

# **Bruyère Health**

## and

# **Bruyère Health Research Institute**

**Research Data Management** 

**Institutional Strategy** 

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(branding update: October 25, 2024)

## **INTRODUCTION**

Research data is a major research asset that is foundational to the advancement of knowledge. Across the Canadian and international research landscape, there is increasing recognition of the need for sound data stewardship practices to be applied to research activities taking place at research institutions and universities. Well-managed data contributes to research excellence by promoting reach, reducing burden on research participants, minimizing risk to projects, improving research efficiency, and increasing the impact and relevance of activities through sharing of data and outputs of research projects.

The global movement towards open access to publicly funded research, including public access to research data and publications, has seen the development of new and evolving governmental and nongovernmental compliance requirements for funded research<sup>1</sup>. In March 2021, the Tri-Agencies, collectively the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC), issued the <u>Tri-Agency Research Data Management Policy</u> to position Research Data Management (RDM) as an essential part of research excellence by ensuring that research is performed ethically, in compliance with applicable privacy and access laws, and makes good use of public funds. The objectives of the policy require that all institutions eligible to receive Tri-Agency funding, including hospital-based research institutions, comply with three requirements:

- 1. **Institutional RDM Strategies**: The development and public posting of an institutional strategy for RDM by March 1, 2023;
- 2. **Data Management Plans:** The preparation of data management plans for all grant applications, starting with specified fall 2022 funding calls; and
- 3. **Data deposit:** The deposit of research data into a digital repository, to be phased in over time as the Canadian research community readies itself. There is no current timeframe or sign that this will be mandatory.

As defined in the Tri-Agency *Framework: Responsible Conduct of Research (2021)*, it is the collective responsibility of all members of the research community to promote a culture of high integrity standards in research activities, to ensure responsible conduct of research, and to abide by applicable laws for the conduct of research and research sponsors' policies and/or requirements<sup>2</sup>.

Bruyère Health and the Bruyère Health Research Institute (Research Institute) recognize their responsibilities to provide an environment that supports and promotes the responsible conduct of research, including supporting researchers in their efforts to establish and implement effective data management practices.

In order to respond and adapt to the changing research landscape in Canada and increasing compliance requirements for RDM, Bruyère Health and the Research Institute developed the following Research Data Management (RDM) Strategy that outlines the approach that will be taken over the next 3 to 5 years to equip our research community with the knowledge, tools and supports to improve meaningful and robust

<sup>&</sup>lt;sup>1</sup> Government of Canada 2019, Dimensions: equity, diversity and inclusion Canada, accessed {2021-02-22}, <u>http://www.nserc-crsng.gc.ca/NSERC-CRSNG/EDI-EDI/Dimensions-Charter\_Dimensions-Charter\_eng.asp</u>

<sup>&</sup>lt;sup>2</sup> Tri-Agency Framework: Responsible Conduct of Research (2021). <u>https://rcr.ethics.gc.ca/eng/framework-cadre-2021.html</u>

RDM practices. This strategy will be a living document subject to recurring evaluation, review, and revision.

#### What is RDM?

RDM is identified by Innovation, Science and Economic Development Canada as one of the four key elements of Canada's *digital research infrastructure* (DRI)<sup>3</sup>. It encompasses the processes applied throughout the lifecycle of a research project to guide the collection, documentation, formatting, secure storage, sharing, re-use, deposit and preservation of research data, and allows researchers to find and access data.

## The Research Data Lifecycle



From: RDM: The Basics presentation, Emma Scott, uLethbridge Library

RDM plays a critical role in building a modernized research system that reflects the four foundational FAIR principles of data: Findability, Accessibility, Interoperability and Reusability. While not all research data is suited to be shared broadly, for ethical, legal, or commercial reasons, adopting best practices in research data management applicable within and between research units and organizations is crucial to maintain and maximize public trust in academic research.

#### What is an RDM Strategy?

An institutional strategy helps to articulate RDM services, infrastructure, and wise practices, and to envision the future of RDM at the institution. The strategy includes actionable ways to:

- Learn about research data management;
- Plan to meet grant and data preservation requirements;
- Deposit data to be shared with the world; and
- Find existing data sets.

