# Securely Managing and Publishing Sensitive Data

Isaac Pratt, PhD February 8, 2023







Library



McMaster University is located on the traditional Territories of the Mississauga and Haudenosaunee Nations, and within the lands protected by the "Dish With One Spoon" wampum agreement.

Laslovarga, "Webster Falls in Winter, Waterdown, Hamilton, Ontario, Canada - Spencer Gorge / Webster's Falls Conservation Area," 23 January 2011, Wikimedia Commons - <a href="https://commons.wikimedia.org/wiki/File:Waterdawn\_Webster\_Falls\_in\_Winter8.ipg">https://commons.wikimedia.org/wiki/File:Waterdawn\_Webster\_Falls\_in\_Winter8.ipg</a>

# **Certificate Program**

The Sherman Centre offers a Certificate of Completion that rewards synchronous participation at 7 workshops. We also offer concentrations in Data Analysis and Visualization, Digital Scholarship, and Research Data Management.

Learn more about the Certificate Program: <a href="https://scds.ca/certificate-program">https://scds.ca/certificate-program</a>
If you would like to be considered for the certificate, verify your participation in this form: <a href="https://u.mcmaster.ca/verification">https://u.mcmaster.ca/verification</a>

At an unspecified point during the workshop, a code will be read aloud. This is the answer to the third question of the form.





# Hello! A bit about RDM Services and me

#### Isaac Pratt, PhD

My background is in Biological Anthropology and Biomedical sciences

I have a PhD in Anatomy & Cell Biology from the University of Saskatchewan.

#### **RDM Services**

- Consulting on any research data management needs
- Creating Data Management Plans
- Advising on issues related to data storage and backup;
- · Facilitating data sharing





## **Outline**

What is sensitive data?

What requirements do I need to follow?

Building a Data Management Plan

Good data management Secure data storage

Sensitive data deposit and sharing







# What requirements do I need to be aware of?

#### **Ethics**

- Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans TCPS 2 (2022)
- •MREB, HIREB

#### **Funders**

- Tri-Agency Research Data Management Policy
- •NIH Data Management & Sharing Policy

#### Data sources

•Data sharing/transfer agreements – MILO Sample Agreements

#### Journals

• Data availability statements and data sharing policies - Frontiers Materials and data policies

#### Privacy legislation

- EU General Data Protection Regulation (GDPR)
- •in Canada based on the National Standard Model Code for the Protection of Personal Information





# **Privacy principles**

There are 10 privacy principles that underpin the Canadian Model Code, including:

- 1) Accountability
- 2) Identifying purposes
- 3) Consent
- 4) Limiting collection
- 5) Limiting use, disclosure and retention

- 6) Accuracy
- 7) Safeguards
- 8) Openness
- 9) Individual access
- 10) Challenging compliance





Library

# **Canadian Ethics principles - TCPS2**

#### Respect for Persons:

 Informed consent, voluntary participation, limiting undue influence, assent process, deception and debrief, etc.

#### Concern for Welfare

 Holistic view of welfare, identify risks, minimize and mitigate risks, procedures in place to address likely harms, data security, etc.

#### Justice:

 Sharing burdens and benefits of research, just exclusion/inclusion, disseminating results, etc.

#### Ethical Duty of Confidentiality

 Researchers shall safeguard information entrusted to them and not misuse or wrongfully disclose it





Gouvernement



#### Tri-Agency Research Data Management Policy

#### <u>Tri-Agency RDM Policy</u> – CIHR:

CIHR currently requires researchers to deposit bioinformatics, atomic, and molecular coordinate data into the appropriate public database.

#### **<u>Data Management Plans</u>** (in pilot phase)

Grants will require data management plans (DMPs) to be submitted at the time of application.

#### **<u>Data Deposit</u>** (launch tbd)

- Grant recipients will be required to deposit into a digital repository research data that supports journal publications and pre-prints from funded research
- Grant recipients are not required to share their data
- First Nations, Métis and Inuit communities
- "researchers should only make data accessible if doing so is ethical, legal, and is in consonance with any commercial or other agreements the researcher has entered into"





# **Funder Requirements**



National Institutes of Health (NIH) <u>Data Management and Sharing</u> <u>Policy</u>

#### **Data Management Plans**:

 NIH requires all applicants planning to generate scientific data to prepare a DMS Plan that describes how the scientific data will be managed and shared.

