# Research Data Management S T R A T E G Y



The Royal's Institute of Mental Health Research affiliated with the University of Ottawa



# **ABBREVIATIONS**

САНО	Council of Academic Hospitals of Ontario
CARE	Collective Benefit, Authority to Control, Responsibility, and Ethics
CFI-IF	Canada Foundation for Innovation – Innovation Fund
CIHR	Canadian Institutes of Health Research
СІТІ	Collaborative Institutional Training Initiative
CNMDP	Cardio-Neuro-Mind Data Platform
DMPs	Data Management Plans
FAIR	Findable, Accessible, Interoperable, and Reusable
GCP	Good Clinical Practice
IMHR	Institute of Mental Health Research
N2	Network of Networks
NSERC	Natural Sciences and Engineering Research Council of Canada
OAC	Ottawa Aboriginal Coalition
OCAP	Ownership, Control, Access, and Possession
RDM	Research Data Management
REB	Research Ethics Board
SSHRC	Social Sciences and Humanities Research Council of Canada



## INTRODUCTION

The Royal's Institute of Mental Health Research (IMHR), affiliated with the University of Ottawa, is one of Canada's foremost research institutes focused on mental health. The IMHR is committed to cutting-edge research, specializing in the development of more personalized and alternative treatment options to help improve patient care locally and globally. As such, good management and stewardship of research data is an important contributor to this innovative work.

In March 2021, the Canadian Institutes of Health Research (CIHR), the Social Sciences and Humanities Research Council of Canada (SSHRC), and the Natural Sciences and Engineering Research Council of Canada (NSERC) released the <u>Tri-Agency Research Data Management Policy</u> to advance research excellence in Canada by ensuring that publicly funded research is supported by sound research data management (RDM) practices. The policy stipulates that "... research data collected through the use of public funds should be responsibility and securely managed and be, where ethical, legal and commercial obligations allow, available for reuse by others". The policy also asserts that all institutions eligible to receive and administer Tri-Agency funding comply with three requirements: (1) the development of an institutional RDM strategy, (2) the integration of data management plans (DMPs) into all funding applications, and (3) the deposit of research data into a digital repository.

In accordance with this policy, the IMHR commits to support research excellence by supporting its researchers in their efforts to establish and implement sound RDM practices. The IMHR also commits to upholding the <u>FAIR principles</u> to ensure high-quality, securely and sustainably stored research data, and where possible and appropriate, their continued findability, accessibility, interoperability, and reusability.

# ABOUT THE ROYAL'S INSTITUTE OF MENTAL HEALTH RESEARCH

The Royal's Institute of Mental Health Research is one of Canada's foremost mental health research hospitals. Through dedicated research focused on incubating innovation, improving treatment interventions, and advancing prevention strategies, the IMHR is proud to be a part of ground-breaking mental health research. The Royal's IMHR is ranked as one of Canada's Top 40 Research Hospitals in 2022.

IMHR researchers specialize in complex and treatment-resistant mental illnesses, and conduct innovative work that is leading to the development of more personalized and alternative treatment options, to help improve patient care. As a member of the Council of Academic Hospitals of Ontario (CAHO), the IMHR is ideally positioned to translate its researchers' cutting-edge discoveries into transformative mental health care.



The IMHR's approach to mental health research falls under three overarching pillars:

INNOVATION	INTERVENTION	PREVENTION
Taking novel approaches to research, and harnessing cutting-edge technologies and tools to better understand the brain.	Informing the development of personalized and alternative treatment options to improve patient care and help people get people better, faster.	Identifying the biological, social, and environmental mechanisms associated with mental illness, and using predictive analytics to develop early intervention
		strategies and inform health systems and policies.

The Royal's IMHR: In Numbers – 2022

NO. OF RESEARCH STAFF	NO. OF RESEARCHERS	NO. OF RESEARCH PROJECTS	
231	72	146	
NO. OF NEW GRANTS AWARDED	NO. OF ACTIVE RESEARCH GRANTS AND CONTRACTS	NO. OF PUBLICATIONS	
20	177	223	
TOTAL TRI-AGENCY FUNDING			
\$795,351.00			

# IMPORTANCE OF RESEARCH DATA AND RESEARCH DATA MANAGEMENT

Research data are essential to the research enterprise and are accepted in the research community as necessary to validate research findings and results. Therefore, rigorous management of research data is important to researchers, institutions, governments, as well as the public. Although the impetus for the development of an institutional RDM strategy was mandated by the Tri-Agency, the development process provided an opportunity for dialogue about the RDM needs at the IMHR. Furthermore, this dialogue encouraged the IMHR to consider its position as a leading research institute, committing to excellence in all aspects of research, including RDM. The IMHR recognizes its responsibility to support its researchers in adhering to international standards and best practices of research.

