Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

# Solving challenges in multi-regional health research

Kim McGrail
CRDCN – Opening Doors to Data
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# Declarations and Acknowledgements

No conflicts to declare



# Overview

- Health Data Research Network Canada
- The origins of challenges for cross-regional research
- Comparability of data (harmonized data / common data models)
- No movement of data (distributed / federated analysis)

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# HDRN Canada

**Health Data Research Network Canada**

is a distributed pan-Canadian network that supports multi-regional data access for transformative and world-leading health data use, working to shape a data future that better supports health and health equity.

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# Member Organizations

AbSPORU
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mælstrom

Manitoba Centre for Health Policy
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NEWFOUNDLAND AND LABRADOR
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# HDRN Canada

# Why is it this way in Canada?

- Constitutional Federation
- Independence
  - Legislation
  - Policies
  - Technology
- Politics

# Multi-regional studies are theoretically possible, but practically infeasible (right now)

- Federation means 13 provincial/territorial (P/T) health and data systems
- Hard to understand data holdings across P/Ts to plan studies
- Data not standardized across P/Ts to enable ‘apples and apples’ analysis
- Data generally not moved across P/T boundaries so hard to analyze it together as one

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# Solving challenges: comparability of data and no movement of data

# Definitions

**Information model**: Describes the characteristics and relationships of information for certain key real-world entities (e.g., “hospitalization”). It does not define how the information is stored or what technology is used.

**Data model**: Establishes how the data element is stored in a specific system. A data model always complies with an information model, explicitly or implicitly.

**Common data model**: A data model agreed upon by a large group of researchers with the aim of reusing it across multiple studies sharing a common purpose.

**Distributed analysis**: Statistical analysis of a distributed data source. The analysis aims to protect local data privacy and does not rely on exchanging line-level data outside of local sites

**Federated analysis**: A type of distributed analysis using federated data. Federated data share the same data model, which simplifies analysis. Federated analysis can also mean automation of technical connections across secure environments.

# Solving Challenges: Implementation of a Common Data Model

- Harmonizing requires deep local knowledge – data generation, idiosyncrasies, and changes over time
- Requires excellent documentation
- Takes a lot of time *but only needs to be done once*

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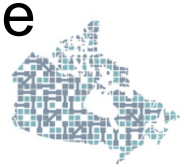
# Solving Challenges: Federated Data Analysis

- Distributed / Federated analysis is the best way to analyze data without having to move them
- Statistically – very possible for many types of analyses (and an area of needed methods development)
- When done well, produces results that are essentially identical to pooled analysis
- Can be done in a privacy sensitive way and in a way that does not require high levels of trust of other secure environments.
- Federation automates the information sharing
- Getting this right will also make international research possible



# Potential for OMOP Common Data Model + Federated Data Analysis

- Simplifying Production of Required Analytic Code
  - CDM provides federated data with the same data model
  - Not limited to a particular CDM, as long as it's a common model
- Supporting Rigorous "as if pooled" Analysis
  - Linear and logistic regression and survival analysis, with or without weights
  - Further development and testing underway

# Summing up

- Canada is a federation and has commitments to Indigenous data sovereignty
- This creates (surmountable) challenges for research using health data not available through CRDCN (StatCan) or CIHI
- Harmonized data and common data models are up-front investments that can have large impact, if the harmonization follows common / generalizable approaches (supporting construct / content validity)
- Distributed analysis / data federation can get around data sharing issues *and can support analyses that are equal to pooled.*
- All creates new opportunities for analyses both within and across regions, and and internationally.

# Thank you!

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