#### **Data Sharing**:

- "Scientific data should be made accessible as soon as possible."
- "certain factors (i.e., ethical, legal, or technical) may necessitate limiting sharing to some extent. Foreseeable limitations should be described in DMS Plans"
- "Consider whether access to shared scientific data derived from humans should be controlled"





# **Journal Requirements**

Journals have increasing requirements for data sharing:

#### **Social Science and Medicine**

- "This journal requires and enables you to share data that supports your research publication where appropriate"
- "If you have made your research data available in a data repository, you can link your article directly to the dataset"
- "we require you to state the availability of your data in your submission if your data is unavailable to access or unsuitable to post"





# **Indigenous Data Sovereignty**

When researchers are working with Indigenous communities, they should abide by principles of indigenous data sovereignty like the <u>CARE principles</u>. For Canadian First Nations, the <u>OCAP principles</u> are recommended:

- Ownership: a community or group owns information collectively in the same way that an individual owns his or her personal information.
- **Control**: First Nations, their communities, and representative bodies are within their rights to seek control over all aspects of research and information management processes that impact them.
- Access: First Nations must have access to information and data about themselves and their communities regardless of where it is held.
- Possession is the mechanism by which ownership can be asserted and protected, through direct physical control of data.





# 1. Plan: Create a Data Management Plan

- A Data Management Plan (DMP) is your plan for how you will create, store, organize, document, secure, preserve, and share your research data.
- A living document which speaks to the management of data both during the active phases of your research and after the completion of the research project.

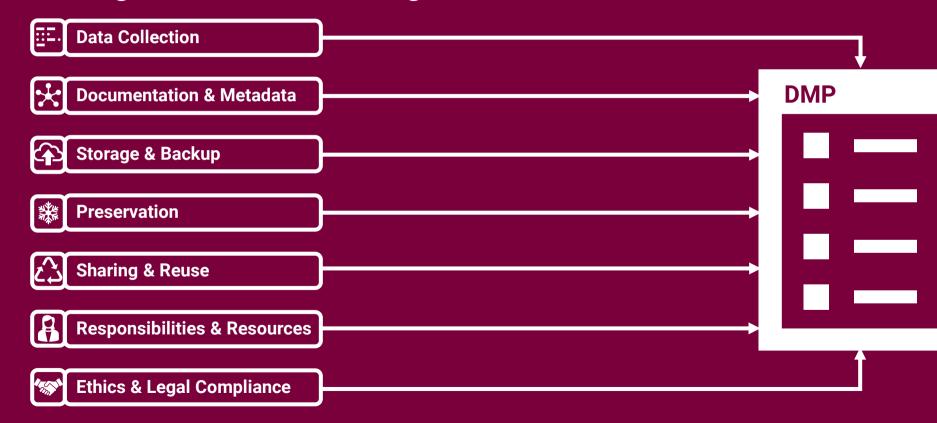


# Why create a DMP?

- A blueprint for how you will be working with your data during your project
- Avoid potential pitfalls and problems before they occur
- Prepare for future stages of research including potential data sharing
- Many research funders require grant applicants to submit a DMP – including the Tri-Agencies (NSERC, CIHR, SSHRC – started 2022) and NIH

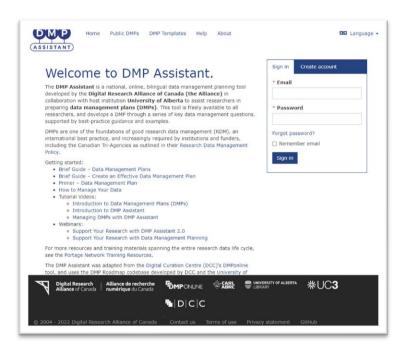


# What goes in a Data Management Plan?





#### Alliance de recherche numérique du Canada



A web-based, bilingual data management planning tool

Available to all researchers in Canada

A guided creation process

Exportable data management plans

assistant.portagenetwork.ca/





# **Data Management Practices**

Good data management Research project management
De-identification

Secure data storage

Data storage practices and controls

3<sup>rd</sup> party tools and services

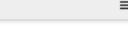
Cybersecurity practices

Encryption





#### HOME <del>▼</del>



#### Soil radiometrics: Field and remc data sets for model building and

242.3k

Contributors: Cassia Read, David H. Duncan, Chiu Yee Catherine Ho, Matt D. Whit Date created: 2017-05-02 09:40 PM | Last Updated: 2018-06-14 11:46 PM