The IMHR aims to develop a cooperative approach to provide its researchers with an environment that enables and supports best RDM practices in alignment with institutional research goals. This institutional RDM strategy is intended to be a living framework, rather than a static policy, that will allow for further dialogue and future changes to occur.

## INSTITUTIONAL READINESS AND SUPPORT FOR RDM

To assess the institutional readiness for RDM, a survey was administered to all IMHR researchers to review their current data management practices and the institute's existing capacity and resources for data management. An environmental scan of existing RDM strategies from other institutes, similar in scope and scale, was also conducted. This information was analyzed to get an overview of the current RDM landscape, assess the researchers' awareness of current RDM support, and identify the RDM needs and challenges across the IMHR.

In the survey, many of the researchers reported that the most significant challenges they face with regards to RDM is lack of time, followed by lack of resources or funding to hire skilled staff to support their data management efforts. However, many of these researchers also reported that they would be interested in RDM-related support for themselves and their research team to help address some of these challenges. To ensure that the perspectives of the researchers are reflected in the strategy, they have been and will continue to be consulted at all points of the strategy development. As this institutional RDM strategy is a living document, it will be revisited and revised when appropriate to meet the requirements, needs, and initiative of the IMHR and its stakeholders.

## **SCOPE AND STAKEHOLDERS**

This strategy is intended to guide the work of the IMHR and its stakeholders with regards to best practices in research data management. For a RDM strategy to be effective, each stakeholder group must understand their role in promoting, supporting, and/or applying best RDM practices. These stakeholders are:

- Researchers
- Clinical Researchers
- Research Trainees
- Research Support Staff
- Research Administrative Staff
- IMHR's Research Ethics Board (REB)
- Information Technology (Research)

The development and implementation of this strategy requires collaboration between the IMHR, its stakeholders, The University of Ottawa, its industry partners, the funding agencies, and the research communities..



## INDIGENOUS DATA SOVEREIGNTY

The Royal's Institute of Mental Health Research is situated on the traditional and unceded territory of the Algonquin Anishinabe Nation.

The <u>Tri-Agency Research Data Management Policy</u> states that "... data related to research by and with the First Nations, Métis, or Inuit whose traditional and ancestral territories are in Canada must be managed in accordance with data management principles developed and approved by these communities, and on the basis of free, prior and informed consent." The IMHR acknowledges that data created in the context of research by and with Indigenous peoples and their communities must be managed in adherence to principles developed and approved by those communities. The IMHR has a long-standing collaboration with the Ottawa Aboriginal Coalition (OAC) who provides guidance on the integration of best Indigenous RDM practices that support Indigenous data sovereignty, such as the First Nations Principles of Ownership, Control, Access, and Possession (OCAP) and the Collective Benefit, Authority to Control, Responsibility, and Ethics (CARE) Principles for Indigenous Data Governance, into general RDM practices.

# THE IMHR'S RESEARCH DATA MANAGEMENT STRATEGY FRAMEWORK

#### **OUR COMMITTMENT**

The IMHR is committed to supporting its researchers in producing the highest quality research by adhering to the requirements for RDM best practices. This includes providing access to RDM support throughout the lifecycle of a research project, assisting in the development and integration of effective DMPs into all funding applications, and encouraging the deposit of research data into a digital repository.

