



Interior Health Research Data Management Strategy

February 23

2023

IH Research Department



Contents

- Land Acknowledgement1
- Introduction to Interior Health’s Research Data Management Strategy.....2
- Background.....3
- Goal 1: 4
- Goal 2: 5
- Goal 3: 6
- Goal 4:..... 7
- Oversight and Review 8
- Definitions.....9
- Acknowledgements.....10



Land Acknowledgement

Interior Health would like to recognize and acknowledge the traditional, ancestral, and unceded territories of the Dãkelh Dené, Ktunaxa, Nlaka'pamux, Secwépemc, St'át'imc, Syilx, and T̓silhqot'in Nations where we live, learn, collaborate and work together.



Introduction to Interior Health's Research Data Management Strategy

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

Interior Health's Research Data Management (RDM) Strategy is a road map to build research capacity by making research data more findable, accessible, interoperable and reusable 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.

An important element of this RDM is the recognition of 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.

This Strategy complies with the 2018 the Canadian Tri-Agencies Research Data Management Policy mandate that requires institutions to create and post their RDM strategies by March 1, 2023.

Strategy Goals

- 1) To promote and strengthen good research data management practices, policies and procedures.
- 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.
- 3) To identify and acquire current and future infrastructure to develop institutional capacity for research data management.
- 4) To ensure research is securely and effectively stored, retained and made available for access and re-use, where appropriate.



Background

The development of this Strategy was based on a foundation of collaboration, both internally and externally, given the need to support harmonized approaches, wherever possible, for the benefit of researchers and ultimately the health system and the people of British Columbia. The resources and templates provided in the Portage, and later the Digital Data Management Alliance, have guided the evolution of the work, from raising awareness, assessment of the current state of readiness and more.

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 research ecosystem in BC.

This Strategy will be used by researchers to understand the status of policies, principles, processes, and educational supports for research data management, both now and in the future. It will also be used by Research Leaders to guide the allocation of resources and infrastructure over time to address its objectives and goals.

There are four goals in this Strategy, each is described in its own section with desired outcomes and accountabilities.

All goals incorporate the essential consideration of Indigenous, Métis and Inuit peoples' data governance, including but not limited to ownership, control and possession, stewardship. Principles of equity, diversity and inclusion are also integrated into each section.



Goal 1:

To promote and strengthen good research data management practices, policies and procedures.

Interior Health's existing organizational supports for Research Data Management include: i) institutional policy and procedures that are inclusive of research but not specific to it, ii) a requirement to describe the details of the data management plan for each study in both the research ethics application and the operational review application, and iii) access to REDCap, a flexible, secure on-line data management tool with appropriate operational policies and user agreements. Institutional approval to conduct research is dependent on data management plans meeting all requirements for compliance with the Tri-Council Policy Statement 2, all applicable policies and legislation and the terms and conditions of agreements.

Desired outcomes:

- A Research Data Management Policy communicating the values, philosophy and expectations of an organizational culture that emphasizes the importance of good data management practices as an enabler of better care and outcomes for patient, families and the public.
- Tools and templates for researchers to support incorporation of good data management approaches into research studies consistent with regulatory, ethical, cultural and contractual requirements.
- Increased access to training, made available through provincial and national collaboration, specific to the needs of both new and established researchers.
- Integration of a distinction-based approach ensuring 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), British Columbia's Declaration on the Rights of Indigenous Peoples Act (DRIPA) and the HSO Cultural Safety Standard.



Goal 2:

To support compliance and ethical integrity of the research data management process with applicable regulations, the Tri-Council Policy Statement 2 (TCPS2) and data agreements.

Research data requests and associated management plans are reviewed by the Interior Health Research Department, the Interior Health Research Ethics Board, and where necessary, the Interior Health Privacy Department to ensure Interior Health data requested for research purposes are collected, transferred and managed in a manner that is compliant with current provincial and federal regulations.