## CONTEXT

#### About Bruyère Health and the Research Institute

Bruyère Health plays a unique role in the region's health care system, providing specialized hospital care, primary care, long-term care, and assisted and independent living for seniors. As Bruyère Health's research arm, the Research Institute aims to improve the experience of human aging by finding new ways to maximize quality of life and better support individuals and caregivers. The Research Institute uses a "research and innovation to clinical integration" philosophy by conducting rigorous, peer-reviewed research and developing and testing new technology that is then mobilized to help people live safely, be mobile and independent. Research Institute's research endeavors and strengths are in aging in place and

<sup>&</sup>lt;sup>3</sup> https://ised-isde.canada.ca/site/digital-research-infrastructure/en

LTC, rehabilitation, primary, palliative, and medically complex care. As an organization committed to world-class research, we recognize the value of developing and fostering rigorous research data management practices.

The Research InstituteI is growing, and research spending is increasing. Bruyère Health is currently number 39 on the Research Infosource's Top 40 Research Hospitals in Canada list<sup>4</sup>. Our research intensity per investigator is number 7 in the small hospital category<sup>5</sup>.

Our existing RDM capacity is limited to the training researchers and staff receive throughout their formal and continuing education, and through regulated training such as the Tri-Council Policy Statement: Ethical Conduct for Research involving Humans (TCPS2), Good Clinical Practice, Responsible Conduct of Research, Health Canada Division 5, and ongoing checks and balances around data security, privacy, etc. put in place by the Bruyère Health Research Ethics Board and our Bruyère Health Privacy Office.

#### **RDM Strategy Advisory Group**

A Bruyère Health RDM Strategy Advisory Group was formed to ensure appropriate representation across Bruyère Health and the Research Institute in the development of the strategy. The Advisory Group includes representation from leadership/management, researchers, the Research Ethics Board, library services, IT services, the Privacy Office, risk management, and others as appropriate. The RDM Terms of Reference are included as Appendix A.

#### **Regional Consultations and Collaboration**

In developing this strategy, the Research Institute participated in a Regional RDM Group including key stakeholders involved in preparing their institutional RDM strategies from uOttawa, Carleton University, and other Ottawa-based RIs (Ottawa Hospital Research Institute - OHRI, CHEO, uOttawa Heart Institute, The Royal, Montfort and Bruyère Health Research Institute) to share information, learnings and documentation and to look at phased in ways to collaborate to streamline and create consistencies around the RDM strategy and associated tools and resources.

#### Methodology to Developing the RDM Strategy

As a small institution with limited resources, and multiple researchers working across different institutions, the approach to developing the RDM strategy included:

- Aligning, as much as possible, the strategy vision, principles and goals with regional partners;
- Accounting, where possible, for Bruyère Health context while keeping the strategy broad enough to address data management needs of multiple and varying stakeholders. The Bruyère Health RDM survey results were used to provide this context (see next section); and
- Utilizing existing resources, including those offered by the Digital Research Alliance of Canada and Portage, as much as possible to ensure reduced duplication of effort.

#### Bruyère Health Current State and Institutional Readiness – RDM Survey Results

A survey was sent to all Research Institute investigators and team members to be completed in September 2022. In total, 32 responses were received, with representation from research teams across the Research Institute. Respondents included 19 researchers, 10 staff members and 3 students (or those marked other). Of these, 26 people or 81% of respondents are involved in handling research data.

<sup>&</sup>lt;sup>4</sup> https://researchinfosource.com/top-40-research-hospitals/2022/list

<sup>&</sup>lt;sup>5</sup> https://researchinfosource.com/top-40-research-hospitals/2022

The survey findings included:

- 1. Most common data sensitivities:
  - Personal health information
  - Personally identifiable information
  - Sensitive Information
- 2. Storage Needs
  - Almost 40% do not know how much data they use
  - Over 20% use between 500 GB and 4TB
  - Almost half expect increased storage needs
  - Need for Back-ups (although the majority who do not create back-ups themselves save to institutional servers which are backed up daily)
- 3. Barriers
  - Lack of time (9/26 respondents) this is interpreted to mean that researchers need support to easily access education, training and tools that are relevant to their discipline and needs.

