

Creating Good Data Our Way

An Indigenous Lens for Epidemiology and Intergenerational Health

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28.1 Introduction

Momentum is building for epidemiological research led by and for Indigenous peoples. Backed by a human rights agenda, this drive is gaining speed due to wider calls to decolonise the social sciences, and increased recognition of the critical importance of incorporating Indigenous expertise in the conceptualisation, development, and execution of effective health research. ‘Decolonising’ epidemiology may involve several processes that are best determined by the communities who contribute their data. In Australia, this has involved acknowledging the complicity of the sciences in the colonisation of Aboriginal and Torres Strait Islander lands, waters, skies, and peoples, and the need for data that reflect the ongoing impact of settler-colonial practices and ideals on our communities. This work has often been conducted within a strengths-based framework, emphasising the inherent assets and resilience of Aboriginal and Torres Strait Islander communities, and the role of culture as the foundation of our individual, social, ecological, and spiritual health and well-being. To decolonise epidemiological research about Indigenous communities, Indigenous peoples must be in control of the definition, collection, and use of their data, following Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG) protocols, which ensure these data serve our self-determined interests and futures.

Hoke and McDade argue that lifecourse interventions based on DOHaD research are ‘rarely situated within the cultural, social, or political-economic context of the populations examined’ [1, p. 190]. Further, there is a lack of research focus on intergenerational or transgenerational events impacting long-term adult health in subsequent generations:

Rather than acknowledging the maternal body as the product of ongoing physiological, social, and political-economic processes, these influences on maternal physiology are often placed within an analytical black box and ignored. [1, p. 191]

Having a better conceptual understanding of the contexts in which people live would allow DOHaD researchers to design better measures to capture data on those concepts and then monitor any changes when interventions are put into place. We suggest that epidemiological methods that centre Indigenous lifeworlds have the potential to measure contextual influences and to identify salutogenic and protective factors that support holistic health and well-being for Indigenous peoples.

This chapter provides an overview of current discourses around centring Indigenous ontologies (ways of being), epistemologies (ways of knowing), and axiologies (ways of doing), also known as Indigenous ‘lifeworlds’, in epidemiology with a particular focus on Indigenous Australian (Aboriginal and Torres Strait Islander)

perspectives. *Mayi Kuwayu*, the National Study of Aboriginal and Torres Strait Islander Wellbeing, will be used as a key example illustrating how epidemiological research may be led, owned, and governed by Indigenous peoples to produce rigorous and meaningful data that reflect Indigenous lifeworlds. Centring Indigenous perspectives may provide valuable tools for the development of the DOHaD lifecourse framework and future studies that seek to address holistic determinants of intergenerational health and well-being.

28.2 Part 1. Centring Indigenous Perspectives in Epidemiology

28.2.1 The Colonial Project as an Origin of Ill health and Disease

It is well known that colonisation and colonialism are determinants of Indigenous ill health [2]. Colonisation by nations including Britain, France, Spain, and others resulted in the mass genocide and/or displacement of Indigenous peoples across the world, and the methodical dismantling of Indigenous lifeways, undermining millennia-long connections to land, culture, and kin. Colonialism, as enacted through historical and ongoing contemporary colonial processes, encompasses a range of risk factors for health and well-being [3]. This includes interpersonal, institutional, and political processes that, at a minimum, aim to control or dominate a population and, at the extreme end of the spectrum, aim to eliminate or exterminate the population.

In Australia, it is estimated that around 90 per cent of the Aboriginal and Torres Strait Islander population lost their lives between 1788 and 1901 because of widespread colonial violence, introduced diseases, and the theft of land and water resources by British settlers [4, 5]. Those who survived were subjected to systematically racist and discriminatory programmes and policies. Many were dispossessed of their traditional lands and forced to live on Christian-run missions, which often forbade the use of any language other than English and actively suppressed important cultural practices. One particular assimilation policy enacted from 1910 to 1970 in Australia led to 11–24 per cent of all Aboriginal children being stolen from their families by government agents and held in Christian-run institutions for ‘re-education’ and training as domestic servants for the White middle classes [6]. They are known collectively as the Stolen Generations. Colonisation has thus generated significant intergenerational trauma for Indigenous peoples, reinforced by ongoing and cumulative ‘biosocial injury’ inflicted by settler-colonial nation states and individuals [7].

