

DATA DISARRAY

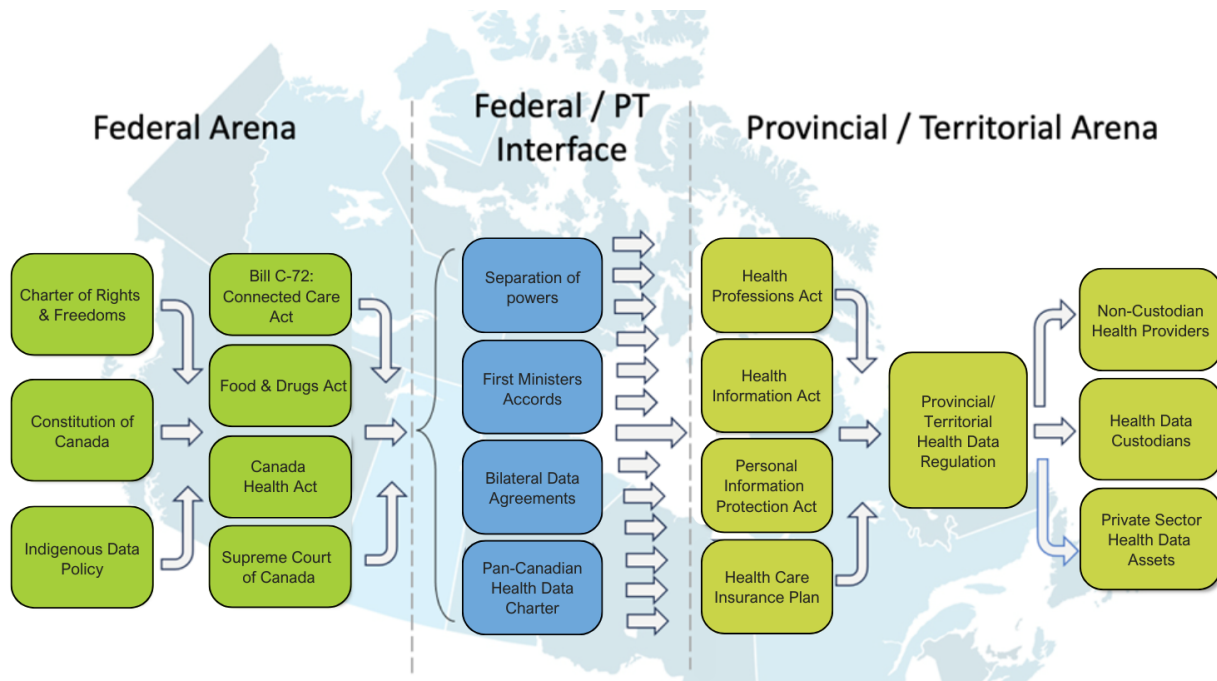
A ROOT CAUSE ANALYSIS OF HEALTH DATA DYSFUNCTION IN CANADA

REPORT SUMMARY

There is a growing recognition that shortfalls in the design and use of health data in Canada are resulting in health system dysfunction and preventable harm to Canadians.¹ Health data is an essential requirement of all health programs and services and is governed by public policy that defines how it can be captured, utilized and shared. Improving quality health programs and services in Canada requires health data optimization, which is best guided by a clear articulation of the current state of health data design and use. To accomplish this, an analysis of health data function in Canada was carried out by:

- Conducting a high-level evaluation of the impact of current national and jurisdictional public policy on health data design and use (figure 1); and
- Considering what this public policy reveals about the attitude of Canada, its jurisdictions, and the health sector toward health data.

Figure 1: Arenas and domains of public policy impacting health data in Canada



This study suggests that there are significant shortfalls in the current approach to health data governance and public policy that impair the provision of quality health programs and services and foster health data-related harm in Canada. The overarching picture that emerges is of a public policy environment that has not been designed, but rather evolved in the absence of a coordinated or informed plan, and generally fails to support the opportunities offered by contemporary digital health information technology. This takes the form of outdated, misaligned or absent health data public policy - across and within jurisdictions - that is perpetuated by the lack of a mechanism or accountability to adopt harmonized and purpose-designed health data public policy that upholds quality health programs and services.

The report concludes that the oversight and regulation of many properties of health data that could promote quality of care and mitigate potential harm - including the assurance that data is used to promote the health and wellbeing of individuals and populations, foster insights through secondary data use, minimize provider burnout, and promote health system efficiency - are almost uniformly absent from public policy. Rather the current public policy approach to health data appears to hinder adherence to the core conditions of the *Canada Health Act*, notably portability, universality, accessibility and comprehensiveness of health service. This may arise from a widespread lack of health data literacy anchored in a poor appreciation of the intimate relationship between health data and quality health programs and services. Attention to health data seems to have been lost in the clamour to procure new and often disconnected information technologies, a drive buttressed by the structural fragmentation of health system oversight in Canada, and the legislated fragmentation of personal health information. The resulting harm to people, populations and the health care system – dating back decades - seems scarcely to have been noticed. Achieving cooperative health data interoperability has been hindered by a will to preserve jurisdictional, organizational and professional data autonomy. Ultimately the needs of the patient, whom the data belongs to, have not been heard.

A wholesale reimagination of health data governance and public policy is required in Canada, without which individuals, health care providers and the health care system will continue to suffer from manifold forms of harm, including morbidity, mortality, financial cost, health provider burnout, and legal and cultural harm. To achieve optimized data function an evidential, cooperative and harmonized approach to health data governance and public policy is required across all levels of service and health system oversight. The public and Indigenous communities as the rightful beneficiaries of their data must be meaningfully engaged in this collective effort.

