

# GUIDING PRINCIPLES:

ENSURING CULTURALLY SAFE HEALTH GENOMICS  
IN PARTNERSHIP WITH ABORIGINAL AND TORRES  
STRAIT ISLANDER PEOPLES

DRAFT

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# EXECUTIVE SUMMARY

Australia is ranked as one of the best healthcare systems in the world. It provides access to the latest healthcare technologies and medications, and a wide range of services across the life span and across the continuum of care from within the home and the community to high-end specialised care. The Australian health workforce is diversely qualified, highly skilled, and competent to deliver safe, high-quality, evidence-based care.<sup>1,2,3</sup> Unfortunately, not all Australian citizens receive equitable access to all that our health care system offers.

Significant health and social disparities exist between Aboriginal and Torres Strait Islander people and non-Indigenous Australians. The *National Agreement on Closing the Gap: Closing the Gap in Partnership 2020*<sup>4</sup> and *Close the Gap 2020 We Nurture Our Culture for Our Future, and Our Culture Nurtures Us*<sup>5</sup> publications highlight the importance of culture to Aboriginal and Torres Strait Islander peoples wellbeing and the urgency to bridge the disparity in health outcomes and experiences within the health system. It specifically highlights that strong culture is fundamental to and directly contributes to improving life outcomes for Aboriginal and Torres Strait Islander individuals, families and communities. To achieve the goals in the National Agreement and to address the health and social priorities identified in the advocacy paper requires a step towards equitable health partnerships and health system co-design with Aboriginal and Torres Strait Islander peoples.

In this context, *Guiding Principles: Ensuring culturally safe health genomics in partnership with Aboriginal and Torres Strait Islander Peoples* (Guiding Principles) represents a key policy in the Australian national health and wellbeing policy environment.<sup>6,7,8,9</sup> The Guiding Principles have been developed by the Aboriginal and Torres Strait Islander Advisory Group on Health Genomics to inform culturally safe and equitable access to genetic services and improve health outcomes for Aboriginal and Torres Strait Islander individuals, families, and communities from the application of new genomics knowledge in a culturally responsive health system.

The Guiding Principles complement and extend the National Health Genomics Policy Framework<sup>10</sup> by providing culturally safe and responsive principles that inform culturally safe and culturally-responsive approaches to delivering every facet of health genomics including clinical services, research, data and workforce.

The Guiding Principles are framed within the overarching Articles in the *United Nations Declaration on the Rights of Indigenous Peoples*<sup>11</sup> and in accordance with the key Aboriginal and Torres Strait Islander peoples' national health agreements and policies.

## What are genetics and genomics?

**Genetics is a term that refers to the study of genes and their roles in inheritance - in other words, the way that certain traits or conditions are passed down from one generation to another. Genetics involves scientific studies of genes and their effects. Genes (units of heredity) carry the instructions for making proteins, which direct the activities of cells and functions of the body.**

**Genomics is a more recent term that 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.<sup>12</sup>**

The Guiding Principles provide a culturally safe extension to the National Health Genomics Policy Framework and the policy scaffold for the implementation of cohesive, culturally responsive processes working in partnership with the Aboriginal and Torres Strait Islander nations in building an enduring foundation of trust.

## ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH GENOMICS GUIDING PRINCIPLES

- 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 peoples in order that 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.
- 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.
- 3 **HEALTH EQUITY:** (a) To ensure the application of genomics in clinical practice and health services 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 peoples and communities; and  
(c) To ensure Aboriginal and Torres Strait Islander peoples, 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.  
(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.
- 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.
- 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 the cultural sovereignty and self-determination rights of future generations.
- 6 **GENOMICS HEALTH WORKFORCE:** To ensure Aboriginal and Torres Strait Islander peoples 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.

### **FOUNDATION BUILT ON TRUST**

**In partnership with Aboriginal and Torres Strait Islander people, individuals, and communities; through culturally safe and responsive conversations; according to our priorities and aspirations; for our benefit; and on our time.**

The Guiding Principles are particularly salient as Aboriginal and Torres Strait Islander peoples, until very recently, have had little opportunity to participate in how clinical genetic services are delivered and genomic research is conducted. This results in few opportunities for Aboriginal and Torres Strait Islander peoples to lead, or even participate in the many and varied disciplines and roles across the health genomics field as it relates to them, either professionally or as the people for whom the service are intended to serve and provide benefit.

Specifically, Aboriginal and Torres Strait Islander peoples should have the opportunity to lead and be equitable partners in the design, development, and delivery of clinical services. This should include rights in relation to the *'how, when, what, and why'* clinical data are collected and *'how the data are stored, governed, analysed and used'*. The Guiding Principles also inform Aboriginal and Torres Strait Islander peoples' health genomics research and apply to equity across areas of commercialisation of medical discovery and computer science. It includes defining and leading governance of core data collections and how to translate the beneficial outcomes back to relevant communities.

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, can support and sustain Aboriginal and Torres Strait Islander cultures of today and for future generations.

The Guiding Principles are living and enduring principles that must be built on trust relationships with Aboriginal and Torres Strait Islander individuals, families, and communities. Building trust in a culturally responsive manner means the foundations of trust must be built at the pace and the timing determined by Aboriginal and Torres Strait Islander peoples. The strength of the foundation of trust is important to enabling Aboriginal and Torres Strait Islander individuals, families and communities to build genuine partnerships and participate in developing culturally safe and responsive health genomics services that enable them to take a lead role in the co-design and reporting of genomic research studies.

# 1 ESTABLISHING CULTURALLY SAFE GENOMIC HEALTH PRINCIPLES IN PARTNERSHIP WITH ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

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## 1.1 CONTEXT

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

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, discriminatory practices, and unjust power relations, which are often at the heart of inequitable health outcomes.<sup>13</sup>

Significant health and social disparities exist between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians. There is also clear evidence of Aboriginal and Torres Strait Islander peoples’ experiences of racism and inequitable access to essential health care.<sup>14</sup> It is a shared responsibility on all levels of government to partner with Aboriginal and Torres Strait Islander peoples<sup>15</sup> and communities to effectively address health inequalities, overcome Indigenous disadvantage and close the life expectancy gap between Aboriginal and Torres Strait Islander peoples and non-Indigenous peoples.<sup>16,17,18,19</sup> [Text Box 1.1]

It is very clear that to make significant change requires a new way of thinking about priority setting with Aboriginal and Torres Strait Islander peoples regarding health and wellbeing and, in working together in a culturally responsive partnership, to close the gaps in Aboriginal and Torres Strait Islander peoples’ life expectancy, health, wellbeing, and education.<sup>20</sup>

This urgent need for change toward equitable partnerships and co-design with Aboriginal and Torres Strait Islander peoples has never been more evident than the recent 10-year national shared decision-making agreement ratified in the July 2020 *National Agreement on Closing the Gap; Closing The Gap in Partnership* developed between the Council of Australian Governments and the Coalition of Aboriginal and Torres Strait Islander Peak Organisations.<sup>21</sup>

*“...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<sup>22</sup> 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.”*

*Lowitja Institute (2020) Close the Gap: We Nurture Our Culture for Our Future, and Our Culture Nurtures Us*

### Text Box 1.1

**Aboriginal and Torres Strait Islander peoples** refers to the many sovereign nations of culturally-diverse Aboriginal and Torres Strait Islander communities. Aboriginal and Torres Strait Islander peoples collectively infers communities, families and individuals and recognises Aboriginal people and the Torres Strait Islander people as two separate groups, each with their own cultural beliefs, kinship systems, including adoption systems and lore.

A key barrier too frequently experienced by Aboriginal and Torres Strait Islander people is accessing health services; an indicator that the health system is not adequately applying Aboriginal and Torres Strait Islander cultural views of health. These views affect how Aboriginal and Torres Strait Islander people can make decisions about which health services to use. In addition, choice of services and accessibility is often limited due to geographical, distance and travel constraints, the number of service centres, hours of operation and staffing levels, as well as barriers of systemic and institutionalised racism. All these factors complicate the clinical health journey experienced by the individual and their family and this, in turn, affects health outcomes.<sup>23,24</sup>

Disclosing one's cultural identity is voluntary; however, identification by individuals and families as being Aboriginal and Torres Strait Islander people is important in terms of access, as it can lead to improving culturally safe health interventions and help inform culturally-responsive approaches from the service. This is a shared responsibility and, therefore, it is important for health professionals to provide Aboriginal and Torres Strait Islander people the opportunity to respond to the question of their Aboriginal and Torres Strait Islander identity. This choice must be respectfully supported by the health professional's offer of information about health services that may be specific for Aboriginal and Torres Strait Islander people.<sup>25,26</sup>



## 2 WHY HAVE ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH GENOMICS PRINCIPLES?

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There are many compelling reasons to have specific principles that guide and inform actions with Aboriginal and Torres Strait Islander peoples that address their priorities and are beneficial to their people. These include, but are not limited to:

