Guiding Principles

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

Prepared by the Aboriginal and Torres Strait Islander
Advisory Group on Health Genomics

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Acknowledgements

The *Ensuring Culturally Safe Health Genomics with Aboriginal and Torres Strait Islander Peoples – Guiding Principles* ('the Guiding Principles') was developed by the Aboriginal and Torres Strait Islander Advisory Group on Health Genomics and supported by funding from the Australian Government. Funding was provided to assist with the development and publication of this document and support the Aboriginal and Torres Strait Islander Advisory Group on Health Genomics facilitator.

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* The Advisory Group gratefully acknowledges the significant contributions of Professor Kelaher, who passed away prior to the completion of this report.

The Aboriginal and Torres Strait Islander Advisory Group on Health Genomics respectfully acknowledges the Traditional Owners and Custodians of Country throughout Australia, and recognises their enduring connection to land, waters, skies and communities.

We pay our deepest respects to Aboriginal and Torres Strait Islander peoples, and to Elders past and present, in recognition of their rich cultures, knowledge systems, and ongoing contributions.

The Aboriginal and Torres Strait Islander Advisory Group on Health Genomics acknowledges the contributions of the individuals of the Advisory Group throughout the development of the Guiding Principles; the contributions of the facilitator of the Advisory Group, Dr Summer May Finlay; and, the support by funding from the Australian Government, Department of Health, Disability and Ageing.

The Artwork

The Guiding Principles' artwork was created by Wongutha artist and designer, Kevin Wilson. It is a visual representation of the principles and how they can protect Aboriginal and Torres Strait Islander people who are involved in genomic health care and research.

The artwork features seven threads – six representing the Guiding Principles, with a double helix at the centre symbolising genomics.

The central double helix, framed by three principles on each side, highlights the cultural safety these offer in protecting and empowering Aboriginal and Torres Strait Islander people.

Woven into the six Guiding Principles, the designs represent songlines, reflecting Aboriginal and Torres Strait Islander Peoples' connection to Country, their legacy as the first researchers, and the continuation of their cultures today.

The threads show how many smaller elements can come together to form something strong, and that nothing is built in a silo.

The colours are drawn from the Aboriginal and Torres Strait Islander Peoples' flags. They are vibrant, positive and future-focused, setting the intention for where the Guiding Principles can guide genomics moving forward.

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Terminology used in this document

Indigenous

‘Indigenous’ refers to the world’s First Nations Peoples so for this document it was considered too broad to reflect the diversity and connection to Country of Aboriginal and Torres Strait Islander cultures. Consequently, Aboriginal and Torres Strait Islander Peoples/people is used throughout to refer to the First Nations people of Australia. It is within this context of reflecting the cultural diversity, languages, kinship, beliefs and connection to Country that this document uses terms in relation to specific fields of health and wellbeing studies such as Aboriginal and Torres Strait Islander (Health) Genomics and Indigenous (Health) Genomics.

When the word Indigenous is used, it relates to the world’s First Nations Peoples and/or Aboriginal and Torres Strait Islander Peoples, or is used in the context of an existing organisation and/or research publication or policy that uses this term.

Aboriginal and Torres Strait Islander Peoples / Aboriginal and Torres Strait Islander people

‘Aboriginal and Torres Strait Islander Peoples’ collectively infers communities, families and individuals and recognises Aboriginal and Torres Strait Islander people as two separate groups. The term ‘Aboriginal and Torres Strait Islander people’ is used as the preferred descriptor throughout this document when referring to the individuals affected by genomics practices.

Gene

A gene is a segment of deoxyribonucleic acid (DNA) that contains instructions for making proteins or controlling how the body functions. Genes are considered the basic units of inheritance. They are passed from parents to children and contain the information needed to determine physical and biological traits. Most genes code for specific proteins, or segments of proteins, which perform various functions in the body. While most small changes in DNA do not affect normal function, some changes can prevent a gene from working properly. This may increase a person’s risk of developing certain health conditions.

Genomics

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. While genetic testing for clinical purposes is already embedded in the health system, the term genomics is used for brevity and to acknowledge the cross-over of issues between genetics and genomics, other than where it is necessary to differentiate between genetics and genomics. The terms genomics and/or ‘genomic knowledge’ are used in this document and refer to the data, information, collections and learnings derived through genomic research. It also refers to the technologies used for testing, analysing and furthering the discovery of genomic knowledge.

Culturally appropriate resources and information about genetics and genomics created by the National Centre for Indigenous Genomics (NCIG) may be accessed at https://ncig.anu.edu.au/resources.

Executive Summary

Australia is widely regarded as having one of the best healthcare systems in the world. It provides access to the latest healthcare technologies, medications and a wide range of services across the continuum of care from within the community to high-end specialised care.

The Australian health workforce is diversely qualified, highly-skilled, and competent in delivering safe, high-quality, evidence-based care. (Australian Commission on Safety and Quality in Health Care, 2017.) Unfortunately, not every Australian citizen experiences equitable access to all that the Australian healthcare system offers.

There are significant health and social disparities between Aboriginal and Torres Strait Islander people and non-Indigenous Australians. Inequity within the healthcare system and society more broadly are key contributors to this unacceptable divide. Combined with the level of comorbidities experienced by Aboriginal and Torres Strait Islander people, their age at diagnosis and their socioeconomic position, these disparities require a refocusing of health care to meet the unique needs of each patient. (Australian Commission on Safety and Quality in Health Care, 2017.)

Aboriginal and Torres Strait Islander people have the right to feel confident and safe when accessing the Australian healthcare system, and the system and its workforce must be able to respond. Health service organisations across the continuum of care must ensure that service provision is equitable, and the quality of care accessed is driven by patient needs.

The application of genomics technology for Aboriginal and Torres Strait Islander Peoples requires culturally safe approaches. This is to ensure that they benefit from newly-created knowledge and have equitable access and equitable health and social outcomes.

In the context of the emergence of genomics within health care, any such benefits will need to be predicated on a culturally-responsive approach to the implementation of Aboriginal and Torres Strait Islander Health Genomics. This applies to both clinical services and the whole health system, including setting research priorities, designing studies, and developing measures to track beneficial outcomes.

After extensive consultation, this document (hereafter referred to as ‘the Guiding Principles’), scaffolded by the *United Nations Human Declaration on Rights of Indigenous Peoples*, has been developed by and for Aboriginal and Torres Strait Islander people to inform culturally safe and equitable access to genetic services and ultimately improve outcomes for Aboriginal and Torres Strait Islander individuals, families and communities.

The Guiding Principles are framed not only by the Articles housed within the *United Nations Declaration on the Rights of Indigenous Peoples*, but also in accord with key Aboriginal and Torres Strait Islander national health agreements and policies including the *National Agreement on Closing the Gap*. (Coalition of Peaks and Australian Government, 2020.)

The Guiding Principles are particularly salient as Aboriginal and Torres Strait Islander people have had little opportunity until very recently to participate in discussions and decision-making on how clinical genetic services are delivered and genomic research is conducted.

Opportunities, such as being partners in the design, development or delivery of clinical services are essential. Having rights in the 'how, when, what and why' of data that are collected, or understanding 'how it is analysed and how it will be used' is also vital.

Aboriginal and Torres Strait Islander people should also be central to relevant areas of the genomics health workforce. This includes, but is not limited to delivering clinical services; genomic health system and health services pathway design and evaluation; and, policy and data analytics.

Similarly, Aboriginal and Torres Strait Islander people should be engaged in, supported to enter, and enabled to thrive in genomics research, commercialisation, fundamental discovery sciences, health data system design, data collection, data sciences and bioinformatics.

These Guiding Principles should be viewed as living and enduring principles that can only be built on the foundations of trust. This trust must be built at a pace determined by Aboriginal and Torres Strait Islander individuals, families and communities, according to their own desires, needs, cultural protocols and aspirations.

Through participation in decision-making and building cultural capability across every facet of the evolving health genomics fields, Australia will mitigate the risks of repeating the mistakes of the past, and, in partnership, support and sustain Aboriginal and Torres Strait Islander cultures today, and for future generations.

