# Improving the Discovery of Restricted Data in Canada

Identifying Metadata Commonalities Across Restricted Data Sources

## **Digital Research Alliance of Canada:**

Access Limited Data Discovery Working Group

#### Presenter:

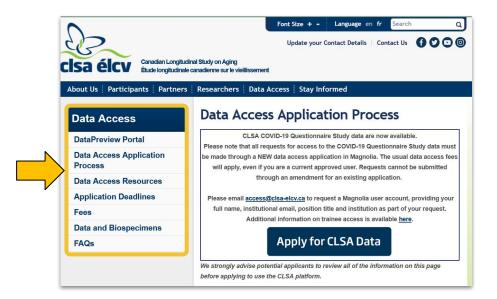
• Kevin Read, University of Saskatchewan (Chair)

#### **Members:**

- Grant Gibson, Canadian Research Data Centre Network
- Amber Leahey, Scholars Portal
- Lynn Peterson, National Research Council
- Sarah Rutley, University of Saskatchewan
- Julie Shi, University of Toronto
- Victoria Smith, Digital Research Alliance of Canada
- Kelly Stathis, DataCite

## What do we mean by restricted data?

Data that are not immediately accessible because they are restricted or only available upon request.



## **Restricted Data Discovery & Access Challenges**

## Where's the data?

Restricted data is hard to find, and even more difficult to access

Data Availability Statement

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

"None of the publications that required an application included metadata sufficiently outlining the requirements for access and approval."

Read KB, Ganshorn H, Rutley S, Scott DR. Data-sharing practices in publications funded by the Canadian Institutes of Health Research: a descriptive analysis. Canadian Medical Association Open Access Journal. 2021;9(4):E980-7. <u>https://doi.org/10.9778/cmajo.20200303</u>

## Accessing restricted data is a known issue

Known researcher access challenges:

- Uncertainty about eligibility for access
- Difficulties navigating the request process
- Lack of standardization for submitting data requests
- Time burden
- Lack of support from data provider(s)

#### These barriers have consequences

Researchers limit their research questions to data they can find and obtain

Researchers may invest a substantial amount of resources into acquiring data that cannot be easily acquired and/or used

Research is constrained when restricted data cannot be used

## **Our Project:** Identifying and Evaluating Restricted Data Sources in Canada

### **Project goals**

- 1. Find (as many) examples of Canadian restricted data sources
- 2. **Evaluate** Canadian restricted data sources based on how well they make their data discoverable and accessible
- 3. **Extract** metadata commonalities from restricted data sources to test alignment with existing metadata schemas

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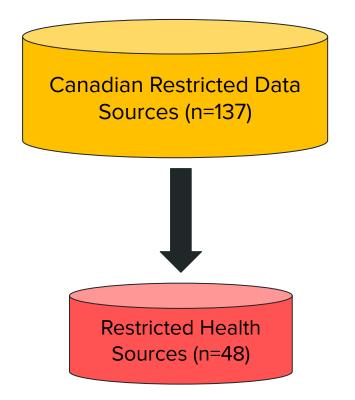
## Canadian restricted data sources

#### Search Strategy:

- Academic websites
- Government websites
- Private sector
- Non-profit sector
- Web-search
- Call to experts

#### Health sources were most prominent (n=48)

• Used health sources as sample for remainder of project



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#### **Evaluating restricted health data sources**