#### Top High-Level Concerns to be Addressed:

- 1. Need to clarify the benefits of RDM and RD sharing
- 2. Need to develop SOPs, policies, procedures and best practices
- 3. RDM education needed, via access to:
  - **online/virtual training** on subjects such as managing and sharing data, how to create a Data Management plan; and
  - $\circ$  personal consultations.
- 4. Avoid duplication of effort e.g., the Bruyère Health REB already requires and vets information on data storage locations.

## **SCOPE**

The RDM Strategy is relevant to all Bruyère Health researchers and their teams including research students/trainees, staff, volunteers and is supported by the Research Institute corporate team. The strategy also supports organizational and regulatory requirements such as privacy, confidentiality, ethics processes, data (including health data) security, etc.

This strategy and any changes to it will be posted on the Bruyere.org website under the Research section along with tools and other resources, including those offered by other organizations.

Appendix B includes definitions and terms used throughout this document and other guiding information relevant to RDM. Appendix C includes links to policies and resources available to support Bruyère Health's RDM strategy.

## **BRUYÈRE HEALTH'S RDM STRATEGY**

#### Vision

Bruyère Health and the Bruyère Health Research Institute are committed to fostering excellence in research data management.

This vision will be achieved through the development or adoption of tools, supports and guidance and through leveraging stakeholder relationships to educate and enable researchers to share and manage research data to the highest standards across the research data lifecycle.

#### **Guiding Principles**

The Bruyère Health RDM Strategy is developed with the following guiding principles front of mind:

- **Research Excellence** Advance impactful RDM practices as an integral part of cultivating research excellence.
- **Researcher-oriented** Support all researchers towards the adoption of RDM practices by developing or leveraging the best possible services and tools and through reducing barriers throughout the research data lifecycle.
- Context-based or Distinction-based Approach Promote flexibility and adaptability, recognizing
  that different research domains have different needs: ensuring the rights, interests, and
  circumstances of the individuals we do research with are respected, including participation from
  underrepresented groups (e.g., Women, persons with disabilities, Indigenous Peoples\*, racialized
  minorities, individuals from the LGBTQ2+ community).

\*Bruyère Health's RDM strategy recognizes that research data created by and with First Nations, Metis and Inuit communities and organizations are managed according to research data management principles developed and approved by these communities and organizations, using principles such as OCAP<sup>6</sup>, OCAS<sup>78</sup>, Inuit Qaujimajatuqangit<sup>9</sup>, USAI Research Framework<sup>10</sup>, and CARE<sup>11</sup>.

#### **RDM Goals**

#### **Goal 1: Foster a culture of RDM-wise practices**

- Take a research-centred approach to promote wise practices around data management planning and data deposit, including permitted uses, preservation and disposal. This:
  - Includes the principle that research results should be made as open as possible, and as closed as necessary, to facilitate access and reuse;

<sup>8</sup> CIHI. A Path Forward: Toward Respectful Governance of First Nations, Inuit, and Metis Data Housed at CIHI. https://www.cihi.ca/sites/default/files/document/path-toward-respectful-governance-fnim-2020-report-en.pdf

<sup>9</sup> Indigenous Innovation Initiative. *Indigenous Knowledges & Data Governance Protocol*. <u>https://indigenousinnovate.org/downloads/indigenous-knowledges-and-data-governance-protocol\_may-2021.pdf</u>

<sup>10</sup> Indigenous Innovation Initiative. *Indigenous Knowledges & Data Governance Protocol*. <u>https://indigenousinnovate.org/downloads/indigenous-knowledges-and-data-governance-protocol\_may-2021.pdf</u>

<sup>11</sup> Research Data Alliance International Indigenous Data Sovereignty Interest Group. (September 2019). *CARE Principles for Indigenous Data Governance*. The Global Indigenous Data Alliance. <u>www.gida-global.org/care</u>

