

# DATA DISARRAY

A ROOT CAUSE ANALYSIS OF HEALTH  
DATA DYSFUNCTION IN CANADA

ALBERTA VIRTUAL CARE COORDINATING BODY

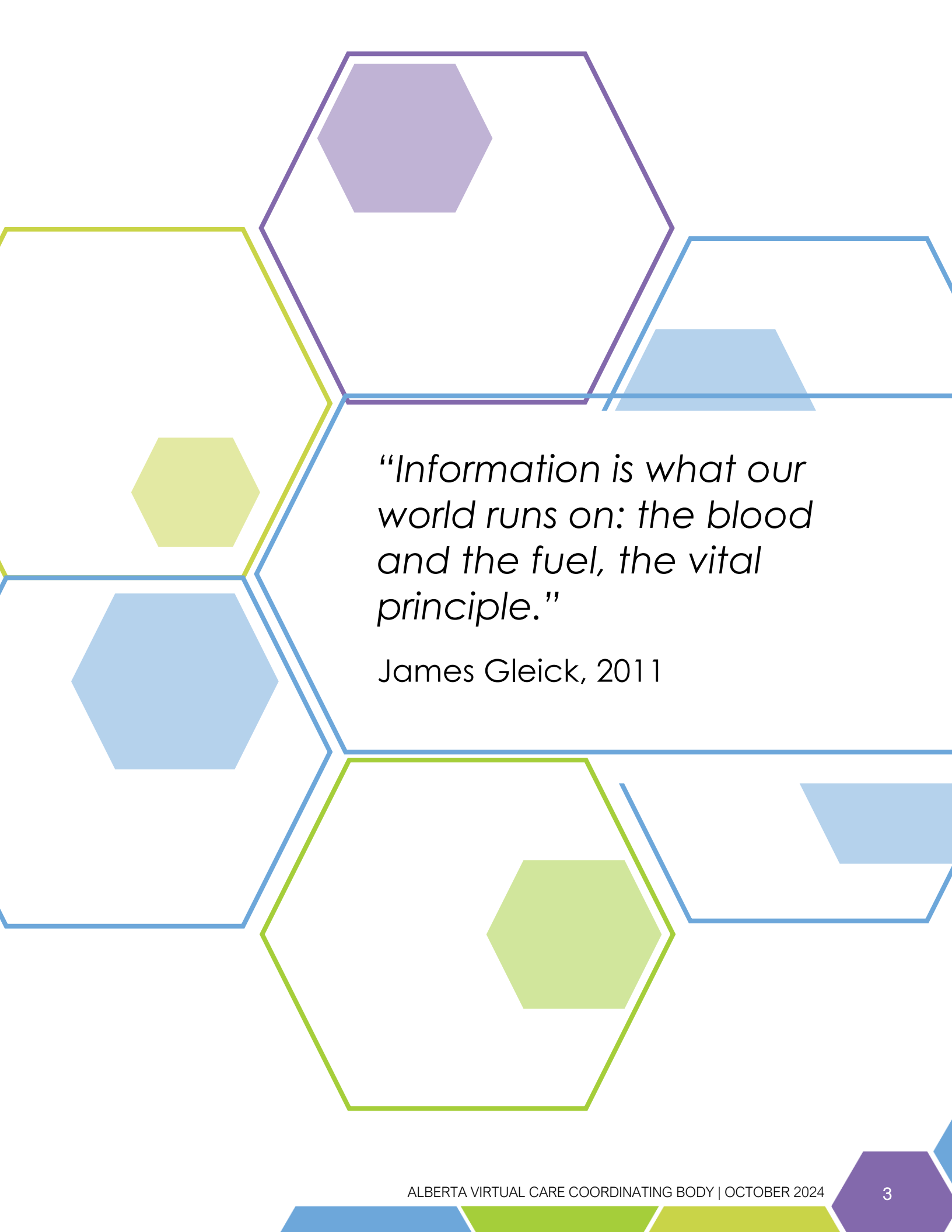
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# STATEMENT OF ACCOUNTABILITY

The reports of the Alberta Virtual Care Coordinating Body (AVCCB) are the product of cooperative principle-based collaboration across diverse members of the public and those working in the health field to promote quality health programs and services that will benefit all people receiving care in Alberta and Canada.

