



Accessing Health and Health-Related Data in Canada

**An Assessment by the Expert Panel on Timely Access to Health
and Social Data for Health Research and Health System Innovation**

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MISSION

To provide Canadians with:

- the best available scientific knowledge to inform debate decision-making
- independent, authoritative and evidence-based assessments on the scientific knowledge underlying current and future issues of public interest.

OPERATIONS

- a not-for-profit organization created February 2006
- Board of Governors, a Scientific Advisory Committee and a small Secretariat
- Member Academies: The Royal Society of Canada, the Canadian Academy of Engineering and the Canadian Academy of Health Sciences
- Core funding from the Government of Canada
- Assessments undertaken for the GoC, other governments, and others
- Assessments do not include recommendations
- 29 Assessments so far; 5 in works

Expert Panel Composition

14 Member Expert Panel with a range of specialities: data custodians; statisticians; privacy, ethics and legal experts; health care administrators; data systems researchers; and industry representatives



Other Participants

- 4 Council staff who formed the assessment team
- 6 consultants who worked with the team editing parts of the report
- 22 expert witnesses who either met with the Panel or were consulted by the assessment team
- 14 peer reviewers who submitted over 700 comments in response to a draft of the final report
- Dr. Lorne Babiuk, VPR at U. of Alberta, who monitored the Panel's consideration of the peer reviewers' comments on behalf of the Board of the Council

Nonetheless...

The Expert Panel is entirely responsible for the content of the report and its members were actively involved in its drafting

The Charge to the Panel

What is the current state of knowledge surrounding timely access to health and social data for health research and health system innovation in Canada?

- Submitted by CIHR through the Ministers of Industry and Health
- Reflects major frustrations encountered by researchers in accessing electronic health care records and other major admin data sets (tax, school, welfare, housing...)
- Also reflects clear awareness of the growing importance of linking health and health-related/social data sets

5 Sub-questions of the Charge

1. What is known about how to address **technological and methodological challenges** (such as variable data quality and comparability) associated with linkage of health and social data from various sources and across jurisdictions? **(CHAPTER 2)**
2. What is known about the **benefits, risks and barriers** to timely access to health and social data for health research and health system innovation in Canada? **(CHAPTER 3)**
3. What are the **ethical, legal, and social** implications of timely access to such data? **(CHAPTER 4)**
4. What are **best practices for improving access** to such data for researchers while ensuring appropriate privacy safeguards and also taking full advantage of the digital data revolution? **(CHAPTER 5)**
5. What are **best practices** in Canada and internationally for **governance frameworks** that facilitate access to such data and maintain public trust in the research enterprise? **(CHAPTER 5)**

In Scope

The assessment examined:

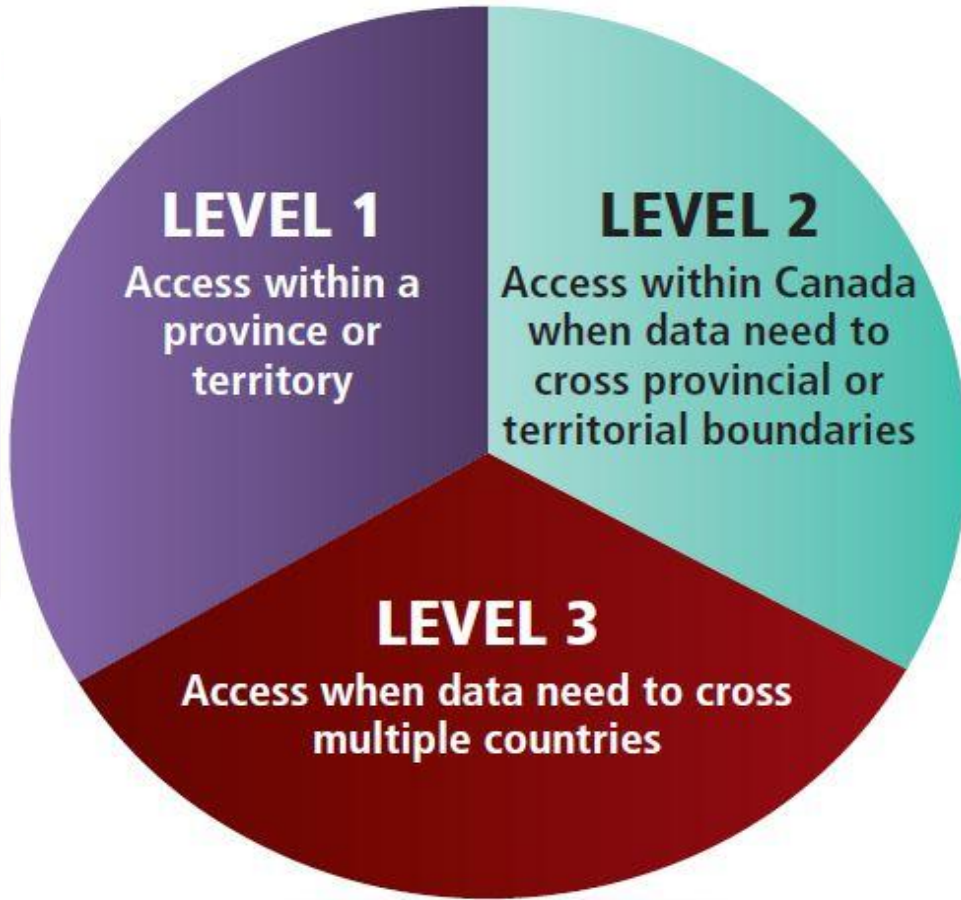
- Methods for enabling access to and integration of health and health-related data sets, such as electronic medical records, administrative data from hospitals, education data, etc.
- Benefits and risks of data access
- Privacy laws and ethics guidelines for data access
- Best practices of leading data collection organizations