Settler-colonialism imposes cultural values, religions, laws, and policies that often go against the rights and values of Indigenous peoples. The concept of settler-colonialism as a health risk factor is well understood within Indigenous populations [8–10]. However, in Australia there is limited ability to examine such links due to an absence of epidemiological data on settler-colonial exposures. This itself is a manifestation of racism, given the lack of research priority and attention to settler-colonialism and its impacts. White racism and discrimination against Indigenous peoples thus perpetuate colonial trauma.

A small number of studies demonstrate poorer outcomes for Aboriginal and Torres Strait Islander peoples who experience individual settler-colonial factors such as discrimination [11–15] and the Stolen Generations [16] versus those who do not. However, most, if not all, of these studies are small-scale, use measures that have not been validated, and are not population representative. In addition, there are no quantitative

studies that identify factors that can act as a buffer against the negative impacts of settler-colonialism. This is critical in taking the next step past identifying associations and towards identifying practical, strengths-based solutions to guide policy and programme development.

Research conducted by Indigenous peoples, for Indigenous peoples, and with Indigenous peoples is a direct challenge to the ongoing colonisation of our lands, cultures, and communities. As Tuck and Yang [17] stated, ‘Decolonization is not a metaphor’. It unsettles the settlers. Indigenous peoples have always conducted research, and we have always used counting as a tool for this research. This fact alone frequently unsettles non-Indigenous researchers in the field of epidemiology who often state that issues of importance to Indigenous peoples, such as culture (the practising of it or revitalisation of it), cannot be quantified. The centring of Indigenous peoples in epidemiology therefore means accounting for settler-colonial-inflicted biosocial injury and centring Indigenous definitions of health and well-being and the determinants thereof within research.

28.2.2 Indigenous Definitions of Health and Well-being

Indigenous identities and concepts of health and well-being are fundamentally connected to the land within an eco-centric relationality or kinship system that defines social and spiritual obligations to family, community, and the land [18, p. 200]. This relationality is reinforced through cultural frameworks where relationships to the past, ancestors, land, and the present are articulated through language, song, dance, storytelling, and maintaining traditional homelands, beliefs, and kinship [19]. As a result, Indigenous definitions of health and well-being are inherently holistic. The Medicine Wheel, or Sacred Hoop, has been used across Turtle Island (North America) to convey Indigenous philosophies of well-being using four quadrants (sometimes represented by the four cardinal directions – North, South, East, and West) to represent the connectedness between the physical, emotional, mental, and spiritual elements of life and the need for balance across these four areas. In Aotearoa (New Zealand), Māori holistic health and well-being also relies on a balance across four fundamentally interconnected elements – *wairua* (spiritual), *whānau* (extended family network), *hinengaro* (the mind), and *tinana* (physical) [20, p. 1141].

In the Australian context, the most used definition of Aboriginal and Torres Strait Islander health is as follows:

‘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. [21, pp. ix–x]

In recent years, several studies have focused on expanding this definition. Garvey and colleagues [22] outlined their *Fabric of Aboriginal and Torres Strait Islander Wellbeing* model based on qualitative research with 359 participants, weaving together eight aspects of well-being: culture; community; family; belonging and connection; holistic health;

purpose and control; dignity and respect; and basic needs. Butler et al. [23] conducted a comprehensive national literature review to identify nine interconnected domains of Aboriginal and Torres Strait Islander well-being, including autonomy, empowerment, and recognition; family and community; culture, spirituality, and identity; Country; basic needs; work, roles, and responsibilities; education; physical health; and mental health. Salmon and her colleagues [19] undertook an international literature review to identify and describe six key cultural domains essential for Aboriginal and Torres Strait Islander well-being: connection to Country; Indigenous beliefs and knowledge; Indigenous language; family, kinship, and community; cultural expression and continuity; and self-determination and leadership. Maintaining and reviving connections to land and culture has been found to be protective of Indigenous health and well-being across a range of studies in Australia and internationally [19, 24].

