RAUGH

The Research Alliance for Urban Goori Health

Data Governance Framework

October 2022

RAUGH acknowledges the Traditional Owners and their custodianship of the lands on which UQ, Metro North and IUIH operate. We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country. We recognise their valuable contributions to Australian and global society.

RAUGH

The Research Alliance for Urban Goori Health (RAUGH) was established in 2021 as a formal partnership between the University of Queensland's Poche Centre for Indigenous Health ('UQ Poche'), Metro North Hospital and Health Service ('Metro North') and the Institute for Urban Indigenous Health (IUIH). A key stakeholder to the Alliance is the Queensland Health's Aboriginal and Torres Strait Islander Health Division. RAUGH's vision is to transform health care delivery and accelerate closing the gap in life expectancy and achieving health equality for urban Aboriginal and Torres Strait Islander (respectfully referred to as Indigenous, hereafter) peoples by ensuring the whole of health care system is responsive to the health and wellbeing needs of First Peoples. This will be achieved through the conduct of health research and capacity building initiatives in the Metro North region. RAUGH is administered through UQ Poche and is bound by UQ data governance policies and procedures.

Purpose and Intent

The effective governance of Indigenous Data empowers Indigenous peoples to make the best decisions on how to support communities and Indigenous peoples in the ways that meet their needs and aspirations. RAUGH is an Indigenous-led research alliance that is committed to working with the Metro North Indigenous community and health services (specifically, but not exclusively, Metro North and IUIH) to co-design new services, programs and policies, and build workforce capacity, to accelerate progress towards achieving health equity and improved health outcomes for urban Indigenous peoples.

This Data Governance Framework ('Framework') is underpinned by Indigenous Data Sovereignty and Indigenous Data Governance. RAUGH acknowledges that Indigenous peoples have the right to exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure. As such, this Framework has been developed to empower self-determination and ensure RAUGH's data structures are accountable to Indigenous peoples living in the Metro North region.

This Framework outlines the elements that comprise RAUGH's approach to data governance and describes in detail how they work together to support the legal, ethical and safe management of our data holdings. This Framework governs all research undertaken by RAUGH and its collaborators and outlines the process for accessing, linking, analysing, sharing and storing Indigenous Health data from Metro North and IUIH. This also includes the requirements overseeing dissemination of research findings from the analysis of data.

Endorsement by Community

This Framework has been endorsed by RAUGH's Governance Committee, whose membership includes Indigenous health service leaders, researchers and is chaired by an Aboriginal Elder.

Definitions

RAUGH adopts the Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective's definitions for:

- *'Indigenous Data'* refers to information or knowledge, in any format or medium, which is about and may affect Indigenous peoples both collectively and individually.
- '*Indigenous Data Sovereignty'* refers to the right of Indigenous peoples 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.
- *'Indigenous Data Governance'* refers to the right of Indigenous peoples to autonomously decide what, how and why Indigenous Data are collected, accessed and used. It ensures that data on or about Indigenous peoples reflects Indigenous peoples' priorities, values, cultures, worldviews and diversity.

Data Governance Principles

RAUGH will follow the **(Findable, Accessible, Interoperable, Reusable) FAIR1 Guiding Principles** for data management and stewardship, as appropriate. The **Accessibility** and **Reusability** of the data is governed by the ethics, data custodian and public health act approvals obtained for each research project and thus, RAUGH collaborators and other researchers wanting to access Indigenous health data will need to follow the same ethical, regulatory and governance processes as RAUGH to access the data. Further, if RAUGH researchers wish to reuse the data for a purpose outside the original ethical, legal and governance approval/s granted, they are required to submit an extension to the original approval/s. Data from Metro North and IUIH will be linked (**Interoperable**) through an approved process and all linked data will be assigned a globally unique and persistent identifier (**Findable**), with RAUGH researchers only having access to de-identified data.