<sup>&</sup>lt;sup>6</sup> OCAP• is a registered trademark of the First Nations Information Governance Centre (FNIGC). <u>https://fnigc.ca/ocap-training/</u>

<sup>&</sup>lt;sup>7</sup> Indigenous Innovation Initiative. *Indigenous Knowledges & Data Governance Protocol*. <u>https://indigenousinnovate.org/downloads/indigenous-knowledges-and-data-governance-protocol may-2021.pdf</u>

- Requires a commitment to the inclusive use of data management practices that strive to make data Findable, Accessible, Interoperable and Reusable (FAIR Guiding Principles).
- Acknowledge that Indigenous Peoples have the right to control the collection, ownership and application of Indigenous data and encourage the use of data management practices, such as the OCAP and CARE principles, to support data sovereignty.

#### Strategies:

- Provide a forum for feedback to advance RDM efforts at the Research Institute
- Facilitate domain-specific opportunities for collaboration (e.g., communities of practice)
- Facilitate access to data management experts for Bruyère Health researchers
- Promote access to video series to provide information on RDM-wise practices
- Evaluate RDM practices and knowledge to determine areas for improvement
- Develop a roadmap to guide and build capacity for RDM over the next 3-5 years

Goal 2: Improve communication, support, training and access to tools, resources, infrastructure, services (Engage in awareness-raising activities)

- Expand RDM training opportunities, in collaboration with other stakeholders where appropriate;
- Provide access to a range of clear and accessible tools, technologies, and support services to meet the needs of researchers throughout the research data life cycle.

#### Strategies:

- Create an RDM resource hub on the bruyere.org website, research section
- Develop and/or promote webinars and training sessions to educate and empower researchers and teams to adopt robust RDM practices
- Promote a holistic view of data management processes across the data life cycle
- Leverage existing networks of research data management experts
- Promote existing tools and resources, such as Portage and the Digital Research Alliance of Canada tools and resources (e.g., the <u>DMP Assistant</u> tool)
- Provide or support access to and training for software, mechanisms and services for reliable and secure storage, backup, registration, deposit (repositories or other platforms) and retention of research data assets in support of current and future access, during and after completion of research projects
- Review, and if required, revise Agreements to ensure clear and comprehensive requirements around ownership and sharing of project data, privacy and information security, and applicable laws and regulations

#### Goal 3: Support organizational capacity including through collaboration with other stakeholders

• Support respectful and mutually beneficial research relations with Ottawa Academic partners, government, not-for-profits, community-based actors and the private sector.

#### Strategies:

- Collaborate with Regional RDM group to share and streamline tools, technologies and service supports
- Respect the use of diverse approaches reflective of various disciplines, research activities and projects

#### **Goal 4: Strengthen RDM Governance**

• Formalize structures and supports to oversee compliance, revision, and implementation of the strategy and associated supports.

#### Strategies:

Maintain the RDM advisory committee to:

- Ensure ongoing compliance with the Research Institute, REB, Bruyère Health policies and procedures, applicable laws and regulations
- Propose revisions/updates to current or new RDM-related policies/processes, tools and resources
- Incorporate sound RDM practices into investigator appointment and renewal documentation
- Ensure equitably, diverse and inclusive representation in RDM-related roles

Spring 2022	Summer 2022	Fall 2022	Winter 2022
<ul> <li>Form advisory group with TOR</li> <li>Regional consultations</li> </ul>			
	<ul> <li>Gather RDM plan templates</li> <li>Confirm support from Carleton/uOttawa reps</li> <li>Continue regional consultations to promote regional solution</li> </ul>		
		<ul> <li>Draft and release</li> <li>Analyze RDM surv</li> <li>Draft institutional</li> <li>Seek feedback/mastrategy from Brucommunity</li> </ul>	RDM survey vey responses RDM strategy ake revisions on draft RDM yère Health research
			<ul> <li>March 1 – publicly release RDM strategy</li> <li>Prepare for development of new and modifications to current policies, procedures, and tools to implement RDMS</li> </ul>