- The historical and contemporary context of Aboriginal and Torres Strait Islander peoples' health and social and emotional wellbeing.
- The unique and diverse cultures of Aboriginal and the Torres Strait Islander peoples.<sup>27</sup>
- Limited opportunities and culturally-responsive 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.
- To ensure equity of access to culturally-respectful safe clinical genomic services and ensure that culturally-responsive approaches deliver the benefits arising from the new genomics knowledge.
- To ensure 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.
- To guide culturally-responsive research that focuses on Aboriginal and Torres Strait Islander peoples' health and wellbeing based on their priorities and expectations of the outcomes.
- By leading and, through the ethical co-design processes of the project, including design setting, data collection, storage, analysis, data use, publication and data disposal, enable full engagement across every aspect of the research; '*nothing about us, without us*'.<sup>28</sup>

### 2.1 ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH DISPARITY

Aboriginal and Torres Strait Islander peoples are among the most socially and economically disadvantaged groups in Australia.<sup>29,30</sup>

The current poor health and social and emotional wellbeing of many Aboriginal and Torres Strait Islander peoples stems largely from the effects of colonial policies and their ongoing legacy of living with generational inequity and racism.<sup>31</sup> These policies have resulted in loss of land, family and community connections, dislocation from country and languages and denial of cultural expression and growth across generations. They affect 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 are 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 effective and safe health care contribute to these gaps. Therefore, it is important that people experience safe and high-quality health care based on their need and to experience the benefits and equitable outcomes from a culturally responsive health system.<sup>32</sup>

Meaningful, lasting relationships with the Aboriginal and Torres Strait Islander communities are integral to redressing past wrongs and moving towards an equitable, culturally responsive 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.”<sup>33</sup>*

**Ngia Brown (2013): United Nations Permanent Forum on Indigenous Issues**

Closing the Gap in Aboriginal and Torres Strait Islander disadvantage is a national priority that the Australian Government and all state and territory governments are committed to addressing.<sup>34</sup> It is the responsibility of all health service organisations to consider and action their part in closing the gap in health disparities experienced by Aboriginal and Torres Strait Islander peoples.<sup>35, 36,37</sup>

**TEXT BOX 2.1:**

**Aboriginal and Torres Strait Islander Peoples Census data**

In the 2016 Census, 798,400 Australians identified as Indigenous, or 3.3% of the total Australian population.<sup>1</sup> These data showed the Aboriginal and Torres Strait Islander population growing at an average rate of 2.2% per year since 2006<sup>1</sup>; compared with the total Australian population growth rate of 1.6% across this same period.

Among the Indigenous Australian population in 2016:

- 91% identified as being of Aboriginal origin
- 4.8% identified as being of Torres Strait Islander origin
- 4.0% were of both Aboriginal and Torres Strait Islander origin

*In 2019, the Aboriginal and Torres Strait Islander population was estimated to be 847,190.<sup>1</sup> The Australian Bureau of Statistics estimates that the Aboriginal and Torres Strait Islander population of Australia will pass one million people by 2027 and could exceed 1.1 million by 2031.<sup>1</sup>*

*Australian Institute of Health and Welfare Profile of Indigenous Australians.*

*<https://www.aihw.gov.au/reports/australias-health/profile-of-indigenous-australians> Accessed 23/02/2021*

*Australian Bureau of Statistics. Estimates and projections of the Aboriginal and Torres Strait Islander population for*

*2006 to 2031 [https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-](https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-and-projections-aboriginal-and-torres-strait-islander-australians/latest-release)*

*peoples/estimates-and-projections-aboriginal-and-torres-strait-islander-australians/latest-release . Accessed 06/04/2021*

*Overview of Aboriginal and Torres Strait 'Overview of Aboriginal and Torres Strait Islander health status 201',*

*Australian Indigenous HealthInfoNet, 2020, [https://healthinonet.ecu.edu.au/learn/health-](https://healthinonet.ecu.edu.au/learn/health-facts/overviewaboriginal-torres-strait-islander-health-status)*

*facts/overviewaboriginal-torres-strait-islander-health-status . Accessed 06/05/2021*

*Australian Bureau of Statistics. Estimates and projections of the Aboriginal and Torres Strait Islander population for*

*2006 to 2031 [https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-](https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-and-projections-aboriginal-and-torres-strait-islander-australians/latest-release)*

*peoples/estimates-and-projections-aboriginal-and-torres-strait-islander-australians/latest-release Accessed 06/04/2021*

## **2.2 UNIQUE AND DIVERSE CULTURES OF ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE**

Aboriginal and Torres Strait Islander peoples have world views that differ from non-Indigenous Australians. Aboriginal and Torres Strait Islander peoples have a holistic view of health that is not adequately met, due to the biomedical and systems-based health care model.<sup>38,39,40</sup>

For Aboriginal and Torres Strait Islander peoples, health is:

*“... not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole Community in which each individual is able to achieve their full potential as a human being, thereby bringing about the total wellbeing of their Community. It is a whole-of-life view and includes the cyclical concept of life–death–life”.<sup>41,42</sup>*

While there are similarities between the many Aboriginal nations and the many Torres Strait Islander groups, there is also much diversity. There are more than 250 Aboriginal and Torres Strait Islander languages spoken, with over 800 dialects across Australia and the many islands of the Torres Strait.<sup>43</sup> Each language is specific to a particular place and people, making language and culture inseparable. Similarities in cultural expression extending across language groups and the islands are seen in the spiritual belief systems, the extended kinship systems, connectedness to country and connectedness to each other. These similarities often co-exist with culturally-diverse expressions of custodianship of country and the different obligations to care for and responsibilities for the continual renewal of country extending to land, waters, islands and seas are also diverse. [See Text Box 2.2]

For health services or an organisation to provide effective care to Aboriginal and Torres Strait Islander individuals, families and communities that regularly access care, it must be culturally responsive. This entails understanding the diverse cultures and values of the people in the organisation's catchment and of the patients using the services.

The Aboriginal and Torres Strait Islander population in Australia is strong and growing in both culture and population numbers.<sup>44,45</sup> Traditional language use is also increasing in line with the growth of strong communities and the revitalisation of cultures and languages.

*Ganinyi ngarri ingga manjawurmagi ngindaji thangani. Thangani gurrijbarra ngangawarra buga yani u, yulngarrawu. Binarri yawurmagi biyirranggu thangani, Thirrili ngarri warawirragi, Thirrili ngarri wilawirragi, Ganbawirragi ngindaji thangani, Yarrangi dinyjili. Ngindaji thangani jurali nhi, Winyiwunggurrangi yarrangi nhingi thangani.*

*Our ancestors that came before, created this knowledge. Our voices carry this knowledge to give to our children to carry forever. They must learn their knowledge so they can stand and speak with strength. So they can follow and know this wisdom. This is our umbilical cord to life. This knowledge is from long ago, listen to our voices.*

**June Oscar AO, spoken in the Bunuba language<sup>46</sup>**

## TEXT BOX 2.2:

### Aboriginal and Torres Strait Islander culture and unique belief systems

Although languages vary across the country, there are shared spiritual beliefs and origins, extended kinship systems, connectedness to country and each other, custodianship of country; and the obligations to care for, and responsibilities for, the continual renewal of country.

Early studies recorded four core concepts are found consistently among Aboriginal and Torres Strait Islander communities.<sup>1</sup> Specifically, in the Arrernte (A), Warlpiri (W), Pitjantjatjara (P) and Luritja (L) language groups of South Australia and the Northern Territory. These concepts are:

- The religious and spiritual interpretations of the profound bonding of people to one another, to their country and to the species of animals and plants inhabiting it. This bonding is continually renewed by its expression in song, dance, verbal narratives of creation stories and re-enacted continually in ceremonial journeys.  
[Cultural concepts expressed across Altyerre (A), Jukurrpa (W), Tjukurpa (P) or Tjukurrpa (L) peoples].
- Extended kinship system; the organisational scaffolding for social roles and authority; the pathways of distribution and communication.  
[Cultural concepts expressed across Walytja (L, P) or Warlajja (W) peoples].
- Country to which people belong; which they may use; always subject to the obligations of looking after it and care ...; including its celebration.  
[Cultural concepts expressed across Ngura (L, P) or Ngurra (W) peoples].
- Which is to have, to hold [and] to care. 'Kanyini' is a verb which reflects a commitment, a full engagement; vitalising again and again all that went before and all that will go after.  
[Cultural concepts expressed across Kanyini (L, P) or Mardarni (W) peoples].

*Franks et al 1996. Keeping company: an inter-cultural conversation. Wollongong: Centre for Indigenous Development Education and Research, University of Wollongong; 1996. Text and interpretation adapted from NSQHS Standards: User Guide for Aboriginal and Torres Strait Islander Health*

## 2.3 TRUST AS THE FOUNDATION

The 2020 *Closing the Gap Agreement, Closing the Gap in Partnership*<sup>47</sup> states in the section 'Prioritising Aboriginal and Torres Strait Islander Cultures' that ".....strong Aboriginal and Torres Strait Islander cultures are fundamental to improved life outcomes for Aboriginal and Torres Strait Islander peoples." The Agreement commits to significant cultural health and wellbeing priority targets, which include languages, connection to country, land, waters, islands, seas and access to culturally-relevant communications.

