Research Data Governance
Information Session
April 23, 2024

The presentation will start at 1:03pm.
DRS Hub

Helpdesk: drs@mcgill.ca
https://www.mcgill.ca/drs/

“A one-stop shop for support and guidance on digital research topics”

“Accompany the researchers”
Agenda

1. Data governance background
2. Research data governance landscape
3. Research Data Governance Working Group
Research Data Management (RDM) Strategy

McGill Institutional RDM Strategy

Recognizing research data as a major research asset is an important steppingstone in the pursuit of academic excellence. Research activities in many domains create increasingly larger volumes of data that are challenging to manage and analyze effectively. Making research outputs discoverable, reproducible, and reusable are foundations and principles of modern scholarship. Research Data Management (RDM) is an integral part of research. RDM practices enable compliance with fast-evolving ethical, legal, cultural, and commercial requirements and are a key factor in safeguarding research when necessary.

As part of its strong commitment to research excellence, McGill will lead in the development of tools, support, and guidance to enable its researchers to manage their research data to the highest standards across the research data lifecycle. The McGill RDM Strategy represents the institutional vision for the enhancement of RDM practices across all academic domains.

The latest version of McGill RDM Strategy is available in two formats:
- Downloadable PDF document: McGill RDM Strategy v3.0

Tri-Agency list of all Institutional Strategies (204)
What is Data Governance (DG)?

A collection of practices and processes ensuring the consistent and proper handling of data so that its value can be leveraged. It ensures that data is:

- Reliable
- Documented
- Accessible
- Secure

Data Governance provides clear responsibilities for managing data quality, integrity, access, security, use, and disposal.

https://www.mcgill.ca/it/it-governance/data-governance
# Data Governance in a nutshell

<table>
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<th>Data Governance IS</th>
<th>Data Governance IS NOT</th>
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<td>• More about <strong>roles</strong> and <strong>people</strong> than data or tools</td>
<td>• IT’s responsibility</td>
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<td>• A system that promotes shared agreement</td>
<td>• Solved by technology</td>
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<td>• Formal (i.e., written down)</td>
<td>• Equally applied across all disciplines &amp; data assets</td>
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<td>• Adds value by supporting project mission/goals</td>
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Many research groups already have some elements of DG in place (formally or informally)

Source: [Stony Brook University](#)
Clear DG can help throughout the research lifecycle

- Research proposals
- DMPs
- Ethics review
- Privacy Impact Assessments
- Cloud solutions approvals
- Data use/sharing agreements
- Data anonymization/de-identification
- Access permissions/administration
- Retention or destruction
- Data deposit
It can be difficult to find clear guidance...

Directives related to DG can be found in various places:

- McGill policies
- Affiliated Research Hospital policies
- Funder policies and guidelines (e.g., Tri-Agency, FRQ, NIH)
- Agreements and contracts with research partners/funders
- Federal and provincial regulations (e.g., Loi 25)
- International regulations (e.g., GDPR, HIPAA)
Starting to develop guidance: Data sensitivity tool

Sensitive research data classification

The goal of the McGill research data classification tool is to help McGill researchers to identify, understand, and better manage research data in ways that are consistent with laws, disciplinary norms, and funder and institutional policies. This classification must always be used in conjunction with all additional compliance requirements applicable (e.g., Research Ethics Board requirements, contracts, agreements, applicable laws, ethical conduct, etc.).

All members of the university community are required to:

- comply with these obligations;
- use sensitive data only for the purposes for which they are collected;
- respect any restrictions for their use, and;
- collect, store, and dispose of data in ways appropriate to minimize the risk of unintended disclosure or compromised data integrity.

There are four levels in this data sensitivity classification. For descriptions and examples of each level of data sensitivity, please use the tabs on the left.

If you have questions about this tool or require support in determining the sensitivity of or safeguarding your research data, please reach out to the DRS team at drs@mcgill.ca.

https://www.mcgill.ca/drs/cybersecurity-0
# Policies and regulations

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<th>Institutional Policies &amp; Directives</th>
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<tr>
<td>Cloud Directive</td>
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<td>Governance of Personal Information</td>
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<tr>
<td>Regulation on Conduct of Research</td>
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<tr>
<td>Ethical Conduct of Research involving Human Participants</td>
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<td>Affiliated Research Hospital policies</td>
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<th>Funder Policies &amp; Directives</th>
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<td>Tri-Agency Responsible Conduct of Research</td>
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<td>Tri-Agency RDM Policy</td>
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<td>Ethical Conduct of Research involving Humans (TCPS2-2022)</td>
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<th>Legislation</th>
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<td>QC – Loi 25, Access Act</td>
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<td>EU – GDPR</td>
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<td>UK – GDPR</td>
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<td>US - HIPAA</td>
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Personal information in research data – New legal requirements

Consent for research participants for each specific purpose
- Collecting, using, sharing, re-using data containing personal information

Sharing and processing research data
- Within and outside of Québec

Data anonymization and destruction
- Anonymization vs. de-identification (Québec regulation on anonymization in development)
- Destruction of data once purposes achieved

Research software selection
- Cloud based solutions
McGill Affiliated Research Hospitals

- Sensitive Research Personal Health Information (PHI)
  - Separate Research Ethics Boards
  - Clinical trials (usually managed by the Affiliates)
- Mix of McGill and Affiliate staff
- Separate legal entities with their own policies & administrations
- Separate IT infrastructure
Collaborations and community partnerships

Multi-site collaborative research:
- Academic institutions
- Industry partners
- Community organizations

Contexts:
- Multiple policy and legal frameworks
- Negotiating and navigating data sharing/data transfer
  (Grants/Partnerships)
- Intellectual property (Legal)
Working with Indigenous data

Define relationship to research via meaningful partnership

- What are the processes that need to be in place?
- How can researchers partner with Indigenous communities to ensure data can be fully leveraged within the community?

Indigenous Data Sovereignty

- To participate, steward, control and access data that is created with or about themselves
- Distinctions-based approach is needed (Tri-Agency RDM Policy)
Working with Indigenous data – Resources

- McGill Office of Indigenous Initiatives
- McGill VPRI Office of Sponsored Research
  - Agreements (no template for Indigenous partnerships, case-by-case)*
- First Nations Information Governance Centre (FNIGC)
McGill RDM Strategy

Goal #3: Establish a formal governance framework for research data at McGill

Form an advisory research data working group to the VP-RI, comprised primarily of faculty members with representatives from key stakeholders (e.g., IT, Library, VP-RI, Provost, Research Ethics Boards, etc.)

- Provide steering and guidance for the development of a framework for research data governance at McGill
- DRS team to coordinate development of framework
Research Data Governance Working Group

Areas of focus:

- Laws, regulations & policies
- McGill Affiliated Research Hospitals
- Indigenous research data
- Collaborations
  - Provincial, federal, international partners
  - Industry partners
  - Community partners
Research Data Governance Working Group

Commitment:
- 1 year (possibility of extension)
- Meetings approx. once a month
- Material to review between meetings

Possible outcomes:
- Recommendations for harmonization of policies with Affiliated Research Hospitals
- Guidelines for roles and responsibilities
- Data Governance toolkit for researchers
Research Data Governance Working Group

RDG WG application form
If you are interested in being a part of the WG, please complete form by Friday May 3, 2024
Contact DRS

drs@mcgill.ca

https://www.mcgill.ca/drs/