28.2.3 Indigenous Rights to Data

Indigenous definitions of well-being and its determinants have not been reflected in large-scale epidemiological data collections. For decades, statistics about Aboriginal and Torres Strait Islander communities have been wholly based on the perspective of the White settler-colonial state [25]. Hundreds of Aboriginal and Torres Strait Islander cultural groups were homogenised under the umbrella term ‘Indigenous’ for comparison to the (equally homogenised) ‘non-Indigenous’ population. This comparison was based on White settler-colonial definitions of health, social, and economic achievement. Sociologist Maggie Walter (Palawa) argued that the result of this comparison was the production of ‘5D Data’, emphasising the Difference, Disparity, Disadvantage, Dysfunction, and Deprivation experienced within the Aboriginal and Torres Strait Islander population [26]. She writes:

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 unfitnes. [26]

When data stressing the ‘Indigenous problem’ present in Australian society are used to inform public health and policy development, the inevitable outcome is a re-colonisation of Aboriginal and Torres Strait Islander communities through programmes and policies designed to correct these perceived deficits. Interventions built on this deficit premise are prone to failure, as has been emphasised time and again by the Australian Government’s own monitoring scheme called *Closing the Gap*, established in 2008. The ‘Gap’ refers to the statistical gaps highlighted by the above-mentioned data, particularly the difference in life expectancy at birth between the Indigenous and non-Indigenous population, which currently sits at 7.8 years for females and 8.6 years for males [27]. According to Government statistics, over half (53 per cent) of the health ‘gap’ between Aboriginal and Torres Strait Islander Australians and the rest of the Australian population is accounted for by just five social determinants (employment and hours worked, highest non-school qualification, level of schooling completed, housing adequacy, and household income) and six ‘health risk factors’ (binge drinking, high blood pressure, overweight and obesity status, inadequate fruit and vegetable consumption, insufficient physical exercise, and smoking) [28]. The remaining 47 per cent of the health gap is currently unaccounted for.

Research seeking to measure the health of Indigenous peoples but exclude them from the development of such research is, quite simply, bad science. 'Bad' in this case may be interpreted in two ways. First, in the production of inaccurate, under-powered, and misleading data that, in Australia and Aotearoa at least, have informed decades of largely ineffective public health policy [29, 30]. Indigenous data must have equivalent explanatory power to non-Indigenous data to achieve health equity [31]. Second, it is now widely considered to be unethical to exclude Indigenous peoples from the development of research about their communities. The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), which enshrines the right to self-determination for Indigenous peoples [32, Article 3], helped to spur a change in the way Australian human research ethics committees considered applications. Many major research ethics and funding bodies now require applicants to actively partner with Aboriginal and Torres Strait Islander individuals, organisations, or communities involved in the proposed research [33].

To counter the deficit discourse of Indigenous health that has been informed by the 5D data approach, Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG) protocols and principles have been developed for research based on the UNDRIP. For First Nations communities in Canada, this has been solidified through Ownership, Control, Access, and Possession (OCAP®), which became a registered trademark of the First Nations Information Governance Centre (FNIGC) in 2015 [34]. In Aotearoa, the Kaupapa Māori approach has been practised for decades, which upholds Māori self-determination and ways of knowing, doing, and being in research communities. In Australia, possible protocols and principles were discussed at a meeting in 2018 with delegates from the Maïam nayri Wingara Indigenous Data Sovereignty Collective and the Australian Indigenous Governance Institute. They defined Indigenous data as 'information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually' [35]. IDS and IDG were defined as follows:

'*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.

'*Indigenous Data Governance*' refers to the right of Indigenous peoples to autonomously decide what, how and why Indigenous Data are collected, accessed, and used. It ensures that data on or about Indigenous peoples reflects our priorities, values, cultures, worldviews, and diversity.

In line with these definitions, they determined that Indigenous peoples in Australia have the following rights [35]:

- To exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination, and infrastructure.
- To have data that are contextual and disaggregated (available and accessible at individual, community, and First Nations levels).
- To have data that are relevant and empower sustainable self-determination and effective self-governance.
- To have data structures that are accountable to Indigenous peoples and First Nations.
- To have data that are protective and respect our individual and collective interests.

