

Fraser Health Research Data Management Institutional Strategy

February 17, 2023

Territorial Acknowledgement

We recognize that Fraser Health provides care on the traditional, ancestral and unceded territories of the Coast Salish and Nlaka'pamux Nations, and is home to six Métis Chartered Communities.

Introduction

Data is the foundation of health research, and health research provides the evidence and innovation needed by the health system to inform and improve health care service delivery, outcomes and policies. Health research is not separate from the health system, it is an integral and essential part of it.

Fraser Health's Research Data Management (RDM) Strategy is a road map to guide research capacity-building by making research data more findable, accessible, interoperable and reusable (FAIR) over a multi-year horizon. In addition, this RDM Strategy is designed to foster a culture that supports researchers in understanding and adopting responsible RDM practices. This RDM Strategy complies with the 2018 Canadian Tri-Agencies Research Data Management Policy mandate that requires institutions to create and post their RDM strategies by March 1, 2023.

The development of this Strategy was done collaboratively with both internal and external partners to support harmonized approaches, wherever possible, for the benefit of researchers and the ultimately the health system and the people of British Columbia. The resources and templates provided in the Portage, and later the Digital Research Alliance of Canada, have guided the evolution of the work, from raising awareness, recruitment of the development team, assessment of the current state of readiness and more.

Internally, collaborators and contributors were diverse and include leaders and knowledge area experts in the Department of Evaluation and Research Services, Library Services, Information and Privacy, System Optimization, and Indigenous Health. The Strategy was reviewed and endorsed by senior leadership including the Vice President responsible for Research.

At the provincial level, the five regional health authorities in British Columbia and the First Nations Health Authority collaborated to align strategies where possible with the support and collaboration of Michael Smith Health Research BC and the BC Ministry of Health. Participants in the provincial working group included Health Authority leads also leading the work internally. This approach enabled leveraging of resources, ideas and approaches to betterment of the health data research ecosystem in BC.

There are four goals in this Strategy, each is described in its own section with desired outcomes and accountabilities. This Strategy will be used by the institution to inform future work and guide the allocation of resources and infrastructure over time to successfully address its objectives and goals.

This Strategy recognizes the autonomy of indigenous peoples and that access and possession of Indigenous data must be respectfully permitted by the relevant authority as defined by the specific communities involved. This applies to the collection, protection, use, and management of data records and information. Therefore, all goals incorporate the essential consideration of First Nations, Métis and Inuit peoples' data governance, including but not limited to ownership, control and possession, and stewardship. Principles of equity, diversity and inclusion (EDI) are also integrated into each section.

Goal 1:

TO DEVELOP, PROMOTE AND STRENGTHEN GOOD RESEARCH DATA MANAGEMENT PRACTICES, POLICIES AND PROCEDURES

Enabling good research data management practices requires institutional leadership and support. Fraser Health will ensure appropriate resources to support researchers in implementing sound research data management practices in line with the [Tri-Agency Research Data Management Policy](#).

The processes and tools created under this goal will strive to embed a distinction-based approach to ensure that the unique rights, interests and circumstances of First Nations, Métis and Inuit are duly incorporated, including compliance with the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), and British Columbia's Declaration on the Rights of Indigenous Peoples Act (DRIPA), the HSO Cultural Safety Standard, and Chapter 9 of the TCPS 2.

DESIRED OUTCOMES

- Clear data management standards for researchers that promote collaborative research and knowledge translation in the health authority, and that align with the broader data management policies, practices, and governance of Fraser Health
- An institutional Research Data Management Policy communicating the values, philosophy and expectations of an institutional culture that emphasizes the importance of good data management practices as an enabler of better care and outcomes for patients, families and the public;
- New tools and templates for researchers to support incorporation of good data management approaches into research studies consistent with regulatory, ethical, cultural and contractual requirements.



