

SUMMARY

GUIDING PRINCIPLES

Ensuring Culturally Safe Health Genomics in Partnership with Aboriginal and Torres Strait Islander Peoples.

Introduction

Genomics describes the study of all of a person's genes (the genome), including interactions of those genes with each other and with the person's environment. Genomics includes the scientific study of complex diseases such as heart disease, asthma, diabetes, and cancer because these diseases are typically caused more by a combination of genetic and environmental factors than by individual genes. Genomics is offering new possibilities for therapies and treatments for some complex diseases, as well as new diagnostic methods.

The Aboriginal and Torres Strait Islander Advisory Group on Health Genomics has developed these Guiding Principles as a framework for ensuring culturally safe genomic health services and research studies that maximise benefits and minimise risks for Aboriginal and Torres Strait Islander peoples. The Guiding Principles are intended to be applied to the range of genomic health services, including diagnostic, prevention and treatment, and all facets of genomics research. The guiding principles complement and extend the National Health Genomics Policy Framework.^{1,2}

These Guiding Principles are directed at the clinical workforce, managers and researchers involved in the planning and provision of genomic health services and research related to Aboriginal and Torres Strait Islander people. The Guiding Principles are also intended to be a useful resource for Aboriginal and Torres Strait Islander peoples and their communities to support their decision making with respect to engaging (or not) with genomics research.

Significant health and social disparities exist between Aboriginal and Torres Strait Islander people and non-Indigenous Australians in relation to health service access and health outcomes. The *National Agreement on Closing the Gap: Closing the Gap in Partnership, July 2020*³ highlights that strong culture is fundamental to and directly contributes to improving life outcomes for Aboriginal and Torres Strait Islander individuals, families and communities.

Aboriginal and Torres Strait Islander peoples have the right to feel confident and safe in accessing the Australian healthcare system, and the system and its workforce must be able to respond to their needs. These Guiding Principles aim to ensure that Aboriginal and Torres Strait Islander individuals, families and communities benefit equitably through culturally safe and responsive genomic health services and research that incorporates their belief systems and keeps dynamic and evolving cultures strong.

Culturally responsive health services and research studies demand commitment to the phrases “*Do nothing about us, without us*”, with Aboriginal and Torres Strait Islander peoples being equal partners in decision-making. Co-design of services and research studies in partnership with Aboriginal and Torres Strait Islander peoples is promoted through these Guiding Principles, as well as the need for

¹ National Health Genomics Policy Framework

<https://www1.health.gov.au/internet/main/publishing.nsf/Content/national-health-genomics-policy-framework-2018-2021> Accessed 20/11/2020

² The term ‘genomics’ is used throughout this document to refer to both the study of single genes (genetics) and the study of an individual’s entire genetic makeup (genome) and how it interacts with environmental or non-genetic factors.

³ National Agreement on Closing the Gap: Closing the Gap in Partnership July 2020. [\[coalitionofpeaks.org.au\]](http://coalitionofpeaks.org.au) Accessed 18/02/2021

greater opportunities for Aboriginal and Torres Strait Islander peoples to participate in the workforce and fulfil leadership roles in genomic health service and research sectors.

It is also recognised that partnership requires a foundation of trust, and that trust takes time to develop through culturally respectful conversations that focus on the priorities and aspirations of Aboriginal and Torres Strait Islander peoples. Trust relationships also need to be built at a pace determined by Aboriginal and Torres Strait Islander peoples, which is reflected in the phrase “*on our time*”.

In summary, these Guiding Principles aim to ensure that Aboriginal and Torres Strait Islander people lead the development of fit-for-purpose, culturally safe and responsive genomic health services and research studies. The Guiding Principles identify the priority areas that support the application of new genomics knowledge and rapidly evolving health technologies in a culturally safe way, incorporating the ancient and contemporary wisdom of Aboriginal and Torres Strait Islander peoples.

THE GUIDING PRINCIPLES

PRINCIPLE 1

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES RIGHTS:

To ensure the United Nations Declaration on the Rights of Indigenous peoples, the Cultural Respect Framework for Aboriginal and Torres Strait Islander Peoples Health and the Australian Charter of Healthcare Rights are applied to Aboriginal and Torres Strait Islander people’s health genomics and self-determination, decision-making and co-design of services are assured and implemented. This includes the duty to obtain the free, prior and informed consent of Aboriginal and/or Torres Strait Islander collaborators or participants.

