Developing a functional Indigenous Data Stewardship Model for Genomics

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**ABSTRACT:**

The intersection of genomics and Aboriginal and Torres Strait Islander people in Australia describe ongoing and continuing impacts from colonisation playing out across health research and health systems (Dodson and Williamson 1999). Genomics data hold immense potential to address diseases and promote health equity. It aids in understanding genomic variations that cause disease and informs optimal treatment decisions to enhance health and wellbeing. Additionally, this information reveals insights into human origins, ancestry and biodiversity. Genomic research involving Indigenous peoples also navigate complex ethical, legal, and cultural considerations.

These are challenges within current colonial structures with the governance of Indigenous genomics data is a critical issue, intersecting with broader discussions on Indigenous rights, sovereignty, and self-determination. The FAIR Principles (Findability, Accessibility, Interoperability, and Reusability) are frequently referenced for data governance and stewardship and primarily focus on the facilitation of increased data sharing (Wilkinson *et al.* 2016). The CARE Principles (Collective benefit, Authority to control, Responsibility and Ethics) were developed to address the tensions between, data ownership, open science and the needs of Indigenous people from around the globe and are complementary to the FAIR principles (Carroll 2020). Missing from the picture are models that represent this complex interaction between culture, context, data, research, and clinical care in the context of genomics required for Indigenous data stewardship.

This project is developing a national ‘Indigenous Genomics Data Stewardship Model’ aligned with current best practice to ensure data processes and data sharing that reflects Aboriginal and Torres Strait Islander principles, centring Indigenous data sovereignty and governance; and developing data standards for data collection, sharing, analysis and reporting.

Informed by an Indigenous research paradigm (Wilson 1996), the methodological approach includes: 1) social network analysis; 2) qualitative explanatory collective case studies; and 3) critical participatory action research. Findings from these methods will contribute to the development of an Indigenous genomics data stewardship model.

This research empowers Indigenous communities to lead genomic research while establishing Indigenous data governance and management in genomics. We will describe the development of the ‘Indigenous Genomics Stewardship Model’, our strategies for enhancing Indigenous identity and recognition within genomics data as well as emerging approaches and guidelines for integrating non-genetic data in Indigenous genomics research and health care.

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