Supporting these rights generates 'good data', which is the antithesis of 5D Data. The concept of good data extends existing global conversations around ethical data and data

justice and incorporates IDS and IDG principles to describe a resource that Indigenous communities may use to address their self-determined interests and needs [36].

It is only since 2020 that Aboriginal and Torres Strait Islander representative organisations have been meaningfully engaged by Australian governments in the development of the *Closing the Gap* agenda and goals. Part of this engagement involved the recognition that Aboriginal and Torres Strait Islander peoples have the right to define our own needs and priorities in the policy arena. This partnership was formalised through the *National Agreement on Closing the Gap* (the Agreement) that commits to a genuine partnership between all Australian Governments and the Coalition of Aboriginal and Torres Strait Islander Peak Organisations [38]. The goal of this partnership will be to improve the life outcomes of Aboriginal and Torres Strait Islander people, acknowledging that supporting and strengthening Aboriginal and Torres Strait Islander cultures is necessary to achieve this goal [37, p. 4]. Large-scale epidemiological data that reflect Indigenous lifeworlds and reinforce IDS and IDG will be key to driving this national agenda.

28.3 Part 2. Mayi Kuwayu and the Future of the DOHaD

28.3.1 Overview of Mayi Kuwayu

Cohort studies, a type of analytical study, have made a considerable contribution to our understanding of human health and have been at the forefront of identifying the influence of social, environmental, and biological processes on health and well-being outcomes. The goal of analytic studies is to identify and evaluate the causes or risk factors of diseases or health-related events [38]. Cohort studies often involve identifying a ‘group’ of people to study and plan the research in advance, collecting data over time. Epidemiology, as the study of the patterns and distribution of disease and arguably health, is often the mechanism or method used in telling the story about the presence or absence of disease and what the likely relationships are between social, environmental, and other exposures under study. Due to their long time frames, expense, and difficulties in proving causation, cohort studies are uncommon when compared to other study designs.

Indigenous cohort studies are not common in settler-colonial states such as Australia, Aotearoa, and Turtle Island (referred to collectively as CANZUS) where Indigenous peoples are often incidentally recruited into studies. This limits the ability to conduct robust analytical studies specific to Indigenous groups, and, critically, the variation in Indigenous populations within CANZUS countries presents numerous challenges. The result is a ‘tyranny of the majority’ and evidence production that is biased towards the majority population while being underpowered for minority groups within those same cohorts. Additionally, these cohorts do not include risk exposures unique to minority groups, nor do they include exposure to unique potentially protective factors.

When the practice of epidemiology is led by Indigenous peoples its potential to contribute towards the achievement of health equity increases exponentially. Mayi Kuwayu is Australia’s largest longitudinal cohort study of Aboriginal and Torres Strait Islander well-being. As of January 2024, over 12,000 individuals have participated in the study that surveys Aboriginal and Torres Strait Islander-identified social and cultural determinants of health and well-being [39]. The Mayi Kuwayu baseline questionnaire

was developed in consultation with Aboriginal and Torres Strait Islander community members, organisations, and research experts over the course of four years from 2014 to 2018 and is revised every two to three years. It includes a range of metrics that reflect community-identified determinants of health and well-being, such as connection to Country (e.g. 'How much of your life have you lived on your tribe's (mob's) Country or Island?') and cultural knowledge and practice (e.g. 'How much time do you spend learning culture, kinship and respect?'). Mayi Kuwayu data adhere to IDS and IDG principles, and all requests for access to and use of the data must be approved by the Mayi Kuwayu Data Governance Committee, which is a group of Aboriginal and Torres Strait Islander community members and external researchers.