Aboriginal and Torres Strait Islander leadership and the engagement with individuals, families and communities is key to addressing disparities in the health gap. The *United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)* ⁴ provides an overarching Human Rights framework for developing and implementing policy. This includes:

- The right to self-determination, with equal rights to the highest attainable standard of physical and mental health.
- The right to participate in decision-making for matters that affect them, which includes the right to maintain control, protect and develop cultural heritage, traditional knowledge and cultural expressions.
- The right to determine priorities and strategies in health at the national and state levels, promoting respect and full application of the provisions of the Declaration.
- The needs of Indigenous Elders, women, youth, children and persons with disabilities are considered in consultation and cooperation with Indigenous peoples.
- Free, prior and informed consent to service provision and participation in research studies.

The Commonwealth Government endorses these values through the *Cultural Respect Framework 2016 - 2026: For Aboriginal and Torres Strait Islander Health* ⁵ and the *Australian Charter of Healthcare*

⁴ United Nations, 2007. *United Nations Declaration on the Rights of Indigenous peoples*. United Nations, Geneva.

⁵ *Cultural Respect Framework 2016-2026; For Aboriginal and Torres Strait Islander Health*.

https://nacchocommunique.files.wordpress.com/2016/12/cultural_respect_framework_1december2016_1.pdf Accessed 23/02/2021

Rights. ⁶ Cultural respect recognises, protects and supports continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander people.

Partnerships and engagement with Aboriginal and Torres Strait Islander people to enable them to lead and set their own health priorities are critical for developing a culturally safe and culturally responsive health system. This needs to be supported by building Aboriginal and Torres Strait Islander peoples' capacity and capability at every level across the health genomics field to help foster strong leadership, self-determination, joint decision-making processes and ethical co-design.

Furthermore, the *National Safety and Quality Health Service (NSQHS) Standards* ⁷ promote active and informed participation by Aboriginal and Torres Strait Islander consumers in decisions about their own care. The *Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research* ⁸ also sets out the national standards for ethical and responsible conduct of research with Aboriginal and Torres Strait Islander peoples. This includes leadership and participation in the prioritisation and conduct of health genomic research to ensure culturally responsive outcomes.

PRINCIPLE 2

CULTURALLY SAFE:

To ensure the rights of future generations are not undermined by decisions made now, it is critical that culture and kinship are key considerations in all applications of genomics. In clinical investigations, this means that the provision of genomic health services will not compromise the legitimate cultural and human rights, values, and expectations of Aboriginal and Torres Strait Islander peoples. In research and service design, projects should be conducted through co-design processes ensuring benefits and outcomes are mapped to cultural and kinship practices and priorities.

Aboriginal and Torres Strait Islander cultures are varied, with more than 250 Aboriginal and Torres Strait Islander nations across the continent of Australia. Culture plays a pivotal role in the health and wellbeing of Aboriginal and Torres Strait Islander people; and their belief systems are built on centuries of unbroken connection to country, encompassing land, waters, islands and seas. Aboriginal and Torres Strait Islander peoples' connection to country has existed for millennia.

The separate Aboriginal nations, and the many island nations in the Torres Strait, are distinct groups in their own right. Consequently, cultural responsiveness in service design and ethical research co-design ensures cultural safety as a key consideration across all aspects of genomics health services and research for Aboriginal and Torres Strait Islander individuals, families and communities.

Kinship is a critical element across all Aboriginal and Torres Strait Islander cultures that defines the relationships between family, lore and culture. Engagement with Aboriginal and Torres Strait Islander peoples must occur to understand the impact of genomic health services and research on the individual, family, kinship dynamics and their communities more broadly. Consideration also needs to be given to variations in cultural protocols and kinship, and for people from other groups living within a community. Flexible models need to be co-designed to meet the needs and wants of the people concerned. This should occur through ongoing consultation and conversations with communities to ensure that culture is protected and sustained through clinical care and research practice.

⁶ *Australian Charter of Healthcare Rights* <https://www.safetyandquality.gov.au/sites/default/files/migrated/Charter-PDF.pdf> Accessed 14/01/2021

⁷ *National Safety and Quality Health Service (NSQHS) Standards* <https://www.safetyandquality.gov.au/standards/nsqhs-standards> . Accessed 14/01/2021

⁸ *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research* <https://aiatsis.gov.au/research/ethical-research/guidelines-ethical-research-australian-indigenous-studies>. Accessed 20/12/20

PRINCIPLE 3

HEALTH EQUITY:

- (a) To ensure the application of genomics in clinical practice and health service delivery provides equitable access, equitable outcomes and optimised benefits through respectful partnerships with Aboriginal and Torres Strait Islander individuals, families and communities, including through partnerships with Aboriginal organisations, such as the Aboriginal Community Controlled Health Sector;
- (b) To ensure mandatory co-design and co-production in all genomic research studies so that health benefits are returned to participants and passed on to Aboriginal and Torres Strait Islander people and communities;
- (c) To ensure Aboriginal and Torres Strait Islander people, communities and organisations are empowered in the development, conduct, analysis and evaluation of clinical and research genomics to improve their respective health journeys and to ensure a healthful future; and
- (d) To ensure all Aboriginal and Torres Strait Islander peoples and communities have the opportunity to benefit from genomics services and research regardless of where they live.