1. Establishing Genomic Health Principles with Aboriginal and Torres Strait Islander People

The World Health Organization (WHO) advocates that '… ***the highest attainable standard of health is a fundamental right of every human being.'***

1.1 Context

The right to health includes access to timely, acceptable and affordable health care of appropriate quality. By taking a human rights-based approach to health, governments can provide strategies and solutions to address and rectify inequities, and remove discriminatory practices and unjust power relations, which are often at the heart of inequitable health outcomes. (United Nations, 2015.)

It is a shared responsibility of all levels of governments to partner with Aboriginal and Torres Strait Islander people and communities to address health inequalities, overcome Indigenous disadvantage, and close the life expectancy gap between Aboriginal and Torres Strait Islander Peoples and non-Indigenous Australians. (Commonwealth of Australia, 2016; QIMR Berghofer, 2019; Close the Gap Campaign Steering Committee for Indigenous Health Equality, 2020; Coalition of Peaks and Australian Government, 2020.)

There is clear evidence that Aboriginal and Torres Strait Islander people do not have equal access to essential health care. (Australian Institute of Health and Welfare, 2015). This shows that we need a national health reform that can better address the health, social, emotional wellbeing and cultural needs of Aboriginal and Torres Strait Islander people.

This urgent need for change is evident in the *National Agreement on Closing the Gap*. A 10-year shared decision-making agreement, developed between the Australian Governments and the Coalition of Aboriginal and Torres Strait Islander Peak Organisations and ratified in July 2020. (Coalition of Peaks and Australian Government, 2020.)

At the centre of the National Agreement are four Priority Reforms that focus on changing the way governments work with Aboriginal and Torres Strait Islander people.

The Priority Reforms will:

- Strengthen and establish formal partnerships and shared decision-making.
- Build the Aboriginal and Torres Strait Islander community-controlled sector.
- Transform government organisations so they work better for Aboriginal and Torres Strait Islander people.
- Improve and share access to data and information to enable Aboriginal and Torres Strait Islander communities make informed decisions.

Making significant change requires a new way of thinking about priority-setting with Aboriginal and Torres Strait Islander people regarding health and wellbeing; and, in working together in culturally-responsive partnership, to close the gaps in Aboriginal and Torres Strait Islander life expectancy, health, wellbeing and education. (Close the Gap Campaign Steering Committee for Indigenous Health Equality, 2020; Lowitja Institute, 2021.)

> *...the benefits that come from our playing a driving role and having legitimate decision-making power over our own lives – 'nothing about us, without us' – should not be underestimated. ... Our culture comes from our lore, a very deep and sacred place. The cultural determinants of our health provide many of the remedies for Aboriginal and Torres Strait Islander health equity and these determinants should be respected, understood, and embraced by all. This report shows us what can be achieved by Aboriginal and Torres Strait Islander people through leadership and self-determination, owning our knowledge, continuing our cultures, and maintaining connections to Country and kin.* (Close the Gap Campaign Steering Committee for Indigenous Health Equality, 2020.)

Too often, Aboriginal and Torres Strait Islander people who access health services encounter a health system that is not adequately applying Aboriginal and Torres Strait Islander cultural views of health and wellbeing. These views influence how Aboriginal and Torres Strait Islander people decide which health services to use.

However, the choice of services is often limited due a range of other factors. These include:

- geographical isolation, distance to and accessibility of the service
- number of service centres, hours of operation and staffing
- determinations of eligibility and control by health service operators
- barriers of systemic and institutionalised racism.

All these factors complicate the clinical health journey experienced by the individual and family, affecting health outcomes. (Thomson, 2005; Bainbridge et al., 2015.)

Disclosing one's cultural identity is voluntary. However, identification by individuals and families as Aboriginal and/or Torres Strait Islander people is essential for access, as it can lead to improving health interventions and prevention. It can also help inform culturally-responsive approaches to health care delivery. This disclosure is a shared responsibility, so health professionals need to provide Aboriginal and Torres Strait Islander people with the opportunity to respond to the question of their identity. (Australian Institute of Health and Welfare, 2013; Australian Indigenous Doctors Association, 2019.)

Aboriginal and Torres Strait Islander people face unique concerns relating to genomics. These include:

- The ongoing and intractable structural inequalities that exist in many facets of daily life.
- The experience of racism and discrimination more broadly.
- How research of the past has marginalised and dehumanised Aboriginal and Torres Strait Islander Peoples.
- The potential misuse and exploitation of research findings and data for purposes that do not protect the rights of Aboriginal and Torres Strait Islander people or enable the equitable share of the benefit of any such research.

The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code of Ethics for Aboriginal and Torres Strait Islander Research is structured according to the four principles of Aboriginal and Torres Strait Islander self-determination; leadership; impact and value; and sustainability and accountability.[1]

Therefore, from a clinical health service perspective, addressing these concerns entails:

- ensuring equitable access and equitable outcomes from investigations or treatments, and
- for these services to be undertaken in a culturally safe and responsive setting.

And from a research study perspective, addressing these concerns means that ethical studies need to:

- provide outcomes that benefit the participants, and/or are identified by the community as a priority issue
- include desired outcomes and expected benefits arising from the research
- ensure culturally safe informed consent and study design
- empower the participants through co-design
- lead to beneficial outcomes from research and the sovereignty of the data custodianship.

These concerns must be central to establishing national efforts to improve Aboriginal and Torres Strait Islander people’s engagement with, and benefit from genomics.

2. Why have Actions Specific to Aboriginal and Torres Strait Islander Health Genomics?

There are many compelling reasons to have specific actions that meet the needs of Aboriginal and Torres Strait Islander Peoples. These include but are not limited to:

- The historical and contemporary context of Aboriginal and Torres Strait Islander Peoples' health as well as their social and emotional wellbeing.
- The unique and diverse cultures, protocols, experiences and needs of Aboriginal and Torres Strait Islander Peoples.
- The limited opportunities within career pathways for Aboriginal and Torres Strait Islander people to study, gain experience and work within the clinical genomics health workforce and genomics research fields.
- Ensuring equity of access to culturally respectful and culturally safe clinical genomic services, equity of health outcomes, and culturally-responsive approaches to deliver the benefits of genomics knowledge.
- Ensuring genomics health research is conducted in culturally safe and responsive ways with and for the benefit of Aboriginal and Torres Strait Islander Peoples, now and for future generations. (Close the Gap Campaign Steering Committee for Indigenous Health Equality, 2020.)

2.1 Historical and Contemporary Context of Aboriginal and Torres Strait Islander Health

Aboriginal and Torres Strait Islander people are among the most socially and economically disadvantaged groups in Australia. (Marmot, 2011.) The current poor health and social and emotional wellbeing of many Aboriginal and Torres Strait Islander people stems from the effects of colonial policies and their ongoing legacy of living with generational inequity and racism. (Australian Health Ministers' Advisory Council's National Aboriginal and Torres Strait Islander Health Standing Committee, 2016.)

These policies have resulted in loss of land, family and community connections, dislocation from Country and languages, and denial of cultural expression across generations. Coloniality affects the physical, emotional, social and spiritual dimensions of wellbeing for Aboriginal and Torres Strait Islander individuals, families and communities.

The continuing impact on health and wellbeing is evident in the unacceptable gaps between Aboriginal and Torres Strait Islander people and other Australians in health outcomes, including infant and child mortality, disease burden, and life expectancy. Significant structural, system and workforce barriers to accessing safe and effective health care contribute to these gaps. Therefore, it is essential for Aboriginal and Torres Strait Islander people to experience safe and high-quality health care based on their needs. (Coalition of Peaks and Australian Government, 2020.)

Meaningful, lasting relationships with the Aboriginal and Torres Strait Islander communities are integral to redressing past wrongs and moving towards an equitable healthcare system for all Australians.

> *We represent the oldest continuous culture in the world; we are also diverse and have managed to persevere despite the odds because of our adaptability, our survival skills and because we represent an evolving cultural spectrum inclusive of traditional and contemporary practices. At our best, we bring our traditional principles and practices – respect, generosity, collective benefit, collective ownership – to our daily expression of our identity and culture in a contemporary context. When we are empowered to do this, and where systems facilitate this reclamation, protection, and promotion, we are healthy, well and successful, and our communities thrive.* (Brown, 2012.)