The intent is to conduct world-first analytical work to provide a robust understanding of how settler-colonial risk factors undermine the health and well-being of Aboriginal and Torres Strait Islander peoples, and how culture, a core strength of Aboriginal and Torres Strait Islander communities, can mitigate these adverse effects. This future work aims to understand some of the unexplained 47 per cent health inequity currently experienced by these communities in Australia, while also identifying how the very essence of Indigeneity (cultural maintenance, strengthening, and expression) is fundamental to improving health and well-being and reducing inequities [40, 41]. This work is critical in that settler-colonialism as manifested in historical and contemporary trauma is likely to have a profound impact on adult and intergenerational health.

28.3.2 Mayi Kuwayu Data and Relationship to DOHaD

The Mayi Kuwayu study was developed in response to calls from Aboriginal and Torres Strait Islander peoples to ensure health and well-being concepts were appropriately measured and captured. It is underpinned by a social epidemiological framework, concerned with the influences of social structures, institutions, and relationships on health and well-being [42, 43]. Therefore, the study is designed to enable the examination of health and well-being, taking into account the varied contexts in which Aboriginal and Torres Strait Islander peoples live, including diversity in exposure to settler-colonial factors, and diversity in opportunities to engage in cultural practice and expression. Further, the study is ideally placed to explore and quantify if, and to what extent, culture buffers the impact of settler-colonial risk factors [42].

Since its first release in 2018, analyses of the data collected have shown a positive relationship between connection to Country, culture, and health and well-being outcomes in relation to Aboriginal Ranger work in Central Australia [44]. Being employed as a Ranger, who uses cultural and environmental knowledge to engage in land management activities on Country, was significantly associated with very high life satisfaction and high family well-being [44]. Preliminary analyses of the full Mayi Kuwayu cohort show that key cultural indicators such as spending time on Country, speaking traditional languages, passing on family knowledge and traditions, and feeling in control of one's life are protective against high psychological distress, diagnoses of anxiety, and low life satisfaction [45].

Mayi Kuwayu has also identified a range of settler-colonial exposures experienced by Aboriginal and Torres Strait Islander people and developed measures to capture participants' exposure to these factors from the individual to the systemic level [39, 42]. These exposures have been classified as either Indigenous Historical Trauma (IHT) or Indigenous

Contemporary Trauma (ICT). Indigenous Historical Trauma items included in the study are the following:

1. Tribe/mob forcibly relocated to missions or reserves
2. Being unsure of which tribe/mob you belong to
3. Having a parent who was part of the Stolen Generations
4. Having an aunt or uncle who was part of the Stolen Generations
5. Having a grandparent or great-grandparent who was part of the Stolen Generations

ICT items include the following:

1. Feeling disconnected from culture
2. Being dislocated from Country
3. Worrying about being stolen when they were growing up
4. Growing up in foster care
5. Growing up in a children's home
6. Having children removed in the past 12 months
7. Experiencing interpersonal discrimination
8. Being a part of the Stolen Generations
9. Having a cousin who is part of the Stolen Generations
10. Having child/ren who are part of the Stolen Generations
11. Having grandchild/ren who are part of the Stolen Generations

Over 60 per cent of Mayi Kuwayu participants report at least one exposure to IHT and 85 per cent report at least one exposure to ICT [46]. Exposure to IHT is associated with significant increases in poorer psychological distress and poorer life satisfaction. Stronger links are observed between any experience of ICT and poorer psychological outcomes, poorer general health, and lower life satisfaction. More than half of the Mayi Kuwayu participants have experienced discrimination in some form, and this is significantly associated with a broad range of poor well-being outcomes, ranging from disconnection from culture to high blood pressure and alcohol dependence [47].

These findings strongly support Hoke and McDade's [1] argument that studies on the DOHaD must consider the broader contexts in which we live as well as the intergenerational and transgenerational events that impact our health and well-being. Centring Indigenous lifeworlds in this research has the extraordinary potential to reveal previously 'hidden' factors that either increase the risk for disease or support good health and protect against biosocial harm. With the understanding that such factors and their contribution to health and well-being are heterogeneous across populations, more investment could be made by research institutions and funders in training DOHaD researchers to develop measures for specific salutogenic or risk factors in diverse populations. Intergenerational and transgenerational studies also require secure, long-term funding to provide more robust evidence as it accrues across time.