Genomic health services and research must benefit Aboriginal and Torres Strait Islander individuals, families, communities and their cultural belief systems more broadly. Aboriginal Community Controlled Health Organisations and Aboriginal Medical Services have been established in response to state-based health services failing to provide culturally safe environments for Aboriginal and Torres Strait Islander people.

In Australia, genomic health services are predominately delivered through state-based health services. Despite the incidence of some genetically determined conditions among Aboriginal and Torres Strait Islander people, uptake of these services is lower than for the general Australian population. A lack of understanding of Aboriginal and Torres Strait Islanders peoples' unique cultures, belief systems, and their historical experiences with the Australian health system, may be contributing to the low uptake of genomic health services.

An understanding of local cultural histories of Aboriginal and Torres Strait Island peoples and what is culturally safe for individuals, families and communities is critical to delivering a responsive clinical service. The design of genomic health services must be guided and/or led by regional Aboriginal and Torres Strait Islander communities to proactively establish equitable partnerships that meet their health care priorities and ensure equitable and beneficial outcomes.

Aboriginal and Torres Strait Islander people leading genomics research is equally critical to advancing and improving health and wellbeing that ensures research priorities focus on beneficial outcomes for the participants and their communities.

PRINCIPLE 4

DATA SOVEREIGNTY:

To ensure, through equivalent partnerships and co-design processes, Aboriginal and Torres Strait Islander peoples' genomics data are defined, collected, managed, stored, analysed, interpreted and used under robust data governance structures.

Data hold extremely important implications for Aboriginal and Torres Strait Islander peoples' ability to exercise their individual, family, community and collective rights to self-determination. Aboriginal and Torres Strait Islander peoples have exceptionally long uninterrupted and culturally rich histories of data collection and preservation of data. This knowledge is dynamic and constantly growing as Aboriginal and Torres Strait Islander culture and knowledge systems evolve with individuals, families and communities continuing to express themselves in new and adapted ways.

Aboriginal and Torres Strait Islander peoples have been collaborating internationally and advocating nationally for Indigenous data sovereignty and governance processes to support these data. Indigenous data sovereignty refers to the right of Indigenous peoples to govern the creation, collection, ownership, application and destruction of data related to Indigenous communities, peoples, lands and resources. Indigenous data sovereignty developed out of a collective frustration of Indigenous people globally and the shared reality that, despite the interest and magnitude of data collected on their respective communities, information collections and reports tend to focus on what is wrong in Indigenous health. Furthermore, it is rare that data collected are used and shared in a manner that directly benefit the communities or reflect their priorities and cultural world views in a way that contributes to cultural strengths and community aspirations.

Consequently, much of the published data are skewed towards deficit and disparity, which become the policy drivers for government funding agencies and research agendas. This subsequently feeds action plans that frequently do not reflect cultural values and health priorities of Aboriginal and Torres Strait Islander peoples. It also misses the opportunity to highlight what Indigenous culture can contribute to their own community's health, and that of society more broadly. Collected and reported data can have a significant influence on decision-making, allocation of resources and driving innovation. Related investment is critical to Aboriginal and Torres Strait Islander peoples' capacity and capability to exercise their human rights and their cultural and kinship responsibilities.

Aboriginal and Torres Strait Islander peoples must be able to lead in the collection of all Aboriginal and Torres Strait Islander health genomics data. The leadership and ethical co-design of the data collection include the data elements, collection process development, and the storage, management, analysis, sharing and use of these data.

The Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective was established in 2017 to progress Indigenous data sovereignty and Indigenous data governance through developing shared understandings and initiating an Australian set of Indigenous data governance protocols. The key priorities are to produce more nuanced data and information than currently exist, provide greater input into the data elements collected, and greater governance of the use of data from Aboriginal and Torres Strait Islander peoples themselves.

**PRINCIPLE
5**

INFORMED CONSENT:

To ensure ethical clinical practice and research guidelines centre on culturally appropriate, free, prior and informed consent as foundational principles. This includes consideration of the implications of decisions made by parents/carers on behalf of children that will affect them as adults; implications for adults dependent upon carers and guardians; and protection of cultural sovereignty and self-determination rights of future generations.