1. DEVELOPING A RESEARCH DATA MANAGEMENT STRATEGY			
Strategic Goals	Current State	Action Items	
<ul> <li>Develop an institutional strategy regarding best RDM practices and foster a culture of RDM across all departments of the institute.</li> <li>Set institutional standards for RDM and promote adherence to these standards.</li> <li>Develop best RDM practices that respects and honours Indigenous Data Sovereignty.</li> </ul>	<ul> <li>Given that The Royal is a research hospital, the IMHR follows guidelines for Good Clinical Practice (GCP) with regards to good research conduct, but do not have institutional policies or guidelines specific to RDM.</li> </ul>	<ul> <li>Conduct an environmental scan of the IMHR's current data management practices and institute's existing capacity and resources for data management.</li> <li>Open the dialogue regarding the RDM challenges and needs at the IMHR.</li> <li>Develop an institutional RDM strategy that aligns with the FAIR principles, funding requirements, publication requirements, and Indigenous Data Sovereignty Principles.</li> </ul>	

#### Timeline:

- The development process started in early 2022.
- Mandated by the <u>Tri-Agency Research Data Management Policy</u>, the IMHR's institutional RDM strategy will be posted by March 1, 2023.
- Development of the strategy will be revisited and revised when appropriate to meet the requirements, needs, and initiative of the IMHR and it stakeholders.

2. BUILDING INSTITUTIONAL CAPACITY TO SUPPORT RDM			
Strategic Goals	Current State	Action Items	
<ul> <li>Determine whether the IMHR needs to invest in/provide additional resources, services, tools, infrastructure, external services (or all) in order to support RDM.</li> <li>Explore the available</li> </ul>	<ul> <li>In 2020, the IMHR was successful in the CFI-IF Competition. This Innovation Fund provided continued investments in infrastructure, across the full spectrum of research.</li> </ul>	<ul> <li>Assess the IMHR's existing capacity and resources for data management.</li> <li>Secure funding to support investments in resources, services, tools, technical infrastructure and/or external</li> </ul>	
resources, services, tools, and		services.	

<ul> <li>infrastructures that the IMHR should invest in to achieve the institute's desired state of RDM practices.</li> <li>Develop an infrastructure/repository to securely manage, preserve, curate, and provide continued access to research data.</li> <li>Integration of the infrastructure into the institute's RDM practices.</li> </ul>	<ul> <li>The Cardio-Neuro-Mind Data Platform (CNMDP) is currently in development at the IMHR, designed to facilitate collaboration and accommodate rapid data inputs, while ensuring sound data management, privacy, and security.</li> <li>The CNMDP includes data capture and management systems and is built to allow secure audited access for approved secondary uses of the data (both internally and externally) with increasing levels of privacy and security.</li> <li>In January 2023, the IMHR hired a Lead, Research IT to provide IT support for all research endeavours.</li> </ul>	<ul> <li>Invest in and develop the CNMDP infrastructure to achieve the IMHR's desired state of RDM practices.</li> <li>Encourage IMHR researchers to integrate the CNMDP infrastructure for data deposit, if and when appropriate.</li> <li>Explore alternative data repositories for research data that are ill-suited for the CNMDP.</li> <li>Allocate sufficient human resources to implement the above action items.</li> </ul>

#### Timeline:

- An assessment the IMHR's existing capacity and resources to support RDM was conducted via a survey in Fall 2022.
- Development of the central infrastructure of the CNMDP was funded in the CFI-IF 2020 Competition and is expected to be completed by December 2023.
- Integration of the CNMDP infrastructure into the IMHR's institutional RDM practices is expected to begin in early 2024.

З.	3. PROVIDING RDM SUPPORT (SERVICES AND TRAINING)				
	Strategic Goals		Current State		Action Items
•	Develop set institutional policies, standards, procedures, and guidelines regarding RDM and make the information accessible. Provide all stakeholders with access to RDM support (services and training) throughout the lifecycle of a research project. Provide researchers with resources for the development and integration	•	The IMHR is a member of the Network of Networks (N2) alliance working to enhance national clinical research capability and capacity. Membership with N2 allows member organizations to have access to its tools and resources for best practices, training, and regulations. In partnership with the Collaborative Institutional Training Initiative (CITI), the IMHR has access to high	•	Develop an institutional directory for RDM-related information to increase access. Foster a culture of sound RDM practices through increased training, workshops, and events. Build services and training that are scalable and responsive to the needs of the researchers, and funding/publication requirements.

of effective DMPs into their	quality, web-based, courses	
funding applications.	that encourage research with	
	human participants to be	
	conducted in a manner that is	
	appropriate, safe, responsible,	
	and ethical and meet the	
	guidelines, regulations and	
	legislation in this country.	

## Timeline:

• Implementation of the IMHR's institutional RDM strategy will start in Spring 2023 and continue for the next two years in line with The Royal's 2020-2025 Strategic Plan.