28.4 Conclusion

The world is currently undergoing a period of disruptive change driven by advances in data science and the convergence of technologies with the potential to enhance and harm Indigenous populations through analytics practice, including cohort studies. This can be addressed by ensuring Indigenous peoples are at the forefront of designing metrics and

analytical studies. Data analytics and the translation of resulting insights into practice are key transformations affecting the future of society and its myriad of cultures. These innovations are a double-edged sword for Indigenous peoples, creating potential opportunities to improve well-being through the delivery of healthcare insights through a digital infrastructure that centres Indigenous values and protocols, but also raising concerns about data misuse and collective harm. Further, longitudinal cohort studies are a cornerstone of epidemiology and are central to knowledge production in DOHaD, but few have been developed by and for Indigenous peoples.

This chapter has argued that it is essential that contextual factors, including inter-generational and transgenerational factors, be accounted for by DOHaD research. Centring Indigenous lifeworlds has the extraordinary potential to identify previously 'hidden' factors and lead to the development of lifecourse interventions that could simultaneously reduce risks and increase protective factors. Through the Mayi Kuwayu study, for the first time in Australia and internationally, we have robust, national, longitudinal data on exposure to settler-colonial factors at the individual to systemic level as well as data on cultural practice and expression that may buffer the effects of settler-colonialism. Incorporating IDS and IDG frameworks and applying an Indigenous lens in the DOHaD research space has the potential to produce better science, better data, and better outcomes for our communities. Mayi Kuwayu is just one example of how Indigenous lifeworlds can be centred to produce a good data story about the origins of health and disease.

References

- Hoke MK, McDade T. Biosocial inheritance: A framework for the study of the intergenerational transmission of health disparities. *Annals of Anthropological Practice*. 2014;**38**(2):187–213. doi: 10.1111/napa.12052
- Paradies Y. Colonisation, racism and indigenous health. *Journal of Population Research*. 2016;**33**(1):83–96. doi: 10.1007/s12546-016-9159-y
- Mitchell TA, Arseneau C, Thomas D. Colonial trauma: Complex, continuous, collective, cumulative and compounding effects on the health of Indigenous peoples in Canada and beyond. *International Journal of Indigenous Health*. 2019;**14**(2):74–94. doi: 10.32799/ijih.v14i2.32251
- Williams AN. A new population curve for prehistoric Australia. *Proceedings of the Royal Society B: Biological Sciences*. 2013;**280**(1761):20130486. doi: 10.1098/rspb.2013.0486
- Australian Bureau of Statistics. Table 9. Indigenous census counts and estimates of the population, states and territories, 1836 onwards. Australian Historical Population Statistics. Cat. No. 3105065001. Canberra, ABS. 2006.
- Australian Institute of Health and Welfare. Aboriginal and Torres Strait Islander Stolen Generations and descendants: Numbers, demographic characteristics and selected outcomes. Cat. No. IHW 195. Canberra, AIHW. 2018.
- Warin M, Kowal E, Meloni M. Indigenous knowledge in a postgenomic landscape: The politics of epigenetic hope and reparation in Australia. *Science, Technology, & Human Values*. 2019;**45**(1):87–111. doi: 10.1177/0162243919831077
- King M, Smith A, Gracey M. Indigenous health part 2: The underlying causes of the health gap. *Lancet*. 2009;**374**(9683):76–85. doi: 10.1016/S0140-6736(09)60827-8
- Sherwood J. Colonisation – It's bad for your health: The context of Aboriginal health. *Contemporary Nurse*. 2013;**46**(1):28–40. doi: 10.5172/conu.2013.46.1.28