Across the practical application of ethical models of informed consent, there exists a persistent tension between the provision of sufficient information in a culturally appropriate and understandable form; and of the simplification of information presented being reduced to an inadequate level of information for participants to make fully informed decisions. Furthermore, research teams may focus on the logistics of consent and the accrual of participant numbers, rather than participant's rights to

self-determination in balancing the risks and benefits of participating in research. These issues are exacerbated when there are cultural and language differences, perceptions of power imbalance between researchers or clinical providers and participants, and whether the consent process is occurring at a time of significant stress or within the context of investigating potential genetic disease.

While there have been positive steps to help protect Aboriginal and Torres Strait Islander peoples' rights within clinical services and research, much work remains to be done to ensure individual, collective and prospective rights and aspirations are respected, protected and ensured. Unfortunately, contemporary consent processes rarely consider the belief systems, cultural practices and kinship obligations of Aboriginal and Torres Strait Islander individuals, family and community. Development of consent processes in partnership with Aboriginal and Torres Strait Islander peoples requires a fundamental shift in the prioritisation, conceptualisation and deployment of informed consent processes. Family or community consent may also be required for clinical genomic testing or for research studies.

The *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research* sets national standards for the ethical and responsible conduct of all Aboriginal and Torres Strait Islander research. The code highlights the imperative for initiating and maintaining culturally responsive engagement with Aboriginal and Torres Strait Islander individuals, families and communities, as well as maintaining a clear understanding of the participants and the potential benefits for them. It also provides a guide for policy makers to partner with Aboriginal and Torres Strait Islander peoples in clinical service design. Priorities for health genomics consent identified by Aboriginal and Torres Strait Islander peoples include:

- How decisions are made by individuals, families and by the community on behalf of the collective.
- How decisions are made by parents, carers and guardians on behalf of children that will affect them in adulthood.
- How decisions are made by, or on behalf of, vulnerable members of the community.
- Exploring and adapting flexible, culturally safe and responsive consent models.

Informed consent is highly complex and different models, such as Dynamic and Tiered consent, need to be considered. However, regardless of the consent model, there are risks and benefits for Aboriginal and Torres Strait Islander peoples that will need to be balanced.

PRINCIPLE 6

GENOMICS HEALTH WORKFORCE:

To ensure Aboriginal and Torres Strait Islander people have equitable access to services, resources, funding, and opportunities to participate as members of a culturally safe genomics workforce; and to have individual and community leadership roles in every clinical and research field contributing to genomics health, from clinical genomics, service design, data sciences, analytics, and to research leadership.

Aboriginal and Torres Strait Islander people have a unique contribution to make to the Australian health workforce, and yet are significantly under-represented. Currently, there are no Aboriginal and Torres Strait Islander clinical geneticists or genetic counsellors in Australia. Furthermore, there are very few examples of roles or opportunities for Aboriginal and Torres Strait Islander people to upskill within the primary or allied health sector, or other genomics related fields where culturally safe and responsive processes are needed.

Workforce disparity contributes to reduced access to culturally safe and responsive health services for Aboriginal and Torres Strait Islander people. Ensuring workforce equity in health genomics requires investment in the Aboriginal and Torres Strait Islander health workforce, including co-creating

pathways from school to university, through to meaningful employment. If opportunities for cultural inclusivity do not improve, current disparities in access to the workforce are likely to be further exacerbated. It also presents a missed opportunity to embrace valuable knowledge and experiences that could facilitate effective partnerships with Aboriginal and Torres Strait Islander people to develop culturally appropriate genomics health services and research studies, which benefit communities and families.

The spectrum of the genomics workforce encompasses a wide range of clinical diagnostic, prevention and treatment services and all facets of genomics research. However, Aboriginal and Torres Strait Islander people are unlikely to work in areas that are unknown to them, and current genomic protocols may not be considered culturally safe. Investment in developing culturally responsive approaches to informing individuals, families and communities of what health genomics is, and what it entails, is an essential prerequisite for Aboriginal and Torres Strait Islander people to reconcile such information with cultural concepts and balance the potential risks and benefits.

Furthermore, increasing cultural competency is a significant workforce priority to enable culturally responsive approaches to improving Indigenous engagement across policy, research, and clinical service design, as well as establishing priorities. Culturally competent systems need to acknowledge the importance of culture at all levels, as well as recognise cultural differences and the need to adapt services to meet culturally unique needs.

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