning culture, kinship and respect?	○	○	○	○	○
Making art, music and paintings?	○	○	○	○	○
Passing on cultural knowledge?	○	○	○	○	○
Participating in social events related to Aboriginal/Torres Strait Islander people (such as NAIDOC week, Sorry Day events, cultural festivals, corroborree, marches or rallies)?	○	○	○	○	○
Contributing to your community (such as participating in community meetings, organising events, volunteering, healing, being on committees or boards)?	○	○	○	○	○
Receiving Aboriginal/Torres Strait Islander healing methods (such as traditional healers, bush medicine)?	○	○	○	○	○

26. Have you ever felt disconnected from Aboriginal/Torres Strait Islander culture?
○ Not at all ○ A little bit ○ A fair bit ○ A lot ○ Unsure

COMMUNITY

27. In the Aboriginal/Torres Strait Islander community <u>where I live now</u>...

	Not at all	A little bit	A fair bit	A lot	Unsure
There are people with cultural knowledge (cultural bosses or elders) I can go to or yarn with.	○	○	○	○	○
There are places for people to meet.	○	○	○	○	○
There are leaders.	○	○	○	○	○
We cope with problems.	○	○	○	○	○
We work together.	○	○	○	○	○
Local Aboriginal/Torres Strait Islander people make community decisions.	○	○	○	○	○
We respect the decisions made by our local community leaders.	○	○	○	○	○
The decisions we make are respected by government.	○	○	○	○	○
Government have the final say in decisions about the community.	○	○	○	○	○
I can get involved in community discussions.	○	○	○	○	○
I trust the leaders.	○	○	○	○	○
I feel listened to.	○	○	○	○	○
I feel respected.	○	○	○	○	○
I feel like a role model.	○	○	○	○	○
I feel like a leader.	○	○	○	○	○
I feel like I belong.	○	○	○	○	○

ABOUT YOU

28. What is your gender? ○ Male ○ Female ○ Other

29. Date of birth (day/month/year)
☐☐ / ☐☐ / ☐☐☐☐

30. Do you sleep in the same place most nights?
○ No ○ Yes

31. Where I live I am…
○ The owner or am buying a house
○ Renting ○ A visitor ○ Homeless

32. If you are renting, are you renting from: *Skip if you are not renting a house or room.*
○ Private rental ○ Government ○ Land Council
○ Housing Cooperative ○ Unsure
○ Other:

33. How many people live with you? ☐☐

34. How many <u>children</u> live with you? ☐☐

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35. Who lives with you? *Select all that apply.*

- ○ No one
- ☐ My partner or spouse
- ☐ My child(ren)
- ☐ My grandchild(ren)
- ☐ Someone else's children
- ☐ My parent(s)
- ☐ My grandparent(s)
- ☐ My sibling(s)
- ☐ My cousin(s)
- ☐ My Aunty(ies) or Uncle(s)
- ☐ Other family (in-laws)
- ☐ Other friends or visitors

36. Is where you live crowded?
○ Not at all ○ A little bit ○ A fair bit ○ A lot ○ Not relevant

37. Your height
☐☐☐ centimetres (cm) ***OR*** ☐ feet ☐☐ inches
○ Unsure

38. Your weight
☐☐☐ kilograms (kg) ***OR*** ☐☐ stone
○ Unsure

39. What is your current relationship status?
○ Partnered ○ Single ○ Other

40. Are you currently employed and/or studying? *Select all that apply*

- ☐ Casual paid work
- ☐ Part-time paid work
- ☐ Full-time paid work
- ☐ Self-employed
- ☐ Studying full-time
- ☐ Studying part-time
- ☐ Part-time unpaid carer
- ☐ Other, specify:
- ☐ Full-time unpaid carer
- ☐ Paid carer (carer's pension)
- ☐ Disabled/sick
- ☐ Retired
- ☐ Not employed but want to work
- ☐ Not employed and don't want to work
- ☐ Community Development Program (CDP, Work for the Dole)

41. What is the highest education you have completed?
○ No school ○ Primary school ○ Some high school
○ Year 10 (School or Intermediate certificate)
○ Year 12 (Higher school, leaving certificate, College)
○ Certificate or diploma (such as child care worker, mechanic)
○ University

42. Have you ever been in prison or youth detention? *Select all that apply.*
○ No ☐ Yes, prison ☐ Yes, youth detention

43. Which words best describe your family's money situation?
○ We have a lot of savings
○ We have some savings
○ We have just enough to get us to the next payday
○ We run out of money before payday
○ We are spending more than we get
○ Unsure

44. Do you receive welfare payments? *(Government/Centrelink)*
○ No ○ Yes ○ Unsure

45. Do you have a Basics Card? *(Cashless debit card)*
○ No ○ Yes ○ Unsure

46. Do you identify as... *Select all that apply.*
☐ Lesbian ☐ Gay ☐ Bisexual ☐ Transgender ☐ Intersex
☐ Queer ○ None of these ○ Prefer not to say
☐ Other:

HEALTH

GENERAL HEALTH

47. How would you rate your general health?
○ Excellent ○ Very good ○ Good ○ Fair ○ Poor

48. How satisfied are you with your life?
○ A lot ○ A fair bit ○ A little bit ○ Not at all

49. How much are you in control of your life?
○ A lot ○ A fair bit ○ A little bit ○ Not at all

50. In the last 4 weeks about how often did you …

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
… feel happy?	○	○	○	○	○
… feel worried?	○	○	○	○	○
… feel nervous?	○	○	○	○	○
… feel hopeless (have no hope)?	○	○	○	○	○
… feel restless or jumpy?	○	○	○	○	○
… feel everything was an effort (have no energy)?	○	○	○	○	○
… feel sad?	○	○	○	○	○
… feel pain?	○	○	○	○	○

If yes, what kind of pain:

MEDICATIONS AND HEALTH CONDITIONS

51. In the last month, did you regularly take any medicine?
○ No ○ Yes

52. If yes, was it for *(select all that apply):*

- ☐ Heart disease
- ☐ Cholesterol
- ☐ Blood pressure
- ☐ Blood clot
- ☐ Diabetes
- ☐ Infections (antibiotics)
- ☐ Birth control
- ☐ Asthma (such as inhaler)
- ☐ Depression
- ☐ Other:
- ☐ Anxiety
- ☐ Other mental health conditions
- ☐ Drug or alcohol problem
- ☐ Arthritis
- ☐ Pain
- ☐ Epilepsy
- ☐ Thyroid problem
- ☐ Stomach problem
- ○ Unsure

53. Has a doctor ever told you that you have…

- ☐ Heart disease
- ☐ High cholesterol
- ☐ High Blood pressure
- ☐ Blood clot
- ☐ Diabetes
- ☐ Skin infection
- ☐ Chest infection
- ☐ Ear infection
- ☐ Sexually transmitted infection
- ☐ Asthma
- ☐ Depression
- ☐ Anxiety
- ☐ Other mental health conditions
- ☐ Other:
- ☐ Drug or alcohol problem
- ☐ Arthritis
- ☐ Epilepsy
- ☐ Thyroid problem
- ☐ Stomach problem
- ☐ Stroke
- ☐ Lung cancer
- ☐ Other cancers
- ☐ Other lung problems
- ☐ Dementia
- ☐ Hearing loss
- ☐ Kidney problems
- ☐ A disability
- ○ None of these conditions
- ○ Unsure

MOBILITY

54. Thinking about your mobility, do you have difficulty…

	Not at all	A little bit	A fair bit	A lot	Not relevant
Taking a bath or shower?	○	○	○	○	○
Getting dressed?	○	○	○	○	○
Walking?	○	○	○	○	○
Climbing stairs or walking up hills?	○	○	○	○	○
Jogging or running?	○	○	○	○	○
At work (job)?	○	○	○	○	○
Caring for children or others?	○	○	○	○	○
Other? Specify:	○	○	○	○	○

The next question is about exercise you did last week. *This includes **light exercise** (such as walking), **moderate exercise** (such as jogging), **and intense exercise** (such as fast running or sport).*

55. Select the days you did 30 or more minutes of exercise last week.

	When you exercised, was it: Light	Moderate	Intense
☐ Monday	○	○	○
☐ Tuesday	○	○	○
☐ Wednesday	○	○	○
☐ Thursday	○	○	○
☐ Friday	○	○	○
☐ Saturday	○	○	○
☐ Sunday	○	○	○

HEALTH CARE

56. Where do you usually go for health care (non-urgent)? *Select all that apply.*

☐ Aboriginal Medical Service or Community Controlled Health Service

☐ GP clinic ☐ Hospital ☐ Traditional Healer ☐ Unsure

☐ Other:

57. If you could choose, where would you go for health care (non-urgent)? *Select all that apply.*

☐ Aboriginal Medical Service or Community Controlled Health Service

☐ GP clinic ☐ Hospital ☐ Traditional Healer ☐ Unsure

☐ Other:

58. In the last six months, how many times have you seen a health provider about your health?

☐☐ times ○ None ○ Unsure

59. Have you had an Aboriginal/Torres Strait Islander Health Check in the last year? Also called an Adult Health Check or 715.

○ No
○ Yes
○ Unsure

ALCOHOL, SMOKING AND GAMBLING

ALCOHOL

60. Do you drink alcohol?

○ Yes - **Answer Questions 61 to 64**
○ I drank in the past, but don't drink now - **Answer Questions 65 to 68**
○ I have never been a drinker - **Go to Question 69**

Answer Questions 61 to 64 if you currently drink alcohol

61. How often do you drink alcohol?

○ Monthly or less
○ 2 to 4 times a month
○ 2 to 3 times a week
○ 4 or more times a week

62. When you drink, how many drinks do you usually have in one day?

○ 1 or 2
○ 3 or 4
○ 5 or 6
○ 7 to 9
○ 10 or more

63. How often do you have six or more drinks in one day?

○ Never
○ Less than once a month
○ Monthly
○ Weekly
○ Daily or most days

64. Do you get shaky if you don't have alcohol?

○ No
○ Yes

Now go to Question 69

Answer Questions 65 to 68 if you used to drink alcohol

65. When you used to drink, how often did you drink alcohol?

○ Monthly or less
○ 2 to 4 times a month
○ 2 to 3 times a week
○ 4 or more times a week

66. When you used to drink, how many drinks did you usually have in one day?

○ 1 or 2
○ 3 or 4
○ 5 or 6
○ 7 to 9
○ 10 or more

67. When you used to drink, how often did you have six or more drinks in one day?

○ Never
○ Less than once a month
○ Monthly
○ Weekly
○ Daily or most days

68. When you used to drink, did you get shaky if you didn't have alcohol?

○ No
○ Yes

Now go to Question 69

SMOKING

69. Do you smoke?
- ○ Yes, I currently smoke - **Answer Questions 70 to 78**
- ○ I smoked in the past, but don't smoke now - **Answer Questions 79 to 87**
- ○ I have never been a smoker - **Go to Question 88**

Answer Questions 70 to 78 if you currently smoke

70. How often do you smoke?
- ○ Less than weekly
- ○ Weekly (not every day)
- ○ Every day

71. How many cigarettes do you usually smoke in one day?

☐☐

72. How soon after waking do you usually have your first smoke?
- ○ 5 minutes or less
- ○ 6-30 minutes
- ○ 31-60 minutes
- ○ 61 or more minutes
- ○ Don't smoke every day

73. How old were you when you started smoking?

☐☐ years

74. Do you want to quit smoking?
- ○ Not at all - **Go to Question 76**
- ○ A little bit
- ○ A fair bit
- ○ A lot
- ○ Unsure

75. Why do you want to quit? *Select all that apply.*
- ☐ Advertising against smoking
- ☐ Medical advice ☐ My health
- ☐ Health of my family
- ☐ Cost ☐ Pregnancy
- ☐ Too many non-smoking areas
- ☐ Pressure from family or friends
- ☐ Other:

76. In the last year, have you tried to quit or reduce the amount you smoke? *Select all that apply.*
- ☐ Tried to quit smoking
- ☐ Tried to reduce smoking
- ○ Have not tried to quit or reduce smoking

77. Do you think your smoking has made you sick?
○ No ○ Yes ○ Unsure

78. Do you think your smoking will make you sick in the future?
○ Not at all ○ A little bit ○ A fair bit ○ A lot ○ Unsure

Now go to Question 88

Answer Questions 79 to 87 if you used to smoke

79. When you used to smoke, how often did you smoke?
- ○ Less than weekly
- ○ Weekly (not every day)
- ○ Every day

80. When you used to smoke, how many cigarettes did you usually smoke in one day?

☐☐

81. How soon after waking did you usually have your first smoke?
- ○ 5 minutes or less
- ○ 6-30 minutes
- ○ 31-60 minutes
- ○ 61 or more minutes
- ○ Don't smoke every day

82. How old were you when you started smoking?

☐☐ years

83. How long ago did you quit?
- ○ 1 to 5 months
- ○ 6 months to a year
- ○ 1 to 2 years
- ○ 2 to 5 years
- ○ More than 5 years

84. What led you to quit? *Select all that apply.*
- ☐ Advertising against smoking
- ☐ Medical advice ☐ My health
- ☐ Health of my family
- ☐ Cost ☐ Pregnancy
- ☐ Too many non-smoking areas
- ☐ Pressure from family or friends
- ☐ Other:

85. What helped you quit? *Select all that apply.*
- ☐ Smoking program ☐ Quitline
- ☐ Online support ☐ Health professional
- ☐ Family or friends
- ☐ Patches, gum, inhaler (NRT)
- ☐ Stop smoking medication
- ☐ Quit on my own
- ☐ Other:

86. Do you think your smoking has made you sick?
○ No ○ Yes ○ Unsure

87. Do you think your past smoking will make you sick in the future?
○ Not at all ○ A little bit ○ A fair bit ○ A lot ○ Unsure

Now go to Question 88

88. Does anyone smoke in your home or in your car?
- ○ No
- ☐ Yes, inside the home
- ☐ Yes, outside the home
- ☐ Yes, in the car

89. How much do you agree?	**Not at all**	**A little bit**	**A fair bit**	**A lot**
Non-smokers miss out on gossip or yarning.	○	○	○	○
My community disapproves of smoking.	○	○	○	○
Smoking is not that risky.	○	○	○	○

GAMBLING

90. Have you bet or spent money gambling in the last year?
- ○ No
- ○ Yes

91. Do you think you've ever had a problem with gambling?
- ○ No
- ○ Yes
- ○ Unsure

YOUR EXPERIENCES

PROGRAMS AND SERVICES

92. Have you ever participated in: *Select all that apply.*

☐ Deadly Runners or Indigenous Marathon Project
☐ Koori or Murri Knockout ☐ Traditional Owner Group
☐ Ranger program ☐ Indigenous Protected Areas
☐ Native Title group ☐ Family Wellbeing Program
☐ Deadly Choices ☐ Language program ☐ NDIS
☐ Any Quit Smoking Program, Service or Activity ☐ ANFPP
○ None of these

93. Do you have any of these services where you live?
Select all that are in your community.

☐ Store or Shop ☐ School ☐ AMS or ACCHO ☐ Ambulance
☐ Church ☐ Sport Club ☐ Youth group
☐ Art or Cultural Centre ☐ Community or Local Council
☐ Justice Group ☐ Police ☐ Fire ○ None of these
☐ Other:

94. Where you live, are any of these services controlled by local Aboriginal/Torres Strait Islander people?
Select all that are controlled by local people.

