

# Factors Affecting Access to Administrative Health Data for Research in Canada

Cynthia Kendell<sup>1, 2</sup>, Geoff Porter<sup>1, 3</sup>, Adrian Levy<sup>4</sup>, Elaine Gibson<sup>5</sup>, Robin Urquhart<sup>1,3,4</sup>



Inspiring Minds

1. Department of Surgery, Nova Scotia Health Authority; 2. Interdisciplinary PhD Program, Dalhousie University; 3. Department of Surgery, Dalhousie University; 4. Department of Community Health and Epidemiology, Dalhousie University; 5. Schulich School of Law, Dalhousie University

## Background

- In Canada, a wealth of administrative health data are captured. Common databases typically include provincial/territorial insurance registries, physician billing claims, inpatient hospitalizations, day surgeries, vital statistics, and prescription medications [1,2].
- The primary use of these data is to facilitate healthcare administration, however, they are increasingly recognized as an invaluable resource for health research [3].
- In most provinces, provincial data repositories facilitate the use of these data for research purposes.
- Nonetheless, researchers across Canada are reportedly experiencing challenges accessing administrative health data for research [3-6].
- In addition, substantial inter-provincial variations in the timeliness of data access across provinces have been reported [6,7].

## Research Questions

- 1) What are the factors affecting access to administrative health data for research purposes in Canada?
- 2) How do these vary across provinces? Why?

## Objectives

- 1) Describe the processes for accessing administrative health data for research purposes in three Canadian provinces
- 2) Explore researchers' experiences with accessing administrative health data for research purposes in each province
- 3) Examine the perspectives of individuals involved in the regulation of data with regard to:
  - a) the use of administrative health data for research,
  - b) regulatory processes and policies,
  - c) their regulatory role,
  - d) their capacity to effectively perform their regulatory role
- 4) Compare and contrast (1)-(3) across provinces

## Methodology and Methods

### Methodology:

- This study will use a qualitative, multiple-case study design.
- A case will be included from each of three provinces: Nova Scotia, Ontario, and British Columbia.
- Each case will be comprised of a provincial data repository and relevant stakeholders.

### Data Collection:

- Two methods: interviews and documents
- In each province semi-structured interviews will be carried out with:
  - Researchers and research staff who have accessed data for research purposes (n=10), and
  - Individuals involved in the regulation and oversight of data access (n=10).
- Total n=60
- Documents will be obtained from online sources and interview participants.

### Analysis:

- Phase 1: Within-case analysis
  - Interview data for each stakeholder group will be analyzed separately using constant comparative analysis.
  - Document analysis will occur iteratively, and will inform interview guide adaptation, and supplement interview data.
- Phase 2: Cross-case analysis
  - Systematic comparison of findings for each individual case for each objective.
  - Development of a general theory on access to administrative health data that applies to all three cases included in the study.

## Expected Contributions and Conclusion

- Expected contributions to existing knowledge:
  - Mid-range theory explaining inter-provincial variations in access to administrative health data in Canada
  - Evidence on whether, and the extent to which, Canadian researchers are experiencing barriers to data access
  - Detailed descriptions of the policies and processes for accessing administrative health data in the provinces included in this study
  - A taxonomy of factors affecting access to administrative health data
- Findings will inform the development and implementation of strategies to improve access to administrative data for research in Canada.
- Potential benefits of improved data access include: improved efficiency of research, timely access to research evidence by decision-makers, and improved healthcare organization and delivery.

## References

1. Lucyk K, et al. Administrative Health Data in Canada: Lessons from History. *BMC Medical Informatics and Decision Making* 2015, 15(1):69.
2. Cadarette SM & Wong L. An Introduction to Health Care Administrative Data. *Canadian Journal of Hospital Pharmacy* 2015, 68(3).
3. The Expert Panel on Timely Access to Health and Social Data for Health Research and Health System Innovation: Accessing Health and Health-Related Data in Canada. Ottawa: ON, Council of Canadian Academies; 2015.
4. Willison DJ. Data Protection and the Promotion of Health Research: If the Laws Are Not a Problem, Then What Is? *Healthcare Policy* 2007, 2(3):39-43.
5. Kephart G. Barriers to Accessing and Analyzing Health Information in Canada: Canadian Institute for Health Information; 2002.
6. Meagher N & McGrail K. Data Access Review Times: A Study: Population Data BC; 2013.
7. Butler A, et al: Multi-province Epidemiological Research Using Linked Administrative Data: A Case Study from Canada. *International Journal of Population Data Science* 2018, 3(3).