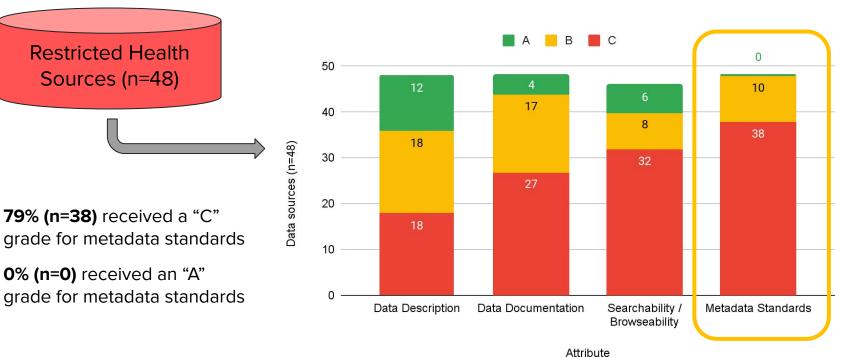


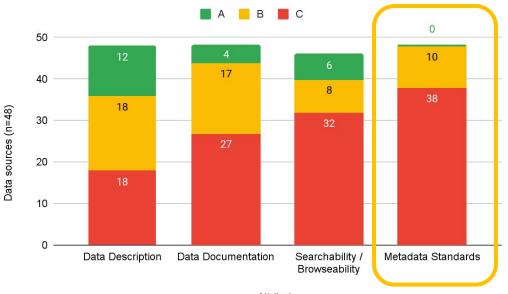
Figure 1. Data Discovery Grades by Attribute in Restricted Health Data Sources

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## **Grading exercise: Emerging questions**

Do data sources describe their dataset(s) and access procedures in similar ways?

Do these similarities map to existing metadata schemas?



Attribute

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## Metadata "element" extraction

Review restricted health data sources to identify:

#### A) Dataset "elements"

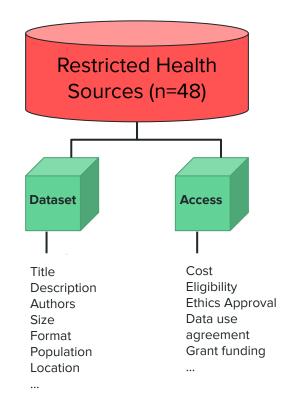
a) Descriptive information they provide about their dataset(s) (e.g., format)

#### B) Access "elements"

a) Descriptive information they provide about their data request process (e.g., application req's)

Are there commonalities across sources?

Can existing metadata standards accommodate these commonalities?



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Patterns found

### **Dataset "Elements"**

Identified **35** common dataset "elements" across sources

#### **Example: Common data characteristics used captured across sources**

Metadata Entity	Sub Entity	Definition	Frequency
Data characteristics			91
	Population	Population studied	26
	Data quality	Data quality measures applied to dataset	19
	Geographic	Geographic location where data was collected	12
	Variables	Variable level information about dataset	11
	Temporal, Date range	The beginning and end date of data collection	9
	Temporal, Start date	The start date for data collection	4
	Temporal, End date	The end date for data collection	4
	Temporal, Reference period	When the data was made available for access	3
	Size of dataset	Size of dataset	3

**Example: Request requirement commonalities across sources** 

Metadata Category	Metadata Subcategory	Access Element	Definition	Frequency
Request requirements			1765	
	Research team information	on		668
		Requestor Name	data request	212
		PI	project for which data is being	185
		Team members	on study where data would be	96
		Primary contact	of the primary person	82
		Student info	of any students engaging with	50
		background	professional qualifications of	25
		Conflict of interest	with any of the data requestors	18
	Research plan			374
		Study purpose	purpose	113
		Study design	of study	82
		External linkages	additional data linkages that	50
		Timeline	length of study where data will	49
		Project title	project where data will be used	47
		Support needed	management, storage, security,	20
	(A 37	Scientific review	of scientific review their study	13
	Request data description	1	description of what data they	184
	Ethics approval			151
		Ethics review	ethics approval has been	100
		Risks/benefits	and benefits of using data	34
		Participant recruitment	they will recruit participants for	17
	Data management			215
		Storage and security	requested data will be securely	134
		Processing	will be processed	42
	2	Access restrictions	restrictions are placed on	39
	Funding		funding must be received to	96
	Intended use			48

#### Access "Elements"

Identified **27** common access "elements" across sources

#### **Dataset "Element" metadata mapping**

Common	Metadata Schemas					
Metadata Alignment (35 elements)	DataCite	DDI Lifecycle	DDI Codebook	DCAT	DATS	
Exact	37.1% (n=13)	91.4% (n=32)	85.7% (n=30)	60% (n=21)	40% (n=14)	
Partial	28.6% (n=10)	8.6% (n=3)	14.3% (n=5)	31.4% (n=11)	45.7% (n=16)	
None	34.3% (n=12)	0% (n=0)	0% (n=0)	20% (n=7)	14.3% (n=5)	

