Contribution ID: **250**   Type: **Poster**

CAREful Indigenous Data and the National Statement: Early reflections on co-designing an Indigenous community-created, client-centric digital platform

Monday 13 October 2025 19:10 (20 minutes)

As demand grows to improve health outcomes for Aboriginal and Torres Strait Islander clients, health practitioners and researchers are increasingly embedding Indigenous perspectives through co-design and applying Indigenous data governance frameworks. This paper shares the preliminary reflections from a research program co-led by a Queensland-based Indigenous community-controlled organisation and an interdisciplinary team of public health experts, data scientists and social scientists based in Australia. The program is grounded in a collaborative governance model involving frontline staff–many of whom identify as Aboriginal and Torres Strait Islander—alongside community members, study investigators, and key staff from the Aboriginal and Torres Strait Islander Community Health Service (ATSICHS-Brisbane) and Queensland University of Technology responsible for the project's implementation.

Co-Design Approach

We discuss the early progress of a public-private funded collaborative program of work to co-produce culturally informed tools and approaches to physical health, social and emotional well-being, guided by principles of CAREful Indigenous Data Governance, Indigenous Data Sovereignty and Australia's National Statement. CAREful Indigenous Data Governance is a principle-based framework developed in response to the need for culturally appropriate, respectful, and reciprocal data practices for Indigenous peoples. Research programs aligning with CAREful Indigenous Data Governance affirm the rights of Aboriginal and Torres Strait Islander communities'rights to collect, access, and govern data about themselves, in alignment with principles of Indigenous autonomy and self-determination. This commitment is reflected in the research program's management practices, including establishing community stewardship structures and integrating client voices from the outset. We examine how these principles co-exist alongside Australia's National Statement on Ethical Conduct in Human Research 2023, published by the National Health and Medical Research Council (NHMRC), Australian Research Council (ARC), and Universities Australia, commonly called the National Statement. The National Statement guides researchers on conducting research with high ethical standards that protect research participants' rights, dignity, and welfare.

Reflections and Learnings

We contend that articulating community-defined needs and goals, respecting cultural protocols, and embedding co-creation principles—particularly those that prioritise cultural safety and First Nations values such as storytelling, relationality, and respect—are critical from the inception of a research initiative and must be sustained throughout its development and implementation. By integrating CAREful Indigenous Data Governance principles, we argue that the research program is better equipped to manage the risks and benefits of community-led research. This integration strengthens the project team's capacity to ensure the program upholds respect for human dignity and adheres to the principles of justice, beneficence, and respect.

Conclusion and Future Directions

The digital tools and protocols resulting from this research program will guide service delivery and support Aboriginal and Torres Strait Islander Peoples so that they can play a direct role in their own health and well-being. When the client-centric digital platform is completed, the efficacy of community-led implementation and reflective practice can be assessed and evaluated.

The contribution of this research program includes a discussion of novel approaches and methods for building an Indigenous community-driven, client-centric digital platform. Our presentation aimed at data science researchers, research software engineers, and research infrastructure specialists, data professionals and early career researchers seeking to expand their knowledge on data governance using culturally appropriate, strengths-based approaches for improving the health and wellbeing of First Nations peoples.

Primary author: HYLAND-WOOD, Bernadette (Queensland University of Technology)

Co-author: ALECKSON, Jarryd (Aboriginal and Torres Strait Island Community Health Service Brisbane)

Presenter: HYLAND-WOOD, Bernadette (Queensland University of Technology)

Session Classification: Poster Session

Track Classification: SciDataCon2025 Specific Themes: CAREful Indigenous Data Governance