# Research

## Data Management Strategy

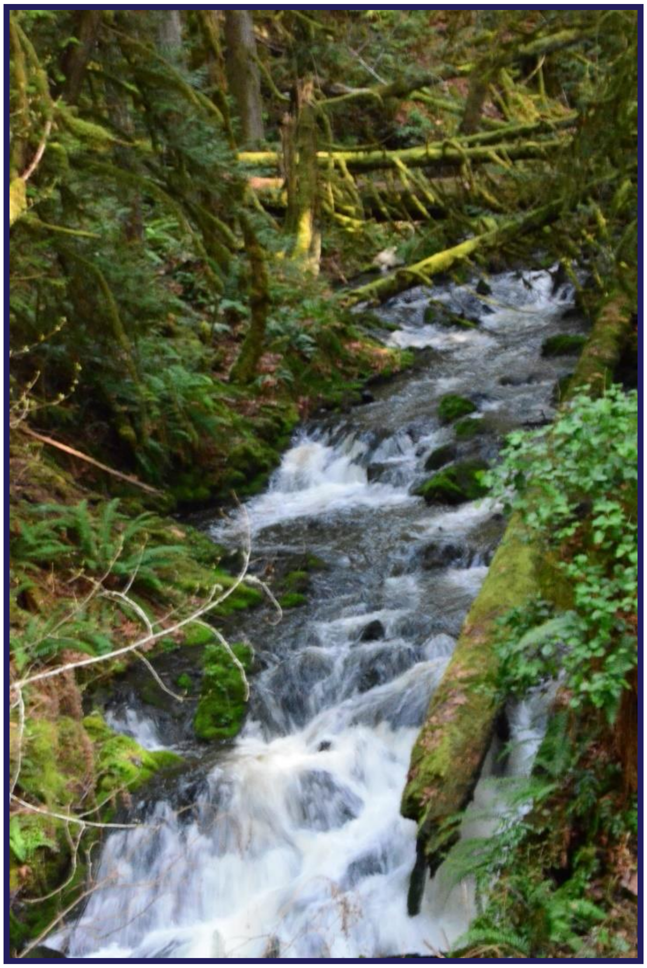
island health

***Designed by Ray MacGuire and Dale Letourneau, Island Health's Cultural Safety Logo signifies the inclusiveness of all cultures and the right of the people to receive health care services that are culturally safe***.

We recognize the ancestral homelands of the three Indigenous families on and around Vancouver Island: the Kwakawaka'wakw, Nuu-chah-nulth, and Coast Salish peoples.

We acknowledge their longstanding and ongoing stewardship of these lands and waters, which sustain life and health.

We are grateful to live and work here, and value the opportunity to partner with Indigenous peoples to build relationships and enable the eight Truth and Reconciliation Commission recommendations for health.[1]



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[1] Truth and Reconciliation Commission of Canada – Calls to Action 18 – 24 and 55 iv.

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# Introduction/Background

Data is the foundation of health research, and health research provides evidence that enables the innovation necessary to optimize health care services, health policies and outcomes. Health research is an *integral and essential part* of a reliable health system and separate from it. Island Health's 2020 to 2025 Strategic Framework recognizes the importance of research through goal 3.2:

> *Island Health will drive innovation and research to improve outcomes for people, care teams and communities. We will encourage teams to be innovative by partnering internally and externally, unleashing creativity and taking risks to generate new ideas and evidence that are then translated into required solutions. Teams, including patients and families, will work together to co-create new knowledge and solutions, making us a leading Canadian health organization.*

Island Health's Research Data Management (RDM) Strategy is an enabler of this objective, a roadmap to build health research capacity by making data more available, accessible, interoperable, and reusable over a multi-year horizon. This RDM Strategy is designed to foster a culture that supports researchers in understanding and adopting responsible and respectful RDM practices in the collection, protection, use, and management of data records and information. This includes recognizing the distinct communities and autonomy of Indigenous peoples[2], and that any access/possession of their data must be sought from and permitted by the relevant authority as defined by the specific communities involved.

This Strategy complies with the 2018 Canadian Tri-Agencies Research Data Management Policy. The resources and templates provided in the Portage Portal, and the Digital Research Alliance of Canada, have guided the work, from raising awareness, recruiting the development teams, assessing the current state of readiness, and planning.