A foundation of trust can only be built in partnership with Aboriginal and Torres Strait Islander peoples, individuals, families, and communities. This must occur through "safe and culturally-respectful conversations; co-design; and within the timeframes negotiated with Aboriginal and Torres Strait Islander peoples, respectively".<sup>48</sup>

In a business sense, trust is the foundation of an agreement and, consequently, also informs the way of working, communicating and achieving outcomes. Trust is critical to the way we engage with others and how we build meaningful relationships. Without trust, or when trust is fragile, beneficial outcomes become limited or not achievable.

Central to Aboriginal and Torres Strait Islander individuals, families and communities' foundation of trust is personal credibility; a person's reputation is a direct reflection of their credibility, and it

precedes them in any interactions or negotiations they might have. Credibility encompasses actions associated with both the person and the organisation and institutions of the people representing them. Credibility encompasses the values of integrity; purpose and intent; capacity and capability; and transparency and accountability.<sup>49,50</sup>

Trust requires commitment to a timely process as the parties come to a mutual understanding and agreement. It is not about metrics such as speed and efficiency, but about allowing the time to build the trust relationships in a natural manner and for this time not to be prescribed by others. This ensures each discussion and the issues can be explored fully. It provides time for the community, with the cultural priorities, and all participants and stakeholders, the opportunity to give appropriate attention to the issues under consideration as deserved in terms of the size or inherent complexity of the issue or longitudinal implications of a research proposal.

### **2.3.1 A Culturally Safe and Responsive Health System**

It is an absolute imperative that Aboriginal and Torres Strait Islander peoples are leading with decision making, setting priorities and identifying the steps for implementation of culturally safe and responsive health genomics practices that are in harmony with community priorities, culture and timeliness for the individuals, families and groups involved. [See Text Box 2.3]

There are many and varied obligations that arise in building the foundations of trust, including, but not limited to: respect; openness; holding each other to account and understanding the deep and enduring social contract involved in trust.

To build a culturally safe and responsive health system requires commitment to the phrase “*Do nothing about us, without us*” and for the imperative to be building the foundation of trust by the values expressed in the phrase “*on our time*”. These succinct phrases establish the cultural context for all engagement with Aboriginal and Torres Strait Islander peoples about health genomics. This includes how to progress partnerships and maintain engagement harmoniously and at the pace required by individuals, families, and communities as the foundations of trust are built.

In summary, to make significant change requires a new way of thinking about setting priorities with Aboriginal and Torres Strait Islander peoples regarding their health and wellbeing. By building a foundation of trust and working together in partnership to harness the strength of our diversity we can ensure a culturally safe and responsive health system.<sup>51,52</sup>

### TEXT BOX 2.3: CULTURAL TERMS: DEFINITIONS AND CONTEXTUAL MEANINGS

Cultural safety identifies, prioritises, and ensures that Aboriginal and Torres Strait Islander health consumers are safe.

**Cultural safety** is determined by Aboriginal and Torres Strait Islander individuals, families, and communities. Culturally safe practice is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practising behaviours and power differentials in delivering safe, accessible, and responsive healthcare free of racism.

**Culturally safe and responsive** health care describes the capacity of systems or organisations to respond to the health care challenges faced by Aboriginal and Torres Strait Islander individuals, families, and communities. Culturally-responsive health care services are achieved through a commitment to the human rights articles in developing accessible and effective health care systems in partnership with Aboriginal and Torres Strait Islander peoples and in understanding and responding to their cultural views, beliefs and knowledge systems, which play an integral role in adherence to health care services.<sup>59, 60, 61</sup>

**Cultural Respect** is about shared respect. It is achieved when the health system is a safe environment developed in partnership with Aboriginal and Torres Strait Islander peoples and where cultural differences are respected. Trust and respect are highly nuanced in Aboriginal and Torres Strait Islander cultures. They are closely linked with the non-Indigenous Australian concepts ethical and fair behaviour, integrity, and reliability. Respect and trust concepts also include the values of accountability and reciprocity, or shared benefit. A further value is transparent and open communication that is also clear, culturally respectful, and linguistically inclusive\*.

**Culturally Safe and Responsive** describes the capacity to respond to the health care challenges faced by Aboriginal and Torres Strait Islander individuals, families, and communities. It is a cyclical and ongoing process, requiring regular self-reflection and proactive responses by service providers to the individual, family, or community with which they interact. It thus requires knowledge and capacity at different levels of intervention: systemic, organisational, professional, and individual.

\* English is often not the first language, with some Aboriginal and Torres Strait Islander people speaking four or five languages other than English.

**National Agreement on Closing the Gap: Closing the Gap in Partnership** <https://coalitionofpeaks.org.au/wp-content/uploads/2020/07/FINAL-National-Agreement-on-Closing-the-Gap-1.pdf> Accessed 19/02/2021

**Australian Indigenous Doctors' Association, AIDA (2013) Position Statement Cultural Safety for Aboriginal and Torres Strait Islander Doctors, Medical Students and Patients** [https://www.aida.org.au/wp-content/uploads/2017/08/Cultural\\_Safety.pdf](https://www.aida.org.au/wp-content/uploads/2017/08/Cultural_Safety.pdf) Accessed 17/02/2021

**Cultural Respect Framework 2016-2019; For Aboriginal and Torres Strait Islander Health.** [https://nacchocommunique.files.wordpress.com/2016/12/cultural\\_respect\\_framework\\_1december2016\\_1.pdf](https://nacchocommunique.files.wordpress.com/2016/12/cultural_respect_framework_1december2016_1.pdf) Accessed 23/02/2021

**Northern Territory Health Aboriginal Cultural Security Framework 2016-2026** <https://digitallibrary.health.nt.gov.au/prodjsui/handle/10137/730> Accessed 23/02/2021

**Australian Health Practitioner Regulation Agency (Ahpra): Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy-2020-2025** <https://www.ahpra.gov.au/About-Ahpra/Aboriginal-and-Torres-Strait-Islander-Health-Strategy/health-and-cultural-safety-strategy.aspx> Accessed 24/02/2021

## 2.4 KEY ENABLERS OF THE ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH GENOMICS PRINCIPLES

The Lowitja Institute 2015 statement is key to this guiding document.

***“It is important that our political leaders (and health policy makers) understand that for Aboriginal and Torres Strait Islander peoples, land, culture, community and identity—and therefore health—are intrinsically linked.”***

The Guiding Principles provide information for: health genomic, clinical service organisations including community-controlled and private health service providers; leaders in government; academic, clinical and research institutions; data agencies; and policy makers to help improve the quality of care and health outcomes in partnership with Aboriginal and Torres Strait Islander peoples. The Guiding Principles identify the priority areas through which the application of new genomics knowledge and rapidly evolving health technologies, including the associated data collection and governance, can be applied in a culturally safe way, incorporating the ancient and contemporary wisdom of Aboriginal and Torres Strait Islander peoples’ strong culture.

The Guiding Principles also recognise the need for more Aboriginal and Torres Strait Islander peoples to be involved in research. This includes leading, identifying priorities, partnership, co-design of study methodology and defining outcomes and benefits to Aboriginal and Torres Strait Islander peoples.

Ensuring that Aboriginal and Torres Strait Islander peoples lead and set research priorities that are culturally responsive and supportive of individuals, families and communities will assure greater degrees of self-determination, decision making and sharing in beneficial outcomes. This includes workforce opportunities across the spectrum of genomics health fields with career opportunities and pathways, provision of increased capacity and capability building, involvement in decision making on health outcome measures, wellbeing priorities and treatment options; and sovereignty and governance over their unique data and with full recognition of cultural and linguistic history.

[See Text Box 2.4]



#### TEXT BOX 2.4: CULTURAL CHANGE ENABLERS

Health genomic service organisations, clinical services, researchers, leaders of government, policy makers, 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 they are 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, emotional and 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 peoples, and that racism in all forms (personal, casual, and institutionalised) must be acknowledged, and owned. Actions must be taken to eliminate bias and reflect on status.

**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 responsive care built on a foundation of trust.

**Recognise** the person, their kinship and culture, holistically – seeing their physical, social, emotional, cultural, and spiritual aspects of health and wellbeing – when providing care across a life span.

**Consider** all aspects of ethical standards in all stages of developing a research study.

**Understand** the mutual commitment of engagement and trust-building, including the contribution to keeping culture strong through leading, partnership, co-design processes and decision making.

**Recognise** the critical cultural responsiveness commitment to the trust values implied by the phrases of “*Do nothing about us, without us*” and “*on our time*”.

**Include** family and community and/or designated decision-makers in all patient planning and decision-making including children, dependent adults and Elders<sup>1</sup>.

**Optimise** care by taking a comprehensive approach to addressing health concerns at the point of service and to achieve equitable outcomes and benefits in relation to clinical services and research, through partnership, shared decision making and co-design.

**Strengthen** links between primary care and acute health service organisations so that patients are not lost to follow-up and receive continuity in care, including empowering individuals in decision-making about their health service pathways.