## BRUYÈRE and BRUYÈRE RI ACTION STEPS AND TIMELINES

#### **SUMMARY**

Research data is a major research asset and an important research output. Supporting researchers and their teams to establish and implement comprehensive data management practices is imperative to ensure compliance with ethical, legal, commercial and tri-agency requirements. Through the RDM survey conducted at Bruyère Health, the Bruyère Health RDM Advisory Group recognizes that we already have sound practices in place, however, we must continue to build on these and to expand our practices to include external sharing of data in appropriate and secure ways.

This strategy is considered a working document and represents the first of three phases of work that will take place over the next three to five years. The strategy may evolve over time as we move into phases two and three and support our researchers to create data management plans with their funding applications and make their data more accessible to the research community.

Appendix A



# **RESEARCH DATA MANAGEMENT ADVISORY GROUP**

**DRAFT Terms of Reference** September 2022

(logo and branding update: October 25, 2024)

Revised with thanks from the University of Ottawa RDM Strategy Working Group TOR

## **Background and Overview**

In Canada, there is increasing recognition of the need for sound data stewardship practices to be applied to research activities taking place at research institutions and universities. Well-managed by-products and outputs of research activities enable researchers to minimize risk to their projects, improve research efficiency, and increase the impact of their activities through sharing of data and outputs of research projects.

The global movement towards open access to publicly funded research, including public access to research data and publications, has seen the development of new and evolving governmental and non-governmental compliance requirements for funded research<sup>12</sup>.

In order to respond and adapt to the changing research landscape in Canada and increasing compliance requirements for RDM, Bruyère Health Research Institute has created the Research Data Management (RDM) Advisory Group to focus on enterprise strategies, policies, regulations, and tools that relate to research data.

This document provides the terms of reference and the organizational structure related to the Research Data Management (RDM) Advisory Group at the Research Institute.

## Mandate

The purpose of the RDM Advisory Group is to foster excellence in the management of research data at the Research Institute. The RDM Advisory Group's primary mandate is to make relevant and timely recommendations, to create and stimulate the critical dialogue that will lead to better and more informed decisions; and to increase the transparency and the level of collaboration between the Research Institute research community, relevant Bruyère Health units, and other research partners.

The RDM Advisory Group will provide recommendations on the development of services and infrastructure that will respond to researcher needs and will help to better position Bruyère Health and the Research Institute to respond to policy requirements. Notably, the Tri-Agency Research Data Management Policy requires that each institution administering tri-agency funds create an institutional research data management strategy. The Advisory Group will serve as a focal point within Bruyère Health and the Research Institute to coordinate, communicate and provide input on the development of services and tools, which will underpin elements of Bruyère Health's RDM institutional strategy.

In all aspects of its work, the RDM Advisory Group recognizes that the voices of researchers are critically important and that the needs of researchers are diverse and ever-changing. Ensuring that researchers have access to the tools, support and resources needed to manage their research data effectively is at the heart of the Advisory Group's mandate.

## **Specific Objectives**

In practice, this responsibility is carried out by performing the following functions:

a) Preparing a draft institutional RDM strategy for review, adoption, and implementation by the Bruyère Health research community;

<sup>&</sup>lt;sup>12</sup> Government of Canada 2019, Dimensions: equity, diversity and inclusion Canada, accessed {2021-02-22}, http://www.nserc-crsng.gc.ca/NSERC-CRSNG/EDI-EDI/Dimensions-Charter\_Dimensions-Charte\_eng.asp

- b) Developing a strategy to communicate and raise awareness about the benefits and best practices for good research data management;
- c) Assessing institutional readiness through a survey of data management practices and requirements by Research Institute researchers and teams;
- d) Formalizing RDM practices by promoting the development of guidelines, procedures and policies through consultation and engagement with the research community;
- e) Proposing a roadmap and timelines for institutional capacity building;
- f) Making recommendations to the Bruyère Health Senior Strategy Team for the development of services and infrastructure and other investments in strategic RDM issues;
- g) Staying abreast of the evolving landscape of RDM and digital research infrastructure, including collaborating with the uOttawa, other Ottawa-based RIs and the Digital Research Alliance of Canada to share best practices, streamline policies and processes, and share resources where appropriate.