☐ Store or Shop ☐ School ☐ AMS or ACCHO ☐ Ambulance
☐ Church ☐ Sport Club ☐ Youth group
☐ Art or Cultural Centre ☐ Community or Local Council
☐ Justice Group ☐ Police ☐ Fire ○ None of these
☐ Other:

DISCRIMINATION/RACISM IN EVERYDAY LIFE

95. How often do these things happen to you?	Not at all	A little bit	A fair bit	A lot
I am treated with less respect than other people.	○	○	○	○
I receive worse service than other people (including at restaurants, stores, Centrelink, housing).	○	○	○	○
People act like I am not smart.	○	○	○	○
People act like they are afraid of me.	○	○	○	○
I am called names, insulted, or yelled at.	○	○	○	○
I am followed around in shops.	○	○	○	○
I am watched more closely than others at work or school.	○	○	○	○
Police unfairly bother me.	○	○	○	○

96. When these things happen, do you think it is because you are Aboriginal/Torres Strait Islander?

○ Not at all
○ A little bit
○ A fair bit
○ A lot

97. How much do these things affect your life?

○ Not at all
○ A little bit
○ A fair bit
○ A lot

DISCRIMINATION/RACISM IN HEALTH CARE

98. How often do these things happen to you <u>when you receive health care</u>?	Not at all	A little bit	A fair bit	A lot
Health care providers do not listen to what I say.	○	○	○	○
I have to wait longer than other people.	○	○	○	○
I receive poorer health care than other people.	○	○	○	○
I go home without the care I need.	○	○	○	○

99. When these things happen, do you think it is because you are Aboriginal/Torres Strait Islander?

○ Not at all
○ A little bit
○ A fair bit
○ A lot

100. How much do these things affect your life?

○ Not at all
○ A little bit
○ A fair bit
○ A lot

WORRIES IN THE FAMILY AND COMMUNITY

101. In the <u>last year</u>, has any one in your close family …	No	Yes	Not relevant
Been badly hurt or sick?	○	○	○
Passed away?	○	○	○
Lost a job?	○	○	○
Had problems at work?	○	○	○
Had an alcohol or drug problem?	○	○	○
Experienced violence?	○	○	○
Had stuff stolen?	○	○	○
Been arrested or been in youth detention or prison?	○	○	○
Had a relationship break up (split up)?	○	○	○
Had children taken away?	○	○	○

102. Are any of these a problem <u>where you live</u>?	Not at all	A little bit	A fair bit	A lot	Unsure
Drinking too much grog?	○	○	○	○	○
Tobacco smoking?	○	○	○	○	○
Drugs?	○	○	○	○	○
Sniffing?	○	○	○	○	○
Racism?	○	○	○	○	○
Gambling?	○	○	○	○	○
Family violence?	○	○	○	○	○
People fighting or not getting along?	○	○	○	○	○
Humbugging (people wanting stuff all the time)?	○	○	○	○	○

FAMILY SUPPORT AND CONNECTION

CARING

103. In my family…

	Not at all	A little bit	A fair bit	A lot	Unsure
We get on together and cope in the hard times.	○	○	○	○	○
We celebrate special days/events.	○	○	○	○	○
We talk with each other about the things that matter.	○	○	○	○	○
We are always there for each other.	○	○	○	○	○
We manage money well.	○	○	○	○	○
We have common interests.	○	○	○	○	○
People are accepted for who they are.	○	○	○	○	○
We have good support from mob.	○	○	○	○	○
We have family knowledge and traditions that we pass on to our children.	○	○	○	○	○

104. Who raised you? *Select all that apply.*

☐ My mother (birth/biological) ☐ My father (birth/biological)
☐ My Aunty(ies) or Uncle(s)
☐ My Grandparent(s) or Great Grandparent(s)
☐ My brother(s) or sister(s) ☐ My cousin(s)
☐ Kinship carer(s) ☐ Myself ☐ Foster or adoptive parents
☐ Other family member(s)
☐ Domestic school (e.g. Cootamundra)
☐ Institution (children's home)
☐ Other carers outside your family (e.g. Station boss)
☐ Other, explain:

105. Do you often care for a sick or disabled family member or friend?

○ No ○ Yes

106. If yes, how many hours each week do you usually spend caring for this person?

☐☐ hours per week ***OR*** ○ Unsure

MISSIONS, STATIONS AND RESERVES

Some groups were forcibly relocated to other places like missions, stations or reserves.

107. Did this happen to your tribe (mob)?

○ No ○ Yes ○ Unsure

If yes, where was your tribe (mob) moved to?

STOLEN GENERATIONS

The Stolen Generations (also known as Stolen Children) are Aboriginal/Torres Strait Islander people removed from their families by government agencies.

108. Growing up, did your family worry about children being Stolen?

○ Not at all
○ A little bit
○ A fair bit
○ A lot
○ Unsure

109. Were any of these people Stolen? *Select all that apply.*

☐ I was Stolen ☐ My brother(s) or sister(s) ☐ My child(ren)
☐ My grandchild(ren) ☐ My parent(s)
☐ My Aunty(ies) or Uncle(s) ☐ My cousin(s)
☐ My Grandparent(s) or Great Grandparent(s)
☐ Other, explain:
○ None of these

110. Were any of your family members reunited with family after being Stolen? *Select all that apply.*

☐ I was reunited ☐ My brother(s) or sister(s) ☐ My child(ren)
☐ My grandchild(ren) ☐ My parent(s)
☐ My Aunty(ies) or Uncle(s) ☐ My cousin(s)
☐ My Grandparent(s) or Great Grandparent(s)
☐ Other, explain:
○ None of these

How did you find out about this survey?

☐ Sent to me in the post ☐ Sent to someone I know
☐ Community researcher ☐ Community organisation
☐ Newspaper ☐ TV
☐ Other:

Know someone else who wants to do this survey? They can fill it out at https://mkstudy.com.au/ or call the Mayi Kuwayu Study on 1800 531 600 (free call).

By completing this survey, you have consented to having your survey responses used for the purposes of this research. For more information, see the Study Information Sheet.

If you have any questions about the Study or if any part of this survey raised concerns, please ring the Study on 1800 531 600 or email mkstudy@anu.edu.au. Contact details for a range of Aboriginal and Torres Strait Islander services are available from: http://www.sewbmh.org.au/location/list.

Thank you very much for taking part.

Appendix 5. Mayi Kuwayu Study Focus Group Details

Location	Organisation Type	Date	Number of Participants			Participant Observation	Audio Transcript
			Females	Males	Age Range (years)		
Albury, NSW	Health service	Jan-Feb '15	2	7	Not reported	No	No
Alice Springs, NT	Ranger group	7/2/17	3	4	30–55	No	Yes
	Women's group	12/5/17	4	0	35–66	Yes	Yes
Bunbury, WA	Health service (two focus groups)	26/4/17	7	1	21–63 (9 not reported)	Yes	Yes
			12	1		No	Yes
	Women's group	27/11/17	10	0	Not reported	Yes	No
Cairns, QLD	University group	4/5/17	3	1	32–66	Yes	Yes
Canberra, ACT	National Indigenous studies conference (three focus groups)	22/3/17	25		Not reported	No	No
	Law and culture group visiting from SA and NT	26/5/17	5	2	Not reported	No	Yes
	Health service	14/11/17	3	2	Not reported	Yes	No
Cowra, NSW	Neighbourhood organisation	18/4/17	5	2	Not reported	No	Yes

Deniliquin, NSW	Community organisation (four focus groups)	Jan–Feb '15	16	9	Not reported	No	No
Perth, WA	National Indigenous health conference	28/11/17	5	1	Not reported	No*	No
			8	1		No*	
			0	5		No*	
			1	6		No*	
			7	1		Yes	
			0	4		No*	
			0	9		No*	
Risdon Cove, TAS	Community organisation	9/12/17	4	4	24–61	Yes	No
Thursday Island, QLD	Community group	6/5/17	2	3	25–62	Yes	Yes
Ulladulla, NSW	Community organisation	19/2/17	4	5	33–78	No	Yes
Wadeye, NT	Community organisation	12/17	2	1	Not reported	No	No

* The notes available from these focus groups were written down by participants on butcher's paper.

[This table has been modified to remove sensitive information]

References

ABORIGINAL AND TORRES STRAIT ISLANDER HEALING FOUNDATION DEVELOPMENT TEAM 2009. *Voices from the campfires: Establishing the Aboriginal and Torres Strait Islander Healing Foundation*. Canberra, ACT: Commonwealth of Australia.

ABORIGINAL LAND COUNCILS AND THE NT GOVERNMENT. 2018. *The Barunga Agreement* [Online]. Alice Springs, NT. Available: https://dcm.nt.gov.au/__data/assets/pdf_file/0003/514272/barunga-muo-treaty.pdf [Accessed 20 March 2020].

ABS. 2013. *4727.0.55.001 - Australian Aboriginal and Torres Strait Islander Health Survey: First results, Australia, 2012-13: Psychological distress* [Online]. Canberra, ACT: Australian Bureau of Statistics. Available: http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/9F3C9BDE98B3C5F1CA257C2F00145721?opendocument [Accessed 29 August 2018].

ABS. 2014. *1200.0.55.008 - Indigenous Status Standard , 2014, version 1.5* [Online]. Canberra, ACT: Australian Bureau of Statistics. Available: https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/1200.0.55.008Main%20Features52014,%20Version%201.5?opendocument&tabname=Summary&prodno=1200.0.55.008&issue=2014,%20Version%201.5&num=&view= [Accessed 29 April 2020].

ABS. 2016a. *2014-15 National Aboriginal and Torres Strait Islander Social Survey (NATSISS): Household survey questionnaire* [Online]. Canberra, ACT: Australian Bureau of Statistics. Available: https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4714.02014-15?OpenDocument [Accessed 6 October 2020].

ABS. 2016b. *2016 Census QuickStats: Bunbury (C)* [Online]. Canberra, ACT: Australian Bureau of Statistics. Available: http://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/LGA51190 [Accessed 7 February 2019].

ABS. 2016c. *2016 Census QuickStats: Thursday Island* [Online]. Canberra, ACT: Australian Bureau of Statistics. Available: https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/SSC32851 [Accessed 22 May 2018].

ABS. 2016d. *2901.0 - Census of population and housing: Census dictionary, 2016: Indigenous Household Indicator (INGDWTD)* [Online]. Canberra, ACT: Australian Bureau of Statistics. Available: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2901.0Chapter36752016 [Accessed 15 August 2019].

ABS. 2017. *2071.0 - Census of population and housing: Reflecting Australia - Stories from the Census, 2016* [Online]. Canberra, ACT: Australian Bureau of Statistics. Available:

https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/2071.0~2016~Main%20Features~Aboriginal%20and%20Torres%20Strait%20islander%20Population%20Article~12 [Accessed 25 February 2020].

[Reference removed]

ABS. 2019. *Glossary: Housing utilisation* [Online]. Available: https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4714.0Glossary12014-15#Housingutilisation [Accessed 30 April 2019].

ADAMS, G. & MARKUS, H. R. 2004. Toward a conception of culture suitable for a social psychology of culture. *In:* SCHALLER, M. & CRANDALL, C. S. (eds.) *The psychological foundations of culture.* Mahwah, NJ: Lawrence Erlbaum Associates, Inc., pp. 335-360.

AIATSIS. 2012. *Guidelines for ethical research in Australian Indigenous studies* [Online]. Canberra, ACT: Australian Institute of Aboriginal and Torres Strait Islander Studies. Available: https://aiatsis.gov.au/sites/default/files/docs/research-and-guides/ethics/GERAIS.pdf [Accessed 9 April 2019].

AIATSIS. 2018. *Indigenous Australians: Aboriginal and Torres Strait Islander people* [Online]. Canberra, ACT: Australian Institute of Aboriginal and Torres Strait Islander Studies. Available: https://aiatsis.gov.au/explore/articles/indigenous-australians-aboriginal-and-torres-strait-islander-people [Accessed 29 March 2019].