3. The Guiding Principles

This guiding document provides information for health genomic and clinical service organisations including community-controlled and private health service providers; academic, clinical and research institutions; data agencies; and leaders in government and policymakers to help them improve the quality of care and health outcomes for Aboriginal and Torres Strait Islander people.

The Guiding Principles identify the priority areas through which the application of new genomics knowledge, and the new and rapidly-evolving health technologies, including data collection, can be applied in a culturally safe way.

Establishing culturally safe and culturally responsive clinical health genomics along with ethical co-design to improve service design will build a health system that better supports strong Aboriginal and Torres Strait Islander cultures and belief systems.

A health system that recognises and embraces the diversity of our population, implements person-centred health care, and addresses systemic racism will benefit all Australians. Knowledge derived from our culturally and genetically-diverse backgrounds will enable Australia to contribute significantly to international genomics, health and wellbeing, Indigenous data sovereignty, and a range of related fields.

The Guiding Principles

Principle 1: Aboriginal and Torres Strait Islander Peoples' Rights

To ensure that the *United Nations Declaration on the Rights of Indigenous Peoples*, the *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2016–2026*, and the *Australian Charter of Healthcare Rights 2019* are applied for the benefit of Aboriginal and Torres Strait Islander people. Self-determination, decision-making and co-design of genetic healthcare services must be enabled and implemented.

Principle 2: Culturally Safe Genomics

It is critical that culture and kinship are a key consideration in all applications of genomics. In clinical investigations, this means that the provision of genomic health services does not compromise the legitimate cultural and human rights, values, protocols and expectations of Aboriginal and Torres Strait Islander people. In research and service design, projects should be conducted through co-design processes ensuring that benefits and outcomes are defined by, and are consistent and aligned with cultural and kinship practices and priorities.

Principle 3: Health Equity

Equity remains a foundational principle to ensure the reduction of health disparities experienced by Aboriginal and Torres Strait Islander people. In the context of genomics, this extends to:

(a) ensuring equity in access to genomics in clinical practice and that health services deliver equitable outcomes and prioritise the receipt of benefits to Aboriginal and Torres Strait Islander people and communities.

(b) requiring that Aboriginal and Torres Strait Islander people, communities and organisations be empowered to develop, conduct, analyse and evaluate clinical and research genomics to improve their respective health journeys and to ensure a healthful future.

Principle 4: Data Sovereignty

Genomics data must be defined, collected, managed, stored, analysed, interpreted and utilised in partnership with and governed by Aboriginal and Torres Strait Islander people through equivalent partnerships, co-design processes, and robust, culturally-appropriate data governance structures and principles.

Principle 5: Informed Consent

Ethical clinical practice and research must be guaranteed, and guidelines modified or developed to embed a commitment to culturally-appropriate, free, prior, informed consent. This includes considering the implications of decisions made by parents and/or carers on behalf of children, or decisions made for those dependent on the guardianship of others that may impact their future health and wellbeing as adults. This is essential to protect any existing cultural protocols and the rights to self-determination of future generations.

Principle 6: Genomics Health Workforce

Aboriginal and Torres Strait Islander people must have equitable access to and equitable outcomes from services, resources and funding. They should also have opportunities to participate as members of a culturally safe genomics workforce, and to have leadership roles in clinical and research fields contributing to genomics health. This includes clinical genomics, service design, data sciences, analytics, genome biology and research leadership.

Foundation Built On Trust

In strong partnership with Aboriginal and Torres Strait Islander people, individuals and communities, through safe and culturally-respectful conversations, according to our priorities and aspirations, for our benefit, and at a pace we decide.

3.1 Enablers of the Aboriginal and Torres Strait Islander Health Genomics Guide

It is important that our political leaders (and health policymakers) understand that for Aboriginal and Torres Strait Islander people, land, culture, community and identity – and therefore health – are intrinsically linked. (Lowitja Institute, 2015.)

The Guiding Principles recognise the need for more Aboriginal and Torres Strait Islander people to be involved in health genomics research. This includes them identifying priorities, having roles in leadership and partnership, co-designing study methodology, and defining outcomes and the benefits to Aboriginal and Torres Strait Islander Peoples.

It is critical to take the required time to build a foundation of trust and ensure that the research outcomes will benefit Aboriginal and Torres Strait Islander participants, individuals, families and communities, whilst maintaining strong culture.

Aboriginal and Torres Strait Islander people can lead and set research priorities that are culturally responsive. This will support individuals, families and communities to achieve greater degrees of self-determination. It will also offer more workforce opportunities across the spectrum of genomics health fields including:

- Creating career opportunities and pathways.
- Providing increased capacity and capability-building.
- Enabling decision-making on health outcome measures, wellbeing priorities and treatment options.
- Ensuring sovereignty and governance over their unique data and with full recognition of cultural and linguistic history.

Health genomic service organisations, clinical services, researchers, leaders of government, policymakers, and private and commercial organisations can achieve the greatest impact when they:

- Strengthen relationships and partnerships with Aboriginal and Torres Strait Islander people, families, and communities – these relationships will be most effective when built on a foundation of mutual trust that values the knowledge and experiences of Aboriginal and Torres Strait Islander people.
- Empower Aboriginal and Torres Strait Islander people to lead and be decision-makers for their own social and emotional wellbeing outcomes.
- Ensure equity in access and quality of care, and equitable outcomes and benefits in a fair and respectful manner according to need and situation.
- Recognise that racist attitudes have a marked impact on social and emotional wellbeing outcomes for Aboriginal and Torres Strait Islander people, and that racism in all its forms (personal, casual and institutionalised) must be acknowledged and owned, and actions must be taken to eliminate bias.
- Demonstrate an understanding of, and respect for, the cultural identity of Aboriginal and Torres Strait Islander patients, families, communities, clients, colleagues, partners and research participants, and provide culturally safe and culturally responsive care, built on a foundation of trust.
- Include family and community and/or designated decision makers in all patient planning and decision-making; including children, dependent adults and Elders.[2]
- Optimise care by taking a comprehensive approach to addressing health concerns at the point of service to ensure equitable outcomes and benefits, both clinical and research, through partnership, shared decision-making and co-design.
- Strengthen health service links between primary care and the acute care sector so that patients are not lost to follow-up and receive continuity of care.
- Strengthen the Aboriginal and Torres Strait Islander workforce, in all aspects of health delivery, by increasing the number of Aboriginal and Torres Strait Islander employees.
- Create pathways to universities and additional studies that promote and support the wellbeing, contribution and value of Aboriginal and Torres Strait Islander people in the workforce.

3.2 Principle 1: Aboriginal and Torres Strait Islander Peoples’ Rights

To ensure that the *United Nations Declaration on the Rights of Indigenous Peoples*, the *Cultural Respect Framework for Aboriginal and Torres Strait Islander Health 2016–2026*, and the *Australian Charter of Healthcare Rights 2019* are applied for the benefit of Aboriginal and Torres Strait Islander people. Self-determination, decision-making and co-design of genetic healthcare services must be enabled and implemented.

The *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP) is ‘a standard of achievement to be pursued in a spirit of partnership and mutual respect’. (United Nations, 2007.)

Australia is a signatory, as evidenced in the overarching ethical and human rights framework, and in salient Aboriginal and Torres Strait Islander Peoples’ health policy documents in Australia. It also articulates the key principles that ground these high-level rights into actions of governments and leaders. (Appendix 1).

There are several key national policy frameworks and agreements that are in accord with, and serve to augment, Australia’s commitment to the overarching rights and the grounding actions articulated in the UNDRIP framework for Indigenous Peoples, including:

- *National Agreement on Closing the Gap*. (Coalition of Peaks and Australian Government, 2020.)
- *Cultural Respect Framework 2004–2009 For Aboriginal and Torres Strait Islander Health*. (Australian Health Ministers’ Advisory Council Standing Committee on Aboriginal and Torres Strait Islander Health Working Party.) Henceforth referred to as ‘the *Cultural Respect Framework 2004-2009*’.
- *Cultural Respect Framework 2016–2026 For Aboriginal and Torres Strait Islander Health*. (Australian Health Ministers’ Advisory Council’s National Aboriginal and Torres Strait Islander Health Standing Committee, 2016.) Henceforth referred to as ‘the *Cultural Respect Framework 2016–2026*’.
- *National Safety and Quality Health Service Standards*. (Australian Commission on Safety and Quality in Health Care, second edition, 2021.)
- *National Aboriginal and Torres Strait Islander Health Plan 2021–2031*. (Department of Health, 2021.) Henceforth referred to as ‘the *Health Plan 2021-2031*’.