Participation of an individual in an AVCCB project, including the publication of a report, does not indicate endorsement of the content of the report by the institution or organization that employs the individual.

Institutional and organizational participation in and endorsement of AVCCB efforts is welcomed and encouraged in support of collective accountability to quality health programs and services.



*“Information is what our world runs on: the blood and the fuel, the vital principle.”*

James Gleick, 2011

# REPORT CITATION

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# FORWARD

*“Information is the lifeblood of medicine. Health information technology is destined to be the circulatory system for that information.”*

David Blumenthal

Albertans and Canadians assume that their health data exists within a well-structured framework that keeps their personal information safely available for use by us and all members of our care team when monitoring and making care decisions. We also assume that the different parts of the health care and research sectors work together seamlessly and efficiently. These assumptions are not well founded.

Our family, from both our personal experience, and through our conversations with hundreds of audiences after seeing *Falling Through the Cracks: Greg’s Story*, have learned that making this assumption is dangerous and potentially harmful.

The Alberta Virtual Care Coordinating Body’s *Interoperability Saves Lives* report clearly showed that there are many gaps and barriers to the access and use of patient’s information resulting in harm and in some cases death.<sup>1</sup> It strongly outlined the reason “why” things must change to elevate the priority of safety for both patients and providers. Health data availability is a critical ingredient to enable significant improvement in the quality of care and the effectiveness of the health system.

This current report – *Data Disarray* - provides a clear picture of what exists and what is absent in terms of policies and regulation with respect to health data. An apt description is that we have a collaborative wasteland dotted with solitary and disconnected pieces of legislation and regulation each serving individual custodian’s health data requirements. This landscape is devoid of the required network based on a broad system view enabling and ensuring all players collaborate for the betterment of everyone’s safety and care. *Data Disarray* paints the Alberta picture, but the situation will be recognized by other jurisdictions as well.

When these two reports - *Interoperability Saves Lives* and *Data Disarray* - are considered together and placed in the context of the principles of the *Pan-Canadian Health Data Charter*, we get much closer to comprehending and appreciating what the vision for Canadian health care should look and feel like.

What must follow is the action to drive significant positive change. We have the current desolate landscape and the unacceptable harm happening and we have sound guiding principles. We must act to create the legislative and regulatory framework to ensure health information interoperability,

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<sup>1</sup> Affleck E et al., *Interoperability Saves Lives*, 2023, ([https://www.albertavirtualcare.org/files/ugd/efde1a\\_43101bc906434781a6d497cd576602c1.pdf](https://www.albertavirtualcare.org/files/ugd/efde1a_43101bc906434781a6d497cd576602c1.pdf))

and to open the immense power of data to create the conditions for safe and continuously improving quality care.

It is critically important that all Albertans, and Canadians replace the assumptions we have with new knowledge and the motivation to expect and ensure substantial improvements are made for all of us today and tomorrow.



Dave Price

Greg's Wings  
Acme, Alberta

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# INTRODUCTION

The way that information can be used has been transformed by digital technology, offering novel opportunities to harness data to drive potent capability and insight. Over the past thirty years, digital transformation has been witnessed in almost every industry and sector of society and is accelerating with the current ascendancy of artificial intelligence.

The health sector has not been an exception; digital health information technology has been adopted worldwide with the bold assertion that it would usher in transformative efficiency and enhance the quality of health programs and services.<sup>2</sup> The early belief that the marriage of health services and digital health information technology would be a fortuitous union was buoyed by the insight that data is the lifeblood of all informed decisions in the health industry.

Yet, for the most part, the opposite has occurred. Globally, health systems have struggled to adapt to the advent of digital technology,<sup>3 4</sup> and Canada has arguably distinguished itself as a particularly poor performer. A 2023 review of the Canadian response to the COVID-19 pandemic in the British Medical Association Journal concluded, *“the picture that emerges is an ill-prepared country with outdated data systems, poor coordination and cohesion, and blindness about its citizens’ diverse needs.”*<sup>5</sup> Likewise, a 2022 study by the RAND Europe research group suggested that fragmented health data in Canada arises from *“a lack of integration, standardisation and interoperability of the technical infrastructure”* that is depriving Canada of almost 6 billion dollars in projected savings annually.<sup>6</sup>