10. Czyzewski K. Colonialism as a broader social determinant of health. *International Indigenous Policy Journal*. 2011;2(1) :Article 5. doi: 10.18584/iipj.2011.2.1.5
11. Priest NC, Paradies YC, Gunthorpe W, et al. Racism as a determinant of social and emotional wellbeing for Aboriginal Australian youth. *The Medical Journal of Australia*. 2011;194(10):546–50. doi: 10.5694/j.1326-5377.2011.tb03099.x
12. Priest N, Paradies Y, Stewart P, et al. Racism and health among urban Aboriginal young people. *BMC Public Health*. 2011;11(1):1–9. doi: 10.1186/1471-2458-11-568
13. Paradies Y. Race, racism, stress and Indigenous health. PhD thesis. Melbourne, University of Melbourne. 2006.
14. Paradies Y, Harris R, Anderson I. The Impact of Racism on Indigenous Health in Australia and Aotearoa: Towards a Research Agenda. Darwin, Cooperative Research Centre for Aboriginal Health. 2008.
15. Thurber KA, Colonna E, Jones R, et al. Prevalence of everyday discrimination and relation with wellbeing among Aboriginal and Torres Strait Islander adults in Australia. *International Journal of Environmental Research and Public Health*. 2021;18(12):6577. doi: 10.3390/ijerph18126577
16. Australian Institute of Health and Welfare. Aboriginal and Torres Strait Islander Stolen Generations and descendants: Numbers, Demographic Characteristics and Selected Outcomes. Canberra, AIHW. 2018.
17. Tuck E, Yang KW. Decolonization is not a metaphor. *Decolonization: Indigeneity, Education & Society*. 2012;1(1):1–40. doi: 10.25058/20112742.n38.04
18. Dudgeon P, Bray A. Cathedrals of the spirit: Indigenous relational cultural identity and social and emotional wellbeing. In: Adams BG, van de Vijver FJR, eds. *Non-Western Identity: Research and Perspectives*. Cham, Springer International Publishing. 2021; 199-214.
19. Salmon M, Doery K, Dance P, et al. Defining the indefinable: Descriptors of Aboriginal and Torres Strait Islander peoples' cultures and their links to health and wellbeing. Canberra, Research School of Population Health, The Australian National University. 2019.
20. Durie M. Understanding health and illness: Research at the interface between science and Indigenous knowledge. *International Journal of Epidemiology*. 2004;33(5):1138–43. doi: 10.1093/ije/dyh250
21. National Aboriginal Health Strategy Working Party. A National Aboriginal Health Strategy. Canberra, National Aboriginal Health Strategy Working Party. 1989.
22. Garvey G, Anderson K, Gall A, et al. The fabric of Aboriginal and Torres Strait Islander wellbeing: A conceptual model. *International Journal of Environmental Research and Public Health*. 2021;18(15):7745. doi: 10.3390/ijerph18157745
23. Butler TL, Anderson K, Garvey G, et al. Aboriginal and Torres Strait Islander people's domains of wellbeing: A comprehensive literature review. *Social Science and Medicine*. 2019;233:138–57. doi: 10.1016/j.socscimed.2019.06.004
24. Bourke S, Wright A, Guthrie J, et al. Evidence review of Indigenous culture for health and wellbeing. *The International Journal of Health, Wellness, and Society*. 2018;8(4):11–27. doi: 10.18848/2156-8960/CGP/v08i04/11-27
25. Lovett R, Prehn J, Williamson B, et al. Knowledge and power: The tale of Aboriginal and Torres Strait Islander data. *Australian Aboriginal Studies*. 2020;2:3–7.
26. Walter M. Data politics and Indigenous representation in Australian statistics. In: Kukutai T, Taylor J, eds. *Indigenous Data Sovereignty: Toward an Agenda*. Canberra, ANU Press. 2016; 79–98.
27. Australian Institute of Health and Welfare. Deaths in Australia. Cat. no. PHE 229. Canberra, AIHW. 2019.