Furthermore, the *Cultural Respect Framework 2016–2021* endorsed and extended the earlier principles in the *Cultural Respect Framework 2004–2009* and aligned with the *Health Plan 2021–2031*.

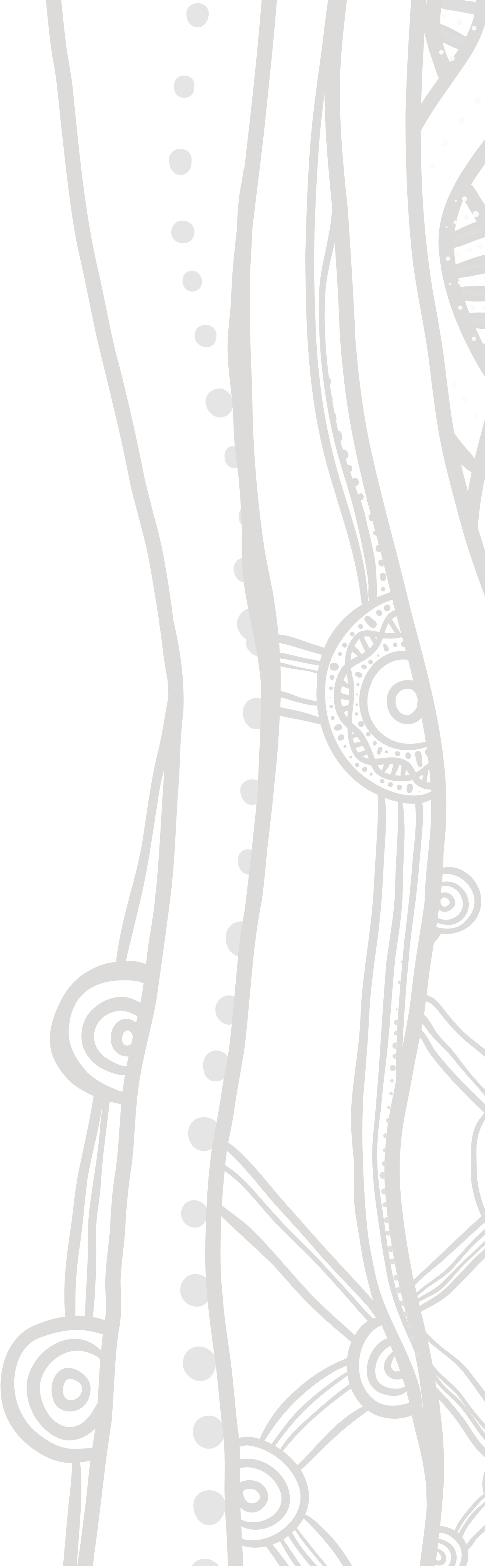
Briefly, the *Cultural Respect Framework 2004–2009* defines cultural respect as:

> ***Recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander people.***

And in conjunction with the legislated national codes for ethical research set out in the following documents:

- *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*. (Australian Institute of Aboriginal and Torres Strait Islander Studies, 2020.)
- *Australian Code for the Responsible Conduct of Research*. (National Health and Medical Research Council, 2018a.)
- *National Statement on Ethical Conduct in Human Research 2025*. (National Health and Medical Research Council, 2025.)
- *Guidelines for Aboriginal and Torres Strait Islander Research*. (National Health and Medical Research Council, 2018b.)

It is possible to frame Aboriginal and Torres Strait Islander people’s health genomics clinical guidelines and to inform all genomics work, including service design and research, by involving Aboriginal and Torres Strait Islander people.



Case Study: National Centre for Indigenous Genomics (NCIG)

An Australian Government-supported Aboriginal and Torres Strait Islander genomics policy exemplifying: self-determination, decision-making control, data sovereignty and governance.

On 6 December 2016 the Australian National University (ANU) National Centre for Indigenous Genomics (NCIG) registered the National Centre for Indigenous Genomics Statute 2016.[3] The purpose of the legislative instrument was to establish:

> *an appropriate framework to ensure Indigenous governance of, and the application of best practice for, the conduct of any research using material in the collection of biological samples, which were obtained from Indigenous people for scientific research from the 1960s until the early 1990s.*

It has since been updated through the National Centre for Indigenous Genomics Statute 2021.[4]

The NCIG provides a practical example of Australian Government-supported Indigenous control and governance possibilities within this space. The ANU, in the John Curtin School of Medical Research, holds a collection of biological samples that were obtained from Indigenous people for scientific research from the 1960s until the early 1990s. The collection includes documents and data relating to the samples.

In recognition of the collection's immense cultural, historical and scientific importance, the ANU committed to ensuring that the collection is held and added to under appropriate Indigenous custodianship. Also, that there is proper engagement with Indigenous people and communities from which the samples and records were collected about any use of the collection for research, and that appropriate consents are obtained for any research using material in the collection.

The ANU Council established the NCIG Statute 2016 to embed a policy framework with Indigenous governance of, and the application of best practice for, the conduct of any research using material in the collection. Consequently, Indigenous Sovereignty is embedded within the governance structures. Indigenous engagement and control of research is facilitated through an Indigenous-majority Governance Board, an Indigenous Collection Access Committee, an identified Indigenous Engagement Officer position, and Indigenous members of the Advisory Board, including Indigenous community representatives.

The NCIG 2019 Annual Report stated that approximately 25% of all DNA variants in the Indigenous genomes it has studied are unknown in people from outside Australia and, of these, approximately 40% are likely to be found in a single region or community. It concludes:

> *Overall, genomic differences among communities across Australia are as great as those between populations across Europe and Asia combined. In medical genomics terms, some Australian Indigenous communities are as different from each other as communities as far apart as North West Europe and South East Asia. So, using information about people from the Northern Territory, for example, as a basis for treating people in South Western Australia, would be equivalent to treating people in the United Kingdom based on information about people from Cambodia.*[5]

3.3 Principle 2: Culturally Safe Genomics

It is critical that culture and kinship are a key consideration in all applications of genomics. In clinical investigations, this means that the provision of genomic health services does not compromise the legitimate cultural and human rights, values, protocols and expectations of Aboriginal and Torres Strait Islander people. In research and service design, projects should be conducted through co-design processes ensuring that benefits and outcomes are defined by, and are consistent and aligned with cultural and kinship practices and priorities.

3.3.1 Cultural Safety

Cultural safety is defined by the consumer, patient, participant and not by the organisation embedding cultural safety.

It is about the people experiencing the health care or interacting with the service, rather than the individual or organisation providing it. Practising cultural safety requires a commitment to avoid and overcome any conscious or unconscious bias and power imbalance between the practitioner and the patient. This is so that Aboriginal and Torres Strait Islander people and their cultures are recognised, respected, protected and nurtured.

Cultural safety is an ongoing learning journey for non-Indigenous Australians to unlearn unconscious bias and racism, and relearn Aboriginal and Torres Strait Islander cultural values. Health genomic and clinical service organisations should establish culturally safe practices that recognise and respect Aboriginal and Torres Strait Islander culture and deliver services that meet the needs, expectations and rights of patients, participants and their families.

These practices, policies and processes must be embedded within the organisation's structures and cultures so that they are sustained regardless of any changes in staff and leadership.

3.3.2 Culture

Aboriginal and Torres Strait Islander cultures are diverse. There are over 260 Aboriginal and Torres Strait Islander nations across Australia, encompassing land, sea and waters.

Culture is recognised as playing a pivotal role in the health and wellbeing of Aboriginal and Torres Strait Islander people.[6,7,8] It is particularly relevant to Aboriginal and Torres Strait Islander belief systems that are built on centuries of unbroken connection to Country, extending to land, waters, islands and seas.