This Strategy was developed in collaboration with internal and external partners. Diverse Island Health collaborators and contributors include leaders and knowledge area experts in Research Operations, Research Ethics, Enterprise Data Management, Applied Health Data Analytics, Information and Privacy Stewardship, Health Information Management, Indigenous Health and Equity, Diversity and Inclusion and the Information Governance Council. At the provincial level, the five regional health authorities in British Columbia and the First Nations Health Authority[3] collaborated to align strategies where possible with the support of Michael Smith Health Research BC and the BC Ministry of Health. The Strategy was also reviewed by a leader within the BC Network Environment for Indigenous Health Research who provided invaluable and appreciated input. This approach enabled leveraging of resources, ideas and approaches to betterment of the health research ecosystem in BC.

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[2] "Indigenous" is inclusive of First Nations, Métis and Inuit peoples.

[3] FNHA has a Research Affiliation Agreement with Simon Fraser University and are therefore adhering to their Strategy.

This Strategy will be used by researchers to understand the status of policies, principles, processes, and educational supports for research data management. It will also be used by Island Health leaders to guide the allocation of resources and infrastructure over time to address our objectives and goals.

There are seven goals in this Strategy; each is described in its own section with context and desired outcomes and accountabilities over a five-year horizon. All goals incorporate the essential consideration of Indigenous peoples' data governance, including but not limited to the principles of ownership, control, access, and possession. 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.

*Island Health's existing organizational supports for Research Data Management include: i) institutional policies and procedures that are inclusive of research but not specific to it; ii) a mandatory requirement to describe the details of the data management plan (DMP) for each study in both the research ethics application and the operational review application, and iii) access to data management options such as REDCap, a flexible, secure on-line tool with appropriate operational policies and user agreements. Institutional approval to conduct research is dependent on DMPs complying with the Tri-Council Policy Statement 2 (TCPS2), all applicable policies and legislation, and the terms and conditions of agreements.*

*The processes and tools created under this goal will strive to embed a distinction-based approach ensuring that the unique rights, interests and circumstances of Indigenous peoples are duly incorporated. This includes compliance with the HSO Cultural Safety Standard, United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), and British Columbia's Declaration on the Rights of Indigenous Peoples Act (DRIPA) and OCAP® (Ownership, Control, Access and Possession) applied to all stages of the data management cycle in a research project.*

**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 for better care and outcomes for Indigenous peoples, patients, families and the public.
- Engagement with Indigenous Community members to further inform the Strategy's ongoing alignment with Indigenous values and data governance principals and interests.
- New tools and templates for researchers to incorporate good data management approaches into research studies consistent with regulatory, ethical, cultural and contractual requirements and better alignment with Island Health's internal data access and disclosure processes.
- Expanded access to training through provincial and national collaboration specific to the needs of new and established researchers, including equity, diversity and inclusion considerations related to data.

**ACCOUNTABILITY**:

- Primary: Research Department
- Collaborators: Indigenous Health and Equity, Diversity and Inclusion; Information Stewardship and Privacy; Decision Support; Health Information Management; Research Ethics and Compliance
- External Collaborators: BC Regional Health Authorities and the First Nations Health Authority

# Goal 2:

## TO SUPPORT ETHICAL INTEGRITY AND COMPLIANCE OF THE RESEARCH DATA MANAGEMENT PROCESS.

*Island Health's research review process currently supports the review and approval of research projects based on compliance with all applicable ethical frameworks, policies, regulatory and legal requirements. They are compliant with the requirements outlined by the Tri-Agency agreement. Understanding ethical obligations related to sensitive data, cultural data, and intellectual property are key components in developing this goal. The research ethics office will provide support and guidance for researchers working in this area. These processes will ensure that Indigenous engagement and autonomous approvals are adhere to a distinctions-based approach.*

*This goal seeks to standardize, support and embed ethical integrity and compliance into DMPs and processes.*

**DESIRED OUTCOMES**

- With the exception of the distinction-based approach for Indigenous research data, all research conducted in Island Health using data from that institution employs standardized data management practices that enable collaboration, where appropriate.
- Data management practices with tools, frameworks and pathways that encourage researchers to demonstrate discipline-specific expertise around these practices.
- Researchers able to develop 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.
- Utilization of existing distinction-based frameworks such as those on BC's Network Environment for Indigenous Health Research's web site.

