**Australian Alliance for Indigenous Genomics**

**New South Wales Indigenous Governance Committee Template**

**Terms of Reference**

*Within these Terms of Reference we respectfully refer to the First Nations Peoples of Australia as Aboriginal and Torres Strait Islander peoples and Indigenous peoples. We also pay our respects to all Aboriginal and Torres Strait Islander peoples whose knowledge, values, advice, leadership and participation we seek, as we co-develop the Australian Alliance for Indigenous Genomics architecture and governance models.*

**Introduction**

The Australian Alliance for Indigenous Genomics (“ALIGN”) is a national consortium, led by the Indigenous Genomics Group at Telethon Kids Institute and the Australian National University (ANU), in partnership with Aboriginal and Torres Strait Islander stakeholders, peak bodies and Communities, as well as research, clinical, industry and institutional partners from across Australia. ALIGN is currently comprised of six nodes of activity: Queensland, New South Wales, the Australian Capital Territory, Victoria, South Australia, and Western Australia. Each node will coordinate efforts to inform core ALIGN activities in 1) Indigenous Governance of genomics research and clinical care; 2) the development of best practice data systems and data sovereignty; 3) genomics policy; and 4) developing capacity. These represent key foundations to ensuring the equitable receipt of benefit from genomics. In addition, each node will coordinate a Flagship Program that lays the foundations and articulates clear plans for what is required to deliver meaningful benefit to Indigenous communities. These flagships will initially focus on a) Pharmacogenomics; b) Precision Medicine; c) Immunogenomics; d) Genome Variation; and e) Rare Diseases (**See** ***Appendix 1*** *&* ***Figure 1****).*

Australia has never established an alliance of this kind before. It represents a commitment from academia, industry, Government, and our Indigenous communities to work collectively to develop a framework – designed by Indigenous people, for Indigenous people – to deliver the benefits of genomic medicine to all Australians.

**Indigenous governance** will both underpin and lead ALIGN’s work, and be instrumental in bringing forward the voices, values, and priorities of Aboriginal and Torres Strait Islander peoples, locally and nationally.

ALIGN’s jurisdictional Indigenous Governance Committees (“IGCs”) have been established to provide leadership, advice, governance and guidance for the development of Aboriginal and Torres Strait Islander genomic structures and models that allow for culturally appropriate and relevant Indigenous priorities, participation and leadership to be centred in all aspects of ALIGN’s functions and growth.

**Background**

Indigenous Australians represent the world’s longest continuously surviving culture, having inhabited the Australian continent for over 60,000 years. From a global perspective, it is likely that Indigenous Australians contain genetic diversity seen in few (if any) other population groups. A more complete understanding of health, disease, and human development is constrained by a lack of involvement of Indigenous people in genomics. Indigenous Australians are underrepresented in the governance of genomics science and remain virtually absent from databases of human genetic variation. Genomics, like any field of science, must reconcile with its history of marginalisation, bias and systemic injustice when dealing with Indigenous peoples. The prioritisation, involvement, conduct, analysis and sharing of genomic data for the benefit of Indigenous Australians is overdue.

ALIGN will build and extend Indigenous leadership in genomic science, research, precision health care, data sciences, and ethics to increase participation in genomics, deliver benefit from its application, and ultimately reduce inequity among Australia’s First Peoples.

**Scope**

The members of the New South Wales Indigenous Governance Committee (NSWIGC) will provide culturally appropriate guidance, advice and leadership to the node researchers, key stakeholders and to ALIGN’s National Indigenous Governance Council (the “Council”), so that the voices and priorities of local Aboriginal and Torres Strait Islander peoples and their communities are heard and embedded within the many different philosophies, protocols and structures that will underpin ALIGN. The essential areas that the NSWIGC will oversee include: working with the node co-ordinator and other key staff to address key ALIGN priorities: (i) Indigenous governance (structures and protocols), (ii) Indigenous data sovereignty and governance, (iii) identifying strategies and resources that build Community and Aboriginal and Torres Strait Islander health service genomic capacity and capability, (iv) identifying, responding to and developing Indigenous genomic policy, and (v) identifying and communicating the genomic and genetic health priorities of Aboriginal and Torres Strait Islander peoples.