Category: 

Project

Description: Repository for model training and testing data sets for the article: Re

Description: Repository for model training and testing data sets for the article: Re White M, Vesk PA. Useful surrogates of soil texture for plant ecologists from airbarder Ecol Evol. 2017;00:1–10. https://doi.org/10.1002/ece3.3417

#### Wiki

This project is home to the soil data for north-west Victoria, Australia used by I Useful surrogates of soil texture for plant ecologists from airborne gamma-ray See the respective data set wiki pages for further information on provenance

Files

Name A Cassia Read, David H Duncan, Chiu Y C Ho, el....
Matt D White, and Peter A Vesk, "Soil
Radiometrics: Field and Remotely-Sensed
Data Sets for Model Building and Validation,"

# **Research Project Management**

- Collaboration: Microsoft teams let you control your team and share and work on documents together in real-time, avoiding multiple versions and copies sent by email.
- Reference Management: Zotero or Endnote support collaboration through shared citation libraries.
- Notetaking software: Obsidian, OneNote, Notion, or an Electronic Lab Notebook allow you to create organized, linked notes that you can use to document your research practices
- REDCap: REDCap is a powerful web tool for collecting and organizing longitudinal data.

Learn more at rdm.mcmaster.ca/organize



-OSF, June 15, 2018, osf.io/uac6x.

## **De-identification definitions**

#### From the TCPS2:

- Coded information direct identifiers are removed from the information and replaced with a code. With access to the code it is possible to re-identify specific participants.
- Anonymized information the information is irrevocably stripped of direct identifiers, a code is not kept, and risk of re-identification of individuals from remaining indirect identifiers is low or very low.
- Anonymous information the information never had identifiers associated with it (e.g., anonymous surveys) and risk of re-identification is low or very low.
  - De-identification is not a 'guarantee' of privacy and risks of re-identification can often remain.





# **De-identifying data**

#### **Pseudonymization**

**Generalization**: grouping specific values into categorized ranges.

• For example, grouping specific ages into age ranges or merging categories into larger groups.

**Suppression**: deleting individual cases or responses.

 For example, if there is only one individual in a particular age range of a specific ethnicity, the ethnicity response for that individual could be deleted to preserve the ethnicity category as a whole.

#### The 'small cell' problem





# K anonymity

**k-anonymity** is a mathematical approach to ensuring a dataset is anonymous.

A dataset has k-anonymity when a particular individual in the dataset cannot be distinguished from k other individuals in the dataset.

'k' is a number set by the researcher - most commonly set to 5. This means it should not possible to isolate a group of fewer than 5 identical individuals.

Amnesia <a href="https://amnesia.openaire.eu/">https://amnesia.openaire.eu/</a>

sdcMicro https://cran.r-project.org/web/packages/sdcMicro/index.html

For a more comprehensive overview see the Portage Network's Reducing Risk Webinar and slides

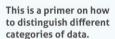




#### A VISUAL GUIDE TO PRACTICAL DATA DE-IDENTIFICATION

https://fpf.org/blog/a-visual-quide-to-practical-data-de-identification/

What do scientists, regulators and lawyers mean when they talk about de-identification? How does anonymous data differ from pseudonymous or de-identified information? Data identifiability is not binary. Data lies on a spectrum with multiple shades of identifiability.





#### **DEGREES OF IDENTIFIABILITY**

Information containing direct and indirect identifiers.



#### **PSEUDONYMOUS DATA**

Information from which direct identifiers have been eliminated or transformed, but indirect identifiers remain intact.



#### **DE-IDENTIFIED DATA**

Direct and known indirect identifiers have been removed or manipulated to break the linkage to real world identities.



In collaboration with

Produced by

#### **ANONYMOUS DATA**

**ANONYMOUS** 

ELIMINATED or

TRANSFORMED

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**ELIMINATED** or

TRANSFORMED

Direct and indirect identifiers have been removed or manipulated together with mathematical and technical guarantees to prevent re-identification.