**ACCOUNTABILITY**:

- Primary: Research Ethics and Compliance Unit (Research Department)
- Collaborators: Indigenous Health and Equity, Diversity and Inclusion, Information Stewardship and Privacy

# Goal 3:

## ENSURE THAT THE ISLAND HEALTH META-DATA MANAGEMENT STRATEGY FULLY SUPPORTS RESEARCH DATA ACCESS NEEDS

*Island Health's Decision Support team currently enables researchers to access a data request process that accommodates and considers support for research, quality improvement, innovation, corporate planning and evaluation purposes. For research, part of the operational review process requires assurance that Island Health has the data requested and has the resources available to support the data provision. Research data requests are reviewed/supported by a number of Decision Support Analysts. Meta-data management is the process of identifying and describing our data holdings such that we know in detail what they represent, where they are located and how to access them. Island Health is investing in enhanced meta-data management infrastructure and processes and will incorporate research requirements in to the design and build.*

**DESIRED OUTCOMES**

- Improved clarity and understanding of use of Island Health data holdings for the Research Community
- Optimizations to the speed of facilitation of data access requests

**ACCOUNTABILITY**:

- Primary: Decision Support
- Collaborators: Applied Health Data Analytics, Innovation, Analytics and Information, Research

# 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-Agencies Research Data Management 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 meta-data tables and codebooks. The process of storing and accessing the data will be developed in a collaborative and inclusive manner.* ***Reusability will be enhanced by the use of FAIR Data Principles.*** *Where Indigenous data is considered, by engaging with Indigenous Communities, Collectives, and Organizations (ICCOs) of British Columbia and 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 or Indigenous community storage solutions are inappropriate or unavailable for use. Design of the solution must take into consideration the data sovereignty requirements of Indigenous communities (i.e., following OCAP® principles, CARE principles).
- Availability of consistent resources and supports to support researchers to prepare their data for submission into the provincial research data storage solution, including robust meta-data and codebooks to assist others in assessing the data for reuse in alignment with FAIR Data Principles.
- Establish 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.
- Develop a shared governance structure to ensure appropriate oversight for the shared digital data repository.

**ACCOUNTABILITY**:

- Primary: Michael Smith Health Research BC
- Collaborators: Island Health Research Department, Decision Support

# Goal 5:

## TO ENHANCE REPORTING AND INTERPRETATION OF RESEARCH RESULTS

*Island Health's research community uses a variety of data collection and reporting tools. These may be accessed by different people or programs in different environments and they prove different levels of integration – from source data to analysis to reporting. REDCap™ is a preferred end-to-end solution providing a secure and powerful data acquisition and management tool. REDCap™ also supplies reporting functionalities to support the querying and organization of data. Current reporting capacity helps enable multiple RDM functions, from data quality through study progression to graphs and tables of the results.*

*This goal predominantly builds on existing capacity to further advance and empower the analytic reporting capacity of REDCap™, including leveraging the international REDCap™ consortium. In addition, opportunities to assess and potentially adopt other tools to complement REDCap™, in particular in collaboration with partners, will be explored under this goal. Most notably, integration with the Island Health Innovation Data Lab (IDL) will support integration of REDCap™ into a broader data access/analysis ecology. That integration will also strengthen the capacity of REDCap™ to support linkage of data coming in via REDCap™ from external researchers with large volumes of Island Health data, where the IDL can provide a full range of technical and administrative supports for that integration.*

### DESIRED OUTCOMES:

- Development of enhanced and innovative tools and processes to support analysis and knowledge exchange.
- Improved accessibility, usability and interactivity of advanced visualization tools.
- Increased efficiency in sharing research results
- Enabled integration of data linked, analyzed and reported from REDCap™ to the IDL

### ACCOUNTABILITY:

- Primary: Research Informatics and Statistics Unit (Research); Innovation Data Lab
- Collaborators: Applied Health Data Analytics, Innovation, Analytics and Information

# Goal 6:

## DEVELOP A DATA DISCLOSURE PARTNERSHIP ENVIRONMENT

*This goal targets the development of processes and environments as necessary to support supplying disclosure and delivery of Island Health-derived data to non-Island Health collaborators and partners in a manner compliant with policy and legislation to which Island Health is subject.*

*With regard to Island Health data holdings, this goal will be achieved via phased development of a service that supports both routine operational access and project based access for non-Island Health data collaborators and customers to Island Health data holdings. The service will entail a combination of access, control and support processes for customers, environments and technology to support disclosure and access to the data.*

*The environments may be Island Health hosted or accessed through Island Health provincial and federal partners such as Health Data Platform BC and the Digital Research Alliance of Canada.*

DESIRED OUCOMES:

- A streamlined process for third parties and Island Health data projects involving third party access Island Health data holdings.
- Effective interoperation of data access/analytical/reporting environments inside and outside the Island Health firewall.
- Broadened range of data contents that are routinely and readily accessible by Island Health researchers and partners from the external community.
- Reduced need for Island Health to import and maintain data assets that can be accessed in other environments.
- Make best possible use of external environments that can supply substantially augmented computational capacity.
- Continue and build on existing partnerships.