> *We nurture our culture for our future, and our culture nurtures us — we have sought to reflect the reciprocal and cyclical relationship between culture and wellbeing, whereby nurturing culture keeps us, and our future generations, healthy and strong.*[9]
>
> Janine Mohamed, CEO, Lowitja Institute, 2020.

These separate nations are also distinctive groups in their own right. Consequently, ensuring cultural safety is a key consideration across all aspects of genomics clinical practice.

3.3.3 Kinship

Kinship is at the heart of Aboriginal and Torres Strait Islander culture. It is the relationship Aboriginal and Torres Strait Islander people have with family, community, lore, Country and culture.

Given the importance of family and the kinship dynamic, deep consideration needs to be given to the impact of genomic clinical practice and research on the individual, family and community to encompass the continued growth of strong contemporary culture.

This means we need to develop flexible models that meet the needs and wants of the people concerned. They should support the ongoing conversations with community about the continued growth of strong culture. They also need to address how stored samples and data are used in light of changing relationships and trust.

The variation in cultural protocols and kinship across Aboriginal and Torres Strait Islander Peoples means that in-depth engagement is critical to inform health genomics priorities at the community level and, where possible, within respective state and territory boundaries, and nationally.

Case Study: Better Indigenous Genetic (BIG) Health Services project

Models and quality of genetic health services for Aboriginal and Torres Strait Islander people.

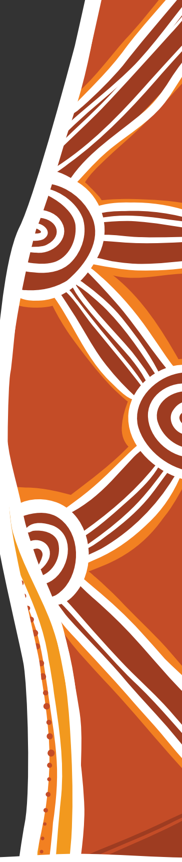
Lowitja Institute (Grant 1365) and the National Health and Medical Research Council Partnership (APP1114437) co-joint funded project.

This research study showed that while families are often included in clinical genomic consultations, the nature of this interaction is episodic.

Data from interviews, and the information collected as part of the BIG health services project, suggest that Aboriginal and Torres Strait Islander families often present at consultations unaware of the nature of the consultation and do not know why family members without health issues have been asked to attend. There were also limited opportunities to discuss the immediate implications of diagnoses for families, and how best to support family members' engagement with genomic health services into the future (e.g. at what age should children with high genetic risk for adult-onset conditions be tested).

Improving the benefits of clinical genomic health services with Aboriginal and Torres Strait Islander people requires providing greater support pre- and post-appointment, as well as more opportunity for ongoing engagement. Clinical genomic health services and Aboriginal Community Controlled Health Organisations are not currently resourced to provide this support.[10]

3.4 Principle 3: Health Equity



Equity remains a foundational principle to ensure the reduction of health disparities experienced by Aboriginal and Torres Strait Islander people. In the context of genomics this extends to:

a. ensuring equity in access to genomics in clinical practice and that health services deliver equitable outcomes and prioritise the receipt of benefits to Aboriginal and Torres Strait Islander people and communities.

b. requiring that Aboriginal and Torres Strait Islander people, communities and organisations be empowered to develop, conduct, analyse and evaluate clinical and research genomics to improve their respective health journeys and to ensure a healthful future.

Clinical and health services do not always provide culturally safe environments for Aboriginal and Torres Strait Islander people. Consequently, Aboriginal Community Controlled Health Organisations and Aboriginal Medical Services were established.[11]

However, in Australia, health genetic services are predominately delivered through state-based health services. Emerging evidence suggests that, despite demand for genetic testing among Aboriginal and Torres Strait Islander patients, and a higher incidence of some genetically-determined conditions,[14][15] there is an under-representation of Aboriginal and Torres Strait Islanders at genetic services.[16][17]

It is critical to take steps to ensure that health genomics, with and for Aboriginal and Torres Strait Islander people, meet the needs and provide benefits to individuals, families and communities as defined by them. Therefore, to ensure services are available to Aboriginal and Torres Strait Islander people, specific measures need to be developed that are designed by and for Aboriginal and Torres Strait Islander people.

Trust is the critical foundational value to ensure equity of access to health genomics, testing, screening programs, clinical services and clinical research. Building trust will create strong partnership with Aboriginal and Torres Strait Islander individuals, families and communities.

There are crucial steps in building trust. This is through respectful conversations and by working together in the co-design, development and workforce participation of the health service pathways. Engagement on what data to collect and how that data are managed, analysed and used is also vital.

Case Study: Machado Joseph Disease Foundation (MJD Foundation)

Machado Joseph Disease (MJD) clinical service development and research provides an exemplar of health genomics in strong partnership with Aboriginal and Torres Strait Islander people.

Clinical health genomics outreach clinics, in strong partnership with Aboriginal and Torres Strait Islanders, identified priorities with the communities living with MJD and built an enduring foundation of trust, at the pace of trust with each community, empowering remote communities across the 'top end' of Australia.

To date, treatment based on genomic medicine has been shown to be beneficial and cost-effective for a limited number of conditions. However, even where treatment does not currently exist, receiving a diagnosis has several benefits. These can include providing certainty, reproductive confidence and access to best-practice medical care, as well as reducing unnecessary investigations, and increasing support and access to education.

Diagnosis can also provide a platform for community activism. For example, Tay-Sachs disease, a degenerative and ultimately fatal condition, has been virtually eliminated from Ashkenazi Jewish communities through activism around genetic testing.[18] Similarly, the discovery that a degenerative neurological condition prevalent among the Aboriginal and Torres Strait Islander people of east Arnhem was caused by a single-gene disorder — Machado Joseph Disease — led to the establishment of the MJD Foundation,[19] an Aboriginal Community Controlled Organisation.

The MJD Foundation supports affected communities and undertakes research to work towards a cure. Ensuring that these benefits are accessible to Aboriginal and Torres Strait Islander people requires broad community engagement and the development of appropriate support services.

The MJD Foundation is recognised nationally and internationally by clinical centres of expertise in diagnosing and treating rare neurological disorders; and by First Nations communities globally as an exemplar of how culturally-respectful health services, in strong partnership, contribute to strong and secure culture.

The MJD Foundation, through its approach, has enabled Aboriginal and Torres Strait Islander communities to build a strong voice in managing the debilitating condition with those affected. They have exemplified self-determination, decision-making control, data sovereignty and governance with actions that included establishing a genomics policy, building Aboriginal and Torres Strait Islander clinical and workforce capacity and capability, and translating the new knowledge this generated to directly benefit the people and communities affected.

3.5 Principle 4: Data Sovereignty

Genomics data must be defined, collected, managed, stored, analysed, interpreted and utilised in partnership with and governed by Aboriginal and Torres Strait Islander people through equivalent partnerships, co-design processes, and robust, culturally-appropriate data governance structures and principles.

Aboriginal and Torres Strait Islander Peoples, in global partnership with Indigenous Peoples, have been working towards and advocating for Indigenous data sovereignty and Indigenous governance processes to support management of genomics data for a number of decades. Activities include raising awareness within Indigenous nations, and nation state data entities, to institute Indigenous data governance principles, protocols, and practices.[20]

Indigenous data sovereignty is defined as:

> *...the right of Indigenous Peoples to govern the creation, collection, ownership and application of their data about Indigenous communities, Peoples, lands, and resources. In its enactment mechanism Indigenous data governance is built around two central premises: the rights of Indigenous nations over data about them, regardless of where it is held and by whom; and the right to the data Indigenous Peoples require to support nation rebuilding.*[21]

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, the information collected is often about what is wrong in Indigenous health.

Very few instances exist where the data collected are used and shared in a manner that directly benefits the communities and contributes to strong culture by reflecting their priorities and cultural world views. Consequently, with the data skewed towards deficit and disparity, the policy drivers for government funding agencies further feed action plans that frequently do not reflect the cultural values and health priorities of Aboriginal and Torres Strait Islanders. This misses the opportunity to highlight what Indigenous culture can contribute.

The Maiam nayri Wingara Indigenous 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.