**Strengthen** the current Aboriginal and Torres Strait Islander workforce in all aspects of health delivery by increasing the number of Aboriginal and Torres Strait Islander employees, creating pathways to universities and additional studies that promote and support the wellbeing, value and contribution of Aboriginal and Torres Strait Islander people in the workforce.

**Support** Aboriginal and Torres Strait Islander people to achieve their goals, empower non-Indigenous people to listen; and promote cultural awareness and respect across the workforce.

**Engage** with Aboriginal and Torres Strait Islander community organisations to build a foundation of trust with individuals and their services in ways that are relevant to their circumstances and priorities that will minimise the risk of overburden to the organisation and staff.



### 3 THE GUIDING PRINCIPLES

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It is evident that there are significant health and social disparities between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians. Inequity within the health care system, and society more broadly of the health and emotional wellbeing, is one of the impacts from living with racism and inequity across many generations.<sup>53,54</sup> Current policy approaches to address these inequities and health disparities acknowledge the critical need to refocus of health care to meet the unique needs of each patient that includes their culture and belief systems.<sup>55,56</sup>

Aboriginal and Torres Strait Islander individuals, families and communities have the same right to feel confident and safe when accessing the Australian healthcare system: the system and its workforce must be able to respond in a culturally-respectful manner to meet their needs. This is particularly true when it comes to the potential opportunities for improving health outcomes using the genomics technology and the new data and knowledge being generated. In this context, Aboriginal and Torres Strait Islander peoples have expressed their concerns relating to health genomics.<sup>57</sup> Specifically:

- From a clinical health service perspective, this entails equitable access and equitable outcomes from investigations or treatments and for these to be undertaken in a culturally safe and responsive setting.<sup>58</sup>
- From a research study perspective, ethical studies need to provide outcomes that benefit the participants, are identified by the community as a priority, and achieve the desired outcomes and expected benefits arising from the research. The informed consent and design of the studies needs to be culturally safe and empower the participants through co-design beneficial outcomes arising from research and sovereignty of the data custodianship.<sup>59</sup>
- The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Code 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.

Consequently, the primary purpose of the Guiding Principles is to ensure Aboriginal and Torres Strait Islander individuals, families and communities benefit equitably and fully through culturally safe access to genomic health services to achieve equitable outcomes, both in terms of health measures and strong culture. These benefits and outcomes are inextricably linked to the need for Aboriginal and Torres Strait Islander led research to inform priorities and partner in the development of culturally safe services and culturally-responsive genomic health options for individuals, families and communities, as well as achievement of culturally safe outcomes based on their understanding of disease.<sup>60</sup> For this to occur, there also needs to be a greater representation of Aboriginal and Torres Strait Islander people within the clinical and research workforce and their involvement in priority setting and in the co-design of health service pathways.

Substantial benefits are to be derived through establishing culturally safe and responsive clinical health genomics and ethical co-design. The improved service design will create a health system to better support strong Aboriginal and Torres Strait Islander culture and belief systems. This will, in turn, benefit all Australians through a health system that recognises and embraces the diversity of our population, implements person-centred health care and addresses systemic racism. Genomics knowledge derived from our culturally-diverse and genetic backgrounds will enable Australia to make significant contributions to international genomics, the health and wellbeing of individuals, Aboriginal and Torres Strait Islander data sovereignty and a range of related fields.

The Guiding Principles must be applied when making policy decisions related to Aboriginal and Torres Strait Islander peoples' genomic health; and through partnerships and co-design processes when developing research and design of service pathways to ensure that Aboriginal and Torres Strait Islander participants benefit and are appropriately acknowledged in the outcomes.

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## THE GUIDING PRINCIPLES

PRINCIPLE	ABORIGINAL AND TORRES STRAIT ISLANDER HEALTH GENOMICS GUIDING PRINCIPLES
1	<b>ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES RIGHTS:</b> 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 peoples in order that 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.
2	<b>CULTURALLY SAFE:</b> 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.
3	<b>HEALTH EQUITY:</b> (a) To ensure the application of genomics in clinical practice and health services delivery provides equitable access, equitable outcomes and optimised benefits through respectful partnerships with Aboriginal and Torres Strait Islander individuals, families and communities; (b) To ensure mandatory co-design in all genomic research studies so that health benefits are returned to participants and passed on to Aboriginal and Torres Strait Islander peoples and communities; and (c) To ensure Aboriginal and Torres Strait Islander peoples, 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.
4	<b>DATA SOVEREIGNTY:</b> 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.
5	<b>INFORMED CONSENT:</b> 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 the cultural sovereignty and self-determination rights of future generations.
6	<b>GENOMICS HEALTH WORKFORCE:</b> 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 in every clinical and research field contributing to genomics health; from clinical genomics, service design, data sciences, analytics, and to research leadership.

### FOUNDATION BUILT ON TRUST

In partnership with Aboriginal and Torres Strait Islander individuals, family, and communities; through safe and culturally-respectful conversations; according to our priorities and aspirations; for our benefit; and on our time.

### 3.1 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 peoples in order that 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.*

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".<sup>61</sup> Australia is a signatory, and the commitment to the Declaration is evidenced in the overarching Ethical and Human Rights framework set out in the Australian Charter of Healthcare Rights<sup>62</sup> and in all key Aboriginal and Torres Strait Islander peoples' health policies, with their attending implementation plans articulating the key principles that ground these high-level Human Rights into actions of governments and leaders. [Represented diagrammatically in Figure 3.1].

Briefly, the UNDRIP outlines several fundamental rights that apply to genomics and health more broadly. UNDRIP Articles provide both an overarching human rights framework for developing policy and grounding articles for implementing these human rights for Aboriginal and Torres Strait Islander peoples' health genomics in Australia. [Table 3.1]

TABLE 3.1 United Nations Declaration on the Rights of Indigenous Peoples Articles	
Providing overarching framework for ethical and human rights	Providing the grounding aspects of ethical and human rights
Self-determination (Article 3)	Equal rights to the enjoyment of the highest attainable standard of physical and mental health (Article 24.2)
Right to participate in decision making in matters which affect them (Article 18)	Right to maintain control, protect and develop their 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)
Free, prior and informed consent (Article 19)	Free, prior and informed consent (Article 19)
Needs of Indigenous Elders, women, youth, children and persons with disabilities should be considered (Article 22.1)	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)
Right to determine priorities and strategies in health (Article 23)	"... at the country level, and States shall promote respect for and full application of the provisions of this Declaration and follow up the effectiveness of this Declaration" (Article 42)

### 3.1.1 United Nations Declaration on the Rights of Indigenous Peoples Articles - Providing overarching frameworks for health genomics

The following key national policy frameworks and agreements are representative of Australia's commitment to UNDRIP, which are in full accordance with the Aboriginal and Torres Strait Islander Peoples Health Genomics Guiding Principles, herein.

Specifically, in July 2020 Australia announced a National Agreement on Closing the Gap: *Closing the Gap in Partnership*<sup>63</sup> reinforcing the Australian Health Ministers' Advisory Council (AHMAC) endorsed *Cultural Respect Framework 2016-2026: For Aboriginal and Torres Strait Islander Health*.<sup>64</sup>

The Cultural Respect Framework, developed by the National Aboriginal and Torres Strait Islander Health Standing Committee (NATSIHSC), was informed by: the *Australian Charter of Healthcare Rights*;<sup>65</sup> the National Health Reform Agreement 2020-2025;<sup>66</sup> *Australian Commission on Safety and Quality in Health Care (ACSQHC): Version 2 of the National Safety and Quality Health Services Standards*;<sup>67</sup> and the attending *ACSQHC User Guide for Aboriginal and Torres Strait Islander Health*.<sup>68</sup>

Furthermore, the *Cultural Respect Framework 2016-2026: For Aboriginal and Torres Strait Islander Health*<sup>69</sup> further endorsed and extended the earlier principles in the *Cultural Respect Framework 2004-2009*<sup>70</sup> and aligns with the *National Aboriginal and Torres Strait Islander Health Plan 2013-2023*<sup>71,72</sup> and corresponding *National Aboriginal and Torres Strait Islander Health Implementation Plan*.<sup>73,74</sup>

The *Cultural Respect Framework 2004-2009*<sup>75</sup> defines cultural respect as:

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

Building on these established principles, in conjunction with the legislated national codes for ethical research, the following national policies apply to Aboriginal and Torres Strait Islander research:

