

## Submission Response

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Guiding Principles: Ensuring Culturally Safe Health Genomics in Partnership with Aboriginal and Torres Strait Islander Peoples

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9 August 2021

The Aboriginal Health Council of Western Australia (AHCWA) welcomes the opportunity to provide feedback to the Commonwealth Department of Health on the *Guiding Principles: Ensuring Culturally Safe Health Genomics in Partnership with Aboriginal and Torres Strait Islander Peoples* (the Guiding Principles).

AHCWA is the peak body for 23 Aboriginal Community Controlled Health Services (ACCHS) in Western Australia. AHCWA exists to support and act on behalf of its Member Services, actively representing and responding to their individual and collective needs. WA ACCHS are located across geographically diverse metropolitan, regional, remote and very remote locations. They respond to complex health issues across the life course. ACCHS deliver the most effective model of comprehensive primary health care for Aboriginal people<sup>1</sup>, and are in a unique position to identify and respond to the local cultural and health issues of Aboriginal people and their communities across WA.

AHCWA supports the development of principles to inform culturally safe and responsive approaches to delivering every facet of health genomics, including clinical services, research, data and workforce. Overall, the Guiding Principles provide a useful resource for improving the provision of genomics services to Aboriginal people. Further feedback on the Guiding Principles and their implementation is provided below.

### **General feedback**

- AHCWA supports efforts to increase the number of Aboriginal people and organisations involved in the provision of genomics services, and to ensure Aboriginal people have opportunities to benefit from genomics should they choose to do so. As the Guiding Principles note, there are ‘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.’
- If these issues are addressed and services and research are made culturally secure, genomics has the potential to help close the gap in health outcomes for Aboriginal people.

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<sup>1</sup> Throughout this submission, AHCWA uses the term ‘Aboriginal’ to respectfully refer to all Aboriginal and Torres Strait Islander people across Western Australia.

- Any research or data collection involving Aboriginal people must be subjected to rigorous ethics approval processes. In WA, any health and wellbeing data being collected about Aboriginal people for the purposes of research must go through the WA Aboriginal Health Ethics Committee (WAAHEC) approvals process. Aboriginal research of any type must be underpinned by Aboriginal leadership, decision making and participation at all levels.
- A shared decision making approach to the use of biological samples and data with Indigenous populations can be found in New Zealand, where Maori people in partnership with the government have developed guidelines that reflect their cultural practices. For instance, when genomic data is no longer needed, the Christchurch Tissue Bank provides participants with the option of disposal with a Maori karakia (blessing). In addition to this, a guardianship group of Maori people has been established and employed to act as spiritual guardians for genomic data and samples.<sup>2</sup>
- There could be additional content in the Guiding Principles relating to Aboriginal organisations and the ACCHS sector in particular, and how the sector's work may intersect with services and research related to genomics. In order to improve the quality of healthcare for Aboriginal people, consideration should be given to the role of the ACCHS sector in genomics research and its translation.
- The Guiding Principles and any accompanying guidelines, processes or procedures would benefit from additional content related to partnerships with Aboriginal communities. Community education should also play a more prominent role.
- There needs to be clarity regarding how the Guiding Principles will be used. What mechanisms will be put in place to ensure they are followed, or to at least encourage compliance? For instance, relevant parties could be required to report against the Guiding Principles when undertaking certain genomics research or providing genomics services. There will need to be a robust framework in place to ensure any guidelines are adhered to.

## **Feedback on specific Principles**

### **Principle 1**

- AHCWA supports Principle 1 and the proposed rights based approach.
- However, as there tends to be some differences between an individual rights approach and a community rights approach, further thought may be needed concerning how this principle can be followed in an effective and culturally appropriate way.

### **Principle 2**

- AHCWA strongly supports Principle 2 relating to cultural safety.
- All genomic healthcare staff must be required to provide culturally safe and responsive services and care. Projects should be conducted through co-design and co-production processes ensuring benefits and outcomes are mapped to community need, kinship structures, protocols, practices and priorities.

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<sup>2</sup> Kowal, E., S. Easteal, and M. Goodna (2016) Indigenous Genomics. Australasian Science. 37(6): p. 18.