## Membership

The Advisory Group's membership is representative of the RDM stakeholder community at Bruyère Health and the Research Institute. The Advisory Group consists of seven to eleven members, including the Co-Chairs. Composition of the Advisory Group shall include broad representation of researchers and administration and ensure the Advisory Group's capacity for strategic planning, engagement with IT and researchers, stakeholder relations, ethical and legal expertise, and technical knowledge.

Advisory Group membership consists of:

- CEO and Chief Scientific Officer of the Research Institute (Co-Chair)
- IS/IT Corporate Advisor (Co-Chair)
- 2 -3 researchers with a senior investigator or investigator appointment, preferably at least one clinician investigator and one researcher with advanced knowledge of equity, diversity and inclusion practices and principles
- 1-2 trainees at the PhD or post doc level
- A representative from risk management (also representing libraries)
- A representative from the Privacy Office
- The Chair and/or Manager of the Bruyère Health Research Ethics office
- Additional stakeholders invited by Co-Chairs
- Research Institute Senior Director of Operations (secretariat)
- Research Institute Research Operations Manager (secretariat)

The Advisory Group will consult with and engage the participation of key stakeholders and others as appropriate.

## Meetings

- In 2022-23, the Group is expected to meet frequently, to prepare a proposed Institutional Strategy. Once the Institutional Strategy is in place, the Group expects to meet bi-monthly or as required.
- The Co-Chairs are responsible for maintaining the agenda, minutes, and action items, with support from the secretariat.
- Members shall not delegate their responsibilities to someone else without prior consent from the Co-Chairs.

## Quorum

To have quorum for decision-making, a minimum attendance is required of:

- At least one of the co-Chairs; and
- At least 50% of the membership.

If meetings are held in person, arrangements will be made to allow members to participate by electronic means or by telephone as appropriate.

## **Reporting and Communication**

The RDM Advisory Group reports to the Bruyère Health Senior Strategy Team (SST).

The Advisory Group is expected to engage in broad consultations and to seek input and collaboration from researchers and other members of the RDM community locally and nationally. The Advisory Group may establish working groups as appropriate. Advisory Group members are encouraged to participate in other discussions at the local, national, or international level in order to further the goal of promoting excellence in the management of research data.

The Advisory Group will abide by all applicable Bruyère Health policies and regulations.

## Periodic Review of Mandate and Terms of Reference

From time to time, at a minimum of every two years, the Advisory Group shall review its Terms of Reference and decide whether it recommends that the Terms of Reference and Mandate continue or be subject to modification. The Terms of Reference may be modified, or the Advisory Group dissolved with the agreement of the Co-Chairs.

## Appendix B

#### DEFINITIONS and GUIDING INFORMATION

**Community of Practice (CoP)** - refers to a group of people who share a common concern, a set of problems, or an interest in a topic and who come together to fulfill both individual and group goals. CoP often focuses on sharing best practices and creating new knowledge with ongoing interactions in meetings or collaborative platforms to communicate, connect and conduct community activities. (https://www.communityofpractice.ca/background/what-is-a-community-of-practice/)

**Confidential Information** - information protected due to proprietary, ethical, or privacy considerations. This classification applies even if there is no law requiring this protection. It includes, but is not limited to information supplied in confidence, any information covered by a non-disclosure agreement, commercially sensitive information including related financial transactions, driver's license numbers or banking information, personal information as defined in the Freedom of Information and Protection of Privacy Act (FIPPA) section 21, and personal health information as in accordance with the requirements of the Ontario Personal Health Information Protection Act (PHIPA) or equivalent applicable legislation. (uOttawa Policy 117: <a href="https://www.uottawa.ca/about-us/policies-regulations/policy-117-information-classification-and-handling">https://www.uottawa.ca/about-us/policies-regulations/policy-117-information-classification-and-handling</a>)

