Unity Health Toronto Research Data Management Strategy (DRAFT)   **Version 4.0**

Purpose

The Tri-Agency (CIHR, NSERC and SSHRC) adopted the Research Data Management (RDM) Policy in 2021, and it is being implemented in stages with the objective to promote RDM and data stewardship practices amongst Canadian researchers.

The Tri-Agency RDM Policy has three key stages:

1. **Institutional RDM strategies** – By March 1st, 2023, each post-secondary institution (including research hospitals) eligible to receive Tri-Agency funds, must develop and publish an institutional RDM strategy on their institution's website.

2. **Data management plans** – By spring 2022, the agencies will identify the initial set of funding opportunities subject to the DMP requirement. The agencies will pilot the DMP requirement in targeted funding opportunities before this date

3. **Data deposit** – After reviewing the published institutional RDM strategies, the agencies will phase in the data deposit requirement. Timelines for this requirement have not been finalized.

In response to the Tri-Agency's RDM Policy, Unity Health Toronto has established a RDM Steering Committee and developed a draft strategy to guide the institution on research data management practices that align with the policy and its requirements.

The purpose of the Institutional RDM Strategy is to foster a culture and develop capacity that supports researchers in adopting responsible RDM practices, following the FAIR Principles[1] to make research data **f**indable, **a**ccessible, **i**nteroperable and **r**eusable. The FAIR principles are complemented by the CARE Principles[2] for Indigenous Data Governance (with considerations for collective benefit, authority to control, responsibility, and ethics), and by the First Nations principles of OCAP[3] on ownership, control, access, and possession.

To support and encourage Unity Health's researchers to adopt the institutional strategy and enhance the use of best practices in RDM, Unity Health will engage in awareness-raising activities, RDM capacity assessment, and will optimize existing supports and offer new resources (e.g. access to RDM tools and infrastructure).

Oversight and Review

The Office of the Vice President Research and Innovation (VPRI) is responsible for overseeing the development of Unity Health's Institutional RDM Strategy. This work is guided by the RDM Steering Committee.

1. Wilkinson MD, et al. (2016). The FAIR Guiding Principles for scientific data management and data stewardship (https://doi.org/10.1038/sdata.2016.18)
2. The CARE Principles for Indigenous Data Governance – retrieved from Global Indigenous Data Alliance (https://www.gida-global.org/care)
3. The First Nations Principles of OCAP – published by First Nations Information Governance Centre (https://fnigc.ca/ocap-training/)

Guiding Principles

Unity Health is committed to providing researchers with an environment that empowers them with resources, knowledge and support to adopt best practices in RDM throughout the research data lifecycle. Unity Health is a member of the Toronto Academic Health Science Network (TAHSN), and TAHSN has established a RDM Working Group to facilitate collaboration and alignment among the TAHSN hospitals and the University of Toronto (UofT). A goal of this working group is to enable the sharing of best practices in RDM and the leveraging of expertise and resources. Through this collaborative effort, a set of guiding principles on RDM have been developed and approved. These guiding principles serve as the core standard for the TAHSN institutions in the development of their individual Institutional RDM strategies. (**Appendix 1**)

Strategy and Roadmap

Goal #1 – Increase Awareness

Objectives	Current Status	Action items	Timeline	Responsibility
1.1 - Establish an advisory group to guide RDM initiatives	An RDM Steering Committee was formed in May 2022 with members from research ethics, privacy, research legal counsel, libraries, IT, the Applied Health Research Centre (AHRC), the hospital's data governance group and the Office of Research Administration	The committee membership will be reviewed and amended from time to time, and meetings will take place regularly to review RDM strategy related work	Meetings are ongoing	VPRI Office
1.2 - Engage our research community to promote the value of RDM	Currently engagement with the Research community has consisted of sharing RDM resources and workshops and obtaining information about current RDM practices via a survey	In addition to our current efforts, we will establish a researcher advisory group to guide our researcher engagement and communication efforts as well as to act as champions for the implementation of our RDM strategy	Q2 2023	VPRI Office
1.3 - Develop awareness materials and resources				

Objectives	Current Status	Action items	Timeline	Responsibility
1.3.1 - Develop a website for RDM resources	Unity Health does not have a dedicated website that hosts RDM resources	A RDM resource website will be created to house RDM materials, news and updates from the Tri-Agency RDM Policies, with links to external RDM resources	Q4 2023 - 24	VPRI Office
1.3.2 - Develop Unity Health RDM materials	Unity Health currently leverages RDM materials and resources developed by UofT	In addition to leveraging UofT's RDM resources, we plan to develop Unity Health specific RDM materials such as guidelines on data management involving patient/participant data, data management plan template for clinical researchers, etc.	Q3 2023 - 24	VPRI Office
1.4 – Monitor and Communicate Tri-Agency RDM requirements and policy	Since the implementation of the Tri-Agency RDM Policy, VPRI Office staff have attended RDM related events and info-sessions	A dedicated RDM representative will be assigned to regularly attend all RDM related meetings and sessions, and maintain communication with the Tri-Agency to ensure alignment with the RDM requirement This individual will participate in other RDM consultations and events hosted by Tri-Agency, TAHSN or other government funding agencies and academic institution network to facilitate the relationship and communication between Unity Health other external stakeholders	Q2 2023-24	VPRI Office