Goal 2:

TO SUPPORT COMPLIANCE AND ETHICAL INTEGRITY OF THE RESEARCH DATA MANAGEMENT PROCESS WITH APPLICABLE REGULATIONS, THE TRI-COUNCIL POLICY STATEMENT 2 AND DATA AGREEMENTS

Compliance with ethical, cultural, policy and regulatory requirements is an integral part of good data management. As a public body, Fraser Health has a duty to ensure that any personal health information used for research is done with appropriate considerations for privacy and confidentiality in compliance with FoIPPA and other relevant privacy legislation. Fraser Health will ensure compliance through formalized RDM practices while maintaining its commitment to streamline the research approvals process in British Columbia. Fraser Health also recognizes the need for a distinctions-based approach for research with First Nations, Métis and Inuit communities that recognizes data related to Indigenous communities must be managed in accordance with principles developed and/or approved by these communities, including the recognition of Indigenous data sovereignty and inclusion of options for renegotiation of the data management plan (DMP).

DESIRED OUTCOMES

- With the exception of a distinction-based approach for Indigenous research data, all research conducted in Fraser Health using data from that institution employ standardized data management practices that enable collaboration, including DMPs where appropriate;
- Dedicated privacy resources in place to efficiently ensure compliance with FoIPPA and other relevant privacy legislation
- Formalized data management practices with tools and pathways that enable compliance with requirements and encourage research teams to develop discipline-specific RDM expertise;
- Seamless integration of DMP requirements into existing operational approval processes that avoids unnecessary duplication;
- Acceptance of a single data management plan for multi-jurisdictional studies across BC institutions involved in a study;
- Recognition of and adaptability for context-specific data types, communities, and data governance that may require diversion from the standard data management practices and may impact the ability to share research data openly.

GOAL 2

TO SUPPORT COMPLIANCE AND ETHICAL INTEGRITY OF THE RESEARCH DATA MANAGEMENT PROCESS WITH APPLICABLE REGULATIONS, THE TRI-COUNCIL POLICY STATEMENT 2 AND DATA AGREEMENTS

DEVELOP DMP PROCESS MAP

Develop process map to ensure appropriate review & oversight of DMPs for internal & external projects



PATHWAYS FOR SENSITIVE DATA

Identify appropriate experts, oversight, and pathways for research involving sensitive personal information



PARTNERSHIPS FOR GOVERNANCE FOR INDIGENOUS RESEARCH DATA

Identify key internal and external partners to develop pathways and governance structures for research data from research involving First Nations, Métis and Inuit communities



FINALIZE DMP OVERSIGHT & PATHWAYS

Finalize the oversight and review pathways for all research data that incorporates distinction-based approach for Indigenous and highly sensitive data



Goal 3:

TO BUILD INSTITUTIONAL CAPACITY FOR RESEARCH DATA MANAGEMENT

Effective research data management requires a foundation of knowledge, capacity and support at the individual and institutional level. Fraser Health will improve infrastructure and institutional capacity for research data management, with specific emphasis on metadata and data curation, through internal and external partnerships.

DESIRED OUTCOMES

- Dedicated internal support for research data management;
- Widespread awareness of research data management policies and standards among internal and external researchers;
- Increased accessibility for training, made available through provincial and national collaboration, specific to the needs of both new and established researchers, including OCAP training provided through the First Nations Information Governance Centre and training specific to working with highly sensitive data sets.



Goal 4:

TO ENSURE RESEARCH DATA IS SECURELY AND EFFECTIVELY STORED, RETAINED AND MADE AVAILABLE FOR ACCESS AND RE-USE, WHERE APPROPRIATE

The storage and accessibility of research data for reuse is a key element of the Tri-Council Policy. Preparing data for storage and use in an adequate, secure, and reliable digital storage solution requires good data preparation along with the development of associated data assets, such as metadata tables, user guides, and codebooks. The process of storing and accessing the data will be developed in a collaborative and inclusive manner, and, where indigenous data is considered, engaging with Indigenous Communities, Centres, and Organizations (ICCOs) of British Columbia, adhering to OCAP principles and/or CARE principles.

DESIRED OUTCOMES

- The creation of a provincially accessible research data storage solution for use by health authority researchers when institutional storage solutions are inappropriate or unavailable. Design of the solution must take into consideration the data sovereignty requirements of indigenous communities (i.e., following OCAP principles, CARE principles) and highly sensitive data;
- Availability of consistent resources and supports for researchers to prepare their data for submission into the provincial research data storage solution, including robust metadata, user guides, and codebooks to assist others in assessing the data for reuse;
- Consistent practices and procedures for storage and access, curation and preservation of the research data within the repository;
- A review process using a distinctions-based approach to ensure requests for access for appropriate reuse are reviewed and approved according to provincially acceptable criteria, including adherence to indigenous sovereignty requirements over indigenous data;
- Shared governance structure ensuring appropriate oversight for the shared digital data repository with a clear and equitable access framework that recognizes the importance of research data for the health authority and the communities that have contributed to research.