**Data deposit** - refers to when the research data collected as part of a research project are transferred to a research data repository. The repository should have easily accessible policies describing data deposits and user licenses, access control, preservation procedures, secure storage and backup practices, and sustainability and succession plans. The deposit of research data into appropriate repositories supports ongoing data-retention and, where appropriate, access to the data. Ideally, data deposits will include accompanying documentation, source code, software, metadata, and any supplementary materials that provide additional information about the data, including the context in which it was collected and used to inform the research project. This additional information facilitates curation, discoverability, accessibility, and reuse of the data.

(Tri-Agency Research Data Management Policy, <u>Frequently Asked Questions</u>, Government of Canada 2021. <u>https://science.gc.ca/site/science/en/interagency-research-funding/policies-and-guidelines/research-data-management/tri-agency-research-data-management-policy-frequently-asked-questions#4i)</u>

Data repositories enable researchers to safely store and share their own data and find data collected by others. Several tools exist to aid researchers in finding appropriate repositories.

- Scholars Portal Dataverse Borealis is a repository primarily for researchers affiliated with Ontario universities, though other researchers are welcome to use it to share and find data here is its guide: <a href="https://learn.scholarsportal.info/all-guides/borealis/">https://learn.scholarsportal.info/all-guides/borealis/</a>
- <u>FRDR (Federated Research Data Repository: https://www.frdr-dfdr.ca/repo/)</u> came online in 2018 it provides a national data discovery site for Canadian researchers and is capable of ingesting and preserving large file sizes.
- <u>re3data (Registry of Research Data Repositories: <u>https://www.re3data.org/</u>) is a global registry of data repositories for many academic disciplines
  </u>
- A list of recommended data repositories can be found via <u>PLOS ONE</u> (<u>https://everyone.plos.org/2015/07/02/plos-recommended-data-repositories/</u>) - many other publishers will provide lists of recommended repositories

- Simmons University maintains <u>a list of data repositories by subject area:</u> <u>https://oad.simmons.edu/oadwiki/Data repositories</u>
- Fairsharing.org site includes <u>a list of databases</u> along with policies, standards, etc.: <u>https://fairsharing.org/databases</u>
- <u>open data sites</u> including international, Canadian and local sites

Source: https://libguides.lakeheadu.ca/c.php?g=613282&p=4276405

**Data management plan** - "a living document, typically associated with an individual research project or program that consists of the practices, processes and strategies that pertain to a set of specified topics related to data management and curation. DMPs should be modified throughout the course of a research project to reflect changes in project design, methods, or other considerations. DMPs guide researchers in articulating their plans for managing data; they do not necessarily compel researchers to manage data differently" (<u>Tri-Agency Research Data Management Policy</u>, **Frequently Asked Questions**, Government of Canada 2021). RDMs should outline procedures and protocols that explicitly address data collection/capture, management, security, integrity, confidentiality, retention, deposit, destruction (when necessary), sharing and publication. Plans should be updated as necessary during any stage of the data lifecycle.

A Data Management Plan (DMP) helps a researcher document:

- What data will be collected in the research project;
- How the data will be defined, described, stored, analyzed, shared, preserved, and if necessary destroyed;
- Who is responsible for which activities;
- When are these activities done.

**Indigenous research** - "research in any field or discipline that is conducted by, grounded in or engaged with First Nations, Inuit, Métis or other Indigenous nations, communities, societies or individuals, and their wisdom, cultures, experiences or knowledge systems, as expressed in their dynamic forms, past and present" (Social Sciences and Humanities Research Council Definition of Terms, Government of Canada 2021).

**Intellectual Property** - means "all materials, concepts, know-how, formulae, inventions, improvements, industrial designs, processes, patterns, machines, manufactures, compositions of matter, compilations of information, patents and patent applications, copyrights, trade secrets, technology, technical information, software, prototypes and specifications, including any rights to apply for protections under statutory proceedings available for those purposes, provided they are capable of protection at law" (**ArticNet Data Management Policy**, ArticNet 2021, 12).