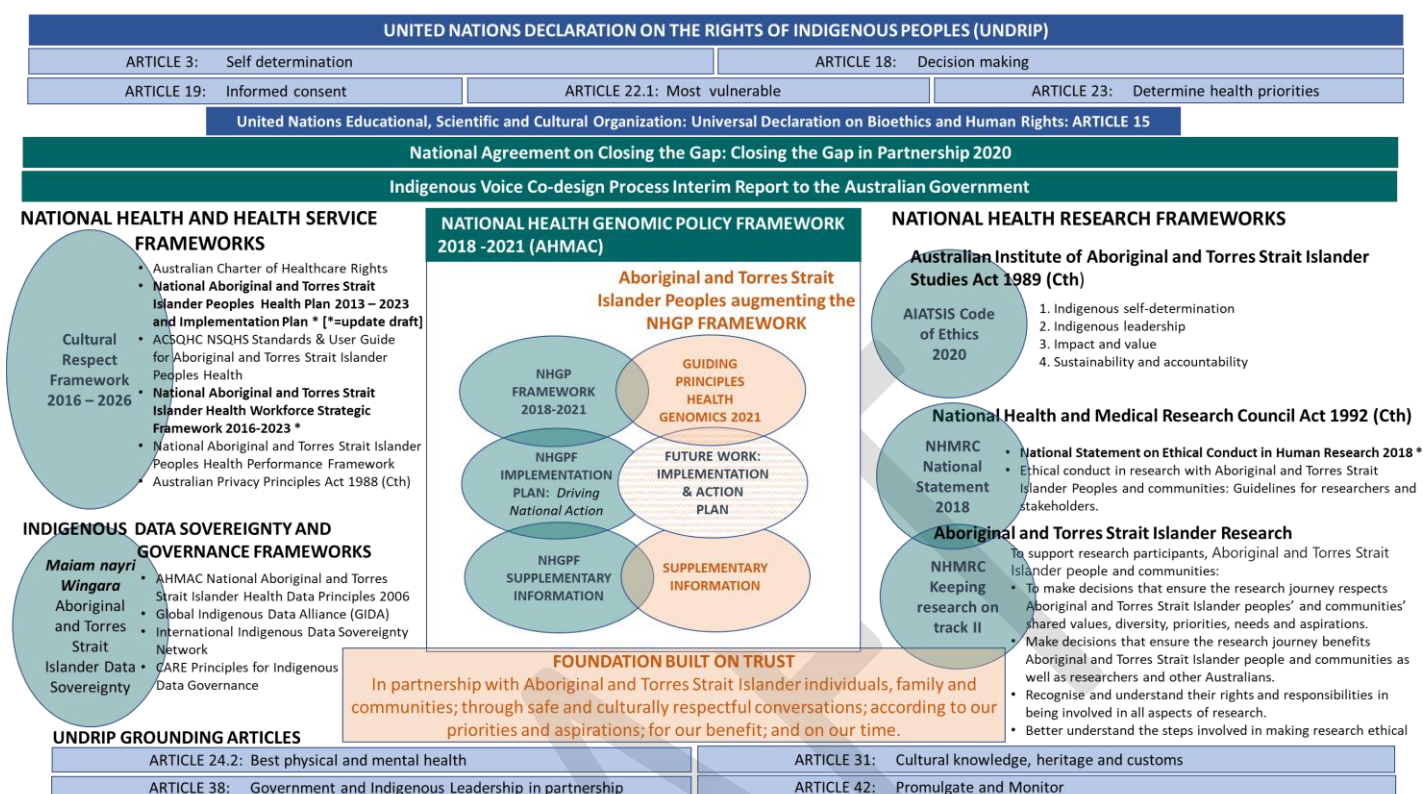
- The *Australian Institute of Aboriginal and Torres Strait Islander Studies Code of Ethics for Aboriginal and Torres Strait Islander Research* (AIATSIS Code of Ethics);<sup>76</sup>
- *National Health and Medical Research Council's Australian Code for the Responsible Conduct of Research* (National Code);<sup>77</sup>
- *National Statement on Ethical Conduct in Human Research 2007* (National Statement, updated 2018);<sup>78</sup> and
- *Guidelines for Aboriginal and Torres Strait Islander Research*.<sup>79,80,81</sup>

These policies support the Aboriginal and Torres Strait Islander Peoples Guiding Principles and help to further inform all aspects and facets of health genomics work involving Aboriginal and Torres Strait Islander peoples across the fields of clinical service and research.

The established agreements and guiding health documents cited above are consistent with the recently released *National Closing the Gap Agreement 2020; Closing the Gap in Partnership*<sup>82</sup> and the *Indigenous Voice Co-design Process Interim Report to the Australian Government*,<sup>83</sup> a whole-of-Government response to the recommendations of the 2018 Joint Select Committee on Constitutional Recognition of Aboriginal and Torres Strait Islander Peoples,<sup>84</sup> which proposed an Indigenous voice not only to Parliament, but also to the Australian Government and to State and Territory Governments. [Represented diagrammatically in Figure 3.1]

**FIGURE 3.1:** A diagrammatic representation of the salient Aboriginal and Torres Strait Islander clinical health and research policy frameworks, placed in context with key Articles from the *United Nations Declaration on the Rights of Indigenous Peoples* (UNDRIP) and the *United Nations*

## Educational, Scientific and Cultural Organization Universal Declaration on Bioethics and Human Rights.



### Explanatory notes to Figure 3.2:

Represented in the top panel of the diagram (blue bars) are the overarching Articles of the UNDRIP and UNESCO Declarations.

The central element of the diagram has the Guiding Principles (pale ochre) showing how they were developed to complement and extend National Health Genomic Policy Framework (green)

The mid-section panel represents the coherence of the Guiding Principles within the broader national Aboriginal and Torres Strait Islander peoples' health policy landscape, for leading and partnering in clinical service design and delivery and equitable access to benefits and outcomes; and to research partnerships for leading priority setting, co-design and culturally safe informed consent ensuring outcomes benefit and acknowledge Aboriginal and Torres Strait Islander peoples.

The bottom panel of the diagram (blue bars) represent the more grounding, culturally-responsive aspects of the Articles in the UNDRIP declaration; thus, helping inform how human rights are embedded in policy and measured against markers of equitable outcome, leading decision making, system priority setting and service co-design and monitoring of culturally-relevant health and wellbeing measures.

### 3.1.2 United Nations Declaration on the Rights of Indigenous Peoples Articles - Grounding values of partnership, decision making and co-design

Aboriginal and Torres Strait Islander leadership and the engagement of individuals, families and communities is key to addressing disparities in the health gap.<sup>85</sup> The Commonwealth Government has endorsed these values in the *Closing the Gap Partnership Agreement* between Commonwealth,



State and Territory governments, the National Coalition of Aboriginal and Torres Strait Islander Peak Organisations; and the Australian Local Government Association<sup>86</sup>. Specifically, it is aligned with and supports the principles articulated in the *Cultural Respect Framework 2016-2023: for Aboriginal and Torres Strait Islander Health* and the *NSQHS Standards*; in particular, health care and health services and systems support and enable active and informed participation by Aboriginal and Torres Strait Islander consumers in decisions about their own care.

Partnerships and engagement with Aboriginal and Torres Strait Islander people leading and setting their health priorities are critical for developing a culturally safe and culturally-responsive genomic health services and genomics research.

Equally, Aboriginal and Torres Strait Islander led design and implementation of services and the prioritisation of research to be conducted, ensure culturally safe clinical genomic services and culturally-responsive outcomes from health genomic research. This rights-based principle creates a culturally-responsive environment in the clinical and research sectors for health genomics with Aboriginal and Torres Strait Islander peoples and is consistent with other national policies. It does this by helping to build capacity and capability at every level across the health genomics field, fostering strong leadership, self-determination, joint decision-making processes and ethical co-design.

The AIATSIS Code,<sup>87</sup> developed by Aboriginal and Torres Strait Islander peoples, sets the national standards for ethical and responsible conduct with and for Aboriginal and Torres Strait Islander peoples. It augments the NHMRC *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for researchers and stakeholders* and the companion policy implementation guide *Keeping Research on Track II*.<sup>88,89</sup>

Further policies that provide support and new opportunities for empowering Aboriginal and Torres Strait Islander peoples' self-determination and decision making in health genomic service fields and Aboriginal and Torres Strait Islander leadership in genomics research are outlined in the *Indigenous Voice Co-design Process Interim Report to the Australian Government*,<sup>90</sup> which is further strengthened by the whole of Government *National Closing the Gap Agreement 2020*.<sup>91</sup> These opportunities for co-design include: health services research; health genomics; environmental and infectious microbiome genomics; and data sovereignty and data governance structures. Helping to ensure Aboriginal and Torres Strait Islander people can completely reshape and reimagine a fit-for-purpose, culturally safe and culturally-responsive health system in which all Australians have equitable access and equitable outcomes from the technology and new knowledge evolving in the genomics fields.

**TEXT BOX 3.1: National Centre for Indigenous Genomics (NCIG)**

***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*.<sup>92</sup> 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.”

The NCIG provides a practical example of Australian government supported Indigenous control and governance possibilities within this space. 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; 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 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.