4. MAINTAINING RDM STANDARDS (APPRAISALS AND RISK ASSESSMENTS)				
Strategic Goals	Current State	Action Items		
<ul> <li>Unify and promote adherence of institutional policies, standards, procedures, and guidelines regarding RDM best practices across all departments of the institute.</li> <li>Ensure that all relevant stakeholders stay compliant with institutional training requirements and certifications.</li> <li>Provide researchers with appraisals, risk assessments, and/or mitigation strategies that offer an appropriate level of risk control for the data they manage.</li> </ul>	<ul> <li>The majority of research conducted at the IMHR is clinical based, thus the IMHR follows guidelines for GCP with regards to good research conduct and data management.</li> <li>In the survey that was administered to the IMHR researchers, all researchers reported a consistent lab specific system of data collection, processing, organization, documentation, storage, and security in adherence with GCP. However, there are no unified institutional policies or guidelines specific to RDM.</li> <li>All researchers reported that their personnel who perform data management tasks are compliant with institutional training requirements and certifications.</li> </ul>	<ul> <li>Unify the institute's RDM practices using set institutional policies, standards, procedures, and guidelines.</li> <li>Ensure that all personnel performing data management tasks have GCP training.</li> <li>Maintain a culture of sound RDM practices through regular audits, appraisals, and risk assessments.</li> <li>Allocate sufficient resources to implement the above action items.</li> </ul>		
Timeline:				

• Implementation of the IMHR's institutional RDM strategy will start in Spring 2023 and continue for the next two years in line with The Royal's 2020-2025 Strategic Plan.

5. LOOKING AHEAD		
Strategic Goals	Current State	Action Items
Commit to continuous     improvements and excellence	• The IMHR recognizes that the RDM landscape is constantly	• This institutional RDM strategy is intended to be a living

against the ever-changing	evolving with improved	framework, rather than a
RDM landscape.	infrastructures, new	static policy, that will allow for
	technologies, and changing	future changes to
	standards and practices.	accommodate the changing
		RDM landscape.
Timeline:		

• Striving for continuous improvements and excellence is an ongoing commitment.



## DEFINITIONS

The following definitions were obtained from the <u>Tri-Agency Research Data Management</u> <u>Policy</u>:

## CARE Principles for Indigenous Data Governance

The CARE Principles for Indigenous Data Governance stands for **C**ollective Benefit, **A**uthority to Control, **R**esponsibility, and **E**thics. The CARE Principles are people- and purpose-oriented, reflecting the crucial role of data in advancing innovation, governance, and self-determination among Indigenous Peoples.

## Data Deposit

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 deposit and user licenses, access control, preservation procedures, storage and backup practices, and sustainability and succession plans.

## Data Management Plan

A 'data management plan' (DMP) is 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.

## FAIR Data Principles

FAIR principles for scientific data management and stewardship are an international best practice for improving the **F**indability, **A**ccessibility, **I**nteroperability and **R**euse of digital assets.

## First Nations Principles of OCAP

The First Nations Principles of OCAP stands for **O**wnership, **C**ontrol, **A**ccess, and **P**ossession. These Principles govern how First Nations own, protect, and control how their information is used. Below are the definitions of the First Nations Principles of OCAP verbatim from the First Nations Information Governance Centre:

**Ownership**: Ownership refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

**Control**: The principle of control affirms that First Nations, their communities and representative bodies are within their rights in seeking to control over all aspects of research and information management processes that impact them. First Nations'



control of research can include all stages of a particular research project from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.

**Access**: First Nations must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

**Possession**: While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete. It refers to the physical control of data. Possession is a mechanism by which ownership can be asserted and protected.

#### Indigenous Data Sovereignty

*Refers to* data related to research by and with Indigenous communities must be managed in accordance with data management principles developed and approved by these communities.

#### **Research Data**

Research data are 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.

#### Research Data Management

Research data management (RDM) refers to the processes applied through the lifecycle of a research project to guide the collection, documentation, storage, sharing and preservation of research data. RDM is essential throughout the data lifecycle—from data creation, processing, analysis, preservation, storage and access, to sharing and reuse (where appropriate), at which point the cycle begins again.

For additional definitions, please consult the Tri-Agency Research Data Management Policy -Frequently Asked Questions, Government of Canada, 2021.