Goal #2 – Assess Institutional Readiness

Objectives	Current Status	Action items	Timeline	Responsibility
2.1 - Conduct a RDM survey to assess data management practices	With guidance from the RDM Steering Committee, a survey on RDM practices was developed and circulated to Unity Health scientists in October 2022. The survey results are being used to shape RDM supports and the drafting of this strategy	It is expected that future surveys may be developed to obtain additional information on RDM practices	Q3 2022-23	VPRI Office
2.2 - Provide adequate RDM services				
2.2.1 - Provide supports for preparing data management plans (DMP)	Currently support for developing a DMP is provided by different groups at the hospital (VPRI Office, Privacy and REB etc.)	Unity Health has adopted the Alliance DMP Assistant Tool, and will develop custom DMP templates specifically designed for clinical research. Unity Health will also develop a guiding document on DMP for researchers that do not wish to use or have no access to the DMP Assistant Tool	Q2 - Q4 2023 - 24	VPRI Office with guidance from the RDM Steering Committee
2.2.2 Data repositories and archiving	Currently researchers deposit research data on Unity Health's internal data server. Data stored on the internal server is secure and backed up regularly Through the RDM survey, researchers have indicated the need of for a data repository that allows secure data sharing	Unity Health is currently reviewing its data server capabilities to address the need for secure access to both internal and external collaborators	~Q4 - 2025 -26	IT

Objectives	Current Status	Action items	Timeline	Responsibility
	with external collaborators			

Goal #3 – Formalize RDM Guidelines and Practices

Objectives	Current Status	Action items	Timeline	Responsibility
3.1 - Develop additional polices related to RDM	Currently Unity Health has guidelines and policies that address specific components of research data management. RDM relevant information can be found in the Information Security Policy, Secure Handling of Confidential Information in Digital Format Policy, Data Governance Framework, Privacy of Personal Health Information and Patient Record Management and Retention Policy	Upon review of the existing documents, it has been recognized that Unity Health needs to develop a high level RDM guiding document that specifies Unity Health's RDM requirements and direct researchers to the existing guidelines and polices for specific information	Q1 2024 -25	VPRI Office
3.2 – Indigenous Data Consideration				
3.2.1 - Indigenous Research Data Consultation	Unity Health supports the principles of OCAP for First Nations data governance and CARE Principles for Indigenous Data Governance. Unity Health has recently appointed a Strategic Lead of Indigenous Wellness, Reconciliation and Partnerships (Indigenous Lead) to help develop a strategy and framework for the	The RDM Steering Committee will consult with the Indigenous Lead on RDM practices around Indigenous research data to ensure compliance with OCAP and CARE Principles	Q2 2023 - 24	VPRI Office / Indigenous Lead

Objectives	Current Status	Action items	Timeline	Responsibility
	advancement of Indigenous health and reconciliation across the institution			
3.2.2 - Develop RDM Guidelines for Indigenous Research	Currently there is no specific guideline for RDM involving Indigenous Research	The RDM Steering Committee will engage Indigenous researchers and their community partners to support the development of a RDM guideline for Indigenous Research	Q4 2024 to Q4 2025	VPRI Office / Indigenous Lead

Appendix 1

UofT's RDM Principles

Draft University of Toronto Institutional Research Data Management Principles Version 2.0, 2022-10-24 (Final version expected before March 1st, 2023)

Context for Shared Research Data Management Principles

The **Research Data Management Principles** are the values related to research data shared between the University of Toronto and its affiliated institutions. The values reflected in Research Data Management Principles guide institutional strategic directions and form the foundation for responsible research data practices.

The research data management (RDM) landscape is dynamic with many considerations needed for researchers to adapt to rapidly evolving and interconnected practices and ideas. A supportive environment for researchers ensures access to coordinated and continuous RDM supports needed to navigate change.

The Research Data Management Principles seek to guide the balance, alignment, and integration of research data management practices that will:

Promote Research Integrity and Excellence

Providing support that promotes and integrates the responsible conduct of research is essential to building and maintaining an environment that fosters research and innovation excellence. Well-managed data is fundamental to the research process and advances discovery and knowledge mobilization. Responsible research data management actions align with the objectives of institutional, national, and international strategic directions for research. RDM practices should foster equity, diversity, and inclusiveness, and provide flexibility for distinction based approaches. Research data managed with integrity and in an ethical and transparent manner strengthens outputs, facilitates excellence and innovation, and increases our global impact in both scholarship and society beyond academia.

Recognize the Value of Data

Research data underpins institutional knowledge building. There is value in data as a distinct research output. Proper documentation and stewardship of data results in the ability to validate results and the replication of studies to support research findings. Well-managed data enables data sharing and reuse, which increases access to results (including the reporting of negative results) and can lead to further discovery and greater reach and impact. In pursuit of research and scholarship variation in the interpretation of data between researchers is expected.