RAUGH in its stewardship of Indigenous data will also conform to the CARE (Collective Benefit, Authority to Control, Responsibility, and Ethics) Indigenous Data Governance Principles2,3 developed by the International Indigenous Data Sovereignty Interest Group in consultation with Indigenous peoples, scholars, non-profit organisations and governments around the world. The International Indigenous Data Sovereignty Interest Group is a network of nation and state based Indigenous data sovereignty networks and individuals, including Australia's Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective.

The CARE Principles are people- and purpose- oriented, reflecting the crucial role of data in advancing innovation, governance, and self-determination among Indigenous peoples. The principles complement the existing data-centric approach represented in the 'FAIR Guiding Principles for scientific data management and stewardship.

- *CARE (Collective Benefit, Authority to Control, Responsibility, and Ethics)*

C **Collective Benefit:** Our research priorities are informed through the lens of Indigenous peoples of the Metro North region communities and clients. Research questions and activities will originate from identified Indigenous peoples' community needs and aspirations or issues identified by health service providers but intended only to improve practice policy and programs for Indigenous peoples. RAUGH is committed to working with Metro North and IUIH to accelerate progress toward achieving equity for urban Indigenous peoples living locally, nationally and internationally.

A **Authority to Control:** RAUGH affirms Indigenous Peoples' rights and interests in their data and is committed to ensuring processes are in place that enable accountability to Indigenous peoples and communities of Metro North region. RAUGH's research and capacity building endeavours are overseen by an Indigenous Reference Group, and where appropriate, research may involve the establishment of consumer and citizen panels, community advisory panels and/or participation of consumers as advisors.

R **Responsibility:** We privilege Indigenous ways of understanding, knowing, and doing and are committed to listening to, privileging and understanding the needs and aspirations of Indigenous peoples of the Metro North region. RAUGH adopts a strength-based approach to all our research, capacity building and engagement activities, including the embedding of cultural safety, reflective of cultural determinants and self-determination principles. We are committed to (i) investing in capacity development of the Indigenous workforce in the Metro North region, and (ii) employing an innovative and novel approach to our research activities to add to the evidence base, with the ultimate goal of improving the performance of health care systems and structures for Indigenous people of the Metro North region.

E **Ethics:** Our data practices are overseen by our Indigenous Reference Group, who are responsible for endorsing research and capacity activities through assessing benefits and harms to Indigenous peoples based on community values and ethics. We apply and use a decolonising agenda framework - which means that Indigenous worldviews, cultural values and language are incorporated into our research projects and activities, our interpretation and translation activities.

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[1] Wilkinson MD, et al., The FAIR Guiding Principles for scientific data management and stewardship. Sci Data. 2016 Mar 15;3:160018. doi: 10.1038/sdata.2016.18. Erratum in: Sci Data. 2019 Mar 19;6(1):6.
[2] Carroll, S.R., et al., The CARE Principles for Indigenous Data Governance. Data Science Journal, 2020. 19(1).
[3] Carroll SR, Herczog E, Hudson M, Russell K, Stall S. Operationalizing the CARE and FAIR Principles for Indigenous data futures. Sci Data. 2021 Apr 16;8(1):108.

Data Governance Concepts

1. Sources of Data

Data will be sourced from available datasets and patient management systems, which may include:

a. Metro North

- Integrated electronic medical record (ieMR)
- Hospital-Based Corporation Information System HBCIS
- Emergency Department Information System (EDIS)
- Metavision (ICU system)

b. via IUIH, Moreton ATSICHS and ATSICHS Brisbane's Northgate clinics

- MMEx patient management system

c. Queensland Health Statistical Services Branch (Data Linkage Unit)

- Queensland Hospital Admitted Patient Data Collection (QHAPDC)
- Queensland Perinatal Data Collection (QPDC)
- Queensland Cancer Registry (QCR)
- Death Registration data1
- Emergency Department Collection (EDC)
- National Hospital Cost Data Collection (NHCDC)
- Community Integrated Mental Health Application (CIMHA)
- Queensland Ambulance Service (QAS) data

2. The Nature of the Data

RAUGH researchers will only receive access to de-identified data from IUIH and Metro North, either as an aggregated dataset, where patient data is aggregated to the level of the clinic or hospital or linked data that has been de-identified by the Queensland Health Data Linkage Team, or via another approved process, after linkage of multiple datasets.