NCIG report that approximately 25 per cent of all DNA variants in the Indigenous genomes it has studied are unknown in people from outside Australia and, of these, approximately 40 per cent 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-western Europe and South-East Asia. So, using information about people from the Northern Territory, for example as a basis for treating people in the south of Western Australia, would be equivalent to treating people in the United Kingdom based on information about people from Cambodia.<sup>93</sup>

## 3.2 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.***

### 3.2.1 Culture

Aboriginal and Torres Strait Islander cultures are varied, with more than 250 Aboriginal and Torres Strait Islander nations across the continent of Australia, encompassing land, waters, islands and seas. Through the continuous unbroken connection of Aboriginal people to country for over 60,000 years and that of the Torres Strait Islander peoples to their region over 2,500 years ago, culture is recognised as playing a pivotal role in the health and wellbeing of Aboriginal and Torres Strait Islander peoples.<sup>94,95,96</sup>

*"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."*<sup>97</sup>

**Janine Mohamed, CEO, Lowitja Institute**



The separate Aboriginal nations and the many island nations in the Torres Strait are distinct groups in their own right. Consequently, ensuring cultural safety is a key consideration across all aspects of genomics clinical practice, including through cultural responsiveness in service design and ethical research co-design with Aboriginal and Torres Strait Islander individuals, families and communities.

### 3.2.2 Kinship

Kinship is a common element across all Aboriginal and Torres Strait Islander cultures that defines the relationship Aboriginal and Torres Strait Islander peoples have with family, lore and culture.

Consequently, engagement must be undertaken to understand the impact of health genomic clinical practice and ethical research co-design on the individual, family and the kinship dynamic of families and their communities more broadly.<sup>98</sup> What this means for health genomics is that flexible models need to be co-designed to meet the needs and wants of the people concerned through conversations with community that are ongoing in relation to the continued growth of strong culture; particularly in regard to the variation in cultural protocols and kinship and for people from other groups living in the community.

#### TEXT BOX 3.2:

***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. Better Indigenous Genetic (BIG) health service services project***

The research study showed that, while family are often included in clinical genomic consultations, the nature of this interaction is episodic. Data from interview and the information collected as part of the Better Indigenous Genetic (BIG) health service services project suggest Aboriginal and Torres Strait Islander families often presented at consultations unaware of the nature of the consultation and also unaware as to why family members without health issues had 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 people requires providing greater support pre- and post- appointment, as well as better opportunity for ongoing engagement. Clinical genomic health services and Aboriginal Community Controlled Health Organisations are not currently resourced to provide this support.<sup>99</sup>

### 3.3 PRINCIPLE 3: HEALTH EQUITY:

***(a) To ensure the application of genomics in clinical practice and health services delivery provides equitable access, equitable outcomes and optimised benefits through respectful partnerships with Aboriginal and Torres Strait Islander individuals, families and communities;***

***(b) To ensure mandatory co-design in all genomic research studies so that health benefits are returned to participants and passed on to Aboriginal and Torres Strait Islander peoples and communities; and***

***(c) To ensure Aboriginal and Torres Strait Islander peoples, 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.***

Aboriginal and Torres Strait Islander health genomics in clinical practice and research must benefit individuals, families, communities and their population more broadly.

Clinical health services do not always provide culturally safe environments for Aboriginal and Torres Strait Islander peoples, and consequently Aboriginal Community Controlled Health Organisations and Aboriginal Medical Services have been established<sup>100</sup>. In Australia, health genomic 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<sup>101, 102</sup> and a higher incidence of some genetically determined conditions,<sup>103, 104</sup> there is a highly-significant under-representation of Aboriginal and Torres Strait Islander peoples employed within state-based genetic services.<sup>105</sup> Aboriginal and Torres Strait Islander peoples' unique cultures, belief systems, views on health and wellbeing, along with their historical experiences with the health system, may have contributed to the low uptake of health genomic service.

An understanding of what is culturally safe to individuals, families and community is critical for delivering a responsive clinical service. Consequently, it is critical for each clinical service to understand the cultural histories of the Aboriginal and Torres Strait Island peoples in their region and to proactively take steps to ensure that health genomics are developed in partnership with their regional Aboriginal and Torres Strait Islander communities to meet the health care priorities and to ensure equitable outcomes are met. Trust is a foundational value critical to ensuring equity of access to health genomics, clinical services and research. Aboriginal and Torres Strait Islander peoples leading health genomics research is critical to advancing and improving health and wellbeing as it will ensure research priorities focus on beneficial outcomes for the participants and for Aboriginal and Torres Strait Islander individuals, families and communities; and will contribute to keeping culture strong.

### TEXT BOX 3.3:

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

***Clinical health genomics outreach clinics, in strong partnership with Aboriginal and Torres Strait Islander peoples, 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.***

#### **Machado Joseph Disease Foundation (MJD Foundation)**

To date, treatment based on genomic medicine has been shown to be beneficial and cost effective for a limited number of conditions.<sup>106</sup> However, even where treatment does not currently exist, the benefits of diagnosis can include providing certainty, reproductive confidence, reducing unnecessary investigations, providing access to best practice medical care 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.<sup>107</sup> Similarly, the discovery that a degenerative neurological condition prevalent among the Indigenous people of east Arnhem was caused by a single-gene disorder, Machado Joseph Disease, led to the establishment of MJD foundation<sup>108</sup> which supports the 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.

MJD Foundation is recognised, nationally and internationally by clinical centres of expertise in diagnosing and treating rare neurological disorders and by Indigenous communities globally as an exemplar of how culturally-respectful health services, in strong partnership, contribute to strong and secure culture. Through its approach, MJD Foundation enabled communities to build a strong voice in managing the debilitating condition with those affected. Establishing genomics policy, building Aboriginal and Torres Strait Islander clinical and workforce capacity and capability, and translating the new knowledge generated, contributed directly to the benefit of the people and communities affected, further exemplifying self-determination, decision-making control, data sovereignty and governance.

### 3.4 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.***

The digital economy is driving an unparalleled growth in new knowledge and understanding, with the value of data being reflected in the significant impact on decision-making, allocation of resources, and innovation.

Aboriginal and Torres Strait Islander peoples have exceptionally long uninterrupted culturally rich histories of data collection and preservation of data. This knowledge is dynamic and constantly growing as Aboriginal and Torres Strait Islander peoples' culture and knowledge systems evolve with individuals, families and communities continuing to express themselves in new and adapted ways.

<sup>109, 110</sup> Consequently, 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.

*"Ganinyi ngarri ingga manjawurrmagi ngindaji thangani. Thangani gurrijbarra nganggarra buga yani u, yulngarrawu. Binarrri yawurrmagi biyirranggu thangani, Thirrili ngarri warawirragi, Thirrili ngarri wilawirragi, Ganbawirragi ngindaji thangani, Yarrangi dinyjili. Ngindaji thangani jurali nhi, Winyiwunggurragi yarrangi nhingi thangani."*

*"Our ancestors that came before, created this knowledge. Our voices carry this knowledge to give to our children to carry forever. They must learn their knowledge so they can stand and speak with strength. So they can follow and know this wisdom. This is our umbilical cord to life. This knowledge is from long ago, listen to our voices."*

**June Oscar AO, spoken in the Bunuba language** <sup>111</sup>

#### 3.4.1 Indigenous Data Sovereignty

Aboriginal and Torres Strait Islander peoples have been collaborating internationally and advocating nationally for Indigenous data sovereignty and Indigenous governance processes to support these data.

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 and reported focuses on what is wrong in Indigenous health. Furthermore, it is rare that the data collected are used and shared in a manner that directly benefit the communities and contribute to strong culture by reflecting their priorities and cultural world views. Consequently, much of the published data are skewed towards deficit and disparity, which become the policy drivers for government funding agencies. Similarly, the developing research agenda further feeds action plans to address disparity that frequently do not reflect the cultural values and health priorities of Aboriginal and Torres Strait Islander peoples and miss the opportunity to highlight what Indigenous culture can contribute. <sup>112</sup> 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." <sup>113</sup>*

### 3.4.2 Aboriginal and Torres Strait Islander Data Sovereignty

The Maiam nayri Wingara<sup>114</sup> Aboriginal and Torres Strait Islander Data Sovereignty Collective<sup>115</sup> was established to progress their peoples' data sovereignty and data governance<sup>116</sup> through developing shared understandings and initiating an Australian set of Indigenous data governance protocols. [See Text Box 3.4]

*".....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." <sup>117</sup>*

The purpose of the collective is to empower Aboriginal and Torres Strait Islander peoples to engage in Indigenous data sovereignty and to advocate for rights, informed by the UN Declaration of the Rights of Indigenous People, using data to inform development. The key priorities are for the production of more nuanced data and information than what currently exists and greater input into the data elements collected and governance over the use of data from Aboriginal and Torres Strait Islander peoples themselves.<sup>118, 119</sup>

To achieve these goals, 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.

In a pandemic, data sovereignty relates to Aboriginal and Torres Strait Islander people knowing and having control over the intellectual property of testing data and knowing where the data is held, who is using it and for what purpose. The rights of Aboriginal and Torres Strait Islander people to exercise self-determination in the use and maintenance of data must be upheld.

### 3.4.3 Aboriginal and Torres Strait Islander Data Governance

The convergence of technology infrastructure, the speed of digital connectivity and enormous volume of data being generated and stored has raised the importance of data governance and security across the globe.

Aboriginal and Torres Strait Islander data hold important cultural heritage and social values in trust among communities. Despite the technological developments and importance of data, Aboriginal and Torres Strait Islander peoples as individuals, families and communities, are excluded from decision-making processes and their knowledge marginalised, particularly when the cultural and ancient knowledge exists as part of an oral tradition.<sup>120</sup> Consequently, the data and the culturally safe governance of 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.