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None	34.3% (n=12)	0% (n=0)	0% (n=0)	20% (n=7)	14.3% (n=5)	

## **Access "Element" mapping**

No existing metadata schema was sufficient to describe the 27 elements we found

Schemas provide general metadata fields about access e.g., "Access Restrictions"

#### General fields cause two main issues:

- Data creator is not prompted to provide sufficient detail
- Data requestor does not receive clear instructions about access process

## What does this all mean?

## **Study findings**

Many Canadian restricted data sources in Canada are available for use, but are difficult to find and access

Lack of discoverability = they do not utilize metadata

#### But!

- Data sources describe their data and access procedures in similar ways
- Descriptions of restricted data could be accommodated by existing metadata schemas

#### However...

Metadata schemas do not accommodate information about the access request process

## **Recommendations**

#### **Digital Research Alliance of Canada:**

- Work with Canadian restricted data sources to adopt metadata
- Make datasets discoverable in aggregators, indexes, and catalogues (e.g., Lunaris)

#### Metadata standards bodies:

• Revise metadata schemas to account for access request processes

#### Data repositories:

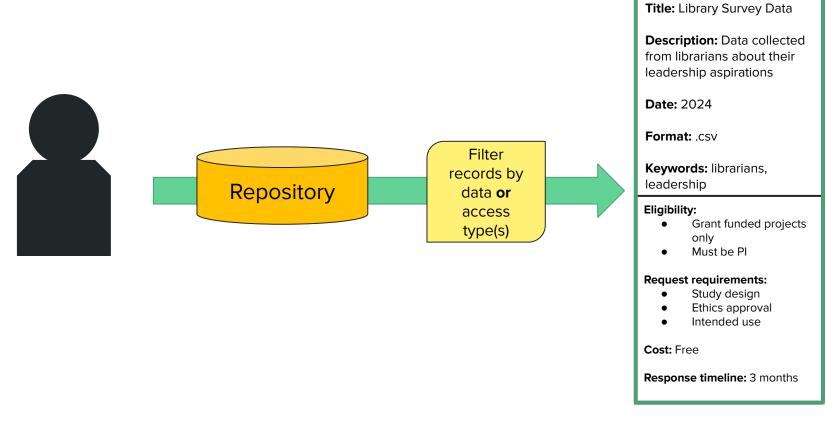
• Incorporate better access metadata into systems that store restricted datasets

#### Imagine...researcher deposits restricted dataset

Dataset Metadata	Access Metadata	
Dataset MetadataTitle: Library Survey DataDescription: Data collectedfrom librarians about theirleadership aspirationsDate: 2024	<ul> <li><b>Eligibility:</b> <ul> <li>Grant funded projects only</li> <li>Must be Pl</li> </ul> </li> <li><b>Request requirements:</b> <ul> <li>Study design</li> <li>Ethics approval</li> <li>Intended use</li> </ul> </li> </ul>	Repository
Format: .csv	Cost: Free	
<b>Keywords:</b> librarians, leadership	Response timeline: 3 months	

# Dataset Record

#### Imagine...researcher looking for data



#### Early next steps towards discovery and access...

#### Incoming Tri-Agency Data Deposit Policy:

- Develop minimal metadata disclosure for researchers collecting restricted data with Tri-Agency funding
- Include both dataset *and* access metadata

#### **Digital Research Alliance of Canada CAM Project:**

- Initiative to store and make available controlled access data (i.e., restricted datasets)
- Incorporate access-specific metadata into the <u>Federated Research Data Repository</u> for restricted datasets



## **Concluding thoughts**

Restricted data deserves to be made discoverable and accessible

Existing metadata schemas, technical infrastructure, and data sharing policies cannot adequately support restricted data

This work is hard – privacy, stewardship, good governance, security are crucial

More investment needed to ensure that this valuable data does not remain hidden and inaccessible

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## **Questions/Comments?**

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