> *...Indigenous data sovereignty in Australia is derived from Aboriginal and Torres Strait Islander Peoples inherent right to govern our Peoples, Country (including lands, waters and sky) and resources as outlined in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), for which Australia has declared its support.*[22]

Aboriginal and Torres Strait Islander people 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 includes the data elements and collection process development, as well as the storage, management, analysis, sharing and use of these data.

Aboriginal and Torres Strait Islander Peoples have exceptionally long, uninterrupted, culturally-rich histories of data collection and preservation. These histories provide a solid foundation to pursue Indigenous data sovereignty in contemporary settings. They also recognise the need to apply Indigenous knowledges and wisdom into decision-making processes and the interpretation of findings.

The key elements, or success factors, that have been identified in achieving Aboriginal and Torres Strait Islander Peoples' data sovereignty are:

- Recognition and understanding that, prior to white settlement, a data continuum[23] stretching across more than 60,000 years existed. This continues to exist and grow today and live through future generations.
- Aboriginal and Torres Strait Islander Peoples' kinship systems are centred on collectivism with a shared responsibility. Therefore, understanding genetic relationships, the influence of the environment, familial structure and careful determination of lineage is key to genomics. These further highlight that the right to self-determination is not just for individuals, but also for families and communities to be involved in the ethical co-design of clinical and research studies.[24]
- Data collected must reflect the interests and priorities of Aboriginal and Torres Strait Islander Peoples.[25] Aboriginal and Torres Strait Islander communities must be able to determine the way in which the data are collected and by whom. They must also be included and supported to use their own governance processes in determining both access to the data and how these are analysed and used. To ensure culturally safe outcomes for Aboriginal and Torres Strait Islander people, the decision-making rights should include the nature of data to be collected, 'naming' the data elements, and using culturally-responsive methods for measuring and reporting indicators.
- Building Aboriginal and Torres Strait Islander Peoples' expertise in the production and management of data and the formation of governance arrangements that allow for data collection in communities.[26] This requires a significant workforce increase in Aboriginal and Torres Strait Islander people, and non-Indigenous people, in the fields of data and computer science, and analytics, who are trained and competent in understanding the management of Aboriginal and Torres Strait Islander data, and how this management has been developed from an Aboriginal and Torres Strait Islander perspective.

3.5.1 Indigenous Data Governance

The merging of technology infrastructure, the speed of digital connectivity, and the enormous volume of data now being generated and stored has raised the importance of data across the world. Data hold great value as they have an impact in influencing decision-making, allocating resources and driving innovation.

Aboriginal and Torres Strait Islander data hold important cultural heritage among communities. They have 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 people are often excluded from decision-making processes and have their knowledge marginalised, particularly when the cultural and ancient knowledge exists as part of an oral tradition.[27]

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) reaffirms Indigenous rights to self-governance and authority to control their Indigenous cultural heritage embedded in their languages, knowledge, practices, technologies, natural resources and territories (i.e. Indigenous data). Indigenous data, which includes data collected by governments and institutions about Aboriginal and Torres Strait Islander people and their territories, is intrinsic to Aboriginal and Torres Strait Islander Peoples' capacity and capability to exercise their human rights and responsibilities to all of creation.

The open data and open science movements often overlook Indigenous Peoples' rights. They focus on sharing data, but ignore power imbalances and historical context. To address this, a network of nation-state based Indigenous data sovereignty networks and individuals (the International Indigenous Data Sovereignty Interest Group, part of the Research Data Alliance) created the *CARE Principles for Indigenous Data Governance.*[28] These CARE Principles emphasise:

C - Collective Benefit

A - Authority to Control

R - Responsibility

E - Ethics

The CARE Principles focus on people and purpose. They reflect the crucial role of data in advancing innovation, governance and self-determination among Indigenous peoples.

Case Study: Maiam nayri Wingara Indigenous Data Sovereignty Collective[29]

Maiam nayri Wingara[30] was established in 2018 to develop Aboriginal and Torres Strait Islander Peoples' data sovereignty principles, to identify Aboriginal and Torres Strait Islander strategic data assets, and thus 'to welcome good knowledge'.

The purpose is to empower Aboriginal and Torres Strait Islander people to engage in Indigenous Data Sovereignty and to advocate for rights, informed by the United Nations Declaration of the Rights of Indigenous People, using data to inform development.

Indigenous data sovereignty in Australia refers to Aboriginal and Torres Strait Islander Peoples' inherent right to govern their communities, resources and Country including lands, waters and sky. It is the right of Aboriginal and Torres Strait Islander Peoples to exercise ownership over Indigenous data.

Data are a significant cultural, strategic and economic assets for Aboriginal and Torres Strait Islander Peoples.

Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous data.

The Maiam nayri Wingara Indigenous Data Sovereignty Collective developed an Australian set of Indigenous data governance protocols and principles at the inaugural Indigenous Data Sovereignty Summit in 2018.

These principles articulate and assert that Aboriginal and Torres Strait Islander people have the right to:

- Exercise control of the data ecosystem, including creation, development, stewardship, analysis, dissemination and infrastructure.
- Data that are contextual and disaggregated (i.e. available and accessible at individual, community and First Nations levels).
- Data that are relevant and empowers sustainable self-determination and effective self-governance.
- Data structures that are accountable to Indigenous Peoples and First Nations.
- Data that are protective and respects their individual and collective interests.

Exercising Indigenous data governance enables Indigenous Peoples and their representative or governing bodies to accurately reflect their stories.

It provides the necessary tools to identify what works, what does not work and why. Effective Indigenous data governance empowers Aboriginal and Torres Strait Islander Peoples to make the best decisions to support their communities and people in the ways that meet their developmental needs and aspirations.[31]

3.6 Principle 5: Informed Consent

Ethical clinical practice and research must be guaranteed, and guidelines modified or developed to embed culturally-appropriate, free, prior, informed consent. This includes considering the implications of decisions made by parents and/or carers on behalf of children, or decisions made for those dependent on the guardianship of others that may impact their future health and wellbeing as adults. This is essential to protect any existing cultural protocols and the rights to self-determination of future generations.

There have been significant positive steps to safeguard Aboriginal and Torres Strait Islander people in clinical services and research study settings. This has been through the development of ethical frameworks and consent, and the development of policies supporting Aboriginal and Torres Strait Islander governance in institutional settings.

The leadership of Aboriginal and Torres Strait Islander people in developing consent processes, along with them leading and partnering across every facet of the health genomics clinical services and research, will serve to improve consent processes for all Australians. In particular, for children, vulnerable seniors, and those from minority ethnic groups, as well as for people living with disabilities, genetic and rare diseases, and their respective family, carers and guardians.

The purpose of these policies and frameworks is to address the priorities identified by Aboriginal and Torres Strait Islander people and to ensure the resulting outcomes and benefits will contribute to strong and healthy communities. However, a fundamental shift in the consent concepts and processes may be required.

For example, in health genomics, family or community consent may be required for clinical testing or for research studies, led by Aboriginal and Torres Strait Islander people. This is particularly relevant and critical to ensure culturally safe access to health genomics across the genomics research field.

The Aboriginal and Torres Strait Islander Health Genomics Guiding Principles, set out in this document, captures the rights-based prerequisite for Aboriginal and Torres Strait Islander people leading the development of co-design policy, consent processes and governance over the many facets of clinical health genomics and research.

3.6.1 Culturally Safe and Responsive Consent Processes

Culturally responsive consent processes with Aboriginal and Torres Strait Islander people are critical for equitable access to clinical services. This major shift in focus requires investment to support the co-design, in order to move away from the standard of lengthy, legalistic consent templates, to flexible, culturally-responsive, multi-layered and dynamic consent processes that are developed with and led by Aboriginal and Torres Strait Islander people.

Consent is required for biological samples to be collected and stored for future use. This consent can be broad, that is, the samples can be used for any project covered under the initial consent. Consent can also be dynamic, where researchers check-in with research participants to gain consent on a project-by-project basis. Dynamic consent is consistent with a patient-centred model of care because it puts ‘the (research) patient in the centre of decision-making as equal partners in the research process’.[32] While dynamic consent is a preferred approach, any consent process should consider changes in the life stages of participants.