The NSWIGC may wish to address other genetic and genomic health and research issues that are relevant to local Aboriginal and Torres Strait Islander peoples. In addition, each IGC will provide guidance on their specific Flagship Program.

**Objectives**

The Members of the NSWIGC will:

* Provide cultural and community context, knowledge, leadership, and advice to the ALIGN NSW node’s investigators and key stakeholders, and bring forward the voices, values, leadership and participation of Aboriginal and Torres Strait Islander peoples to develop culturally appropriate:
  + Indigenous data sovereignty and governance frameworks, models and policy.
  + Genomic and related research projects, and consent, privacy and confidentiality processes.
  + Opportunities for building genetic and genomic health capacity and capability within Aboriginal and Torres Strait Islander communities, health services and the broader health systems.
  + Indigenous genetic and genomic health and research leadership models.
  + Resources that support communities and services to improve access to genetic health services.
  + Support to the NSW node’s Flagship Program.
* Identify and facilitate opportunities for two-way genetic and genomic health learning between Aboriginal and Torres Strait Islander peoples and the co-development of ALIGN’s governance structures.
* Continue to build local communications and governance structures.
* Ensure that the operations and practices of the NSW node are consistent with community standards and expectations and supports the efforts of ALIGN and its Indigenous Governance mechanisms (e.g. the Council and other similar structures).

**Composition/Membership of** NSWIGC Members will:

* Identify as Aboriginal and/or Torres Strait Islander and will be selected to ensure they represent the diversity of Indigenous Communities within NSW.
* Demonstrate that they are able to represent their respective Communities directly or indirectly as appropriate spokespeople.
* Respect each other and all other parties relevant to the conduct of the IGC and its outcomes;
* Establish and adhere to the cultural values, protocols and behaviours of the NSWIGC.
* Engage broadly with Aboriginal and Torres Strait Islander peoples to understand and bring forward their views, values and opportunities for leadership and participation in the co-development of ALIGN’s governance models and structures.
* Attend a majority of set meetings or provide adequate notice of their non-attendance at meetings.
* Retain their own cultural intellectual property, ideas, contributions and advice and agree to share, where appropriate and identified, this valuable content with each other and the node staff in the development of ALIGN’s Indigenous Governance structures and models.
* Explicitly identify and make known to the node staff and secretariate any content they wish to remain private and not for the public domain such as research publications, policies, presentations or similar public facing forums/materials.
* Be invited by the NSW node or ALIGN staff, to participate, lead, and/or be acknowledged as authors in the development and publication of journal articles, presentations, policies, podcasts and other opinion or communications pieces where appropriate.

The NSW IGC will:

* Be comprised equally (where possible) of males and females, and a blend of older and younger members will be encouraged.
* Have between x and xx members.
* At the first meeting nominate a Chair and Deputy Chair for a period of 24 months, and thereafter, nominate a new Chair and Deputy Chair (gender balance recommended).
* In the case that new/additional members be required, nominations will be decided with consultation between the current NSW IGC members, the NSW node members, and the ALIGN leadership, as appropriate.

**Conflict of Interest**

All members of the NSWIGC will be expected to register any perceived or potential conflicts of interest at the beginning of their membership term and declare any conflict at the start of each meeting.

**Confidentiality Agreement**

All members of the NSWIGC will be expected to sign Telethon Kids Institute’s Declaration of Confidentiality at the beginning of their membership term.

**Meetings**

* The NSWIGC will meet [insert number of times annually] times a year with additional meetings as determined by the NSWIGC and the node.
* Meetings will be held [in person/virtually/in hybrid format/in a combination of formats].
* The duration of meetings will be no longer than [insert duration of meeting times] hours. The sitting members will determine the meeting times on a majority rules basis. NSWIGC members may also be required to pre-read meeting documents and if necessary and/or appropriate consult with other internal and external groups.
* NSWIGC members may also be consulted on an ad-hoc basis between meetings if required.

**Quorum**

A quorum shall consist of [insert number required for quorum – generally half number of members + 1] members. In the absence of a quorum, any discussion or decisions will require authorisation by the NSWIGC members either prior to or at the next meeting.