Experts in Canada concur - *Connecting the Dots*, a 2023 report from the Canadian Council of Academics, observed that *“although Canada has worked for decades to improve the collection and use of health data, it has largely failed to share those data efficiently across organizations, regions, and provincial/territorial borders.”*<sup>7</sup> The report concluded that *“the barriers that prevent the establishment of robust health data sharing systems are not technical, but rather fundamentally political and cultural.”*<sup>8</sup>

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<sup>2</sup> RAND office of media relations, RAND Study says health information technology can improve quality and efficiency; more evidence needed about how to put the technology into wider use, 2006, (<https://www.rand.org/news/press/2006/04/11.html>)

<sup>3</sup> Koppel R. Great promises of healthcare information technology deliver less. In: Weaver, C., Ball, M., Kim, G., Kiel, J. (eds) Healthcare Information Management Systems. Health Informatics. Springer, Cham, 2016, ([https://doi.org/10.1007/978-3-319-20765-0\\_6](https://doi.org/10.1007/978-3-319-20765-0_6))

<sup>4</sup> World Health Organization, Meeting on secondary use of health data, 2022, (<https://www.who.int/europe/news-room/events/item/2022/12/13/default-calendar/meeting-on-secondary-use-of-health-data>)

<sup>5</sup> Clark J et al., The world expected more of Canada, 2023, (<https://www.bmj.com/content/bmj/382/bmj.p1634.full.pdf>)

<sup>6</sup> Marco Hafner et al., The potential socio-economic impact of telemedicine in Canada, 2022

<sup>7</sup> Council of Canadian Academies, Connecting the dots - Expert panel on health data sharing, 2023, ([https://cca-reports.ca/wp-content/uploads/2023/10/Connecting-the-Dots\\_ENdigital\\_FINAL.pdf](https://cca-reports.ca/wp-content/uploads/2023/10/Connecting-the-Dots_ENdigital_FINAL.pdf))

<sup>8</sup> IBID



In 2022, the Competition Bureau of Canada observed that “*disparate privacy and data governance rules across provinces and territories can reduce data sharing among health care providers, impede innovation and lower the adoption of digital health care solutions.*”<sup>9</sup>

The Expert Advisory Group of the pan-Canadian Health Data Strategy came to a similar conclusion in 2022, stating that “*failure to collaborate across Canada to build a learning health system risks continued escalation of health care costs, underperformance of health services and poor health outcomes including avoidable illness and death, low levels of innovation, perpetuation of health inequities, and ineffective responses to future public health threats.*”<sup>10</sup> The group concluded, “*at an extreme, there is a risk of irreparable fragmentation of health data that will harm individuals, communities, and all of Canada due to unaligned and often competing interests that may erode the common values that have defined our health system to date.*”<sup>11</sup>

In 2023, the Alberta Virtual Care Coordinating Body (AVCCB) suggested that the fragmentation of health data in Canada results in widespread harm to individuals, populations, and health system function, and observed that most forms of health data-related harm are unchecked and overlooked in public policy.<sup>12</sup> Likewise, in 2023 the Public Policy Forum, a Canadian think tank noted that Canada is “*lagging*” behind other nations in its use of health data and “*sound[ed] the alarm about Canada’s chronic, subpar performance on data, the vital currency of a digital-age [health] system.*”<sup>13</sup>

***Why have we in Canada established an approach to health data that is leading to the harm of individuals?***

These references are a small sample of a growing list of thought leaders who suggest that health data design and use in Canada is deeply troubled and contributes to health system dysfunction and preventable harm to Canadians. For a nation that holds its health service in high regard, the question must be asked: how has this happened? Why are we in Canada taking an approach to health data that harms people? This is an important question, for if one hopes to fix a problem, it is prudent to first understand its root cause.

The purpose of this report is to shed light on the genesis of health data dysfunction by conducting a root cause analysis of current health data design and use in Canada.