3.6.2 How Parent, Carer and Guardian Decisions Affect Children into Adulthood

Children, as outlined by the *United Nations Convention on the Rights of the Child*, have fundamental rights that need to be considered when decisions are being made for them.[33] Particular consideration needs to be given to how decisions are made regarding the collection and use of genomics samples and data; specifically, in decisions made by parents and/or carers that impact a child into the future.

When parents and/or carers are making genetic health decisions, they are often doing so at a very stressful time. Consent can be asked for at the same time as a clinical encounter involving the investigation of a long-standing and complex health challenge. Aboriginal and Torres Strait Islander people often need time to consider such matters and consult more broadly across relevant kinship systems.

In practice, consideration needs to be given to the use of dynamic consent. Dynamic consent is defined as ‘an approach to informed consent that enables on-going engagement and communication between individuals and users of data and their families’.[34] This will allow an adult, whose samples and data are maintained from childhood, or someone who had consent given legally on their behalf, to be able to decide later how their information will continue to be used.

Other culturally responsive scenarios for which special consideration needs to be given, and dynamic consent processes explored, are for clinical consent processes where there is significant risk to other family members or communities. A key aspect of this consideration is the potential impact of decisions on the self-determination rights of future generations.

If data are to be stored for future use, provisions should be made at the time of initial consent for the management of data following the death of the original research participant. This should include contact details for next of kin to enact the participant’s preferences for the management of their data. It should also include provision for the repatriation of samples and data where required and/or the culturally-respectful process for destruction of the sample.

Historically, data has been collected from Aboriginal and Torres Strait Islander people without such measures in place and, in some cases, in the absence of appropriate consent. Where this is the case, data management and future use of the data should be discussed with the participant or, if the individual cannot be identified, with the family of the participant or the community where the data originated.

3.7 Principle 6: Genomics Health Workforce

Aboriginal and Torres Strait Islander people must have equitable access to and equitable outcomes from services, resources and funding. They should also have opportunities to participate as members of a culturally safe genomics workforce, and to have leadership roles in clinical and research fields contributing to genomics health. This includes clinical genomics, service design, data sciences, analytics, genome biology and research leadership.

Nationally, Aboriginal and Torres Strait Islander people are significantly under-represented in the health workforce and this under representation also contributes to inequities in access to health services for Aboriginal and Torres Strait Islander people.

In 2016, Aboriginal and Torres Strait Islander people represented 1.8% of the health workforce, despite being 3.3% of the Australian population.[35] To address this issue and reach population parity, the *National Aboriginal and Torres Strait Islander Workforce Strategic Framework and Implementation Plan 2021–2031* has set an ambitious target with Aboriginal and Torres Strait Islander people to represent 3.43% of the national workforce by 2031. This target is based on the projected proportion of the Aboriginal and Torres Strait Islander population in 2031.[36]

As genomics applications increase, the workforce capacity, skill and capability have to expand accordingly. The spectrum of workforce needs encompasses, but is not limited to:

- clinical diagnostic and treatment services
- clinically-related health services
- clinical data and genomic data sciences
- treatment discovery
- genomics research
- epidemiology and analytics
- computer system and platform design for data storage
- health data security, intellectual property and commercialisation.

There needs to be an investment in Aboriginal and Torres Strait Islander people developing the health genomics workforce and building cultural competency across the health system.

Equitable access to culturally safe genomics services and research involves creating education and career pathways with Aboriginal and Torres Strait Islander people across every facet of the health genomics sector. This means creating pathways from school to university to meaningful employment, upskilling the existing workforce, and supporting new and emerging workforce needs.

Without this investment, Australia risks revisiting and perpetuating past experiences and past cultural transgressions by delivering what it thinks is needed. Instead of investing in Aboriginal and Torres Strait Islander people actively leading, co-designing and conducting research in partnership with, and for the benefit of, Aboriginal and Torres Strait Islander people.

The *National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan* indicates that there need to be opportunities and clearly articulated strategies to support Aboriginal and Torres Strait islander people to enter and build careers in the health genomics sector.

Clinical specialties need to be developed, as do research pathways, and career and training opportunities into information technology and data science.

Critically, there are significant gaps in the workforce of Aboriginal and Torres Strait Islander people for clinical geneticists, genetic counsellors and data scientists. And while there are some genomics upskilling opportunities for Aboriginal and Torres Strait Islander people in the allied health sector (such as through SING – the Summer Internship for Indigenous Peoples in Genomics[37]) significantly more needs to be done to ensure educational and career opportunities for Aboriginal and Torres Strait Islander people in clinical genomics.

Consequently, the current health genomics workforce must develop career pathways and professional placement opportunities with Aboriginal and Torres Strait Islander people so they can lead, co-design and build culturally-responsive capacity and capabilities across the rapidly evolving health genomics space. Therefore, the entire health genomics workforce must have equitable access to career pathways in health genomics. This includes health workers, health practitioners, specialists, genomics experts, genetic counsellors, data analysts and scientists, epidemiologists, researchers and computer scientists.

Increasing cultural competency is also a significant workforce priority and national priority. This spans policy, research and clinical service design, including improving Aboriginal and Torres Strait Islander engagement within science.

Aboriginal and Torres Strait Islander people must be able to conceptualise and culturally understand what clinical genomics entails to be able to balance the potential benefits with potential risks. This is a critical first step to building trust with individuals, families, and communities.

Case Study: Better Indigenous Genomics (BIG) Health Services[38]

Aboriginal and Torres Strait Islander health workforce and health genomics work design study.

An exemplar for strong culture, self-determination, decision-making control, data sovereignty and governance, and co-design. Built on a foundation of trust and 'in our time'.

Projects to understand how best to achieve this are underway in Western Australia and Queensland.

Genetic Health WA, the Western Australian Register of Developmental Anomalies, the Office of Population Health Genomics, Philanthropy (Roy Hill Community Foundation, Borlaug Foundation, Stan Perron Charitable Foundation), the statewide public health diagnostic genomics capacity (PathWest), and the Aboriginal Health Council of WA have been partnering through co-design and implementation on Aboriginal genomic workforce development and capacity building since 2011.

This formally commenced with the first meeting of the WA Health Department Senior Aboriginal Leaders Group to discuss clinical genomics. Subsequent clinical initiatives have included:

- Cadetships in both genomic policy and clinical genomics.
- Supporting Aboriginal Health Worker and Health Practitioner capacity development (particularly in remote communities).
- Improved links between Aboriginal-controlled health care organisations and clinical genetic services and allied health.
- A dedicated clinical position for Aboriginal genetic counselling.
- Clinical implementation of initial genomic reference data, whole genomic sequencing, and new phenotyping and digital health technologies (e.g. 3D facial analysis).

Along with other measures to improve culturally-appropriate genomic care, including the creation of counselling resources, and Indigenous language translations (Lyfe Languages) of genomic and precision medicine language.

Appendix 1 - Acronyms used in these guidelines

AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
ANU	Australian National University
BIG	Better Indigenous Genetic
MJD	Machado Joseph Disease
NCIG	National Centre for Indigenous Genomics
NHMRC	National Health Medical Research Council
SING	Summer Internship for Indigenous Peoples in Genomics
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples
UNESCO	United Nations Educational, Cultural and Scientific Organization
WHO	World Health Organization

Appendix 2 – Key frameworks diagram

A diagrammatic representation of the salient Aboriginal and Torres Strait Islander clinical health and research policy frameworks.

These are placed in context with key Articles from the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP) and the *UNESCO Universal Declaration on Bioethics and Human Rights*.

Figure 1 Snapshot (See next page for full diagrammatic)

Explanatory notes to Figure 1

The overarching framework for ethical and human rights articulated in the UNDRIP Articles are shown in the green sections. Specifically, the Articles represented at the top of the diagram are representative of the key overarching human rights principles of:

- Self-determination (Article 3).
- Exercising the right to self-determination (Article 4).
- The right to participate in decision-making in matters which affect them (Article 18).
- Free, prior and informed consent (Article 19).
- The needs of Indigenous elders, women, youth, children and persons with disabilities should be considered (Article 22.1).
- The right to determine priorities and strategies in health (Article 23).