AIATSIS. 2019. *Indigenous Australian languages* [Online]. Canberra, ACT: Australian Institute of Aboriginal and Torres Strait Islander Studies. Available: https://aiatsis.gov.au/explore/articles/indigenous-australian-languages [Accessed 29 March 2019].

AIATSIS. 2020. *The Barunga Statement* [Online]. Canberra, ACT: Australian Institute of Aboriginal and Torres Strait Islander Studies. Available: https://aiatsis.gov.au/barunga-statement [Accessed 20 March 2020].

AIATSIS AND THE LOWITJA INSTITUTE. 2013. *Research right way: Aboriginal and Torres Strait Islander research ethics: A domestic and international review* [Online]. Available: https://www.nhmrc.gov.au/sites/default/files/documents/Indigenous%20guidelines/evaluation-literature-review-atsi-research-ethics.pdf [Accessed 28 September 2018].

AIATSIS AND THE LOWITJA INSTITUTE 2017. *Changing the narrative in Aboriginal and Torres Strait Islander health research: Four Cooperative Research Centres and the Lowitja Institute: The story so far.* Carlton South, VIC: The Lowitja Institute.

AIHW. 2013. *Indigenous statistics: Quality and availability* [Online]. Available: http://www.aihw.gov.au/indigenous-statistics-quality-availability/ [Accessed 24 August 2014].

AIHW. 2016. Australian burden of disease study: Impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011. *Australian Burden of Disease Study series no. 6, Cat. no. BOD 7*. Canberra, ACT: Australian Institute of Health and Welfare.

AIHW. 2017. Aboriginal and Torres Strait Islander health performance framework 2017: Supplementary online tables. *Cat. no. WEB 170*. Canberra, ACT: Australian Institute of Health and Welfare.

AIHW. 2018. Aboriginal and Torres Strait Islander Stolen Generations and descendants: Numbers, demographic characteristics and selected outcomes. *Cat. no. IHW 195*. Canberra, ACT: Australian Institute of Health and Welfare.

AIHW. 2019. Supplementary tables. *Aboriginal and Torres Strait Islander people: A focus report on housing and homelessness*. Canberra, ACT: Australian Institute of Health and Welfare.

ALLEN, J. S. & JOBSON, R. C. 2016. The decolonizing generation: (Race and) theory in anthropology since the eighties. *Current Anthropology*, 57 (2), 129-148.

ANDERSON, H. & KOWAL, E. 2012. Culture, history, and health in an Australian Aboriginal community: The case of Utopia. *Medical Anthropology*, 31 (5), 438-457.

ANTAC. 2020. *About us* [Online]. Aṉangu Ngangkaṟi Tjutaku Aboriginal Corporation. Available: https://www.antac.org.au/about-antac/about-us [Accessed 15 June 2020].

ANTONOVSKY, A. 1979. *Health, stress, and coping: New perspectives on mental and physical well-being,* San Francisco, CA, Jossey-Bass.

ANTONOVSKY, A. 1987. *Unraveling the mystery of health: How people manage stress and stay well,* San Francisco, CA, Jossey-Bass.

ANTONOVSKY, A. 1996. The salutogenic model as a theory to guide health promotion. *Health Promotion International,* 11 (1), 11-18.

APPADURAI, A. 2004. The capacity to aspire: Culture and the terms of recognition. *In:* RAO, V. & WALTON, M. (eds.) *Culture and public action.* Stanford, CA: Stanford University Press, pp. 59-84.

ARMSTRONG, R. M. 2011. Questions and answers in Indigenous health. *Medical Journal of Australia,* 194 (10), 491.

AUSTRALIAN GOVERNMENT. 1975. *Racial Discrimination Act 1975* [Online]. Available: https://www.legislation.gov.au/Details/C2016C00089 [Accessed 9 April 2019].

AUSTRALIAN INDIGENOUS GOVERNANCE INSTITUTE. 2018. *4.1 Aboriginal and Torres Strait Islander leadership* [Online]. Available: http://toolkit.aigi.com.au/toolkit/4-1-indigenous-leadership [Accessed 26 September 2018].

AUSTRALIAN INDIGENOUS HEALTHINFONET. 2019. *History of Closing the Gap* [Online]. Available: https://healthinfonet.ecu.edu.au/learn/health-system/closing-the-gap/history-of-closing-the-gap/ [Accessed 23 May 2020].

AUSTRALIAN LAW REFORM COMMISSION. 1986. *Recognition of Aboriginal customary laws (ALRC Report 31)* [Online]. Available: https://www.alrc.gov.au/sites/default/files/pdfs/publications/ALRC31.pdf [Accessed 26 February 2016].

AUSTRALIAN LITERACY AND NUMERACY FOUNDATION. 2019. *Indigenous first language* [Online]. Available: https://alnf.org/program/firstlanguages/ [Accessed 3 October 2019].

AYUNERAK, P., ALSTROM, D., MOSES, C., CHARLIE, J. C. S. & RASMUS, S. M. 2014. Yup'ik culture and context in southwest Alaska: Community member perspectives of tradition, social change, and prevention. *American Journal of Community Psychology,* 54 (1-2), 91-99.

BALS, M., LENE TURI, A., SKRE, I. & KVERNMO, S. 2011. The relationship between internalizing and externalizing symptoms and cultural resilience factors in Indigenous Sami youth from Arctic Norway. *International Journal of Circumpolar Health,* 70 (1), 37-45.

BAMBLETT, L. 2011. Straight-line stories: Representations and Indigenous Australian identities in sports discourses. *Australian Aboriginal Studies*, 2, 5-20.

BANDURA, A. 1986. *Social foundations of thought and action: A social cognitive theory,* Englewood Cliffs, NJ, Prentice-Hall, Inc.

BANNER, S. 2005. Why terra nullius? Anthropology and property law in early Australia. *Law and History Review,* 2 (1), 95-131.

BARBOUR, R. S. 1998. Mixing qualitative methods: Quality assurance or qualitative quagmire? *Qualitative Health Research,* 8 (3), 352-361.

BARRETT, M. 2020. *An introduction to directed acyclic graphs* [Online]. Available: https://cran.r-project.org/web/packages/ggdag/vignettes/intro-to-dags.html [Accessed 16 April 2020].

BARTLETT, B. 1998. *Origins of persisting poor Aboriginal health.* Master of Public Health, University of Sydney.

BATTAGLIA, M. P. (ed.) 2008. *Purposive sample,* Thousand Oaks, CA: SAGE Publications, Inc.

BATTISTE, M. 2007. Research ethics for protecting Indigenous knowledge and heritage: Institutional and researcher responsibilities. *In:* DENZIN, N. & GIARDINA, M. (eds.) *Ethical futures of qualitative research: Decolonizing the politics of knowledge.* Walnut Creek, CA: Left Coast Press, pp. 111-127.

BÉHAGUE, D., GONÇALVES, H. & VICTORA, C. 2008. Anthropology and epidemiology: Learning epistemological lessons through a collaborative venture. *Ciência & Saúde Coletiva*, 13 (6), 1701-1710.

BEN-NUN, P. 2008. *Respondent fatigue* [Online]. Thousand Oaks, CA: SAGE Publications, Inc. Available: https://methods.sagepub.com/reference/encyclopedia-of-survey-research-methods [Accessed 11 April 2019].

BEN-SHLOMO, Y. & KUH, D. 2002. A life course approach to chronic disease epidemiology: Conceptual models, empirical challenges and interdisciplinary perspectives. *International Journal of Epidemiology,* 31 (2), 285-293.

BÉTEILLE, A. 1998. The idea of Indigenous people. *Current Anthropology,* 39 (2), 187-192.

BETHUNE, R., ABSHER, N., OBIAGWU, M., QARMOUT, T., STEEVES, M., YAGHOUBI, M., TIKOO, R., SZAFRON, M., DELL, C. & FARAG, M. 2019. Social determinants of self-reported health for Canada's indigenous peoples: A public health approach. *Public Health*, 176, 172-180.

BIDDLE, N. & SWEE, H. 2012. The relationship between wellbeing and Indigenous land, language and culture in Australia. *Australian Geographer,* 43 (3), 215-232.

BISHOP, B. J., VICARY, D. A., MITCHELL, J. R. & PEARSON, G. 2012. Aboriginal concepts of place and country and their meaning in mental health. *The Australian Community Psychologist,* 24 (2), 26-42.

BITTENCOURT, N. F. N., MEEUWISSE, W. H., MENDONÇA, L. D., NETTEL-AGUIRRE, A., OCARINO, J. M. & FONSECA, S. T. 2016. Complex systems approach for sports injuries: Moving from risk factor identification to injury pattern recognition — Narrative review and new concept. *British Journal of Sports Medicine,* 50 (21), 1309-1314.

BLEAKLEY, J. W. 1928. *The Aboriginals and half-castes of Central Australia and North Australia: Report.* Melbourne, VIC: Government Printer.

BOURCHIER, D. 2018. *Elsie Seriat awarded an OAM for service to the Indigenous community of Thursday Island* [Online]. ABC Radio. Available: https://www.abc.net.au/radio/canberra/programs/breakfast/elsie-seriat-awarded-order-of-australia-medal/9856546 [Accessed 12 February 2019].

BOURDIEU, P. 1984. *Distinction: A social critique of the judgement of taste,* London, Routledge & Kegan and Paul, Ltd.

BOURDIEU, P. 1986. The forms of capital. *In:* RICHARDSON, J. G. (ed.) *Handbook of theory and research for the sociology of education.* Westport, CN: Greenwood Press, pp. 241-258.

BOURKE, C. & EDWARDS, B. 1994. Family and kinship. *In:* BOURKE, C., BOURKE, E. & EDWARDS, B. (eds.) *Aboriginal Australia: An introductory reader in Aboriginal studies.* Brisbane, QLD: University of Queensland Press.

BOURKE, S. 2012. *They return as Ancestors: Indigenous human remains, repatriation and bioanthropology.* Honours in Biological Anthropology, Australian National University.

BOURKE, S. 2015. *The construction of Indigenous Australian obesity.* MPhil in Medical Anthropology, University of Oxford.

BOURKE, S., WRIGHT, A., GUTHRIE, J., RUSSELL, L., DUNBAR, T. & LOVETT, R. 2018. Evidence review of Indigenous culture for health and wellbeing. *The International Journal of Health, Wellness and Society,* 8 (4), 11-27.

BREUNIG, R., HASAN, S. & HUNTER, B. 2019. Financial stress and Indigenous Australians. *Economic Record,* 95 (308), 34-57.

BRIGGS, C. L. 2007. Anthropology, interviewing, and communicability in contemporary society. *Current Anthropology,* 48 (4), 551-580.

BRÖCKLING, U., KRASMANN, S. & LEMKE, T. (eds.) 2011. *Governmentality: Current issues and future challenges*. Abingdon: Routledge.

BRONFENBRENNER, U. & MORRIS, P. A. 2006. The bioecological model of human development. *In:* DAMON, W. & LERNER, R. M. (eds.) *Handbook of child psychology.* New York, NY: John Wiley & Sons, Inc., pp. 793-828.

BROUGH, M. 2007. *National emergency response to protect Aboriginal children in the NT* [Online]. Available: https://parlinfo.aph.gov.au/parlInfo/download/media/pressrel/8ZFN6/upload_binary/8zfn61.pdf;fileType=application%2Fpdf#search=%22media/pressrel/8ZFN6%22 [Accessed 21 January 2020].

BROWN-SARACINO, J., THURK, J. & FINE, G. 2010. Beyond groups: Seven pillars of peopled ethnography in organizations. *In:* ATKINSON, P. & DELAMONT, S. (eds.) *SAGE qualitative research methods.* Thousand Oaks, CA: SAGE Publications, Inc., pp. 548-566.

BUCCI, M., MARQUES, S. S., OH, D. & HARRIS, N. B. 2016. Toxic stress in children and adolescents. *Advances in Pediatrics,* 63 (1), 403-428.

BURBANK, V. K. 2011. *An ethnography of stress: The social determinants of health in Aboriginal Australia*. New York: Palgrave Macmillan.

BURGESS, C. P., BERRY, H. L., GUNTHORPE, W. & BAILIE, R. S. 2008. Development and preliminary validation of the 'Caring for Country' questionnaire: Measurement of an Indigenous Australian health determinant. *International Journal for Equity in Health,* 7, 26.

BURNIE, R. 2019. *Aboriginal healers treat patients alongside doctors and nurses at Lyell McEwin Hospital* [Online]. ABC News. Available: https://www.abc.net.au/news/2019-02-20/aboriginal-healers-treat-patients-alongside-doctors-and-nurses/10826666 [Accessed 15 June 2020].

CAJETE, G. 1999. *Igniting the sparkle: An Indigenous science education model,* Skyand, NC, Kivaki Press.

CALLAGHAN, P. & GORDON, P. 2014. *Iridescence: Finding your colours and living you stories*, Hazelbrook, NSW, MoshPit Publishing.

CALMA, T. 2005. *Social justice report 2005* [Online]. Australian Human Rights Commission. Available: http://www.humanrights.gov.au/our-work/aboriginal-and-torres-strait-

islander-social-justice/publications/social-justice-report-6 [Accessed 16 March 2015].

CAMPBELL, J. T. 1814. *Establishment of the Native Institution 1814: Government and General Order* [Online]. Available: http://www.records.nsw.gov.au/state-archives/digital-gallery/lachlan-macquarie-visionary-and-builder/public-notices/full-transcript-establishment-of-the-native-institution-1814 [Accessed 10 December 2014].

CARR, E. S. 2010. Enactments of expertise. *Annual Review of Anthropology*, 39 (1), 17-32.

