# Digital Research Services Hub

# **Research Data Governance Information Session**

April 23, 2024

The presentation will start at 1:03pm.





#### **DRS Hub**

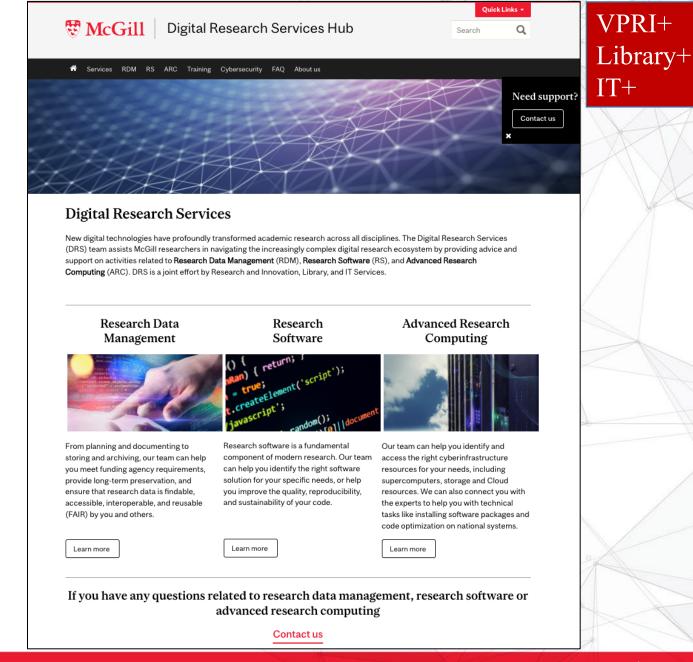
#### Helpdesk:

drs@mcgill.ca

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

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

"Accompany the researchers"





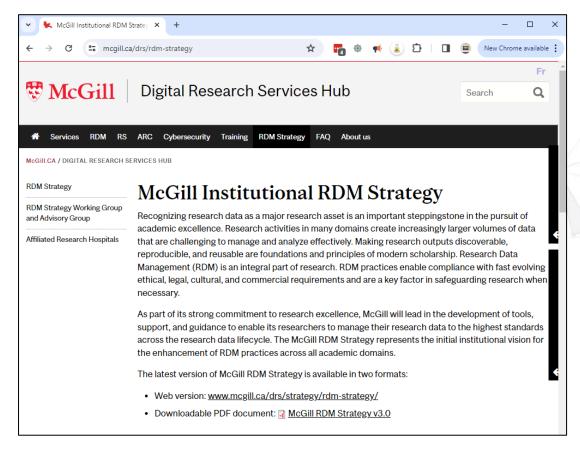
#### **Agenda**

VPRI+ Library+ IT+

- 1. Data governance background
- 2. Research data governance landscape
- 3. Research Data Governance Working Group

#### Research Data Management (RDM) Strategy





McGill Institutional RDM Strategy



Tri-Agency list of all Institutional Strategies (204)





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 IS	Data Governance IS NOT
<ul> <li>More about roles and people than data or tools</li> </ul>	IT's responsibility  Calvad by the sky alarms
A system that promotes shared agreement	<ul> <li>Solved by technology</li> <li>Equally applied across all disciplines &amp; data assets</li> </ul>
Formal (i.e., written down)	discipilites & data assets
<ul> <li>Adds value by supporting project mission/goals</li> </ul>	

Many research groups already have some elements of DG in place (formally or informally)

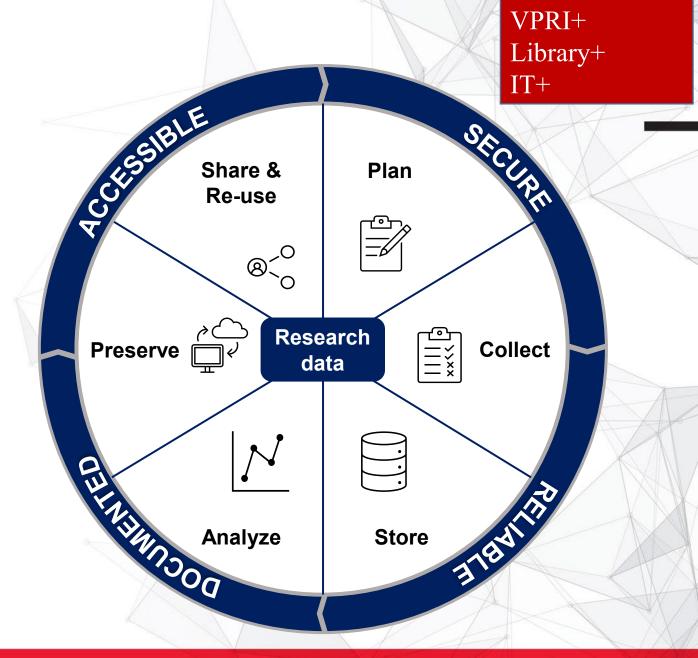
Source: Stony Brook University





### 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



#### 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

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Sensitive research data classification

Very high sensitivity

High sensitivity

Moderate sensitivity

Low sensitivity

#### 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 <a href="mailto:drs.@mcgill.ca">drs.@mcgill.ca</a>.

https://www.mcgill.ca/drs/cybersecurity-0





# **Institutional Policies & Directives**

Cloud Directive

Governance of Personal Information

Regulation on Conduct of Research

Ethical Conduct of Research involving Human Participants

Affiliated Research Hospital policies

# Funder Policies & Directives

Tri-Agency Responsible Conduct of Research

Tri-Agency RDM Policy

Ethical Conduct of Research involving Humans (TCPS2-2022)

#### Legislation

QC – *Loi 25, Access Act* 

EU – GDPR

UK – GDPR

US - HIPAA



#### 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





- 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

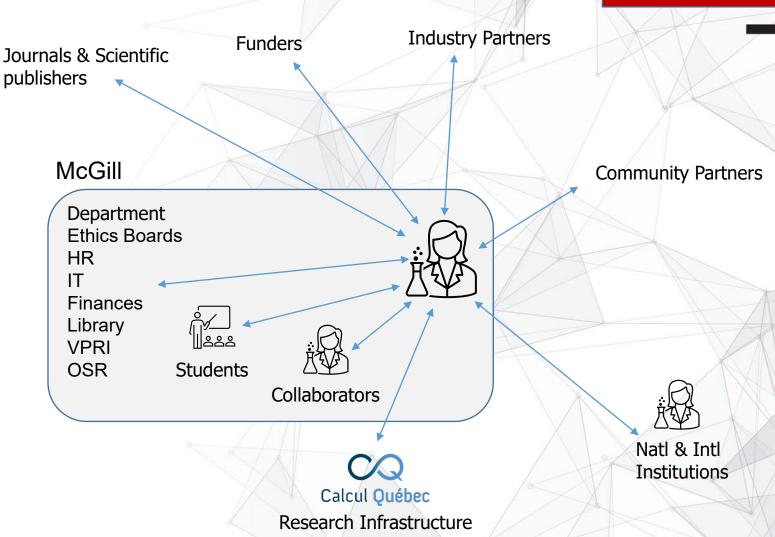
#### VPRI+ Library+ IT+

# 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)







#### 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 (<u>Tri-Agency RDM Policy</u>)





- ➤ 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)





# 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





#### **Areas of focus:**

- ➤ Laws, regulations & policies
- ➤ McGill Affiliated Research Hospitals
- > Indigenous research data
- > Collaborations
  - > Provincial, federal, international partners
  - > Industry partners
  - Community partners





#### **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**

VPRI+ Library+ IT+

# **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/