Out of Scope

The assessment did *not*:

- Deal with privately-funded research and private sector access to data
- Deal with social data not related to health
 - For this assessment the Panel considered social data as non-health data that could influence health outcomes and thus uses the term ***health-related data***

Clarifying Definitions 1



Panel used this tri-level distinction to highlight issues and best practices that arise in connection with each level of access

Alternative Definitions of Levels

Level 1: Relevant data are under the control of entities within a single jurisdiction in Canada

Level 2: Relevant data are under the control of entities from multiple jurisdictions in Canada

Level 3: Relevant data are under the control of entities within Canadian and international jurisdictions

Clarifying Definitions 2

Data linkage: brings together information from different data sets, typically focusing on the individual as being the common element

- Often only requires access to data from a single jurisdiction (i.e. Level 1)

Data pooling: brings together the same or similar information about different individuals from different data sets

- Often requires access to data sets from multiple jurisdictions (Levels 2 & 3)
- Note that research projects often require both linked and pooled data

Clarifying Definitions 3

Distributed Analysis: Brings together the results of analysis performed on different data sets in a way that doesn't require the data themselves to be pooled or even transmitted

- Often is a way to conduct multi-jurisdiction analysis without violating concerns about sharing data (e.g., privacy-related concerns)

Data harmonization: Produces inferentially equivalent data thus allowing data from different sources to be compared or combined

- Often/ideally accomplished through adoption of common standards (*prospective* harmonization)

Clarifying Definitions 4

Complex environment of dissimilar entities: Quasi-system consisting of all institutions, organizations, departments and in many cases informal programs or even individuals that are involved in the provision of access to health and health-related data for research and system innovation

- In most cases the entities are only loosely organized or coordinated
- No over-all governance mechanism; leaves systemic issues unaddressed
- Nonetheless, questions re privacy, research, information and network governance apply at the level of the “quasi system”
- Some have called it an “ecosystem”
- Others have call it a “hodge-podge” (and some even a “mess”)

Elements of Assessment Methodology

Focus on two Key Questions:

- How do we improve access to data for researchers while still protecting the privacy of individuals?
- What kind of governance frameworks will enable this?

Focus on Best Practices:

- Panel identified **6 entities** in Canada and internationally that provide timely access to data (4 months or less) and determined common principles and specific practices that enable them to do so

Canadian

- MCHP (Manitoba)
- ICES (Ontario)
- BORN (Ontario)

International

- SAIL (Wales)
- Data Linkage WA (Australia)
- Farr Institute @ Scotland

Key Finding #1

Technological and Methodological Challenges of Access to Health Data

For effective research with health and health-related data, disparate sources of data must be linked, pooled or otherwise jointly analyzed. Challenges involved in doing so can include (i) ensuring the data are **harmonized** where standards differ and (ii) satisfying differing **privacy regimes** (and perhaps differing degrees of strictness in interpreting those laws).