CENTERS FOR DISEASE CONTROL AND PREVENTION. 2012. *Lesson 1: Introduction to epidemiology* [Online]. Available: https://www.cdc.gov/csels/dsepd/ss1978/lesson1/quizanswers.html [Accessed 24 January 2020].

CENTRAL LAND COUNCIL. 2019. *CLC rangers* [Online]. Available: https://www.clc.org.au/index.php?/articles/info/clc-rangers1 [Accessed 30 May 2019].

CHANDLER, M. J. & LALONDE, C. 1998. Cultural continuity as a hedge against suicide in Canada's First Nations. *Transcultural Psychiatry,* 35 (2), 191-219.

CHANDLER, M. J., LALONDE, C., SOKOL, B. & HALLETT, D. 2003. Personal persistence, identity development, and suicide: A study of Native and non-Native North American adolescents. *Monographs of the Society for Research in Child Development,* 68 (2), 1-130.

CHATURVEDI, S., ARORA, N. K., DASGUPTA, R., & PATWARI, A. K. 2011. Are we reluctant to talk about cultural determinants?. *The Indian Journal of Medical Research,* 133 (4), 361-363.

CHEATER, A (ed.). 1999. *The anthropology of power: Empowerment and disempowerment in changing structures*. London: Routledge.

CHUA, L. & MATHUR, N. 2018. Who are 'we'?. *In:* CHUA, L. & MATHUR, N. (eds.) *Who are 'we'?: Reimagining alterity and affinity in anthropology*. Oxford: Berghahn Books, pp. 1-34.

CLIFFORD, J. 1983. On ethnographic authority. *Representations,* 2, 118-146.

CLIFFORD, J. 1989. The others: Beyond the 'salvage' paradigm, *Third Text*, 3 (6), 73-78.

COALITION OF PEAKS. 2020. *Circuit breaker needed as the cycle of failure continues in 2020 Closing the Gap report* [Online]. Available: https://www.naccho.org.au/circuit-breaker-needed-as-the-cycle-of-failure-continues-in-2020-closing-the-gap-report/ [Accessed 8 April 2020].

COLLINS ENGLISH DICTIONARY. 2012. *Corroboree* [Online]. HarperCollins Publishers. Available: https://www.dictionary.com/browse/corroboree [Accessed 4 October 2019].

COLQUHOUN, S. & DOCKERY, A. M. 2012. The link between Indigenous culture and wellbeing: Qualitative evidence for Australian Aboriginal peoples. *CLMR Discussion*

Paper Series 2012/01 [Online]. Available: http://www.ncsehe.edu.au/wp-content/uploads/2013/09/2012.01_LSIC_qualitative_CLMR1.pdf [Accessed 29 March 2019].

COMMONWEALTH OF AUSTRALIA 1937. *Aboriginal welfare: Initial conference of Commonwealth and State Aboriginal authorities*. Canberra, ACT: L.F. Johnston, Commonwealth Government Printer.

COMMONWEALTH OF AUSTRALIA 2019. *Closing the Gap report 2019*. Canberra, ACT: Department of the Prime Minister and Cabinet.

COMMONWEALTH OF AUSTRALIA 2020a. *Closing the Gap report 2020*. Canberra, ACT: Department of the Prime Minister and Cabinet.

COMMONWEALTH OF AUSTRALIA 2020b. *National base map with external territories* [Online]. Available: http://maps.ga.gov.au/interactive-maps/#/theme/national-location-information/map/nationalmap [Accessed 20 June 2020].

CORBIN, J. & STRAUSS, A. 2008. *Basics of qualitative research: Techniques and procedures for developing grounded theory,* Thousand Oaks, CA: SAGE Publications, Inc.

COUNCIL OF AUSTRALIAN GOVERNMENTS. 2008. Close the gap: Indigenous health equality summit. *Statement of Intent* [Online]. Available: https://www.humanrights.gov.au/sites/default/files/content/social_justice/health/statement_intent.pdf [Accessed 25 January 2015].

CSDH. 2008. *Closing the gap in a generation: Health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health*, Geneva: World Health Organisation.

CURRIE, C., WILD, T., SCHOPFLOCHER, D., LAING, L., VEUGELERS, P., PARLEE, B. & MCKENNITT, D. 2011. Enculturation and alcohol use problems among Aboriginal university students. *Canadian Journal of Psychiatry,* 56 (12), 735-742.

D'AMICO-SAMUELS, D. 2010. Undoing fieldwork: Personal, political, theoretical and methodological implications. *In:* HARRISON, F. V. (ed.) *Decolonizing anthropology: Moving further toward an anthropology for liberation.* Arlington, VA: American Anthropological Association, pp. 68-87.

DAHMS, H. F. 2008. How social science is impossible without critical theory: The immersion of mainstream approaches in time and space. *In:* DAHMS, H. F. (ed.) *No social science without critical theory.* Bingley: Emerald Group Publishing Limited, pp. 3-61.

DANIEL, M., LEKKAS, P., CARGO, M., STANKOV, I. & BROWN, A. 2011. Environmental risk conditions and pathways to cardiometabolic diseases in Indigenous populations. *Annual Review of Public Health,* 32, 327-347.

DAVIES, C. A. 2008. *Reflexive ethnography: A guide to researching selves and others,* Abingdon, Routledge.

DAVIS, S. L. & CHAPA, D. W. 2015. Social determinants of health: Knowledge to effective action for change. *The Journal for Nurse Practitioners*, 11 (4), 424-429.

DEN HARTOG, D. N., HOUSE, R. J., HANGES, P. J., RUIZ-QUINTANILLA, S. A., DORFMAN, P. W., ABDALLA, I. A., ADETOUN, B. S., ADITYA, R. N., AGOURRAM, H., AKANDE, A., AKANDE, B. E., AKERBLOM, S., ALTSCHUL, C., ALVAREZ-BACKUS, E., ANDREWS, J., ARIAS, M. E., ARIF, M. S., ASHKANASY, N. M., ASLLANI, A., AUDIA, G., BAKACSI, G., BENDOVA, H., BEVERIDGE, D., BHAGAT, R. S., BLACUTT, A., BAO, J., BODEGA, D., BODUR, M., BOOTH, S., BOOYSEN, A. E., BOURANTAS, D., BRENK, K., BRODBECK, F., CARL, D. E., CASTEL, P., CHANG, C.-C., CHAU, S., CHEUNG, F., CHHOKAR, J. S., CHIU, J., COSGRIFF, P., DASTMALCHIAN, A., COLETA, J. A. D., COLETA, M. F. D., DENEIRE, M., DICKSON, M., DONNELLY-COX, G., EARLEY, C., ELGAMAL, M. A. E., EREZ, M., FALKUS, S., FEARING, M., FIELD, R. H. G., FIMMEN, C., FRESE, M., FU, P., GORSLER, B., GRATCHEV, M. V., GUPTA, V., GUTIERREZ, C., HARTANTO, F. M., HAUSER, M., HOLMBERG, I., HOLZER, M., HOPPE, M., HOWELL, J. P., IBRIEVA, E., ICKIS, J. C., ISMAIL, Z., JARMUZ, S., JAVIDAN, M., JESUINO, J. C., JI, L., JONE, K.-Y., JONES, G., JORBENADSE, R., KABASAKAL, H., KEATING, M., KELLER, A., KENNEDY, J. C., KIM, J. S., KIPIANI, G., KIPPING, M., KONRAD, E., KOOPMAN, P. L., KUAN, F.-Y., KURC, A., LACASSAGNE, M.-F., LEE, S. M., LEEDS, C., LEGUIZAMON, F., LINDELL, M., LOBELL, J., LUTHANS, F., MACZYNSKI, J., MANSOR, N., MARTIN, G., MARTIN, M., MARTINEZ, S. M., MESSALLAM, A., et al. 1999. Culture specific and cross-culturally generalizable implicit leadership theories: Are attributes of charismatic/transformational leadership universally endorsed? *The Leadership Quarterly,* 10 (2), 219-256.

DEPARTMENT OF HEALTH. 2019. *Frequently asked questions — Implementation Plan* [Online]. Available: https://www1.health.gov.au/internet/main/publishing.nsf/Content/implementation-plan-faq [Accessed 18 February 2020].

DERVIN, F. 2012. Cultural identity, representation and othering. *In:* JACKSON, J. (ed.) *The Routledge handbook of language and intercultural communication.* Abingdon: Routledge, pp. 181-194.

DESMOND, M. 2014. Relational ethnography. *Theory and Society,* 43 (5), 547-579.

DIEZ ROUX, A. V. 2012. Conceptual approaches to the study of health disparities. *Annual Review of Public Health,* 33, 41-58.

DOCKERY, A. M. 2011. *Traditional culture and the wellbeing of Indigenous Australians: An analysis of the 2008 NATSISS*. Perth, WA: The Centre for Labour Market Research, Curtin Business School, Curtin University.

DOUGLAS, H. & WALSH, T. 2013. Continuing the Stolen Generations: Child protection interventions and Indigenous people. *The International Journal of Children's Rights,* 21 (1), 59-87.

DUDGEON, P., MALLARD, J., OXENHAM, D. & FIELDER, J. 2002. Contemporary Aboriginal perceptions of community. *In:* FISHER, A., SONN, C. & BISHOP, B. (eds.) *Psychological sense of community: Research, applications, and implications.* New York, NY: Kluwer Academic/Plenum Publishers, pp. 247-267.

DUDGEON, P. & OXENHAM, D. 1989. The complexity of Aboriginal diversity: Identity and kindredness. *Black Voices,* 5 (1), 22-38.

DUDGEON, P., WRIGHT, M., PARADIES, Y., GARVEY, D. & WALKER, I. 2010. The social, cultural and historical context of Aboriginal and Torres Strait Islander Australians. *In:* PURDIE, N., DUDGEON, P. & WALKER, R. (eds.) *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice.* Canberra, ACT: Commonwealth of Australia, pp. 25-42.

DURIE, M. 1985. A Māori perspective of health. *Social Science & Medicine,* 20 (5), 483-486.

DURIE, M. 2004. Understanding health and illness: Research at the interface between science and indigenous knowledge. *International Journal of Epidemiology,* 33 (5), 1138-1143.

EADES, S., READ, A. W., STANLEY, F. J., EADES, F. N., MCCAULLAY, D. & WILLIAMSON, A. 2008. Bibbulung gnarneep ('solid kid'): Causal pathways to poor birth outcomes in an urban Aboriginal birth cohort. *Journal of Paediatrics and Child Health,* 44 (6), 342-346.

ELLA, R., SMITH, P., KELLAHER, M., BOYD, S. & HILL, T. 1998. *Securing the truth: NSW Government submission to the Human Rights and Equal Opportunity Commission Inquiry into the separation of Aboriginal and Torres Strait Islander children from their families*. Sydney, NSW: NSW Department of Aboriginal Affairs.

ENS, E. J., PERT, P., CLARKE, P. A., BUDDEN, M., CLUBB, L., DORAN, B., DOURAS, C., GAIKWAD, J., GOTT, B., LEONARD, S., LOCKE, J., PACKER, J., TURPIN, G. & WASON, S. 2015. Indigenous biocultural knowledge in ecosystem science and management: Review and insight from Australia. *Biological Conservation,* 181, 133-149.

ERIKSSON, M., GHAZINOUR, M. & HAMMARSTRÖM, A. 2018. Different uses of Bronfenbrenner's ecological theory in public mental health research: What is their value for guiding public mental health policy and practice? *Social Theory & Health,* 16 (4), 414-433.

EVANS, M. M. & SINCLAIR, A. 2016. Navigating the territories of Indigenous leadership: Exploring the experiences and practices of Australian Indigenous arts leaders. *Leadership,* 12 (4), 470-490.

FABIAN, J. 1990. Presence and representation: The Other and anthropological writing. *Critical Inquiry,* 16 (4), 753-772.

FAHCSIA 2009. *The Longitudinal Study of Indigenous Children: Key summary report from Wave 1*. Canberra, ACT: Department of Families, Housing, Community Services, and Indigenous Affairs.

FARMER, P. 2004. An anthropology of structural violence. *Current Anthropology,* 45 (3), 305-317.

FAYED, S. T., KING, A., KING, M., MACKLIN, C., DEMERIA, J., RABBITSKIN, N., HEALY, B. & GONZALES, S. 2018. In the eyes of Indigenous people in Canada: Exposing the underlying colonial etiology of hepatitis C and the imperative for trauma-informed care. *Canadian Liver Journal,* 1 (3), 115-129.

FENTON, S. & CHARSLEY, K. 2000. Epidemiology and sociology as incommensurate games: Accounts from the study of health and ethnicity. *Health,* 4 (4), 403-425.

FERNANDES, D. 2018. As more Aboriginal children are removed from families, critics say government risks a second Stolen Generation. *PRI's The World* [Online]. Available: https://www.pri.org/stories/2018-10-09/more-aboriginal-children-are-removed-families-critics-say-government-risks-second [Accessed 7 August 2019].

FFORDE, C., BAMBLETT, L., LOVETT, R., GORRINGE, S. & FOGARTY, B. 2013. Discourse, deficit and identity: Aboriginality, the race paradigm and the language of representation in contemporary Australia. *Media International Australia,* 149 (1), 162-173.

FINE, G. A. 2003. Towards a peopled ethnography: Developing theory from group life. *Ethnography,* 4 (1), 41-60.

FIRST NATIONS NATIONAL CONSTITUTIONAL CONVENTION. 2017. *Uluru Statement from the Heart* [Online]. Alice Springs, NT: Referendum Council. Available: https://www.referendumcouncil.org.au/sites/default/files/2017-05/Uluru_Statement_From_The_Heart_0.PDF [Accessed 2 March 2020].