GOAL 4

TO ENSURE RESEARCH DATA IS SECURELY AND EFFECTIVELY STORED, RETAINED AND MADE AVAILABLE FOR ACCESS AND RE-USE, WHERE APPROPRIATE.

CONSULT ON REPOSITORY NEEDS

Consult Fraser Health research community on best practices and needs for research repositories.



DEVELOP RESEARCH DATA REPOSITORY STANDARDS

Work with provincial partners to adopt consistent research data repository standards.



SUPPORT PROVINCIAL SOLUTION FOR RESEARCH DATA REPOSITORY

Collaborate with provincial partners to support a provincial research data repository.



SUPPORT INDIGENOUS-LED LONG TERM DATA PRESERVATION PATHWAYS & PROCESSES

Support and adopt indigenous-led pathways and practices for long-term preservation of research data involving First Nations, Inuit and Métis people.



Oversight and Review

The Director, Evaluation and Research Services, is responsible for the oversight and implementation of the RDM and will periodically (no less than once a year) report to the Vice President responsible for Research, who holds overall accountability for the Strategy. The Director, Evaluation and Research Services, will also oversee updates to the Strategy, which is a living document.

The Director, Evaluation and Research Services will work collaboratively with their counterpart Directors within System Optimization, Health Information Management, and Privacy and Information, to advocate and incorporate the resource and infrastructure needs of the RDM, as applicable, into their operational planning processes.

Progress to attain the goals of this Strategy will be monitored annually to ensure continued alignment with Fraser Health operational priorities and mandates.

Definitions

CARE Principles for Indigenous Data Governance: Collective benefit, Authority to Control, Responsibility and Ethics

Data: Data are facts, measurements, recordings, records, or observations collected by researchers and others, with a minimum of contextual interpretation. Data may be in any format or medium taking the form of text, numbers, symbols, images, films, video, sound recordings, pictorial reproductions, drawings, designs or other graphical representations, procedural manuals, forms, diagrams, workflows, equipment descriptions, data files, data processing algorithms, software, programming languages, code, or statistical records.

Distinction-based approach: Work with Indigenous, Métis, and Inuit people is conducted in a manner that acknowledges the specific rights, interests, priorities and concerns of each, while respecting and acknowledging these distinct Peoples with unique cultures, histories, rights, laws, and governments.

DMP – Data Management Plan

EDI – Equity, Diversity and Inclusion

FAIR: Findable, Accessible, Interoperable, and Reusable

Indigenous Data: Indigenous data is any information that is from or about any Indigenous person or their community, territory or nation, including but not limited to their languages, knowledges, customs or traditions, intellectual property and ideas. Indigenous data are also relational and reciprocal, and need to reflect and be held by the community as a collective, and are equally as important to pass down through generations as a part of lifelong journeys of coming to be. (INDIGENOUS INNOVATION INITIATIVE (2021). Indigenous Knowledges and Data Governance Protocol. Toronto: Indigenous Innovation Initiative. Available from: www.indigenousinnovate.org. – accessed 2023 January 11)

OCAP – Ownership Control Access Possession

OCAS – Ownership Control Access and Stewardship

Research Data – Data used as primary sources to support research, scholarship, or artistic activity, and that are used as evidence in the research process and/or are

commonly accepted in the research community as necessary to validate research findings and results. All other digital and non-digital content have the potential of becoming research data. Research data may be experimental data, observational data, operational data, third party data, public sector data, monitoring data, processed data, or repurposed data.

Research Data Management (RDM) – Processes applied through the life cycle of a research project to guide the collection, documentation, storage, sharing and preservation of research data.

Tri-Agency: The umbrella term used to describe the three Canadian Government research funding agencies: Canadian Institutes of Health Research (CIHR) Natural Sciences and Engineering Research Council (NSERC) Social Sciences and Humanities Research Council (SSHRC)

UNDRIP – United Nations Declaration on the Right of Indigenous People

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