**Integration with National Indigenous Governance Council**

* The Chair and one other member, or alternatively 2 nominated members, will be required to attend both face to face and online meetings of ALIGNs’ Council, ensuring a gender balance where possible.
* Members who attend the Council meetings will be asked to verbally update the NSWIGC Members at the next meeting of the outcomes of the Council meeting, however the national secretariate will provide formal minutes.

**Secretariate**

* The NSWIGC will be supported by a secretariate comprising staff and resources from the respective NSW node and will include the Node Co-ordinator with administration assistance.
* The secretariate will be tasked in consultation with the NSWIGC Chair, with: preparing meeting agendas, taking, finalising and distributing meeting minutes, setting meeting dates, inviting key stakeholders and presenters, confirming meeting venues and online meeting links, co-ordinating travel and honorariums (where appropriate), co-ordinating policy development and other communications as required.
* The secretariate will support the NSWIGC to develop and provide an annual report of the meetings, including a summary of the work achieved in addressing the key deliverables set out above and other key work or recommendations raised through the NSWIGC.

**Honorarium and Travel Support**

* Members who are not remunerated through their employer will be eligible to claim an honorarium for attendance at all prescribed meetings.
* All members will have reasonable travel costs funded for all prescribed meetings of the NSWIGC.
* The secretariate staff will provide the necessary forms for and will facilitate the payments of honoraria for relevant members.
* Where the lead institution within the respective jurisdictional node does not have an honorarium schedule, ALIGN’s co-ordination team (managed by Prof Alex Brown) will provide an honorarium schedule for consideration and use.

**Values and Conduct of the Meetings**

* All members of the NSWIGC, NSW node staff, presenters and invited guests will adhere to the values of the NSWIGC, and are personally responsible for their words, actions and behaviours.
* Members can continue to add to and develop their values and rules of conduct, but these should be adhered to at a minimum, and will include:
* Respect for all peoples and opinions so that everyone is able to speak and be heard.
* Maintain a respectful and considered tone when talking to each other, the support staff and invited guests.
* Understand that a difference of opinion can be valuable and is not a sign of disrespect.
* That lateral violence, discrimination, harsh words or belittling language will not be tolerated, and members or guests may be asked by the Chair to remove themselves from the meeting if they demonstrate these or similar behaviours.

**Terms of Reference**

The Reference Group Terms of Reference will be reviewed annually.

**Accepted [insert date accepted]**

**Review date [insert annual review date]**

**Related documents:**

**Appendix 1**

***From the MRFF grant application***

Directly responding to the GHFM (Genomic Health Future Mission) objectives, and to achieve our vision, the program aims to: 1. Establish an Indigenous genomics alliance that provides national leadership, coordination and alignment of expertise, facilitates connection between key stakeholders and maximises meaningful benefit from Indigenous genomic research. 2. Enhance Indigenous community understanding of, involvement in, and leadership of genomics research and health care. 3. Identify, develop, and communicate critical genomic policies of direct relevance to Indigenous Australians, health care providers, and policy operatives. 4. Define, share and support the implementation of nationally consistent, culturally appropriate, ethical, best-practice, genomic data and sample storage, management and sharing to maximise benefit to Indigenous Australians. 5. Build the capability of an Indigenous Genomics clinical and research workforce. 6. Collaboratively define, plan and implement clearly articulated pathways to benefit for Indigenous Australians as a direct result of genomics research and health care. Our (ALIGN) structure and collaborative scientific program (Figure 1) will be geared towards the clear articulation and implementation of efforts that deliver benefit to Indigenous Australians in the planning for and deployment of national genomics health care and research. Guided by the scientific and operational leadership of CI Brown (Australian National University/Telethon Kids Institute) and technical leadership of CI MacArthur (Centre for Population Genomics), ALIGN will establish Centres of Excellence in Indigenous Genomics across the country (Aim 1). These federated ‘nodes’ will initially focus on the establishment of Indigenous Governance mechanisms in each jurisdiction with the explicit objective of enabling community engagement and leadership of genomic efforts (Aim 2). Aligning activities and expertise across the nation, and supported by the scientific and operational leadership team, each Centre of Excellence will synergistically develop and/or respond to major genomic priorities to embed Indigenous leadership and ensure the articulation of culturally appropriate policy (Aim 3), as well as best-practice approaches to data sovereignty, data system development and sample management (Aim 4).

**Figure 1**