FIRST PEOPLES' ASSEMBLY OF VICTORIA. 2020. *Factsheet: About the First Peoples' Assembly* [Online]. Available: https://www.firstpeoplesvic.org/download/factsheet-about-the-first-peoples-assembly/ [Accessed 2 March 2020].

FISCHER, E. F. 2007. *The good life: Aspiration, dignity, and the anthropology of wellbeing,* Stanford, CA, Stanford University Press.

FISCHLER, C. 2011. Commensality, society and culture. *Social Science Information,* 50 (3-4), 528-548.

FITZGERALD, T. 2006. Walking between two worlds: Indigenous women and educational leadership. *Educational Management Administration & Leadership,* 34 (2), 201-213.

FLOOD, J. 2006. *The original Australians: Story of the Aboriginal people,* Crows Nest, NSW, Allen and Unwin.

FOGARTY, W., BULLOCH, H., MCDONNELL, S. & DAVIS, M. 2018a. *Deficit discourse and Indigenous health: How narrative framings of Aboriginal and Torres Strait Islander people are reproduced in policy*. Melbourne, VIC: The Lowitja Institute.

FOGARTY, W., LOVELL, M., LANGENBERG, J. & HERON, M. -J. 2018b. *Deficit discourse and strengths-based approaches: Changing the narrative of Aboriginal and Torres Strait Islander health and wellbeing*. Melbourne, VIC: The Lowitja Institute.

FOLEY, W. 2005. Tradition and change in urban indigenous food practices. *Postcolonial Studies,* 8 (1), 25-44.

FONDA, M. 2009. Towards cultural wellbeing: Implications of revitalizing traditional Aboriginal religions. *Canadian Issues,* Winter, 73-79.

FOUCAULT, M. 1978 [2001]. Governmentality. *In:* FAUBION, J. D. (ed.) *Essential works of Foucault, 1954-1984: Power*. London: Penguin.

FOX, R. G. & KING, B. J. 2020. Introduction: Beyond culture worry. *In:* FOX, R. G. & KING, B. J. (eds.) *Anthropology beyond culture: Body, age and identity* (2nd ed.). Abingdon: Routledge, pp. 1-21.

FRANKLIN, M.-A. & WHITE, I. 1991. The history and politics of Aboriginal health. *In:* REID, J. & TROMPF, P. (eds.) *The health of Aboriginal Australia.* Marrickville, NSW: Harcourt Brace Jovanovich, pp. 1-36.

FREDERICKS, B. 2013. Commentary on nutrition and older Indigenous Australians: Service delivery implications in remote communities: A narrative review. *Australasian Journal on Ageing,* 32 (4), 198-199.

FREEMAN, D. 1983. *Margaret Mead and Samoa: The making and unmaking of an anthropological myth,* Canberra, ACT, ANU Press.

FUNSTON, L. & HERRING, S. 2016. When will the Stolen Generations end? A qualitative critical exploration of contemporary 'child protection' practices in Aboriginal and Torres Strait Islander communities. *Sexual Abuse in Australia and New Zealand,* 7 (1), 51-58.

GALEA, S., RIDDLE, M. & KAPLAN, G. A. 2010. Causal thinking and complex system approaches in epidemiology. *International journal of epidemiology,* 39 (1), 97-106.

That sugar film, 2015. Directed by GAMEAU, D. Australia: Madman Entertainment.

GANESHARAJAH, C. 2009. Indigenous health and wellbeing: The importance of Country. *Native Title Research Report No. 1/2009*. Canberra, ACT: Australian Institute of Aboriginal and Torres Strait Islander Studies.

GARDINER, G. & BOURKE, E. 2000. Indigenous populations, 'mixed' discourses and identities. *People and Place,* 8 (2), 43-52.

GEERTZ, C. 1973. *The interpretation of cultures*. New York, NY: BasicBooks.

GOODA, M. 2011. *Social Justice Report 2011*. Sydney, NSW: Australian Human Rights Commission.

GOUDREAU, G., WEBER-PILLWAX, C., COTE-MEEK, S. & MADILL, H. 2008. Hand drumming: Health-promoting experiences of Aboriginal women from a northern Ontario urban community. *Journal of Aboriginal Health,* 4 (1), 72-83.

GRAEBER, K. 2010. "Personal communication, 2006": Authorship and ownership in anthropology. *Michigan Discussions in Anthropology,* 18 (1), 174-208.

GRAY, M. 2012. A mile wide, inch deep: The future for Indigenous social surveys? *In:* HUNTER, B. & BIDDLE, N. (eds.) *Survey analysis for Indigenous policy in Australia: Social science perspectives.* Canberra, ACT: ANU E-Press, pp. 307-320.

GRIFFITHS, K., COLEMAN, C., LEE, V. & MADDEN, R. 2016. How colonisation determines social justice and Indigenous health: A review of the literature. *Journal of Population Research,* 33 (1), 9-30.

GUPTA, A. & FERGUSON, J. 1997. Beyond "culture": Space, identity, and the politics of difference. *In:* GUPTA, A. & FERGUSON, J. (eds.) *Culture, power, place: Explorations in critical anthropology*. London: Duke University Press, pp. 33-51.

HAEBICH, A. 1988. *For their own good: Aborigines and government in the southwest of Western Australia, 1900-1940,* Nedlands, WA, University of Western Australia Press for the Charles and Joy Staples South West Region Publications Fund Committee.

HARARI, Y. N. 2015. *Sapiens: A brief history of humankind,* New York, NY, HarperCollins Publishing.

HE KITENGA. 2017. *Taking action* [Online]. Available: https://www.otago.ac.nz/hekitenga/2017/otago672775.html [Accessed 20 February 2020].

HENRY, E. & FOLEY, D. 2018. Indigenous research: Ontologies, axiologies, epistemologies and methodologies. *In:* BOOYSEN, L. A. E., BENDL, R. & PRINGLE, J. K. (eds.) *Handbook of research methods in diversity management, equality and inclusion at work.* Cheltenham: Edward Elgar Publishing, pp. 212-227.

HENRY, R. 2000. Dancing into being: The Tjapukai Aboriginal Cultural Park and the Laura Dance Festival. *The Australian Journal of Anthropology,* 11, 322-332.

HERISING, F. 2005. Interrupting positions: Critical thresholds and queer pro/positions. *In:* BROWN, L. & STREGA, S. (eds.) *Research as resistance: Critical, Indigenous, and anti-oppressive approaches.* Toronto, ON: Canadian Scholars' Press, pp. 127-151.

HERSKOVITS, M. J. 1973. *Cultural relativism: Perspectives in cultural pluralism,* New York, NY, Vintage Books.

HEWITT, B. 2012. *The Longitudinal Study of Indigenous Children: Implications of the study design for analysis and results*. St Lucia, QLD: Institute for Social Science Research.

HIGH COURT OF AUSTRALIA 1992. *Mabo v Queensland (No 2) (1992)* 175 CLR 1, 55; [1992] HCA 23. Canberra, ACT.

HORN-MILLER, K. 2013. What does Indigenous participatory democracy look like? Kahnawà:ke's community decision making process. *Review of Constitutional Studies,* 18 (1), 111-132.

HOUSE OF COMMONS 1837. *Report of the Parliamentary Select Committee on Aboriginal tribes (British settlements.)*. London: William Ball, Aldine Chambers, Paternoster Row, and Hatchard and Son, Piccadilly.

HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON ABORIGINAL AFFAIRS 1979. *Aboriginal health: Report from the House of Representatives Standing Committee on Aboriginal Affairs*. Canberra, ACT: Commonwealth of Australia.

HULME, A., THOMPSON, J., NIELSEN, R. O., READ, G. J. M. & SALMON, P. M. 2019. Towards a complex systems approach in sports injury research: Simulating running-related injury development with agent-based modelling. *British Journal of Sports Medicine,* 53 (9), 560-569.

HUMAN RIGHTS AND EQUAL OPPORTUNITY COMMISSION 1997. *Bringing them home: National inquiry into the separation of Aboriginal and Torres Strait Islander children from their families*. Canberra, ACT: Commonwealth of Australia.

HUNTER, B. 2012. Is Indigenous poverty different from other poverty? *In:* HUNTER, B. & BIDDLE, N. (eds.) *Survey analysis for Indigenous policy in Australia: Social sciences perspectives.* Canberra, ANU: ANU E-Press, pp. 192-222.

HUNTER, J. & SCHMIDT, F. 2004. *Methods of meta-analysis: Correcting error and bias in research findings,* London: SAGE Publications, Ltd.

[Reference removed]

INDA, J. X. (ed.). 2015. *Anthropologies of modernity: Foucault, governmentality, and life politics*. Oxford: Blackwell Publishing.

INHORN, M. 1995. Medical anthropology and epidemiology: Divergences or convergences? *Social Science & Medicine,* 40 (3), 285-290.

INTERNATIONAL INDIGENOUS COHORT COLLABORATIVE 2020. *International Indigenous Cohort Collaborative: Summary report of an international Indigenous cohort expert consensus panel.* Unpublished.

IOANNIDIS, J., FANELLI, D., DUNNE, D. & GOODMAN, S. 2015. Meta-research: Evaluation and improvement of research methods and practices. *PLOS Biology,* 13 (10), e1002264.

IOANNIDIS, J. P. A. 2018. Meta-research: Why research on research matters. *PLOS Biology,* 16 (3), e2005468.

ISLAM, M. M. 2019. Social determinants of health and related inequities: Confusion and implications. *Frontiers in Public Health*, 7 (11). DOI: 10.3389/fpubh.2019.00011.

IVORY, W. M. F. 2009. *Kunmanggur, legend and leadership a study of Indigenous leadership and succession focussing on the north west region of the Northern Territory of Australia.* PhD, Charles Darwin University.

JANKE, T. (ed.) 2007. *Writing cultures: Protocols for producing Indigenous Australian writing,* Surry Hills, NSW: Australia Council for the Arts.

JOHNSTON, E. 1991. *Royal Commission into Aboriginal Deaths in Custody*. Canberra, ACT: Commonwealth of Australia.

JONES, R., THURBER, K., WRIGHT, A., CHAPMAN, J., DONOHOE, P., DAVIS, V. & LOVETT, R. 2018a. Associations between participation in a ranger program and health and wellbeing outcomes among Aboriginal and Torres Strait Islander people in Central Australia: A proof of concept study. *International Journal of Environmental Research and Public Health,* 15 (7), e1478.

JONES, R., THURBER, K. A., CHAPMAN, J., D'ESTE, C., DUNBAR, T., WENITONG, M., EADES, S. J., STRELEIN, L., DAVEY, M., DU, W., OLSEN, A., SMYLIE, J. K., BANKS, E. & LOVETT, R. 2018b. Study protocol: Our cultures count, the Mayi Kuwayu Study, a national longitudinal study of Aboriginal and Torres Strait Islander wellbeing. *BMJ Open,* 8 (6), e023861.

KAGAWA SINGER, M., DRESSLER, W., GEORGE, S., BAQUET, C. R., BELL, R. A., BURHANSSTIPANOV, L., BURKE, N. J., DIBBLE, S., ELWOOD, W., GARRO, L., GRAVLEE, C. C., GUARNACCIA, P., HECHT, M. L., HENDERSON, J., HRUSCHKA, D., LEWIS-FERNÁNDEZ, R., LIKE, R., MOUTON, C., MYERS, H. F., PAGE, J. B., PASICK, R., PESCOSOLIDO, B., SCHOENBERG, N., STONER, B., STRAYHORN, G., SZALACHA, L., TRIMBLE, J., WEISNER, T. S. & WILLIAMS, D. 2016. Culture: The missing link in health research. *Social Science & Medicine,* 170, 237-246.

KANAREK, J. 2013. Critiquing cultural relativism. *The Intellectual Standard* [Online], 2. Available: http://digitalcommons.iwu.edu/tis/vol2/iss2/1 [Accessed 14 July 2020].

KESSLER, R., ANDREWS, G., COLPE, L., HIRIPI, E., MROCZEK, D., NORMAND, S., WALTERS, E. & ZASLAVSKY, A. 2002. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychological Medicine,* 32 (6), 959-76.

KETHEESAN, S., RINAUDO, M., BERGER, M., WENITONG, M., JUSTER, R. P., MCEWEN, B. S. & SARNYAI, Z. 2020. Stress, allostatic load, and mental health in Indigenous Australians. *Stress*. DOI: 10.1080/10253890.2020.1732346.

KIDD, R. 2000. *Black lives, Government lies,* Sydney, NSW, University of New South Wales Press, Ltd.

KING, C. 1997. Here come the anthros. *In:* ROBBEN, A. C. G. M. & SLUKA, J. A. (eds.) *Ethnographic fieldwork: An anthropological reader* (2nd ed.). Chichester: Wiley-Blackwell, pp. 207-209.

KING, M., SMITH, A. & GRACEY, M. 2009. Indigenous health part 2: The underlying causes of the health gap. *The Lancet,* 374, 76-85.

KINGSLEY, J., MUNRO-HARRISON, E., JENKINS, A. & THORPE, A. 2018. "Here we are part of a living culture": Understanding the cultural determinants of health in Aboriginal gathering places in Victoria, Australia. *Health and Place*, 54, 210-220.

KINGSLEY, J., TOWNSEND, M., PHILLIPS, R. & ALDOUS, D. 2009. "If the land is healthy… it makes the people healthy": The relationship between caring for Country and health for the Yorta Yorta Nation, Boonwurrung and Bangerang Tribes. *Health & Place,* 15, 291-299.