Desired outcomes:

- With the exception of the distinction-based approach for Indigenous research data, all research conducted in Interior Health using data from that institution employs standardized data management practices that enable collaboration, and a DMP that complies with applicable requirements where appropriate.
- Standardized data management practices with tools and pathways that enable compliance (adherence) with requirements, encouraging researchers to be or become the experts.
- A single DMP for multi-jurisdictional studies that is accepted across BC institutions involved in a study.
- Recognition that context-specific data types, communities, and data governance may require diversion from the standard data management practices and may impact the ability to share research data openly.



Goal 3:

To identify and acquire current and future infrastructure to develop institutional capacity for research data management.

A number of initiatives are active within Interior Health to advance support for data management and reporting at an institutional level: Research data request facilitation supported via the IH Research Department in collaboration with Digital Health and the Data and Analytics Department; development of an IH-wide governance framework with clear data stewardship roles & responsibilities; as well as the development of a cloud environment to further support secure access to key datasets.

Desired outcomes:

- Sustained capacity for facilitation of research requests for IH data (including Digital Health analyst support).
- Finalized IH data governance framework and clearly defined data stewardship for all IH data content areas.
- Established process to facilitate access to IH Cloud environment for researcher to access and analyze IH data securely.
- Streamlined data sharing agreement processes.



Goal 4:

To ensure research 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 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 for use. Design of the solution must take into consideration the data sovereignty requirements of Indigenous communities (e.g., following OCAP principles, CARE principles).
- Resources and tools to support researchers in preparing their data for submission into the provincial research data storage solution, including robust metadata and codebooks to assist others in assessing the data for reuse.
- Consistent practices and procedures for storage, access, curation, and preservation of the research data within research data repositories.
- 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.
- Participation in the collaborative development of, and eventual participation in, a shared governance structure to ensure appropriate oversight for the shared digital data repository.



Oversight and Review

The Corporate Director, Research is responsible for the oversight and implementation of the RDM and is accountable to the Vice President Medicine and Quality. The Corporate Director, Research, will also oversee updates to the Strategy, which is a living document. Progress to attain the goals of this Strategy will be monitored annually to ensure continued alignment with Interior Health operational priorities and mandates.

Engagement with Indigenous Communities, Collectives and Organizations will continue into 2023 and beyond. Revisions will be made to inform and ensure this Strategy is aligned with a distinctions-based approach and its commitment to recognize the autonomy of indigenous peoples and ensure that possession of Indigenous data is respectfully permitted by the relevant authority as defined by the specific communities involved for all research conducted within Interior Health.



Definitions

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

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

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



Acknowledgements

The collaboration, commitment and efforts of the following individuals are gratefully noted and appreciated.

British Columbia

- Cindy Trytten, Director, Research
- Elizabeth (Sarah) Bennett, Manager, Research Ethics and Compliance
- Dawn Waterhouse, Research Business Manager
- Julia Bickford, Regional Director, Research, Evaluation and Analytics, Northern Health
- Courtney Defriend, Director of Research and Knowledge Exchange, First Nations Health Authority
- Mathew Fleury, Manager, Research and Knowledge Exchange, First Nations Health Authority
- Terri Fleming, Director, Research Ethics BC
- Stephania Manusha, Director, Clinical Trials Administration, Vancouver Coastal Health
- Joleen Wright, Director, Data Release and Access Management, Vancouver Coastal Health
- Waqar Mughal, Program Director, Michael Smith Health Research BC
- Kate Keetch, Director, Research and Evaluation, Fraser Health
- Sara O'Shaughnessy, Manager, Research Ethics and Compliance, Fraser Health

Interior Health

- Deanne Taylor, Corporate Director, Research
- Holly Buhler, Manager, Research Data & Special Projects
- Dorothy Herbert, Coordinator, Research Ethics Board
- Patric Yuen, Leader, Information Privacy
- Darcy Doberstein, Manager, Strategy and Accountability
- Dan Geistlinger, Director, Data Management