AGGREGATED

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#### DIRECT IDENTIFIERS Data that identifies a person without additional information or by linking to information in the public domain (e.g., name, SSN)





#### SELECTED **EXAMPLES**

Name, address, phone number, SSN, government-issued ID (e.g., Jane Smith, 123 Main Street, 555-555-5555)

Unique device ID, license plate, medical record number. cookie, IP address (e.g., MAC address 68:A8:6D:35:65:03)

Same as Potentially Identifiable except data are also protected by safeguards and controls (e.g., hashed MAC addresses & legal representations)





Unique, artificial

pseudonyms replace

direct identifiers (e.g.,

(unique sequence not

used anywhere else)

HIPAA Limited Datasets.

John Doe = 5L7T LX619Z)





except data are also

and controls





generalized, perturbed,

3.2 = 3.0-3.5, gender:

female = gender: male)

Same as Pseudonymous, Data are suppressed.

protected by safeguards swapped, etc. (e.g., GPA:



PROTECTED

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and controls

protected by safeguards to hide whether an



For example, noise is Very highly aggregated calibrated to a data set data (e.g., statistical data, census data, or individual is present or population data that not (differential privacy) 52.6% of Washington, DC residents are women)



#### POTENTIALLY **IDENTIFIABLE**





KEY

CODED



Clinical or research

curator retains key

diabetes, HgB 15.1

(e.g., Jane Smith,

g/dl = Csrk123)

datasets where only



**PSEUDONYMOUS** 

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ELIMINATED or



PROTECTED

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# Linking file/key

- You may need or want to keep a file linking the participant names and IDs or pseudonyms. Keep in mind your data is not anonymous if a linking file exists
- Linking files should be encrypted and stored on separate devices or systems than the data.
- Linking files and the included personal information should be destroyed/deleted when no longer required to increase privacy.





#### **De-identification**

# **Recordings and transcripts**

- Video and audio recordings are inherently more identifiable than transcripts
- Researchers should transcribe recordings and limit access and may delete original recordings if they are no longer needed.
- Direct identifiers in transcripts should be pseudonymized or generalized where possible – not just name but also locations, ages, genders, etc





# Data storage administrative controls

- . Don't collect identifiers that aren't relevant to the research
- Data should be de-identified as soon as possible, with pseudonyms replacing names
- Researchers should work from de-identified data and not from identifiable data where possible
- Linking files/keys should be stored separately from de-identified data
- Data should only be made accessible to team members who need access





# Data storage technological controls

- Store data on password protected devices
- Data stored on internet-connected devices needs to be encrypted
- Data should be stored in a secured environment or server rather than on individual computers or devices
- Back up devices need to follow the same requirements
- Data must be encrypted and password protected when shared email should not be used for high risk data





# **Cloud storage**

- Public cloud services (Google Drive, Dropbox) cannot be used for medium/high risk data but are fine for low risk data
- Institutional services such as MacDrive or OneDrive accessed through McMaster may be used in combination with encryption
- OneDrive is less flexible when working with outside collaborators but Teams
- MacDrive can create a shared folder that collaborators can access and can create encrypted folders
- Researchers using cloud storage should be careful about who they share files with and should enable security features like MFA





# **Evaluating 3rd party services**

- High risk data should stay on campus and with the researchers, not on 3<sup>rd</sup> party platforms.
- Terms of use should be examined closely to see what platforms are doing with data – this may not align with regulatory requirements
- Data storage location should be in Canada, ideally in Ontario
- Data should be shared in a de-identified form when possible
- Individual contractors should sign confidentiality agreements





# **Backup Strategies (3-2-1)**

A good data storage plan needs to balance accessibility and convenience against security and reliability.



Copies of your data (at least!)

#### Example:

- 1 copy stored locally on **hard drive** for analysis
- 1 copy stored on **cloud storage** platform
- 1 copy stored in a secure campus drive

2

Copies are on-hand (easily accessible) on different systems (internal hard drive, cloud storage, etc.)