KIRMAYER, L. J., GONE, J. P. & MOSES, J. 2014. Rethinking historical trauma. *Transcultural Psychiatry,* 51 (3), 299-319.

KOVACH, M. 2005. Emerging from the margins: Indigenous methodologies. *In:* BROWN, L. & STREGA, S. (eds.) *Research as resistance: Critical, Indigenous, and anti-oppressive approaches.* Toronto, ON: Canadian Scholars' Press, pp. 19-36.

KOVACH, M. 2009. *Indigenous methodologies: Characteristics, conversations, and contexts,* Toronto, ON, University of Toronto Press.

KRIEGER, N. 2011. *Epidemiology and the people's health: Theory and context,* Oxford, Oxford University Press.

KUKUTAI, T. & TAYLOR, J. (eds.) 2016. *Indigenous data sovereignty: Toward an agenda,* Canberra, ACT: ANU Press.

KUKUTAI, T. & WALTER, M. 2015. Recognition and indigenizing official statistics: Reflections from Aotearoa New Zealand and Australia. *Statistical Journal of the International Association for Official Statistics,* 31 (2), 317-326.

LANGELLIER, B. A., YANG, Y., PURTLE, J., NELSON, K. L., STANKOV, I. & DIEZ ROUX, A. V. 2018. Complex systems approaches to understand drivers of mental health and inform mental health policy: A systematic review. *Administration and Policy in Mental Health and Mental Health Services Research,* 46, 128-144.

LAPP, H. E., AHMED, S., MOORE, C. L. & HUNTER, R. G. 2019. Toxic stress history and hypothalamic-pituitary-adrenal axis function in a social stress task: Genetic and epigenetic factors. *Neurotoxicology and Teratology,* 71 (1), 41-49.

LEERSSEN, J. 2006. The downward pull of cultural essentialism. *In:* WINTLE, M. (ed.) *Image into identity: Constructing and assigning identity in a culture of modernity.* Amsterdam, NL: Editions Rodopi B.V, pp. 31-52.

LEGG, S. 2005. Foucault's population geographies: Classifications, biopolitics and governmental spaces. *Population, Space and Place,* 11, 137-156.

LÉVI-STRAUSS, C. 1969. *The elementary structures of kinship: Les structures élémentaires de la parenté,* Boston, MA, Beacon Press.

LOUTH, S. 2012. *Overcoming the "shame" factor: Empowering Indigenous people to share and celebrate their culture.* Available: https://eprints.usq.edu.au/23010/1/overcoming_the_shame_factor.louth.s.pdf [Accessed 4 March 2019].

LOVETT, R. 2013. *Mob and country: A role for identity in alcohol screening for Indigenous Australians living in the ACT and region.* PhD, Australian National University.

LOVETT, R. 2016. Aboriginal and Torres Strait Islander community wellbeing: Identified needs for statistical capacity. *In:* KUKUTAI, T. & TAYLOR, J. (eds.) *Indigenous data sovereignty: Toward an agenda.* Canberra, ACT: ANU Press, pp. 213-231.

LOVETT, R. 2017a. Mayi Kuwayu conceptual model. *Mayi Kuwayu IPAG 6 June 2017*. Canberra, ACT: Unpublished.

LOVETT, R. 2017b. *'Mayi Kuwayu' [Ngiyampaa: To follow Aboriginal people over a long time] – A national study of Aboriginal and Torres Strait Islander wellbeing: HREA project description*. Unpublished.

LOVETT, R., LEE, V., KUKUTAI, T., CORMACK, D., RAINIE, S. C. & WALKER, J. 2019. Good data practices for Indigenous data sovereignty and governance. *In:* DALY, A., DEVITT, K. & MANN, M. (eds.) *Good data.* Amsterdam, NL: Institute of Network Cultures, pp. 26-36.

LOVETT, R., THURBER, K., CHAPMAN, J., SCHIRMER, J. & COLEMAN, C. 2017. *Caring for country and wellbeing: Views, values, and experiences of Aboriginal and Torres Strait Islanders living in the Murray Local Land Services region*. Canberra, ACT: University of Canberra.

LOWITJA INSTITUTE 2014. *Cultural determinants of Aboriginal and Torres Strait Islander health roundtable: Report*. Melbourne, VIC: The Lowitja Institute.

LOWITJA INSTITUTE. 2018. *Deficit discourse and Aboriginal and Torres Strait Islander health policy* [Online]. Available: https://ncis.anu.edu.au/_lib/doc/ddih/Deficit_Discourse_summary_report_WEB.pdf [Accessed 4 March 2020].

LOWITJA INSTITUTE. 2020. *About* [Online]. Available: https://www.lowitja.org.au/page/about-us [Accessed 22 January 2020].

Mabo and Others v. Queensland (No. 2). (1992) HCA 23; (1992) 175 CLR 1 F.C. 92/014.

MANNING, M., AMBREY, C. L. & FLEMING, C. M. 2015. Indigenous wellbeing in Australia: Evidence from HILDA. *Working Paper No. 101/2015*. Canberra, ACT: Centre for Aboriginal Economic Policy Research, Australian National University.

MARCUS, G. E. 1995. Ethnography in/of the world system: The emergence of multi-sited ethnography. *Annual Review of Anthropology,* 24, 95-117.

MARMION, D., OBATA, K. & TROY, J. 2014. *Community, identity, wellbeing: The report of the second National Indigenous Languages Survey*. Canberra, ACT: Australian Institute of Aboriginal and Torres Strait Islander Studies.

MARMOT, M. 2011. Social determinants and the health of Indigenous Australians. *Medical Journal of Australia*, 194 (10), 512-513.

MARMOT, M., ALLEN, J., BOYCE, T., GOLDBLATT, P. & MORRISON, J. 2020. *Health equity in England: The Marmot Review 10 years on*. London: Institute of Health Equity.

MARMOT, M., SMITH, G. D., STANSFELD, S., PATEL, C., NORTH, F., HEAD, J., WHITE, I., BRUNNER, E. & FEENEY, A. 1991. Health inequalities among British civil servants: The Whitehall II study. *Lancet*, 337 (8754), 1387-1393.

MARMOT, M. & WILKINSON, R. (eds.) 1999. *Social determinants of health*, Oxford: Oxford University Press.

MARMOT, M. & WILKINSON, R. (eds.) 2005. *Social determinants of health* (2nd ed.), Oxford: Oxford University Press.

MAYAM NAYRI WINGARA. 2018. *Key principles* [Online]. Available: https://www.maiamnayriwingara.org/key-principles [Accessed 9 July 2020].

MAYI KUWAYU STUDY 2016. *'Mayi Kuwayu' [Ngiyampaa: To follow Aboriginal people over a long time] — Longitudinal study of Aboriginal and Torres Strait Islander wellbeing: Research proposal*. Canberra, ACT: Unpublished.

MAYI KUWAYU STUDY 2017a. *Bunbury test survey 26th April 2017*. Unpublished.

MAYI KUWAYU STUDY 2017b. *Cairns test survey 4th May 2017*. Unpublished.

MAYI KUWAYU STUDY 2017c. *MK survey development protocol*. Unpublished.

MAYI KUWAYU STUDY 2017d. *Survey draft 6th November 2017*. Unpublished.

MAYI KUWAYU STUDY 2017e. *Survey draft 30th October 2017*. Unpublished.

MAYI KUWAYU STUDY 2017f. *Canberra test survey draft 14th November 2017*. Unpublished.

MAYI KUWAYU STUDY 2018a. Mayi kuwayu: The national study of Aboriginal and Torres Strait Islander wellbeing. *Baseline survey*. Canberra, ANU: Australian National University.

MAYI KUWAYU STUDY 2018b. *MK survey_180129_meeting notes and changes*. Unpublished.

MAYI KUWAYU STUDY. 2020. *Indigenous data sovereignty principles* [Online]. Available: https://mkstudy.com.au/indigenousdatasovereigntyprinciples/ [Accessed 9 July 2020].

MCCALLUM, K. & HOLLAND, K. 2010. Indigenous and multicultural discourses in Australian news media reporting. *Australian Journalism Review,* 32 (2), 5-18.

MCCALMAN, J., TSEY, K., BAIRD, B., CONNOLLY, B., BAIRD, L. & JACKSON, R. 2009. 'Bringing back respect': The role of participatory action research in transferring knowledge from an Aboriginal men's group to youth programs. *Australasian Psychiatry,* 17, S59-S63.

MCPHAIL-BELL, K., APPO, N., HAYMES, A., BOND, C., BROUGH, M. & FREDERICKS, B. 2017. Deadly Choices empowering Indigenous Australians through social networking sites. *Health Promotion International,* 33 (5), 770-780.

MEDIC, G., WILLE, M. & HEMELS, M. E. 2017. Short- and long-term health consequences of sleep disruption. *Nature and Science of Sleep,* 9, 151-161.

MEDICINE, B. 2001. *Learning to be and anthropologist and remaining "native": Selected writings,* Urbana, IL, University of Illinois Press.

MELBOURNE LAW SCHOOL. 2017. *Uluru Statement from the Heart: Information booklet* [Online]. Available: https://law.unimelb.edu.au/__data/assets/pdf_file/0010/2764738/Uluru-Statement-from-the-Heart-Information-Booklet.pdf [Accessed 2 March 2020].

MORE ABORIGINAL AND TORRES STRAIT ISLANDER TEACHERS INITIATIVE. 2014. *Aboriginal and Torres Strait Islander teacher workforce analysis* [Online]. On behalf of the Australian Education, Early Childhood Development and Youth Affairs Senior Officials Committee, the National Teaching Workforce Dataset, and the More Aboriginal and Torres Strait Islander Teachers Initiative. Available: http://matsiti.edu.au/wp-content/uploads/2014/09/MATSITI-Data-Analysis-Report-2014.pdf [Accessed 14 February 2020].

MORETON-ROBINSON, A. 2015. *The White possessive: Property, power, and Indigenous sovereignty,* Minneapolis, MN, University of Minnesota Press.

MORPHY, F. 2016. Indigenising demographic categories: A prolegomenon to indigenous data sovereignty. *In:* KUKUTAI, T. & TAYLOR, J. (eds.) *Indigenous data sovereignty.* Canberra, ACT: ANU Press, pp. 99-115.

MOWBRAY, M., FOR THE WHO COMMISSION ON SOCIAL DETERMINANTS OF HEALTH, 2007. Social determinants and Indigenous health: The international experience and its policy implications. *International symposium on the social determinants of Indigenous health, Adelaide, April 2007.* Geneva, CH: World Health Organization.

NACCHO 2011. *Constitution for the National Aborginal Community Controlled Health Organisation*. Canberra, ACT: National Aborginal Community Controlled Health Organisation.

NAKATA, M. 1998. Anthropological texts and Indigenous standpoints. *Australian Aboriginal Studies,* 2, 3-12.

NAKATA, M. 2007. *Disciplng the savages: Savaging the disciplines,* Canberra, ACT, Aboriginal Studies Press.

NARAYAN, K. 1993. How native is a "native" anthropologist? *American Anthropologist,* 95 (3), 671-686.

NATIONAL ABORIGINAL HEALTH STRATEGY WORKING PARTY 1989. *A national Aboriginal health strategy*. Canberra, ACT: National Aboriginal Health Strategy Working Party.

NATIONAL ARCHIVES OF AUSTRALIA. 2016. *The 1967 referendum — Fact sheet 150* [Online]. Available: http://www.naa.gov.au/collection/fact-sheets/fs150.aspx [Accessed 8 November 2016].

NATIONAL HEALTH SERVICE. 2018. *Why lack of sleep is bad for your health* [Online]. Available: https://www.nhs.uk/live-well/sleep-and-tiredness/why-lack-of-sleep-is-bad-for-your-health/ [Accessed 15 August 2019].

NATIONAL INDIGENOUS AUSTRALIANS AGENCY. 2019. *Indigenous rangers — Working on Country* [Online]. Available: https://www.niaa.gov.au/indigenous-affairs/environment/indigenous-rangers-working-country [Accessed 16 March 2020].

NATIONAL MUSEUM OF AUSTRALIA. 2019. *Wave Hill Walk-Off* [Online]. Available: https://www.nma.gov.au/defining-moments/resources/wave-hill-walk-off [Accessed 13 February 2019].

NATSIHC 2003. *National strategic framework for Aboriginal and Torres Strait Islander health*. Canberra, ACT: National Aboriginal and Torres Strait Islander Health Council.

NAZARUK, M. 2011. Reflexivity in anthropological discourse analysis. *Anthropological Notebooks,* 17 (1), 73-83.

NELSON, L. W. 1996. Hands in the chit'lins: Notes on native anthropological research among African American Women. *In:* ETTER-LEWIS, G. & FOSTER, M. (eds.) *Unrelated kin: Race and gender in women's personal narratives.* London: Routledge, pp. 183-199.

NHMRC. 2014. *6. Assessment criteria* [Online]. National Health and Medical Research Council. Available: https://www.nhmrc.gov.au/book/nhmrc-funding-rules-2015/6-assessment-criteria [Accessed 9 July 2018].

NSW GOVERNMENT. 1969. *Aborigines Act 1969* [Online]. Available: https://www.legislation.nsw.gov.au/acts/1969-7.pdf [Accessed 15 January 2020].

NSW MURRAY LOCAL LAND SERVICES. 2019a. *Aboriginal communities* [Online]. Available: https://murray.lls.nsw.gov.au/about-lls/cultural-heritage [Accessed 9 April 2019].

NSW MURRAY LOCAL LAND SERVICES. 2019b. *Regional profile* [Online]. Available: https://murray.lls.nsw.gov.au/our-region/region-profile [Accessed 8 April 2019].

O'MARA, P. 2010. Health impacts of the Northern Territory intervention. *Medical Journal of Australia,* 192 (10), 546-548.