The value of data and the critical importance for culturally safe governance of data is reflected in the significant impact they have in influencing decision-making, allocation of resources and driving innovation. Resource allocation and investment is critical to Aboriginal and Torres Strait Islander peoples' capacity and capability to exercise their human rights and, importantly, their cultural and kinship responsibilities, including to country, encompassing lands, waters, islands and seas.

#### **TEXT BOX 3.4: MAIAM NAYRI WINGARA ABORIGINAL AND TORRES STRAIT ISLANDER DATA SOVEREIGNTY COLLECTIVE**

**Established in 2017 to develop Aboriginal and Torres Strait Islander data sovereignty principles and to identify Aboriginal and Torres Strait Islander strategic data assets; and thus ‘to welcome good knowledge’.** 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 is a significant cultural, strategic, and economic asset 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 has developed an Australian set of Indigenous data governance protocols and principles at the inaugural “Indigenous Data Sovereignty Summit” in 2018.<sup>121</sup>

These principles articulate, and assert the right of Aboriginal and Torres Strait Islander peoples to:

1. Exercise control of the data ecosystem, including creation, development, stewardship, analysis, dissemination and infrastructure.
2. Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
3. Data that is relevant and empowers sustainable self-determination and effective self-governance.
4. Data structures that are accountable to Indigenous Peoples and First Nations.
5. Data that is protective and respects our 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 doesn’t 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.

### **3.4.4 Aboriginal and Torres Strait Islander Knowledge and Knowledge Systems**

Knowledge and cultural heritage are at the heart of Aboriginal and Torres Strait Islander identity. Aboriginal and Torres Strait Islander knowledge is dynamic and constantly evolving. This is because Aboriginal and Torres Strait Islander culture and knowledge systems evolve as individuals, families and communities continue to express themselves in new and adapted ways including language, art and the application of this knowledge to new settings and priorities in health and wellbeing.<sup>122, 123</sup> The communal nature of Aboriginal and Torres Strait Islander knowledge means that the responsibility usually rests with one of a small number of people to act as custodians of that knowledge for the benefit of the whole community and to pass it on to the next generations.<sup>124</sup>

### 3.4.5 Protection of Aboriginal and Torres Strait Islander Knowledge

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (Article 31) confers the rights of Aboriginal and Torres Strait Islander peoples:

*“..... to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions...” including the right “...to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions” .*

Australia is a signatory to the United Nations Declaration on the Rights of Indigenous Peoples.

Australian governments, academic institutions and businesses all have crucial roles to play in ensuring that they respect Aboriginal and Torres Strait Islander peoples’ rights throughout their policies, strategies, operations, and networks. This is particularly important due to the global nature and economic value arising from the new knowledge economy.

More specifically, growth in the knowledge-based economy in Australia is driving massive data collections, data warehouses, aggregation of data sets, and large-scale data analytics capability. The speed and scale of these developments are creating an urgent imperative for Aboriginal and Torres Strait Islander knowledge systems and Aboriginal and Torres Strait Islander intellectual property to be appropriately acknowledged for the contributions that they currently make and appreciated for their capacity to contribute even more.<sup>125</sup>

A lack of a legal clarity around Aboriginal and Torres Strait Islander knowledge under Australia intellectual property law is a significant impediment to the recognition of the rights of Aboriginal and Torres Strait Islander peoples as owners of their comprehensive and evolving knowledge systems and, thereby, has limited their rights as beneficiaries.<sup>126</sup>

Despite the United Nations Convention on Biological Diversity (genetic resources and Indigenous knowledge) and the UNDRIP establishing international covenants to protect the rights of Indigenous peoples globally, there remains a significant deficit within intellectual property law to protect Aboriginal and Torres Strait Islander knowledge and cultural heritage and to ensure that decision making and outcomes associated with this knowledge benefit the traditional owners.

A number of guidelines have been developed internationally and nationally that encourage businesses to show leadership and establish due diligence processes to ensure they are respecting Indigenous rights.<sup>127,128 129</sup> *The Australian Business Guide to Implementing the UN Declaration on the Rights of Indigenous Peoples*<sup>130</sup> embeds the rights of Aboriginal and Torres Strait Islander peoples into their strategies, operations and interactions with Aboriginal and Torres Strait Islander peoples as business partners.

The implementation of appropriate and effective Aboriginal and Torres Strait Islander knowledge policies, and clarity in intellectual property law, has the potential to drive development, opportunities and entrepreneurship in this industry, while also protecting against inappropriate use of Indigenous knowledge.



### 3.5 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.***

Aboriginal and Torres Strait Islander people must be fully informed about any data that is collected from them, how it will be used, who maintains ownership of the genetic material, as well as clarity about the potential health benefits of genomics services and research.

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. These tensions play out further between the legal and ethical requirements of constituent ethics committees, the research team which remains focused on the logistics of consent and in the accrual of participant numbers; and to the participant's rights to self-determination and the balance between the risk and benefit in consideration of involving themselves or agreeing to participate in research or clinical testing. This is further exacerbated when there are cultural and language differences between the research proponents and the participants, perceptions of power imbalance between research or clinical providers and participants and whether or not the consent process is occurring at a time of significant stress, concern, 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, persistent tensions and inequities remain in the current informed consent models in both data conceptualisation, collection and its governance. The underlying assumptions in contemporary informed consent processes and the potential benefit of new knowledge to the individual and society rarely consider the belief systems, cultural practices and kinship obligations of Aboriginal and Torres Strait Islander individuals, family and community. Furthermore, there are communication issues related to geographical distance, communication infrastructure and whether English is the first language in many remote and regional areas.

To move forward in partnership with Aboriginal and Torres Strait Islander peoples requires a fundamental priority shift in the conceptualisation and deployment of informed consent processes. This is particularly relevant and critical to culturally safe access to health genomics to improve access and health outcomes and across the breadth of genomics research fields. In health genomics, family or community consent may be required for clinical testing or for research studies. Multiple layers of agreement, consent and approvals are often required when working with Aboriginal and Torres Strait Islander communities. Autonomy may have both individual and collective elements that need to be considered and discussed. Most consent processes fail to even consider these culturally-appropriate forms of communication, governance and decision making. This is particularly relevant in the context of the collection, use, interpretation, and management of biological material and data.



## Culturally safe and Responsive Consent Processes

The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) *Code of Ethics for Aboriginal and Torres Strait Islander Research*<sup>131</sup> and the guide for the implementing this ethical code<sup>132</sup> provide a best practice policy framework and outline specific actions to guide culturally safe and responsive engagement. They highlight the imperative for initiating and maintaining culturally-responsive engagement with Aboriginal and Torres Strait Islander individuals, families and communities across research studies and with clear understanding of the participants in the process and its benefits.<sup>133, 134</sup> The AIATSIS Code of Ethics also provides a guide for policy makers to partner with Aboriginal and Torres Strait Islander peoples in clinical service design. Critical to these processes is to have Aboriginal and Torres Strait Islander people lead, set priorities, and participate in all aspects of health genomic research and health decision making.<sup>135,136</sup>

There is an urgent requirement for investment for Aboriginal and Torres Strait Islander peoples to lead these important ethical complexities relating to consent and to be supported to work in partnership to develop culturally safe and responsive engagement that must attend to matters of cultural practice and the complex systems of kinship. These matters are also reflected internationally among other Indigenous peoples.<sup>137</sup> Examples of priorities identified by Aboriginal and Torres Strait Islander peoples for health genomics include:

*How decisions are made by individuals, families and by the community on behalf of the collective.*

There are many examples of international and national government health and research organisations research guidelines that have detailed methods for seeking consent from Indigenous peoples.<sup>138</sup> These guidelines generally share some common features or broad principles of conducting appropriate research with Indigenous people, such as consideration of matters of reciprocity, respect, equality, responsibility, survival and protection and spirit and integrity.<sup>139,140,141,142,143</sup> Many guidelines mention the need for both community and individual consent for research. However, there are few specific examples of consent models, and those that exist may not offer the flexibility or robustness required for consent with heterogeneous Aboriginal and Torres Strait Islander peoples and communities.

There is an urgent need for the health genomic consent processes to be developed with Aboriginal and Torres Strait Islander peoples that are flexible and can be adapted by the many nations and language groups across Australia and the Torres Strait Islands to support and enable consent and decision making with individuals, family and the community. These consent processes need to reflect the cultural practices, languages and kinship structures of each group. These processes will require sharing information in language. Ensuring information is in language that is meaningful to Aboriginal people will support access to services and will also aid in building trust and dispelling myths about genomics.

Currently, few viable options exist, or too little investment has been made in developing and trialling consent models. However, the whole-of-government response in the *National Closing the Gap Agreement 2020; Closing the Gap in Partnership*<sup>144</sup>, the Indigenous Voice Co-design Process *Interim Report to the Australian Government*<sup>145</sup> and the Lowitja Institute advocacy paper *Close The Gap 2020: We Nurture Our Culture for Our Future, and Our Culture Nurtures Us*<sup>146</sup> all highlight the need for Aboriginal and Torres Strait Islander peoples to lead and partner, through co-design, in the development of culturally safe and responsive consent processes for Aboriginal and Torres Strait Islander individuals, families and communities.