3. Data Access and Usage

Data will be accessed and used in accordance with appropriate ethical, site-specific and data custodian approvals and upon endorsement from RAUGH's Indigenous Reference Group.

4. Data Integration and Linkage

Data integration is a method of bringing together data from different sources, but relating to the same individual, organisation, event or other unit.

Data linkage is a technical process within data integration by which identifying information from different sources is used to identify records relating to the same unit. Within RAUGH, we use these terms interchangeably.

Metro North, IUIH and UQ are committed to transforming health care delivery for urban Indigenous peoples through a whole of healthcare system approach and coordinated care across the primary and tertiary health care sectors. To achieve this goal, RAUGH will integrate Indigenous health data between Metro North hospitals and services and IUIH member clinics in the Metro North region (Moreton ATSICHS and ATSICHS Brisbane's Northgate clinics) to better understand 'patient journeys' across the health continuum. This will enable the identification of gaps and barriers in the health system that are inhibiting Indigenous peoples in the region from receiving equitable and culturally appropriate care.

Indigenous health data from Metro North and IUIH member clinics will be linked through a data linkage process approved by both institutions and their respective data custodians. Where possible, it will be performed by **Queensland Health's Data Linkage Unit**[4]. In the event it is determined that this is not appropriate, RAUGH will work with MNHHS and IUIH to implement a third-party data extraction software solution, such as GRHANITE, that enables the flow of de-identified data to UQ.

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[4] For more information on the Data Linkage process refer to: Queensland Data Linkage Framework: Queensland Data Linkage Framework (health.qld.gov.au).

GRHANITE was developed by the University of Melbourne and is used by the national ATLAS Surveillance Network operating in around 40 Aboriginal Community Controlled Health Services and led by Professor James Ward.

In the mid to long term, the objective is to create the digital infrastructure required to facilitate integration of Indigenous health data across the health system, starting with IUIH and Metro North. Standardised and harmonised Indigenous health records, aligned with best-practice Indigenous data principles and governance practises, will enable person-centric, equitable and coordinated care for Indigenous people in Metro North region and more broadly.

5. Legal, Regulatory and Governance

a. **Ethics and Public Health Act.** Access to data for research requires ethical approval in addition to approval from the data custodians. RAUGH researchers will prepare a Human Research Ethics (HREC) Application and submit this to one of Metro North's HRECs (TPCH/RBWH). Upon receiving ethical approval, a Public Health Act (PHA) application will be prepared and submitted to Queensland Health's Health Innovation, Investment and Research Office (HIIRO). Where appropriate, RAUGH researchers will work with data custodians to gain consolidated ethical approval for the use of health information for research projects.

b. *Information Privacy Act 2009.* RAUGH is legally required to comply with the Information Privacy Principles (IPPs) set out in the *QLD information Privacy Act 2009* and is bound by the University of Queensland's Privacy Management policy.

c. **Site Governance and Data Sharing Agreement.** RAUGH will work with Metro North's Governance Office and IUIH to complete a Site Specific Assessment (SSA) application for each site where data has been requested from. As part of this process, a Data Sharing Agreement governing the use of the data will be put in place between Metro North, IUIH and UQ.

6. Secure Storage Environment

Data will be stored on UQ's secure Research Data Management (RDM) shared drive, in accordance with UQ's policies and procedures. The RDM ensures that research data remains accurate, authentic, reliable, and complete; retains integrity and improves the reproducibility of research; is secure, minimising the risk of data loss; can be reused; is available in accordance with the Australian Code for the Responsible Conduct of Research and the FAIR guiding principles, and meets requirements of regulatory bodies.

7. Dissemination of Research Findings

Once research findings have been approved for release by RAUGH members, they will be communicated to Indigenous people living in the Metro North region through MNHHS and IUIH community newsletters and community engagement events, forums and invited opportunities. Further, all of RAUGH's current and past projects (including outcomes) will be published on its website, with community encouraged to contact the Alliance if they have any questions or concerns.