Encourage the Implementation of Data Management Plans

A data management plan (DMP) is an essential part of designing and executing effective research approaches, from the inception to completion of a project. Proper planning improves data stewardship. A DMP provides direction and guidance for consistent actions across a project, increasing the reproducibility, visibility, and reuse of the research outputs. The creation and maintenance of DMPs should reflect best practices for managing data, improving project efficiencies, and mitigating risk.

Facilitate Long-Term Access Through Data Deposit

There is value in maintaining long-term access to data which supports research findings and serves as the basis for further inquiry. Data should be properly prepared, documented, and retained with assigned custodianship and, when possible, under the care of a designated repository. This facilitates the availability of results, and that data should be 'as open as possible, and as closed as necessary'.

Reflect Institutional Practices and Standards

It is essential that data practices abide by legal and ethical frameworks, adhere to institutional policies and procedures, and consider expectations of sponsors and research partners. Approaches to RDM will be diverse and should reflect the distinct needs and practices required for different types of data and projects. This involves reflecting institutional guidance, ethical standards, community principles, disciplinary standards, and established best practices in RDM decisions.

Honour Indigenous Community-Driven Principles

Meaningful and respectful research honours Indigenous cultures and knowledge and data should be managed in a way that leads to beneficial change and the rebuilding of trust. All research developed and conducted should support Indigenous data sovereignty and be in alignment with community-driven principles (such as CARE and OCAP principles). There is recognition that each community is distinct, and relationships and research approaches will reflect these differences. Approaches should promote Indigenous perspectives, incorporate more holistic Indigenous methodologies, and minimize bias stemming from other cultural frameworks. The outcomes of such research should enable capacity development and community empowerment. Developing institutional direction and guidance requires engagement with Indigenous leaders, researchers, and communities.

Strengthen Partnership and Collaboration

Tremendous value is placed in fostering meaningful collaborations and research partnerships. Research is strengthened through relationships and engagement with communities, not-for profits, government entities, the private sector, and academic researchers, local and global. Mutually beneficial research relationships outline the division of responsibilities related to data actions and ownership.

Safeguard Confidential and Sensitive Data

Confidential and sensitive data are subject to specific ethical, legal, and contractual obligations. Research conducted must be aligned with the [Tri-Council Responsible Conduct of Research (RCR)](#) and the [Policy Statement on Ethical Conduct for Research Involving Human (TCPS 2)](#) including core principles of respect for persons, concern for welfare, and justice. There must be adequate levels of infrastructure, security, and guidance in place to assist in mitigating any risk of harm and ensure the ethical treatment of data.

Integrate Excellence in All Disciplinary Approaches

Scholars engage in diverse research and scholarly endeavours which represent a variety of subject areas and research methodologies. Decisions around the treatment of data should reflect the best practices and standards appropriate for the types of data that a project includes. Flexibility in distinct approaches to data should be recognized and supported, and that research both benefits from and contributes to disciplinary communities of practice.

Reflect Through Communication and Engagement Opportunities

The research data landscape is dynamic and constantly evolving. There is a commitment to continuous engagement and communication with both our research community and external stakeholders. Ongoing learning from research communities will inform supports that are representative of diverse needs and practices. It is a priority to raise awareness and increase researcher knowledge of the evolving expectations of research data management practices.

Provide Infrastructure that Supports Diverse and Complex Programs of Research

Robust and coordinated infrastructure is vital to practices throughout the research data lifecycle and should be secure and bring consistency, interoperability, and equitable access. Infrastructure resources should be reflective of needs, scalable to meeting growth efficiently, and evolve in response to engagement with stakeholders.

Ensure Support Services are Available

There is a commitment to provide comprehensive and coordinated support services for data management. These services aim to increase the implementation of best practices for conducting effective research by engaging researchers and enhancing organizational expertise.

Commit to Advocacy and Support for Researchers' Needs

The institution should be a voice representing the needs and values of the research community as well as advocating to protect the rights of individual researchers and those participating in research. This involves a commitment to the betterment of research practices through continuous reflection, acting as leaders to influence change, and building mechanisms to assist researchers to practice standards and meet obligations.

Oversight
Version Information

Date	Version Code	Description
October 24, 2022	Draft 2.0	*Draft University of Toronto Institutional Research Data Management Principles Version 2.0, 2022-10-24*
August 17, 2022	Draft 1.0	*Draft University of Toronto Institutional Research Data Management Principles Version 1.0, 2022-08-17*
May 31, 2022	Draft 0.1	*Draft University of Toronto Approach for Research Data Management Strategy Version 0.1, 2022-05-31*

Document Administration

This document was created under the oversight of the Digital Research Infrastructure Advisory Committee and Researcher Council and the Toronto Academic Health Science Network Research Committee RDM Policy Table. These committees seek to enable the creation and sustainment of a coordinated, agile, rich, diverse, effective, efficient, and secure collection of digital research infrastructure and services that meet the complex and varied needs of our research community.