O'SULLIVAN, D. 2014. Indigeneity, ethnicity, and the State: Australia, Fiji, and New Zealand. *Nationalism and Ethnic Politics,* 20 (1), 26-42.

OFFICE OF THE HIGH COMMISSIONER FOR HUMAN RIGHTS. 1966. *International Covenant on Economic, Social and Cultural Rights* [Online]. Geneva: United Nations. Available: https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx [Accessed 30 January 2020].

OXENHAM, D., CAMERON, J., COLLARD, K., DUDGEON, P., GARVEY, D., KICKETT, M., KICKETT, T., ROBERTS, J. & WHITEWAY, J. 1999. *A dialogue on Indigenous identity: Warts 'n' all,* Perth, WA, Gunada Press.

OXFAM AUSTRALIA. 2015. *Aboriginal and Torres Strait Islander cultural protocols* [Online]. Available: https://www.oxfam.org.au/wp-content/uploads/2015/11/2015-74-atsi-cultural-protocols-update_web.pdf [Accessed 29 March 2019].

PANTER-BRICK, C. 2014. Health, risk, and resilience: Interdisciplinary concepts and applications. *Annual Review of Anthropology*, 43 (1), 431-448.

PARADIES, Y. 2006. Beyond Black and White: Essentialism, hybridity and Indigeneity. *Journal of Sociology,* 42 (4), 355-367.

PARADIES, Y. 2007. Racism. *In:* CARSON, B., DUNBAR, T., CHENHALL, R. D. & BAILIE, R. (eds.) *Social determinants of Indigenous health.* Crows Nest, NSW: Allen & Unwin, pp. 65-88.

PARADIES, Y. 2016. Colonisation, racism and indigenous health. *Journal of Population Research,* 33 (1), 83-96.

PARADIES, Y., HARRIS, R. & ANDERSEN, I. 2008. The impact of racism on indigenous health in Australia and Aotearoa: Towards a research agenda. *Discussion paper series no. 4.* Casuarina, NT: Cooperative Research Centre for Aboriginal Health.

PARK, L. & JACOBS, E. 2018. Cultural determinants of health and healthy ageing for older adults with limited-English proficiency. *Innovation in Aging*, 2 (1), 195.

PAULHUS, D. L. 2013. *Vancouver Index of Acculturation (VIA)* [Online]. Available: http://www.midss.org/sites/default/files/via.american.pdf [Accessed 7 November 2018].

PEARLIN, L. I., MENAGHAN, E. G., LIEBERMAN, M. A. & MULLAN, J. T. 1981. The stress process. *Journal of Health and Social Behavior,* 22 (4), 337-356.

PELS, P. 2018. Anthropology should never be fully decolonized… *Etnofoor*, 30 (20), 71-76.

PENMAN, R. 2006. Aboriginal and Torres Strait Islander views on research in their communities. *Occasional paper no.16.* Canberra, ACT: Commonwealth of Australia.

PHIPPS, P. 2016. Indigenous festivals in Australia: Performing the postcolonial. *Ethnos,* 81 (4), 683-696.

PHIPPS, P. & SLATER, L. 2010. *Indigenous cultural festivals: Evaluating impact on community health and wellbeing.* Melbourne, VIC: RMIT Globalism Research Centre.

PHOLI, K., BLACK, D. & RICHARDS, C. 2009. Is 'Close the Gap' a useful approach to improving the health and wellbeing of Indigenous Australians? *Australian Review of Public Affairs,* 9 (2), 1-14.

PLEMMONS, D. 2011. A broader discussion of authorship. *Science and Engineering Ethics,* 17, 389-398.

POOLE, F. 1994. Socialization, enculturation and the development of personal identity. *In:* INGOLD, T. (ed.) *Companion encyclopedia of anthropology: Humanity, culture and social life*. London: Routledge, pp. 831-861.

PORTER, J. D. H. 2006. Epidemiological reflections of the contribution of anthropology to public health policy and practice. *Journal of Biosocial Science*, 38 (1), 133-144.

PRICE, P. C., JHANGIANI, R. & CHIANG, I.-C. A. 2015. *Reliability and validity of measurement* [Online]. Available: https://opentextbc.ca/researchmethods/chapter/reliability-and-validity-of-measurement/ [Accessed 27 November 2018].

PRIME MINISTER OF AUSTRALIA. 2020. *Communique — Coalition of Aboriginal and Torres Strait Islander Peak Organisations* [Online]. Available: https://www.pm.gov.au/media/communique-coalition-aboriginal-and-torres-strait-islander-peak-organisations [Accessed 8 April 2020].

RADFORD, K., DELBAERE, K., DRAPER, B., MACK, H. A., DAYLIGHT, G., CUMMING, R., CHALKLEY, S., MINOGUE, C. & BROE, G. A. 2017. Childhood stress and adversity is associated with late-life dementia in Aboriginal Australians. *The American Journal of Geriatric Psychiatry,* 25 (10), 1097-1106.

RAPPORT, N. 2014. *Social and cultural anthropology: The key concepts,* Abingdon, Routledge.

READING, C. L. & WIEN, F. 2009. *Health inequalities and social determinants of Aboriginal peoples' health*. Prince George, BC: National Collaborating Centre for Aboriginal Health.

REDFIELD, R., LINTON, R. & HERSKOVITS, M. J. 1936. Memorandum for the study of acculturation. *American Anthropologist,* 38 (1), 149-152.

REILLY, R. E., DOYLE, J., BRETHERTON, D., ROWLEY, K., HARVEY, J., BRIGGS, P., CHARLES, S., CALLEJA, J., PATTEN, R. & ATKINSON, V. 2008. Identifying psychosocial mediators of health amongst Indigenous Australians for the Heart Health Project. *Ethnicity and Health,* 13 (4), 351-373.

REYNOLDS, H. 2003. *The law of the land,* Camberwell, VIC, Penguin Books Australia, Ltd.

REYNOLDS, H. 2006. *The other side of the frontier: Aboriginal resistance to the European invasion of Australia,* Sydney, NSW, University of New South Wales Press, Ltd.

RIGNEY, L-I. *The first perspective: Culturally safe research practices on or with Indigenous peoples*. Proceedings of the 1999 Chacmool Conference, 1999a University of Calgary. 629-636.

RIGNEY, L-I. 1999b. Internationalization of an Indigenous anticolonial cultural critique of research methodologies: A guide to Indigenist research methodology and its principles. *Wicazo Sa Review,* 14 (2), 109-121.

RIGNEY, L-I. 2006. Indigenous Australian views on knowledge production and Indigenist research. *In:* KUNNIE, N. & GODUKA, I. (eds.) *Indigenous peoples' wisdom and power: Affirming our knowledge through narratives*. Burlington, VT: Ashgate, pp. 629-636.

ROBBEN, A. C. G. M. & SLUKA, J. A. (eds.) 2012. *Ethnographic fieldwork: An anthropological reader,* Chichester: Wiley-Blackwell.

RODRIGUEZ, K. L., SCHWARTZ, J. L., LAHMAN, M. K. E. & GEIST, M. R. 2011. Culturally responsive focus groups: Reframing the research experience to focus on participants. *International Journal of Qualitative Methods,* 10 (4), 400-417.

ROSEWARNE, C., VAARZON-MOREL, P., BELL, S., CARTER, E., LIDDLE, M. & LIDDLE, J. 2007. The historical context of developing an Aboriginal community-controlled health service: A social history of the first ten years of the Central Australian Aboriginal Congress. *Health and History,* 9 (2), 114-143.

RUBENSTEIN, R. A. 1984. Epidemiology and anthropology: Notes on science and scientism. *Communication and Cognition,* 17 (2/3), 163-185.

RUDMIN, F. 2009. Constructs, measurements and models of acculturation and acculturative stress. *International Journal of Intercultural Relations,* 33 (2), 106-123.

RYAN, T. 2016. Seen but unseen: Missing visible Indigenous women in the media and what it means for leadership in Indigenous Australia *Platform: Journal of Media and Communication,* 7, 26-34.

RYDER, A. G., ALDEN, L. & PAULHUS, D. L. 2000. Is acculturation unidimensional or bidimensional?: A head-to-head comparison in the prediction of demographics, personality, self-identity, and adjustment. *Journal of Personality and Social Psychology,* 79, 49-65.

SAGGERS, S. & GRAY, D. 1991. Policy and practice in Aboriginal health. *In:* REID, J. & TROMPF, P. (eds.) *The health of Aboriginal Australia.* Marrickville, NSW: Harcourt Brace Jovanovich, pp. 381-420.

SALMON, M., DOERY, K., DANCE, P., CHAPMAN, J., GILBERT, R., WILLIAMS, R. & LOVETT, R. 2018. *Defining the indefinable: Descriptors of Aboriginal and Torres Strait Islander peoples' cultures and their links to health and wellbeing.* Canberra, ACT: Research School of Population Health, Australian National University.

SARNYAI, Z., BERGER, M. & JAWAN, I. 2015. Allostatic load mediates the impact of stress and trauma on physical and mental health in Indigenous Australians. *Australasian Psychiatry,* 24 (1), 72-75.

SAX INSTITUTE. 2018a. *45 and Up Study* [Online]. Available: https://www.saxinstitute.org.au/our-work/45-up-study/ [Accessed 9 July 2018].

SAX INSTITUTE. 2018b. *SEARCH* [Online]. Available: https://www.saxinstitute.org.au/our-work/search/ [Accessed 9 July 2018].

SAX INSTITUTE. 2019. *Questionnaires* [Online]. Available: https://www.saxinstitute.org.au/our-work/45-up-study/questionnaires/ [Accessed 1 May 2019].

SAYER, A. 1992. *Method in social science: A realist approach (2nd ed.),* London, Routledge.

SEIDMAN, S. (ed.) 1994. *The postmodern turn: New perspectives on social theory,* Cambridge: Cambridge University Press.

SENTINA, M., MASON, E. & JANKE, T. 2018. Legal protection of Indigenous knowledge in Australia: Supplementary paper 1. *Indigenous knowledge: Issues for protection and management.* Sydney, NSW: Terri Janke and Company.

SHERWOOD, J. 2010. *Do no harm: Decolonising Aboriginal health research.* PhD, University of New South Wales.

SHERWOOD, J. 2013. Colonisation — It's bad for your health: The context of Aboriginal health. *Contemporary Nurse,* 46 (1), 28-40.

SHONKOFF, J. P., GARNER, A. S., SIEGEL, B. S., DOBBINS, M. I., EARLS, M. F., GARNER, A. S., MCGUINN, L., PASCOE, J. & WOOD, D. L. 2012. The lifelong effects of early childhood adversity and toxic stress. *Pediatrics,* 129 (1), e232-e246.

SINCLAIR, A. 2004. Journey around leadership. *Discourse: Studies in the cultural politics of education,* 25 (1), 7-19.

SLATER, L. 2010. 'Calling our spirits home': Indigenous cultural festivals and the making of a good life. *Cultural Studies Review,* 16 (1), 143-154.

SLEEP HEALTH FOUNDATION. 2019. *Sleep Health Foundation – Australia's leading advocate for healthy sleep* [Online]. Available: https://www.sleephealthfoundation.org.au/ [Accessed 15 August 2019].

SMITH, L. T. 1999. *Decolonizing methodologies: Research and indigenous peoples,* London, Zed Books.

SMYLIE, J., FIRESTONE, M., COCHRAN, L., PRINCE, C., MARACLE, S., MORLEY, M., MAYO, S., SPILLER, T. & MCPHERSON, B. 2011. Our Health Counts: Community report. *Urban Aboriginal health database research project* [Online]. Available: http://www.ourhealthcounts.ca/images/PDF/OHC-Report-Hamilton-ON.pdf [Accessed 9 February 2017].

SMYLIE, J., MARTIN, C. M., KAPLAN-MYRTH, N., STEELE, L., TAIT, C. & HOGG, W. 2004. Knowledge translation and indigenous knowledge. *International Journal of Circumpolar Health,* 63 (Supplemetary 2), 139-143.

SNEATH, D. 2016. *Tribe* [Online]. Cambridge Encyclopedia of Anthropology. Available: http://www.anthroencyclopedia.com/entry/tribe [Accessed 28 September 2018].

SNIVELY, G. & WILLIAMS, W. L. (eds.) 2016. *Knowing home: Braiding Indigenous science with Western science: Book one,* Victoria, BC: University of Victoria.

SOUTH WEST ABORIGINAL LAND AND SEA COUNCIL. 2020. *Noongar* [Online]. Available: https://www.noongarculture.org.au/noongar/ [Accessed 29 May 2020].

SPIVAK, G. C. 1990. Strategy, identity, writing. *The postcolonial critic: Interviews, strategies, dialogues.* London: Routledge.

SPIVAK, G. C. 2009. *Outside in the teaching machine,* Abingdon, Routledge.

STATS NZ. 2015. *How is our Māori population changing?* [Online]. Available: http://archive.stats.govt.nz/browse_for_stats/people_and_communities/maori/maori-population-article-2015.aspx [Accessed 2 March 2020].

STONEHAM, M. J., GOODMAN, J. & DAUBE, M. 2014. The portrayal of Indigenous health in selected Australian media. *International Indigenous Policy Journal* [Online], 5 (1). Available: https://espace.curtin.edu.au/bitstream/handle/20.500.11937/33658/197036_197036.pdf?sequence=2&isAllowed=y [Accessed 28 August 2019].

STRATEGIC REVIEW OF HEALTH INEQUALITIES IN ENGLAND POST-2010. 2010. *Fair society, healthier lives: The Marmot review* [Online]. Available: http://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review [Accessed 12 October 2020].