- a "production" (working) copy
- a "production backup" copy



Copy is in another location ("off-site") from the others with a *trusted* service provider





# Long term/archival storage

- Researchers should consider how they will preserve data over the long term. Many research funders require data to be retained for a set period.
- Storing data on campus servers (department/faculty/RHPCS) is preferable to storing data on an external drive
- Keeping data on your laptop isn't a good preservation plan
- Publishing/depositing data to an online data repository is a good option for researchers who are comfortable making data open



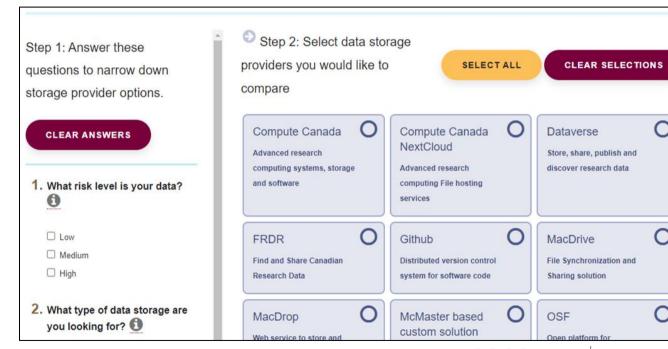


# **Research Data Storage Finder Tool**

http://u.mcmaster.ca/storagefinder

McMaster RDM Services
has a **Data Storage**Finder, an interactive tool
to help you find a vetted
storage provider
depending on risk, volume,
and other needs

This tool also allows you to compare feature sets of selected options.







# **Encryption**

#### Encrypt individual files

 Microsoft Office or other applications can be used to password protect and encrypt documents on a file by file basis.

#### Encrypt your whole drive

Full disk encryption is available on Windows, Mac, iOS, and Android. This
protects every file on your device so you don't need to worry about missing a file.
You can also encrypt entire external drives.

#### Create "virtual encrypted disks"

 Disk Utility on Mac or VeraCrypt (3<sup>rd</sup> party software) can create encrypted virtual disks, where you can store sensitive data files





# How should I protect my data?

# **Enable Multi-Factor Authentication (MFA)**

- Also known as 2 Factor Authentication (2FA)
- Requires more than one code or 'Factor' to login – typically 2 factors: password and a security code sent to your phone number or generated by a linked authenticator app
- Many other web services (Gmail, Dropbox, etc) provide MFA



an't use my Microsoft Author





#### **Password Best Practices**

Make sure your online information is secure by ensuring your password is:

- ✓ **Strong**: Make a strong password by combining a series of numbers, letters, and symbols into a long series of words. Try to combine them into something memorable like L1br@ryt1pS.
- ✓ **Unique**: Use a different password for each important website/service
- ✓ Secret: Never share your passwords with anybody via email or text.
- ✓ Up to date: Change your passwords in response to platform breaches
- ✓ **Devices**: Use a strong password on your computer and phone, too



Tip: Remembering multiple passwords can be difficult. Use a trusted password manager to keep track of your passwords for you. Some examples are BitWarden and 1Password.



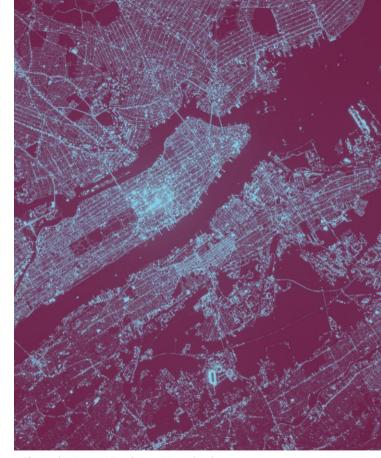


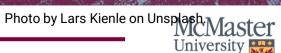
# **Publishing Data**

What do you plan to do with your data once it's been published? How will you ensure that your data remains accessible (to you and others) long-term?

Consider whether you can publish your data in an online repository for preservation and sharing.









# **Data Sharing**

 Culture of reproducible research increases confidence in research results and avoids article retractions.

 Leads to new collaborations – potential for meta-analyses over a wider topic area.

 Better informed policymakers in healthcare and science as well as hospital stakeholders, professional associations, patient advocates.

 Long term preservation and archiving of data by established repositories.