**Metadata** - describes the characteristics of other data. It enables researchers to find and use data. It includes:

- The name of the data creator(s) or collector(s)
- The date and time the data was collected
- The format the data is in
- An overview of the research project (i.e., methods, materials, participants, etc.)
- Keywords that describe the data contents
- Information about where the data is/will be stored, and who can/ how to access it
- The language the data is presented in

Because research data is so diverse, specific disciplines follow different metadata standards. The following resources are designed to help you apply the appropriate metadata to your data set, preparing it for submission to a repository.

- <u>DataONE</u> provides best practices in describing your data
- The <u>Digital Curation Centre (DCC)</u> provides information about accepted metadata standards by discipline
- The <u>Quartz guide to bad data</u> lists real-world data problems
- FAIR principles for metadata

From: https://libguides.lakeheadu.ca/c.php?g=613282&p=4265292

**Researcher** - Any individual with an academic or research appointment who is autonomous regarding their research activities (CIHR definition of independent researcher). (<u>CIHR Glossary of Funding-Related Terms</u>)

**Research Data** - data that are used as primary sources to support technical or scientific enquiry, research, scholarship, or creative practice, 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. Research data may be experimental data, observational data, operational data, third party data, public sector data, monitoring data, processed data, or repurposed data. What is considered relevant research data is often highly contextual, and determining what counts as such should be guided by disciplinary norms."

(Tri-Agency Research Data Management Policy, <u>Frequently Asked Questions</u>, Government of Canada 2021).

**Research Data Management** - "the storage of, access to, and preservation of data produced from one or more investigations, or from a program of research. Research data management practices cover the entire lifecycle of the data, from planning the investigation to conducting it, and from backing up data as it is created and used to preserving data for the long term after the research has concluded. It also includes data-sharing, where applicable"

(Social Sciences and Humanities Research Council <u>Definition of Terms</u>, Government of Canada 2021).

**Research Project** – an undertaking intended to extend knowledge through a disciplined inquiry or systematic investigation.

<u>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans - TCPS2 (2022)</u>, definition of Research

## Appendix C

### External Policies and Resources

- <u>Bill C-15: An Act respecting the United Nations Declaration on the Rights of Indigenous Peoples</u>, Government of Canada
- <u>Borealis</u> The Canadian Dataverse Repository used by uOttawa, Carleton, and other Canadian universities
- CARE Principles for Indigenous Data Governance, Global Indigenous Data Alliance
- CIHR Research Data Management Learning Module, Government of Canada
- <u>CESSDA data management guide for the social sciences</u> Written specifically for social scientists, this guide consists of these chapters: plan, organize & document, process, store, protect, archive & publish and discover.
- **Dataverse North Metadata Best Practices Guide** Lists the metadata elements in Dataverse with recommendations and examples.
- **MANTRA** Research data management training modules from the University of Edinburgh.
- From: https://libguides.lakeheadu.ca/c.php?g=613282&p=4261046
- National Inuit Strategy on Research, Inuit Tapiriit Kanatami
- Portage Network
  - **<u>DMP Assistant</u>** Provides a template for a data management plan by taking researchers through key questions related to their data.
  - Portage DMP training resources (including DMP exemplars)
- Principles of Ethical Métis Research, National Aboriginal Health Organization Métis Centre
- **Records Express** <u>Best practices for file naming (Records Express)</u> Suggestions from the Chief Records Officer at the National Archives (U.S.) for file naming conventions.
- **<u>SHERPA/JULIET</u>** -Includes funders' policies on open access to research data.
- SSHRC Research Data Archiving Policy, Government of Canada
- The First Nations Principles of OCAP, First Nations Information Governance Centre
- <u>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2)</u>, Government of Canada
- <u>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) Chapter 9</u>, Government of Canada
- Tri-Agency Framework: Responsible Conduct of Research, Government of Canada
- Tri-Agency Research Data Management Policy, Government of Canada
- Tri-Agency Statement of Principles on Digital Data Management, Government of Canada