Possible Solutions Outlined in Chapter 2

- CNODES – pools summary statistics on Adverse Drug Reactions generated at different sites across Canada
- DataSHIELD – mimics fully pooled data analysis when, in reality, individual-level data remain with their original custodian

Key Findings #2 and #3

Benefits of Access to Health Data

Evidence shows that timely access to data enables significant research that can have far-reaching effects on patient outcomes and on innovation in the health system

Risks of Access to Health Data

The risk of potential harm resulting from illicit access to data is tangible but low. The level of risk can be further lowered through effective governance mechanisms.

- Data breaches rarely happen at institutions set up specifically for maintaining large volumes of health data
- No examples of data breaches at 6 best practice entities
- **Note personal view of some panel members regarding vested interests and fear of potentially embarrassing results**

Key Finding #4

Legal and Ethical Considerations of Access to Data

Timely access to data is hindered by variable legal structures and differing interpretations of the key terms *identifiable* and *de-identified* across jurisdictions.

- Instead of rigidly classifying data as either identifiable or non-identifiable, it is useful to view de-identification as a continuum and to adjust access controls accordingly.
- Concept of ***proportionality***: keep the measures to protect confidentiality proportional to the risk of potential disclosure and the potential harm that could result

Key Finding #5

Governance

There is evidence that a shift is occurring among leading entities from a “data custodianship” model to a “data stewardship” model, where the promotion of access for research is an explicit goal. Central to the success of this shift is the adoption of good governance practices, specifically in privacy governance, research governance, information governance, and network governance.

- Note asymmetric incentives for data custodians
- Correction of asymmetry would seem to require changes in mandate
- Note connection between governance and the question of leadership with respect to the “complex environment”

Key Finding #5

Examples of Governance Best Practices (see 13 “earmarks” in report)

- **Privacy governance**
 - Dedicated processes (complementary to REBs) that specifically evaluate privacy concerns when enabling data access
- **Research governance**
 - Harmonization of the REB process to minimize the number of approvals (and improve timeliness) when performing cross-subject or cross-jurisdictional research
- **Information governance**
 - Use of new technologies and robust de-identification techniques to improve confidentiality safeguards
 - Development of systematic models for characterizing risk and adoption of a proportionate approach to governance
- **Network governance**
 - Implementation of standards to enable prospective harmonization if possible
 - Establishment of multinational consortia with clear rules and protocols for data access by researchers from different jurisdictions

Personal Observation re Leadership

- Allied with the prohibition re making recommendations, the Panel was advised re a similar constraint re issuing a call for “leadership”
- Nonetheless, the Panel did note that best practice organizations had all resulted from environmental reviews mandated “from above”
- The following wording passed Council’s editors:

“Clarifying the responsibilities of key entities in Canada’s [or Alberta’s] complex environment could be a positive step in enabling timely access to health and health-related data for research [with reference to an example detailed in Table 5.2]”

Critical Issue: Culture of Caution

“The ethical and legal frameworks currently in place in Canada appear to strike a balance between enabling research and respecting privacy. In practice, however, lack of knowledge and trust has led to a conservative implementation of these frameworks. Indeed, evidence suggests that current data use is too often subject to undue restrictions that inhibit timely access and adversely affect health and social outcomes.”

Next Steps

- Panel members are speaking at conferences to raise awareness of report's findings
- CIHR is pleased with the report and we believe is considering how best to engage stakeholders
- Ideally, review of the report by stakeholders within individual jurisdictions will identify opportunities for improvement

Summary

- Our health and data resources in Canada and perhaps especially in Alberta are extensive and highly regarded for their breadth and reliability
- These resources, linked with health-related data from (e.g.) Stats Canada and others, can be used to improve the quality of care and develop system improvements without compromising privacy
- Access to these data is constrained by the culture of caution
- Establishing a culture of trust would seem to be the way forward, but will require widespread engagement by all parties

Final Thought

- The benefits of fully utilizing our high quality data resources to improve the health system will increase as technology continues to develop and digitized data become more abundant
- Eliminating the sense of “hodge-podge” that some see as characterizing the current environment of entities involved in health data is essential if the health system is to become a “learning organization”... an organization that analyzes data, learns from its mistakes, and takes action to fix them

Thank you

The full report and executive summary is available for download from the Council's website,

www.scienceadvice.ca

Questions regarding the Council should be directed to **Cate Meechan**, Director of Communications,

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