The summary findings of this report are as follows:

HEALTH DATA GOVERNANCE

1. It is unclear who oversees the design and use of health data in Canada, the provinces, and territories.
2. Health data oversight has largely defaulted to the provinces and territories, but is not mandated in public policy.
3. There is no mechanism for harmonizing health data public policy across health system stakeholders and jurisdictions.
4. The current custodial model of health data oversight employed in most jurisdictions unintentionally fosters the fragmentation of health data and promotion of health data-related harm.
5. The scope of legislative and regulatory oversight of health data is largely consistent across provinces and territories, focusing almost exclusively on personal access, privacy, and the security of health information.
6. Although health information legislation in Canada is generally permissive of sharing health data for legitimate health service it does not obligate it to support health and wellbeing.
7. Patient access to health information is generically enabled in legislation, but not enforced in digital health technology design and regulation.

HEALTH DATA POLICY GAPS

8. Canadian public policy at all levels has traditionally neglected to identify if, or how, health data is to be designed and used to support the provision of quality health programs and services.
9. There is a consistent absence of the acknowledgment of most forms of health data-related harm, including the capacity to damage the health and wellbeing of Canadians and health workforce, at all levels of health data public policy in Alberta and Canada.
10. The integration of principles of Indigenous data sovereignty into health data design and use are often absent in governmental public policy.
11. Health information technology is almost wholly unregulated with respect to its capacity to promote the health and wellbeing of Canadians and mitigate harm and foster innovation.
12. Individuals who design and use health data systems in Canada do not require any data literacy training, defined credentials, or knowledge assets.

Based on the findings the following recommendations were made:

ACCOUNTABILITY TO QUALITY HEALTH PROGRAMS & SERVICES

- 1 Health data public policy must promote the provision of quality health programs and services.
- 2 Health data public policy must minimize all forms of health data-related harm, meaning:
 - Breaches of health data privacy and security.
 - Damage to physical or emotional health and wellbeing.
 - Breaches of cultural rights to personal or community health data.
 - Breaches of legal and ethical rights to personal health data.
 - Failure to benefit from science and use health data for public good.
 - The misuse of data to create misinformation, information, or circumstances that may intentionally or unintentionally promote discrimination, inequities, or profit without social license.
 - Failure to optimize health system function and efficiency.
 - Damage to health workforce wellbeing.
 - Failure to support health innovation.

GOVERNANCE

- 3 There must be clarity about health data oversight in Canada:
 - Is health data a federal, provincial/territorial, Indigenous, or shared power and, if shared, what the distribution of accountability is.
 - Within provinces and territories establish who or what peoples, organization(s), or authority oversee(s) health data design and use.
- 4 Health data legislation should support the principles of Indigenous data sovereignty and governance, and mandate mechanisms to tangibly implement principles in collaboration with Indigenous communities.
- 5 Optimized health data public policy must be developed in the context of open and transparent public and Indigenous consultation, and through the meaningful inclusion of public and Indigenous representation in strategic oversight.
- 6 Health data legislation should be harmonized across Canada through a model law approach.
- 7 A functional process for harmonizing jurisdictional health data legislation and public policy should be established.

PUBLIC POLICY

- 8 Health data design and use should be accountable to the principles of the pan-Canadian Health Data Charter.

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- 9** The five conditions of the *Canada Health Act* should be applied to the design and use of health data as suggested by the *pan-Canadian Health Data Charter*. Specifically:
- Health data public policy should uphold the portability, accessibility, universality, and comprehensiveness of health data.
 - The implications of the public administration of health data should be considered to clarify the use of personal health information to support quality health services and programs, open science and digital health innovation.
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- 10** Consideration should be given to amending the *Canada Health Act* to embed accountability of jurisdictional Health Quality Councils to the spirit and intent of the Act, thereby promoting quality of care by mandating quality council oversight of the portability, accessibility, universality, and comprehensiveness of health data.
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- 11** Health data public policy must foster person-centric health data architecture.
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- 12** There should be comprehensive health data legislation that incorporates in one or more complementary acts:
- Accountability to the *pan-Canadian Health Data Charter*.
 - Accountability to the provision of quality health programs and services.
 - The mitigation of all nine forms of health data-related harm.
 - Compulsory patient access to their comprehensive personal health information in a digital format that is open and portable.
 - Conditions to support person-centered health data architecture.
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- 13** Health information privacy legislation must move beyond mere permissibility of data sharing to a duty to share personal health information within the bounds of appropriate privacy and security safeguards, to foster quality health programs and services, and minimize all forms of health data-related harm.
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- 14** The custodial model should be evolved to a stewardship model of health data oversight as proposed in the third report of the *pan-Canadian Health Data Strategy* Expert Advisory Group.²
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- 15** Examples of best practice, like the European Health Data Space, should be leveraged to inform evidential Canadian health data public policy.
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REGULATION

- 16** To support comprehensive team-based care, all health professionals should be governed by the same health data legislation and regulations or, otherwise be enabled to interact with health data in a consistent manner when performing similar duties, regardless of workplace location or context.

² Government of Canada, Pan-Canadian health data strategy: Toward a world-class health data system, 2022, (<https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-03-toward-world-class-health-data-system/expert-advisory-group-report-03-toward-world-class-health-data-system.pdf>)

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- 17** To uphold the health and wellbeing of the public and the capacity of their members to provide competent and compassionate team-based care, health profession regulators should advocate for:
- The harmonization of health data legislation and regulation across all health professions.
 - The regulation of health information technology.
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18 Health profession regulators should adopt data literacy standards for their registrants and compatible health data Standards of Practice based on a model law approach that supports person-centric team-based care.

19 Health information technology should be regulated for safety in alignment with other medical devices covered in the *Food and Drugs Act*.

HEALTH DATA LITERACY

20 Health data literacy must be promoted for the health workforce and public alike.