28. Australian Institute of Health and Welfare. Social Determinants and Indigenous Health. Canberra, AIHW. 2020. www.aihw.gov.au/reports/australias-health/social-determinants-and-indigenous-health (Accessed 6 June 2022.)
29. Kukutai T, Walter M. Recognition and indigenizing official statistics: Reflections from Aotearoa New Zealand and Australia. *Statistical Journal of the IAOS*. 2015;31(2):317–26. doi: 10.3233/sji-150896
30. Walter M. The voice of Indigenous data: Beyond the markers of disadvantage. *Griffith Review*. 2018;60:256–263. www.griffithreview.com/articles/voice-indigenous-data-beyond-disadvantage/ (Accessed 27 January 2022.)
31. Reid P, Paine S-J, Curtis E, et al. Achieving health equity in Aotearoa: Strengthening responsiveness to Māori in health research. *The New Zealand Medical Journal*. 2017;130(1465):96–103.
32. United Nations. United Nations Declaration on the Rights of Indigenous Peoples 2007. A/RES/61/295. Geneva, UN. 2007. www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html (Accessed 6 June 2022.)
33. Australian Institute of Aboriginal and Torres Strait Islander Studies. Code of ethics. Canberra, AIATSIS. 2020. <https://aiatsis.gov.au/research/ethical-research/code-ethics> (Accessed 27 January 2022.)
34. First Nations Information and Governance Centre. The First Nations Principles of OCAP®. Akwesasne, FNIGC. 2022. <https://fnigc.ca/ocap-training/> (Accessed 22 June 2022.)
35. Maiam nayri Wingara. Key principles. 2019. www.maiamnayriwingara.org/key-principles (Accessed 22 June 2022.)
36. Lovett R, Lee V, Kukutai T, et al. Good data practices for Indigenous data sovereignty and governance. In: Daly A, Devitt K, Mann M, eds. *Good Data*. Amsterdam, Institute of Network Cultures. 2019; 26–36.
37. Department of the Prime Minister and Cabinet. National Agreement on Closing the Gap. Canberra, Commonwealth of Australia. 2020. www.closingthegap.gov.au/national-agreement/national-agreement-closing-the-gap (Accessed 25 January 2022.)
38. Song JW, Chung KC. Observational studies: Cohort and case-control studies. *Plastic and Reconstructive Surgery*. 2010;126(6):2234–42. doi: 10.1097/PRS.0b013e3181f44abc
39. Lovett R, Brinckley M-M, Phillips B, et al. Murrathalpu mayingku ngiya kiyi. Minyawaa ngiyani yata punmalaka; wangaaypu kirrampili kara [Ngiyampaa title]; In the beginning it was our people's law. What makes us well; to never be sick. Cohort profile of Mayi Kuwayu: The National Study of Aboriginal and Torres Strait Islander Wellbeing [English title]. *Australian Aboriginal Studies*. 2020;2:8–30.
40. Dudgeon P, Milroy H, Walker R. Working together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice. Canberra, Australian Government Department of the Prime Minister and Cabinet. 2014. www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/working-together-aboriginal-and-wellbeing-2014.pdf (Accessed 25 January 2022.)
41. Australian Institute of Health and Welfare. National Aboriginal and Torres Strait Islander Health Plan 2021–2031. Canberra, AIHW. 2021. www.health.gov.au/resources/publications/national-aboriginal-and-torres-strait-islander-health-plan-2021-2031 (Accessed 22 June 2022.)
42. Jones R, Thurber KA, Chapman J, et al. Study protocol: Our cultures count, the Mayi Kuwayu Study, a national longitudinal study of Aboriginal and Torres Strait Islander wellbeing. *BMJ Open*. 2018;8(6):e023861. doi: 10.1136/bmjopen-2018-023861

43. Krieger N. *Epidemiology and the People's Health: Theory and Context*. Oxford, Oxford University Press. 2011.
44. Wright A, Yap M, Jones R, et al. Examining the associations between Indigenous Rangers, culture and wellbeing in Australia, 2018–2020. *International Journal of Environmental Research and Public Health*. 2021;**18**(6):3053. doi: 10.3390/ijerph18063053
45. Lovett R. Culture as a salutogenic factor for indigenous health in Australia. Unpublished.
46. Lovett R, Brinckley M-M, Colonna E, et al. Quantifying exposure to settler-colonial risks and links to Aboriginal and Torres Strait Islander people's wellbeing outcomes in Australia: Evidence from the Mayi Kuwayu Study. Unpublished.
47. Thurber KA, Colonna E, Jones R, et al. Prevalence of everyday discrimination and relation with wellbeing among Aboriginal and Torres Strait Islander adults in Australia. *International Journal of Environmental Research and Public Health*. 2021;**18**(12):6577. doi: 10.3390/ijerph18126577