### Traditional "data sharing" citation another publication citing researcher/ your findings research team ••• "data available on publication research data researcher/ research team peer review

#### The future of data sharing? collaborations . . . new reflections on . . . your original data **A** = . . . researcher/ research data publication research team peer review new research another trusted data + your researcher/ data repository research data research team another publication researcher/ interpreting your publication w research team data in a new way bigger dataset

# **Sharing sensitive data**

If you want to publish or share sensitive data, there a few main options:

- Anonymize the dataset: remove, replace, or redact all sensitive information from datasets prior to upload in an open repository.
- Data can be shared through closed access portals with restricted access mechanisms and Data Sharing/Transfer Agreements
  - Examples of this kind of web portal include ICES and CIHI

Remember you must have patient/participant consent to share data

Portage's <u>Research Data Management Language for Informed Consent</u>









# Ok, so where do I put everything?

A **data repository** is a web platform and storage space for researchers to deposit data sets associated with their research.

#### Repositories provide:

- long-term storage and access to research data beyond the life of a grant, research project, or individual careers.
- Discoverability and findability for datasets through features like indexing and DOIs.
- Easy-to-use shared platforms made for research.







Search -

Enter text search terms

Examples: histone, BN000065

GCA 001890125



Search O

Examples: Taxon:9606, BN000065, PRJEB402

Assembly: GC

Submit >

Searching ENA

vw.genome.gov/page.cfm?pageID=10506376)

oject ID: 403566~The DNA was provided by Ronald P. de Vries (r.devries@cbs.knaw.nl)~The strain

III P. de Vries (r.devries@cbs.knaw.nl)~Assembly and annotation done by JGI.~The JGI and bution and use of large scale sequencing data adopted by the larger genome sequencing community

our intention to publish the work of this project in a timely fashion and we welcome collaborative

Text Search Comment

URL -- http://genome.jgi is available from CBS-

collaborators endorse the and urge users of this c interaction on the project

Advanced Search

Sequence Search

Xref Search

Organism:

Sequence Versions

Ilus versicolor CBS 583.65

About ▼

Accession:

GCA 001890125

**Assembly Name:** 

Aspve1

Assembly Level:

scaffold

Strain:

CBS 583.65

Genome Representation:

full

Total Length: 33126810

Ungapped Length: 33121003

N50: 2487993

₽ View:

IMX

♣ Download: XMI

WGS Set FMBI

WGS Set FASTA

All Seg EMBL

All Seg FASTA

Show

Show

**ш** Assembly Statistics:

# Example: European **Nucleotide Archive**

ENQUIRY

QUICK STUDY LOOKUP V

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Log

#### A Long Term Open Label Rollover Trial Assessing the Safety and Tolerability of Combination Tipranavir and Ritonavir Use in HIV-1 Infected Subjects

Study Details Study Documents Administrative

Administrative Details Usage

Phase

Phase 2/Phase 3

Condition or Disease
HIV Infections

Intervention/treatment

CENTER FOR GLOBAL CLINICAL RESEARCH DATA

Tipranavir

Example: Vivli

**Brief Summary** 

The objective of this study is to determine the long term safety and tolerability of multiple oral doses of tipranavir (Aptivus) and ritonavir with a focus on the long term safety of the development dose (500 mg tipranavir/200 mg ritonavir BID) when administered with other antiretroviral medications.





# FRDR Zero knowledge encryption for sensitive data

- FRDR is working on a pilot project to add optional zero-knowledge encryption to the repository.
- "Zero-knowledge encryption" means that FRDR will never be able to access your data. All datasets are encrypted, and their keys stored in a separate researcher-managed platform. This allows you to deposit your data in a trusted repository for archival but maintain complete control over access to the data.
- Interested in piloting this service? Email us: rdm@mcmaster.ca









McMaster RDM webpage: <u>rdm.mcmaster.ca</u>

Contact RDM services at: <a href="mailto:rdm@mcmaster.ca">rdm@mcmaster.ca</a>

Upcoming RDM webinars: <a href="mailto:rdm.mcmaster.ca/events">rdm.mcmaster.ca/events</a>

Recorded RDM webinars: <u>u.mcmaster.ca/learn-rdm</u>

Make an appointment with a Research Data Management Specialist: u.mcmaster.ca/rdm-appointments





# **RDM Community of Practice**

- Monthly meetings of people interested in RDM at McMaster
- February Allison Van from Spark on RDM in Social Sciences.
  - Thursday Feb. 23 11 AM
- March Dr. Claudia Emerson on medical ethics.
  - Thursday March 30<sup>th</sup> 11 AM
- Connect with other researchers practicing RDM across the university!
- https://u.mcmaster.ca/rdm-community