SUTTON, P. 2009. *The politics of suffering: Indigenous Australia and the end of the liberal*. Melbourne: Melbourne University Press.

[Reference removed]

SWAN, P. & RAPHAEL, B. 1995. *Ways forward: National Aboriginal and Torres Strait Islander mental health policy national consultancy report*. Canberra, ACT: Department of Health and Ageing.

TALLBEAR, K. 2014. Standing with and speaking as faith: A feminist-indigenous approach to inquiry. *Journal of Research Practice*, 10 (2), Article N17.

TASMANIAN ABORIGINAL CENTRE. 2019. *Waranta tangara takariliya mumirimina, lungkana risdon cove-ta* [Online]. Available: http://tacinc.com.au/3rd-may-1804/ [Accessed 19 February 2019].

TASMANIAN ABORIGINAL CENTRE. 2020. *About us* [Online]. Available: http://tacinc.com.au/about-us/ [Accessed 30 May 2020].

TASMANIAN GOVENMENT. 2019. *Aboriginal Lands Act 1995* [Online]. Available: https://www.legislation.tas.gov.au/view/html/inforce/current/act-1995-098 [Accessed 26 February 2020].

TAULI-CORPUZ, V. 2016. Preface. *In:* KUKUTAI, T. & TAYLOR, J. (eds.) *Indigenous data sovereignty: Toward an agenda.* Canberra, ACT: ANU Press, pp. xxi-xxiii.

TAULI-CORPUZ, V. 2017. Report of the Special Rapporteur on the rights of indigenous peoples on her visit to Australia. *A/HRC/36/46/Add.2.* Geneva, CN: United Nations.

TAYEB, M. 1994. Organizations and national culture: Methodology considered. *Organization Studies,* 15 (3), 429-445.

TAYLOR, J. & KUKUTAI, T. 2015. *Report to the Academy of the Social Sciences in Australia on the workshop 'Data sovereignty for Indigenous peoples: Current practice and future needs'* [Online]. Canberra, ACT: Academy of the Social Sciences in Australia. Available: https://socialsciences.org.au/publications/data-sovereignty-for-indigenous-peoples-current-practice-and-future-needs/ [Accessed 22 April 2020].

TEDLOCK, B. 1991. From participant observation to the observation of participation: The emergence of narrative ethnography. *Journal of Anthropological Research,* 47 (1), 69-94.

THAT SUGAR MOVEMENT. 2020. *That sugar film* [Online]. Available: https://thatsugarmovement.com/film/ [Accessed 17 June 2020].

THOMAS, D. P., BAINBRIDGE, R. & TSEY, K. 2014. Changing discourses in Aboriginal and Torres Strait Islander health research, 1914–2014. *Medical Journal of Australia,* 201 (1), S1-S4.

THOMPSON, S. & GIFFORD, S. 2000. Trying to keep a balance: The meaning of health and diabetes in an urban Aboriginal community. *Social Science & Medicine,* 51, 1457-1472.

THOMPSON, S. J., GIFFORD, S. M. & THORPE, L. 2000. The social and cultural context of risk and prevention: Food and physical activity in an urban Aboriginal community. *Health Education and Behaviour,* 27, 725-743.

THURBER, K. A., BANKS, E., BANWELL, C. & THE LSIC TEAM 2015. Cohort profile: Footprints in Time, the Australian Longitudinal Study of Indigenous Children. *International Journal of Epidemiology,* 44 (3), 789-800.

TRIGGER, D. S. & DALLEY, C. 2010. Negotiating Indigeneity: Culture, identity, and politics. *Reviews in Anthropology,* 39 (1), 46-65.

TROSTLE, J. A. 2005. *Epidemiology and culture,* Cambridge, Cambridge University Press.

TRUTH AND RECONCILIATION COMMISSION. 1998. *Truth and Reconciliation Commission of South Africa report: Volume one* [Online]. Available: https://www.justice.gov.za/trc/report/finalreport/Volume%201.pdf [Accessed 3 March 2020].

TRUTH AND RECONCILIATION COMMISSION OF CANADA 2015. *Honouring the truth, reconciling for the future: Summary of the final report of the Truth and Reconciliation Commission of Canada*. Winnipeg, MB: National Centre for Truth and Reconciliation.

TRZEPACZ, D., GUERIN, B. & THOMAS, J. 2014. Indigenous Country as a context for mental and physical health: Yarning with the Nukunu Community. *The Australian Community Psychologist,* 26 (2), 38-53.

TUDGE, J. R. H., MOKROVA, I., HATFIELD, B. E. & KARNIK, R. B. 2009. Uses and misuses of Bronfenbrenner's bioecological theory of human development. *Journal of Family Theory & Review,* 1 (4), 198-210.

TURNER, P. 2020. *It is time governments front up to their failure to Aboriginal and Torres Strait Islander people* [Online]. Available: https://www.naccho.org.au/it-is-time-

governments-front-up-to-their-failure-to-aboriginal-and-torres-strait-islander-people/ [Accessed 8 April 2020].

UDDIN, N. 2011. Decolonising ethnography in the field: An anthropological account. *International Journal of Social Research Methodology*, 14 (6), 455-467.

UN. 1948. *Universal Declaration of Human Rights* [Online]. Geneva, CN: United Nations. Available: https://www.un.org/en/universal-declaration-human-rights/ [Accessed 30 January 2020].

UN. 2007. *United Nations Declaration on the Rights of Indigenous Peoples* [Online]. Geneva, CN: United Nations. Available: https://www.un.org/development/desa/indigenouspeoples/wp-content/uploads/sites/19/2018/11/UNDRIP_E_web.pdf [Accessed 30 January 2020].

UN. 2020. *United Nations Declaration on the Rights of Indigenous Peoples* [Online]. Geneva, CN: United Nations. Available: https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html [Accessed 30 January 2020].

UNIVERSITY OF OXFORD. 2018. *The Million Women Study* [Online]. Available: http://www.millionwomenstudy.org/introduction/ [Accessed 9 July 2018].

VANCE, A., MCGAW, J., WINTHER, J., RAYNER, M., WHITE, S. & SMITH, A. 2017. Mental health care for Indigenous young people: Moving culture from the margins to the centre. *Australasian Psychiatry*, 25 (2):157-160.

VASS, G. 2012. 'So, what is wrong with Indigenous education?' Perspective, position and power beyond a deficit discourse. *Australian Journal of Indigenous Education,* 41 (2), 85-96.

VICTORIA, J. L. E. 2016. Anthropology of power: Beyond state-centric politics. *Anthropological Theory*, 16 (2-3), 249-262.

WAGNER, R. 2016. *The invention of culture,* London, University of Chicago Press, Ltd.

WAHLQUIST, C. 2019. *Indigenous leaders welcome SA Labor's vow to take Uluru statement to polls* [Online]. Guardian News & Media. Available: https://www.theguardian.com/australia-news/2019/jul/06/indigenous-leaders-welcome-sa-labors-vow-to-take-uluru-statement-to-polls [Accessed 2 March 2020].

WALDRAM, J. B. 2009. Is there a future for "Culture" in acculturation research? An anthropologist's perspective. *International Journal of Intercultural Relations,* 33 (2), 173-176.

WALLERSTEIN, N. 1992. Powerlessness, empowerment, and health: Implications for health promotion programs. *American Journal of Health Promotion,* 6 (3), 197-205.

WALTER, M. 2005. Using the 'power of the data' within Indigenous research practice. *Australian Aboriginal Studies,* 2, 27-34.

WALTER, M. 2010. The politics of the data: How the Australian statistical Indigene is constructed. *International Journal of Critical Indigenous Studies,* 3 (2), 45-56.

WALTER, M. 2013. *The 2014 National Aboriginal and Torres Strait Islander Social Survey is an anachronism* [Online]. ON LINE opinion. Available: https://www.onlineopinion.com.au/view.asp?article=15317&page=2 [Accessed 28 January 2020].

WALTER, M. 2016. Data politics and Indigenous representation in Australian statistics. *In:* KUKUTAI, T. & TAYLOR, J. (eds.) *Indigenous data sovereignty: Toward an agenda.* Canberra, ACT: ANU Press, pp. 79-98.

WALTER, M. 2018. The voice of Indigenous data: Beyond the markers of disadvantage. *Griffith Review* [Online], 60. Available: https://www.griffithreview.com/articles/voice-indigenous-data-beyond-disadvantage/ [Accessed 28 January 2020].

WANG, Z., HOY, W. & MCDONALD, S. 2000. Body Mass Index in Aboriginal Australians in remote communities. *Australian and New Zealand Journal of Public Health,* 24 (6), 570-575.

WEINREICH, P. 2009. 'Enculturation', not 'acculturation': Conceptualising and assessing identity processes in migrant communities. *International Journal of Intercultural Relations,* 33 (2), 124-139.

WEIR, J. K. 2012. *Country, Native Title and ecology*. Canberra, ACT: ANU E-Press and Aboriginal History, Inc.

WEISS, M. G. 2001. Cultural epidemiology: An introduction and overview. *Anthropology & Medicine,* 8 (1), 5-29.

WEISS, M. G. 2018. Cultural epidemiology: Conceptual framework and current directions of an interdisciplinary field. *Bulletin of the Institute of Ethnography SASA,* 66 (2), 245-253.

WELL LIVING HOUSE. 2018. *Our Health Counts Toronto* [Online]. Available: http://www.welllivinghouse.com/what-we-do/projects/our-health-counts-toronto/ [Accessed 9 July 2018].

WESLEY-ESQUIMAUX, C. & CALLIOU, B. 2010. *Best practices in Aboriginal community development: A literature review and wise practices approach*. Banff, AB: The Banff Centre.

WESTERMAN, F. R. C. 1969. Here come the anthros. *Custer died for your sins.* New York, NY: Perception Records.

WHITBECK, L. B., CHEN, X., HOYT, D. R. & ADAMS, W. 2004. Discrimination, historical loss, and enculturation: Culturally specific risk and resiliency factors for alcohol abuse among American Indians. *Journal of Studies on Alcohol,* 65 (4), 409-418.

WHITBECK, L. B., HOYT, D. R., STUBBEN, J. D. & LAFROMBOISE, T. 2001. Traditional culture and academic success among American Indian children in the upper Midwest. *Journal of American Indian Education,* 40 (2), 48-60.

WHITE, H. 2019. What is anthropology that decolonising scholarship should be mindful of it?. *Anthropology Southern Africa*, 42 (2), 149-160.

WHO. 1995. Physical status: The use and interpretation of anthropometry: Report of a WHO expert committee. *WHO Technical Report Series: 854*. Geneva, CN: World Health Organisation.

WILLIAMS, C. 2015. Aboriginal astronomy and the natural world. *Australasian Science,* 36 (8), 16-19.

WILSON, K. 2003. Therapeutic landscapes and First Nations peoples: An exploration of culture, health and place. *Health & Place,* 9, 83-93.

WILSON, R. A. 2016. Kinship past, kinship present: Bio-essentialism in the study of kinship. *American Anthropologist,* 118 (3), 570-584.

WILSON, S. 2001. What is an Indigenous research methodology? *Canadian Journal of Native Education,* 25 (2), 175-179.

WINKELMAN, M. 2009. *Culture and health: Applying medical anthropology,* San Francisco, CA, Jossey-Bass.

WRIGHT, A., THURBER, K. A., YAP, M., DU, W., BANKS, E., WALKER, J., IRWIN, F., SANDERS, W. & LOVETT, R. 2020. Who responds? An examination of response rates to a national postal survey of Aboriginal and Torres Strait Islander adults, 2018-2019. *BMC Medical Research Methodology,* 20, 149. DOI: 10.1186/s12874-020-00970-8.

YODER, Y. J., WHITBECK, L. B., HOYT, D. R. & LAFROMBOISE, T. 2006. Suicidal ideation among American Indian Youths. *Archives of Suicide Research,* 10 (2), 177-190.

ZIMMERMAN, M. & RAPPAPORT, J. 1988. Citizen participation, perceived control, and psychological empowerment. *American Journal of Community Psychology,* 16 (2), 725-750.

ZIMMERMAN, M. A., RAMIREZ-VALLES, J., WASHIENKO, K. M., WALTER, B. & DYER, S. 1996. The development of a measure of enculturation for Native American youth. *American Journal of Community Psychology,* 24 (2), 295-310.

ZIMMERMAN, M. A., RAMIREZ, J., WASHIENKO, K. M., WALTER, B. & DYER, S. 1994. Enculturation hypothesis: Exploring direct and positive effects among native American youth. *In:* MCCUBBIN, H. L., THOMPSON, E. A., THOMPSON, A. L. & FROMER, J. E. (eds.) *Resiliency in ethnic minority families, vol I: Native and immigrant American families.* Maddison, WI: Center for Excellence in Family Studies, University of Wisconsin, pp. 199-220.

ZUBRICK, S. R., DUDGEON, P., GEE, G., GLASKIN, B., KELLY, K., PARADIES, Y., SCRINE, C. & WALKER, R. 2010. Social determinants of Aboriginal and Torres Strait Islander social and emotional wellbeing. *In:* PURDIE, N., DUDGEON, P. & WALKER, R. (eds.) *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice.* Canberra, ACT: Commonwealth of Australia, pp. 75-90.

ZUBRICK, S. R., SILBURN, S. R., LAWRENCE, D. M., MITROU, F. G., DALBY, R. B., BLAIR, E. M., GRIFFIN, J., MILROY, H., DE MAIO, J. A., COX, A. & LI, J. 2005. *The Western Australian Aboriginal Child Health Survey: The social and emotional wellbeing of Aboriginal children and young peopl*e. Perth, WA: Curtin University of Technology and Telethon Institute for Child Health Research.