*How decisions are made by parents, carers and guardians, or on behalf of children, will affect them into adulthood.*

The *United Nations Convention on the Rights of the Child* outline the fundamental human rights that need to be considered when decisions are being made for children.<sup>147</sup> The rights of children, whose parents/carers may have given consent for genomic material to be collected on their behalf need to be explicit in the study design, with potential risk and benefits and opt-out options clearly articulated. Decisions made on behalf of a child may not hold true for the changing circumstances or inherent development of that individual as they age. Other considerations include whether consent can be enduring; or should there be consideration of re-consent at future time points that are both reflective of the rights of individuals and consistent with culturally-appropriate forms of autonomy and decision making.

*How decisions are made by, or on behalf of, vulnerable members of the community.*

The United Nations Declaration on the Rights of Indigenous Peoples (Article 22.1) outlines rights expressly referring to children, youth and people living with physical and/or cognitive disability, which includes people living with rare and undiagnosed diseases. The clinical care and any research study design needs to be explicit, with potential risk and benefits and fairness and unbiased opt-out options clearly articulated. Consideration must also be given for consent provided on behalf of the elderly and infirmed.

Ensuring these rights requires special consideration to be given to dynamic and longitudinal opt-out clauses that will allow an adult whose samples and data were maintained from childhood, or for someone who had consent made legally on their behalf, to make decisions in the future about how their personal data will continue to be used or otherwise.

*Exploring and adapting flexible, culturally safe and responsive consent models*

Internationally, there are a number of consent processes postulated to be able to support or be adapted to support Indigenous nations. These include a global framework<sup>148</sup> and national platforms with Aboriginal and Torres Strait Islander peoples<sup>149</sup>, Maori peoples in Aotearoa<sup>150</sup> and with First Nations peoples in Canada<sup>151 152</sup>. While there are lessons from these examples, investment is required to explore suitable flexible, culturally-responsive consent processes that can be adapted and implemented through partnerships with Aboriginal and Torres Strait Islander peoples. Two potential consent platforms should be considered: dynamic consent and tiered informed consent.

**Dynamic consent** was developed in response to challenges to the informed consent process presented by participants agreeing to 'future research' on collections of biological samples and the associated data.<sup>153</sup> 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.*<sup>154</sup> This consent can be used to provide a broad consent for collection and storage of biological material or data. The model enables flexibility of research priority setting, as the researchers are required to seek specific consent from the research participants on a project-by-project basis, thus giving opportunity to participants to be engaged in priority setting and oversight on the use of the collection. 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"*<sup>155</sup>. Dynamic consent is dependent upon continuous engagement and while demanding on the researcher there is an ongoing burden of responsibility placed on the participants for consenting each project and the continuous review to take into account changes in the life stages of participants. All these factors place an inequitable burden for those people living in regional and remote regions, particularly where English is not the first language.

**Tiered Informed Consent** is another form of broad consent, one in which the research participants have the option of giving consent and tailoring the scope of their consent based on their preferences and priorities. Participants may wish to only consent to participation in specific types of research or for their data or biological specimens for discrete research purposes and whether their samples and data are identifiable or anonymised. With tiered consent, participants can also stipulate specified institutions or particular researcher groups that they endorse to act in a manner consistent with implied and explicit levels of consent.

Informed consent is highly complex. Dynamic and tiered consent are two models from a large number of less well-publicised consent models. Regardless of the consent model, there are risk and benefit tensions for Aboriginal and Torres Strait Islander peoples that will need to be balanced and, thus, each would require further exploration for different cases.

Changes to consent processes and the setting of research priorities in health genomics in partnership with Aboriginal and Torres Strait Islander peoples must support '*do nothing about us, without us*' and the concept of '*on our time*'.

Investment in Aboriginal and Torres Strait Islander leaders to partner in developing consent processes will also serve to improve consent processes for all Australians, particularly for children, those from minority ethnic groups, people living with disabilities, genetic and rare diseases and vulnerable seniors, as well as their respective family, carers and guardians. It also helps all Australians to better understand the importance of strong culture for Aboriginal and Torres Strait Islander peoples' health and wellbeing.

## 3.6 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.***

As genomics applications and the size and value of data collections increase, the workforce needs to expand accordingly. While the spectrum of these workforce needs encompasses the clinical diagnostic and treatment services, clinically-related health services, clinical data and genomic data sciences and treatment discovery, it is not limited to these fields. The growth in the health genomics workforce applies across the entire breadth of genomics research, including epidemiology and analytics, computer system and platform design for data sovereignty, governance, intellectual property and the commercialisation.

Aboriginal and Torres Strait Islander peoples have a unique contribution to make to the Australian health workforce, and yet are significantly under-represented in the current health workforce. Workforce disparity contributes to reduced access to culturally safe and responsive health services for Aboriginal and Torres Strait Islander peoples. 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 in the primary or allied health sector or other fields where culturally safe and responsive processes are needed.

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 increase, then the prospect of equitable access to the healthcare benefits and equitable health outcomes from clinical genomics and research will diminish over time and further exacerbate the disparity and gaps in the health benefits arising from this new technology. More critically, Australia risks perpetuating the past policy transgression by delivering what it thinks is needed rather than working with Aboriginal and Torres Strait Islander peoples to lead and work in partnership on health genomic priorities for the benefit of the community and strong culture.

### 3.6.1 A Culturally Safe and Responsive Health Genomics Workforce

Nationally, Aboriginal and Torres Strait Islander peoples are significantly under-represented in the health workforce, which contributes to inequities in access to health services for the Aboriginal and Torres Strait Islander people. In 2016, Aboriginal and Torres Strait Islander people represented only 1.8 percent of the health workforce, despite comprising 3.3% of the Australian population.<sup>156</sup> To address this issue and reach parity, the National Workforce Plan 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 Aboriginal and Torres Strait Islander population in 2031<sup>157</sup>.

In line with the National Aboriginal and Torres Strait Islander Health Workforce Strategic Framework and Implementation Plan there needs to be opportunities and clearly articulated strategies to support Aboriginal and Torres Strait Islander people to enter the workforce and build careers in the health genomics sector. Pathways into clinical specialties and primary care need to be developed, as do research pathways and career and training opportunities in information technology and data science. Critically, there are currently no Aboriginal and Torres Strait Islander clinical geneticists or

genetic counsellors. While some opportunities exist for Aboriginal and Torres Strait Islander people to increase their genomics skills, such as the *Summer Internship for Indigenous Peoples in Genomics*<sup>158</sup>, there is clearly significantly more that needs to be done.

Ensuring educational and career opportunities for Aboriginal and Torres Strait Islander people in clinical genomics, such as medicine, laboratory diagnostic testing, treatment, and primary health care services, and increased funding for the Aboriginal and Torres Strait Islander community controlled health sector,<sup>159</sup> demands a long-term commitment in setting priorities with Aboriginal and Torres Strait Islander people for education, career and workplace opportunities in the genomics health workforce.

A contributing factor is the lack of cultural competence in the education sector and in many workplaces, which often creates impediments and poor acceptance of the different cultural perspectives and skills that Aboriginal and Torres Strait Islander people can bring to harnessing and creating new knowledge. To address barriers to engagement, partnership and co-design of health services and research opportunities in health genomics and related sciences, there is a need for greater cultural competency in science to enable education and training to become more culturally responsive.<sup>160</sup>

Consequently, the current health genomics workforce must develop career pathways and placement opportunities in partnership with Aboriginal and Torres Strait Islander people to enable leadership in co-design, priority setting and building culturally responsive capacity and capabilities across the rapidly evolving health genomics space. Therefore, there must be Aboriginal and Torres Strait Islander led investment in building the whole of the health genomics workforce capacity and capability. For Aboriginal and Torres Strait Islander individuals, families and communities, this means equitable access to career pathways in health genomics and across every facet of the health sector.

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### 3.6.2 Cultural Competence

Aboriginal and Torres Strait Islander people are unlikely to work in areas that are unknown to them and, depending on cultural protocols, may not be considered a culturally safe sector of work. 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 peoples to be able to reconcile information with cultural concepts and to balance the potential benefits with the potential risks.

Aboriginal and Torres Strait Islander individuals, families, and communities must be able to conceptualise and culturally understand what clinical genomics entails in order to be able to balance the potential benefits with potential risks. This is a critical first step to building trust and a prerequisite in establishing culturally safe and responsive health genomics services. This step is critical for ensuring equitable access to opportunities and roles in the health genomics workforce and in ensuring that these roles are culturally safe and the processes are culturally responsive to different cultural protocols.

Increasing cultural competency is a significant workforce priority across policy, research and clinical service design, establishing priorities and culturally-responsive approaches for improving Aboriginal and Torres Strait Islander engagement with science. Cultural competence is seen in systems that acknowledge and incorporate at all levels, *'the importance of culture, assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally-unique needs'*<sup>162</sup>.

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