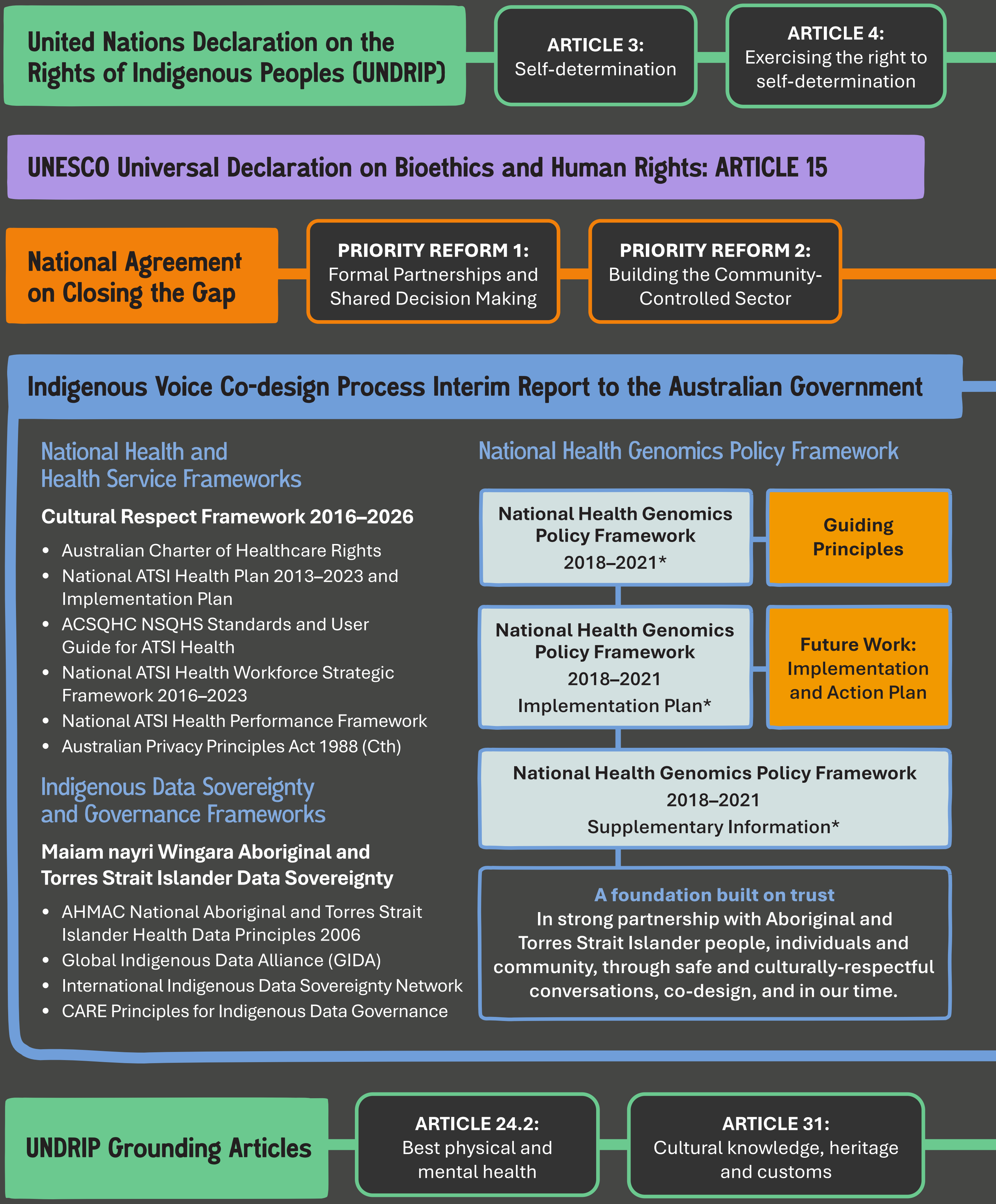
Included in the overarching rights is the UNESCO Universal Declaration on Bioethics and Human Rights (Article 15) that guides and informs human research ethical considerations.

The UNDRIP Articles shown at the bottom of the diagram are representative of the more grounding, culturally-responsive aspects of the declaration. They ensure that these rights are embedded in policy and are also measured against markers of equitable outcome, decision-making, system and service co-design, and the monitoring of culturally-relevant health and wellbeing measures. These are:

- Equal rights to the enjoyment of the highest attainable standard of physical and mental health (Article 24.2).
- The right to maintain control, protect and develop Indigenous peoples' cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources (Article 31).
- States in consultation and cooperation with Indigenous Peoples, shall take the appropriate measures, including legislative measures, to achieve the ends of this Declaration (Article 38).
- States shall promote respect for and full application of the provisions of this Declaration and follow up the effectiveness of this Declaration (Article 42).

The mid-section of the diagram focuses on the health genomics policy landscape. It shows how this current guiding document fits within the broader Aboriginal and Torres Strait Islander Peoples' health policy landscape. Specifically, for clinical service design and delivery and equitable access to benefits and outcomes as well as research co-design and informed consent. All these aspects connect to ensure culturally-respectful outcomes, benefits and acknowledgements to Aboriginal and Torres Strait islander participants.

Figure 1
The key Aboriginal and Torres Strait Islander health and research policy frameworks.



United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)

ARTICLE 3:
Self-determination

ARTICLE 4:
Exercising the right to self-determination

UNESCO Universal Declaration on Bioethics and Human Rights: ARTICLE 15

National Agreement on Closing the Gap

PRIORITY REFORM 1:
Formal Partnerships and Shared Decision Making

PRIORITY REFORM 2:
Building the Community-Controlled Sector

Indigenous Voice Co-design Process Interim Report to the Australian Government

National Health and Health Service Frameworks

Cultural Respect Framework 2016–2026

- Australian Charter of Healthcare Rights
- National ATSI Health Plan 2013–2023 and Implementation Plan
- ACSQHC NSQHS Standards and User Guide for ATSI Health
- National ATSI Health Workforce Strategic Framework 2016–2023
- National ATSI Health Performance Framework
- Australian Privacy Principles Act 1988 (Cth)

Indigenous Data Sovereignty and Governance Frameworks

Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty

- AHMAC National Aboriginal and Torres Strait Islander Health Data Principles 2006
- Global Indigenous Data Alliance (GIDA)
- International Indigenous Data Sovereignty Network
- CARE Principles for Indigenous Data Governance

National Health Genomics Policy Framework

National Health Genomics Policy Framework
2018–2021*

Guiding Principles

National Health Genomics Policy Framework
2018–2021
Implementation Plan*

Future Work: Implementation and Action Plan

National Health Genomics Policy Framework
2018–2021
Supplementary Information*

A foundation built on trust
In strong partnership with Aboriginal and Torres Strait Islander people, individuals and community, through safe and culturally-respectful conversations, co-design, and in our time.

UNDRIP Grounding Articles

ARTICLE 24.2:
Best physical and mental health

ARTICLE 31:
Cultural knowledge, heritage and customs

* Under review and update at the time of publication.

ARTICLE 18:
Decision-making

ARTICLE 19:
Informed consent

ARTICLE 22.1:
Most vulnerable

ARTICLE 23:
Determine health priorities

PRIORITY REFORM 3:
Transforming Government Organisations

PRIORITY REFORM 4:
Shared Access to Data and Information at a Regional Level

National Health Research Frameworks

AIATSIS Code of Ethics 2020

Australian Institute of Aboriginal and Torres Strait Islander Studies Act 1989 (Cth)

1. Indigenous self-determination
2. Indigenous leadership
3. Impact and value
4. Sustainability and accountability

National Health and Medical Research Council Act 1992 (Cth)

NHMRC National Statement 2025

- National Statement on Ethical Conduct in Human Research 2025
- Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders.

Aboriginal and Torres Strait Islander Research

NHMRC Keeping research on track II

To support research participants, Aboriginal and Torres Strait Islander people and communities:

- To make decisions that ensure the research journey respects Aboriginal and Torres Strait Islander people and communities' shared values, diversity, priorities, needs and aspirations.
- Make decisions that ensure the research journey benefits Aboriginal and Torres Strait Islander people and communities as well as researchers and other Australians.
- Recognise and understand their rights and responsibilities in being involved in all aspects of research.
- Better understand the steps involved in making research ethical.

ARTICLE 38:
Government leadership in partnership

ARTICLE 42:
Promulgate and monitor

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