The analysis was carried out by focusing on Canadian and provincial public policy through two lenses:

<sup>9</sup> Government of Canada, Unlocking the power of health data, 2022, (<https://competition-bureau.canada.ca/unlocking-power-health-data>)

<sup>10</sup> Pan-Canadian Health Data Strategy Expert Advisory Group, Toward a World-class Health Data System, 2022, (<https://www.canada.ca/en/public-health/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.html>)

<sup>11</sup> IBID

<sup>12</sup> Affleck E et al., Interoperability Saves Lives, 2023, ([https://www.albertavirtualcare.org/files/ugd/efde1a\\_43101bc906434781a6d497cd576602c1.pdf](https://www.albertavirtualcare.org/files/ugd/efde1a_43101bc906434781a6d497cd576602c1.pdf))

<sup>13</sup> Frangou C, Unlocking health care - How to free the flow of life-saving health data in Canada, 2024, (<https://ppforum.ca/wp-content/uploads/2024/01/UnlockingHealthcare-LifeSavingDataInCanada-PPF-Jan2024-EN-2.pdf>)

- Conducting a high-level evaluation of the impact of national and jurisdictional public policy on health data design and use; and
- Considering what existing public policy reveals about the attitude of Canada, its jurisdictions, and the health sector to health data, and how these attitudes manifest a *Canadian health data culture*.

### AUTHOR'S NOTE

In this report, jurisdictional public policy will be limited to an examination of Alberta legislation, regulation, and policy. However, the methodology could be applied to examine health data public policy in other provinces or territories.



# EXECUTIVE 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.<sup>14</sup> 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; and
- Considering what this public policy reveals about the attitude of Canada, its jurisdictions, and the health sector toward health data.

This study found 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 to uphold 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. Instead, 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 reimagining 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 established mechanism for harmonizing health data public policy across health system stakeholders and jurisdictions.

### EXISTING HEALTH DATA LEGISLATION AND REGULATION

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 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, 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*.
- 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.
- 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.
- 11 Health data public policy must foster person-centric health data architecture.
- 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.
- 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.
- 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.<sup>15</sup>
- 15 Examples of best practice, like the European Health Data Space, should be leveraged to inform evidential Canadian health data public policy.

<sup>15</sup> 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>)

## 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.
- 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.
- 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.

# DEFINITIONS & TAXONOMY

The standardization of key terms used in this report is best practice. The definitions and the relationship between terms have been selected for their accuracy and precedent as industry standards.



## DIGITAL HEALTH

*“The use of digital information technology, communication tools, services, and processes to deliver health care programs and services to facilitate health and wellbeing.”<sup>16</sup>*



## HEALTH DATA

*“Observations, facts, or measurements which relate to the physical or mental health status of individuals, health system performance, and socio-economic, community and health system characteristics.”<sup>17</sup>*



## HEALTH INFORMATION

*“Health data that have been analyzed or interpreted to provide insight or a narrative related to the physical or mental health status of individuals, health system performance, and socio-economic, community, and health system characteristics.”<sup>18</sup>*



## PUBLIC POLICY

*“An institutionalized proposal or a decided set of elements like laws, regulations, guidelines, and actions to solve or address relevant and real-world problems, guided by a conception and often implemented by programs.”<sup>19 20</sup>*

<sup>16</sup> The definition was adapted from Medical Council of Canada, Clinical informatics, 2022, (<https://mcc.ca/objectives/medical-expert/clinical-informatics/>)

<sup>17</sup> Pan-Canadian Health Data Strategy Expert Advisory Group, Toward a World-class Health Data System, 2022, (<https://www.canada.ca/en/public-health/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.html>)

<sup>18</sup> IBID

<sup>19</sup> Wikipedia, Public policy, last updated 2024, ([https://en.wikipedia.org/wiki/Public\\_policy](https://en.wikipedia.org/wiki/Public_policy))

<sup>20</sup> Turgeon J and J-F Savard, Public Policy, in L. Côté and J.-F. Savard (eds.), Encyclopedic Dictionary of Public Administration, 2012, ([https://dictionnaire.enap.ca/Dictionnaire/64/index\\_by\\_author.enap?by=aut&id=14](https://dictionnaire.enap.ca/Dictionnaire/64/index_by_author.enap?by=aut&id=14))





## HEALTH DATA-RELATED HARM

*“Damage suffered by individuals, populations, or the health system arising from the use, non-use, or misuse of health data.”<sup>21</sup>*



## DATA CUSTODIAN

*“An individual or organization responsible for the secure collection and/or storage of health data and the curation of health data use, disclosure, retention, and disposal. Primarily concerned with security and privacy of health data.”<sup>22</sup>*