## Principle 3

- AHCWA strongly supports all three components of Principle 3 relating to health equity.
- Regarding 3(a), in addition to partnerships with individuals, families and communities, the principle should also include partnerships with Aboriginal organisations, such as ACCHS. These partnerships will be fundamental to realising the aims under other principles.
- AHCWA suggests 'co-production' is added to 3(b) to strengthen the reference to co-design. The inclusion of co-production will highlight the need for Aboriginal people and organisations to be part of the conducting of genomic research studies, not just their design and evaluation. Again, AHCWA suggests that in addition to research benefits being passed on to Aboriginal peoples and communities, some reference should be made to the role of Aboriginal organisations in this process.
- AHCWA supports 3(c) and notes it is consistent with commitments made under the draft *National Aboriginal and Torres Strait Islander Health Plan 2021-2031*. Aboriginal people and organisations must be directly involved in research that impacts their lives, including the development of research proposals, the conducting of research, data collection, analysis, interpretation and write up. Again, it is important that ACCHS are involved in these processes, particularly as there are existing regional governance mechanisms in place for ACCHS within a region to assess the relevance of research proposals to their communities.
- To ensure equity is achieved, there will need to be a strong focus on rural and remote communities, and a commitment to ensuring people have the same opportunities to benefit from genomics irrespective of where they live. This could be expressed by including something like the following: "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."

## Principle 4

- While AHCWA supports the content in Principle 4, we consider that this principle could be made more robust. (Some of the content regarding Principle 4 later in the Guiding Principles helps to strengthen this principle – it is the summary version of the principle that may require further development.)
- The Guiding Principles must consider how trust and respect will be established with Aboriginal people and communities as genomic initiatives are developed. In the past, genetic initiatives and projects have jeopardised the cultural and intellectual property of Aboriginal people.<sup>3</sup>
- The mistrust of governments and their agencies by Aboriginal people and their communities is an ongoing legacy of colonisation and dispossession. As such, best-practice collection and ethical use of data, integrity in data reporting and the acknowledgement of data sovereignty are essential principles.
- The summary version of this principle could be strengthened by incorporating further content from the Australian Indigenous Data Governance protocols and principles developed at an Indigenous Data Sovereignty Summit in 2018 by the Maïam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty

<sup>3</sup> [https://humanrights.gov.au/sites/default/files/content/pdf/social\\_justice/sj\\_report96.pdf](https://humanrights.gov.au/sites/default/files/content/pdf/social_justice/sj_report96.pdf)

Collective (noting that this collective is referred to in the Guiding Principles). As quoted in the Guiding Principles, this includes the rights of Aboriginal people to:

- Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure.
- Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels).
- Data that is relevant and empowers sustainable self-determination and effective self-governance.
- Data structures that are accountable to Indigenous peoples and First Nations.
- Data that is protective and respects our individual and collective interests.
- Hence, data sovereignty means more than the use of 'robust data governance structures', and the 'equivalent partnerships and co-design processes' referred to will need to be robust enough to allow Aboriginal people to 'exercise control of the data ecosystem' as outlined above.
- The delegates of the 2018 summit endorsed an interpretation of Indigenous Data Sovereignty as 'the right of Indigenous people to exercise ownership over Indigenous Data. Ownership of data can be expressed through the creation, collection, access, analysis, interpretation, management, dissemination and reuse of Indigenous Data.' The United Nations Declaration on the Rights of Indigenous Peoples definition of Indigenous Data Sovereignty, quoted on page 32 of the Guiding Principles, is also useful in making clearer what is required to fully realise data sovereignty.
- The Guiding Principles, including Principle 4, must also reflect the commitments made and the work being delivered under Priority Reform Four of the *National Agreement on Closing the Gap*, which relates to shared access to data and information.

## Principle 5

- AHCWA supports Principle 5 and the proposal later in the document for the Aboriginal-led development of improved consent models.
- To ensure informed consent, as committed to under Principle 5, steps will need to be taken to provide relevant information in a culturally appropriate way. It will likely also 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.
- The development of culturally appropriate processes for obtaining consent must be led by Aboriginal people. It is also essential that procedures for obtaining informed consent from Aboriginal people appropriately engage individuals, families and communities (as the Guiding Principles acknowledge).
- Aboriginal 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.

## Principle 6

- AHCWA supports Principle 6 and any efforts to build the Aboriginal workforce in health genomics.

- Opportunities to invest in ACCHS should be considered, given their existing connections and relationships with Aboriginal communities. Through sustainable funding, ACCHS staff could be trained and upskilled to provide genomic specific health care and advice in their communities. Hence, AHCWA strongly agrees with the following statement from the Guiding Principles: '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, 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.'
- Consideration also needs to be given to how the required training and upskilling will be implemented for the Aboriginal health workforce in regional and remote areas.

## **Conclusion**

As stated above, AHCWA supports efforts to increase the number of Aboriginal people and organisations involved in the provision of genomics services, and to make genomics services and research culturally secure. If mechanisms are developed to ensure they are followed, the Guiding Principles can play an important role in ensuring genuine co-design and co-production with Aboriginal people in the health genomics space. However, further consideration is needed regarding the ACCHS sector's role in services and research related to genomics.

*The Aboriginal Health Council of Western Australia advocates on behalf of 21 Aboriginal Medical Services in Western Australia, to ensure that the health needs of the State's communities are represented at all levels.*