### **ACCOUNTABILITY**:

- Primary: Innovation, Analytics and Information
- Collaborators: Applied Health Data Analytics, Decision Support

# Goal 7:

## BUILD SUSTAINABLE OPERATIONAL CAPACITY TO ATTAIN AND MAINTAIN THE STRATEGY'S OUTPUTS

*This goal addresses the operational considerations of sustaining the Research Data Management Strategy.*

*All of the desired outcome goals in the RDMS require ongoing review and maintenance to remain relevant and useful. Furthermore, a minimum viable capacity is required to deliver its goals and support ongoing change and quality management.*

**DESIRED OUTCOMES:**

- The minimum or better human resource complement required to support the ongoing sustainment of the targeted RDMS outcomes is put in place.
- That sustainable funding is allocated, within the specific areas accountable, to sustain the projected cost of ongoing expenses required to maintain service.
- RDM services that are reliable and consistent, able to support both initiatives with relatively short turn-around times as well as those with multi-year time horizons.
- The supports and services addressed in the RDMS goals are responsive and able to provide consistent service levels while also adapting to changes in the broader environment that drive new or modified requirements.

### **ACCOUNTABILITY**:

- Research/Decision Support/Innovation, Analytics and Information/ Applied Health Data Analytics

# Oversight and Review

The Director, Research is responsible for the oversight and implementation of the RDM accountable to the Vice President, Practice, Quality, Research and Chief Nurse & Allied Health Officer and the Vice President Medicine, Quality and Research and Chief Medical Officer. The Director, Research, will also oversee updates to the Strategy, which is a living document designed to be updated over time.

Engagement with Indigenous Communities, Collectives and Organizations will continue into 2023 and beyond, with revisions made to inform and ensure this Strategy is aligned with a distinctions-based approach, 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 at Island Health.

Leaders within Research, Innovation, Analytics and Information, Applied Health Data Analytics, Decision Support and Privacy and Information Stewardship are accountable for deploying the necessary resources and infrastructure for goals they are accountable for into their operational planning processes. They will report progress to the senior leaders in their respective areas. In addition, progress made to address all goals in this Strategy will be incorporated into an annual report to the accountable VPs.

An annual progress report will be shared with the Island Health Information Governance Council from the time of its approval. Specific areas of concern during its implementation may be brought forward for consultation purposes on an ad hoc basis to ensure continuous progress.

**Signed:**

Cindy Trytten Digitally signed by Cindy Trytten
Date: 2023.02.27 08:31:38 -08'00'

**Cindy Trytten**
**Director, Research**
**Island Health**

# Definitions

**CARE** Principles for Indigenous Data Governance – Collective benefit, Authority to Control, Responsibility and Ethics[4]

**Distinctions-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 these distinct Peoples with unique cultures, histories, rights, laws, and governments.

**DRIPA - Declaration on the Rights of Indigenous Peoples Act (Declaration Act), BC**

**DMP** – Data Management Plan

**EDI** – Equity, Diversity and Inclusion

**FAIR** – Findable, Accessible, Interoperable, and Reusable[5]

**HSO** – Health Standards Organization

**OCAP –** Ownership Control Access and 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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[4] https://static1.squarespace.com/static/5d3799de845604000199cd24/t/6397b1aff7a6fb54defdf687/1670885815820/dsj-1158_carroll.pdf

[5] https://www.nature.com/articles/sdata201618

# Acknowledgements

The collaboration, commitment and efforts of the following individuals are gratefully noted and appreciated. Their shared desire to create a stronger and better data ecosystem for health research at Island Health and in BC will benefit the health and wellness of the Indigenous peoples, patients, families, and communities that we serve.

**Island Health**
Bindy Bains, Director, Health Information Management
E. Sarah Bennett, Manager, Research Ethics and Compliance
Susannah Campbell, Regional Manager, Records Management and Transcription
Donna Conway, Executive Director, Decision Support
Victor Espinosa, Manager, Research Informatics and Statistics
Kathleen Harris, Manager, Cultural Safety, Indigenous Health, Equity, Diversity and Inclusion
Dr. Ken Moselle, Director, Applied Health Data Analytics
Simon Munn, Research Privacy Specialist
Graham Payette, Corporate Director, Innovation, Innovative Analytics and Information
Dr. Diane Sawchuck, Lead, Evidence, Evaluation and Knowledge Translation
Cindy Trytten, Director, Research
Dr. Dawn Waterhouse, Research Business Manager

**British Columbia**
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Holly Buhler, Regional Practice Lead, Interior Health
Courtney Defriend, Director of Research and Knowledge Exchange, First Nations Health Authority
Tara Erb, Network Coordinator, BC Network Environment for Indigenous Health Research
Mathew Fleury, Manager, Research and Knowledge Exchange, First Nations Health Authority
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