## INDIGENOUS DATA SOVEREIGNTY

*“The ability for Indigenous Peoples, communities, and Nations to participate, steward, and control data that is created with or about themselves.”<sup>23</sup>*



## PERSON-CENTRED DATA ARCHITECTURE

*“The design of health data around the individual as owner and basic unit of care to assure that their comprehensive and complete health data follows them over time and location for the entire course of their care journey.”<sup>24</sup>*



## DATA LITERACY

*“Data literacy is the ability to understand data and health data practices sufficiently to meaningfully interpret data and effectively communicate that meaning. Most importantly data literacy requires understanding the meaning of data, how it fits into a broader context, and what conclusions can and can’t be derived from that data.”<sup>25</sup>*



## HEALTH INFORMATION TECHNOLOGY

*“The electronic systems health care providers – and increasingly, patients – use to store, share, and analyze health information.”<sup>26</sup>*

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<sup>21</sup> E Affleck et al. Human factor health data interoperability, Longwoods, Healthcare Papers, 2024. (<https://www.longwoods.com/content/27272/human-factor-health-data-interoperability>)

<sup>22</sup> Pan-Canadian Health Data Strategy Expert Advisory Group, Building Canada’s Health Data Foundation, 2021, (<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-02-building-canada-health-data-foundation/expert-advisory-group-report-02-building-canada-health-data-foundation.pdf>)

<sup>23</sup> University of Toronto Libraries, Research guides, (<https://guides.library.utoronto.ca/indigenoustudies/datasovereignty>)

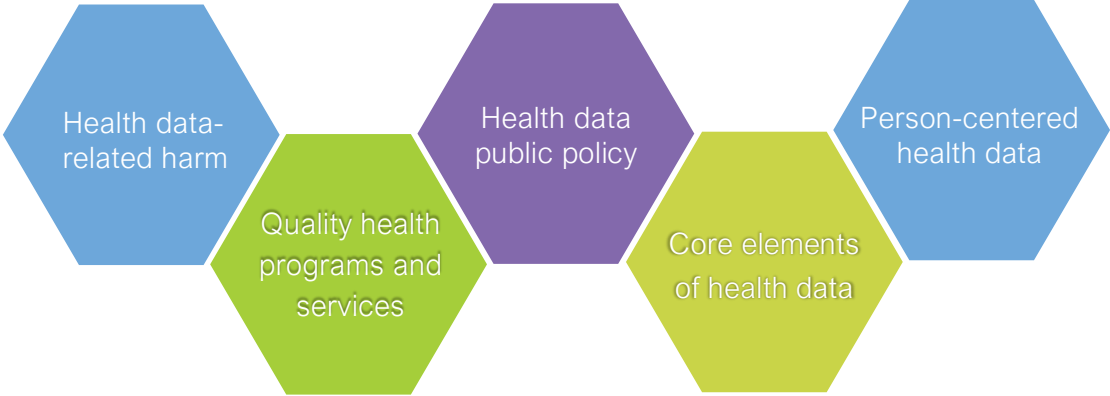
<sup>24</sup> This definition is proposed by the authors of this report.

<sup>25</sup> National Library of Medicine, Data literacy, (<https://www.nlm.gov/guides/data-glossary/data-literacy>)

<sup>26</sup> The US Department of Health and Human Services, Health IT: Advancing America’s Health Care, n.d., (<https://www.healthit.gov/sites/default/files/pdf/health-information-technology-fact-sheet.pdf>)

# KEY IMPERATIVES

To conduct a root cause analysis of the current state of health data design and use in Canada, the following key imperatives were defined and considered:



## HEATH DATA-RELATED HARM

Just as health data must be designed to deliver quality health programs and services, its use must also minimize harm to individuals, populations, and the health care system. In this report, harm arising from the use, non-use, or misuse of health data is categorized according to the AVCCB health data-related harm framework (Table 1).<sup>27</sup>

<sup>27</sup> Affleck E et al., Interoperability Saves Lives, 2023, ([https://www.albertavirtualcare.org/files/ugd/efde1a\\_43101bc906434781a6d497cd576602c1.pdf](https://www.albertavirtualcare.org/files/ugd/efde1a_43101bc906434781a6d497cd576602c1.pdf))

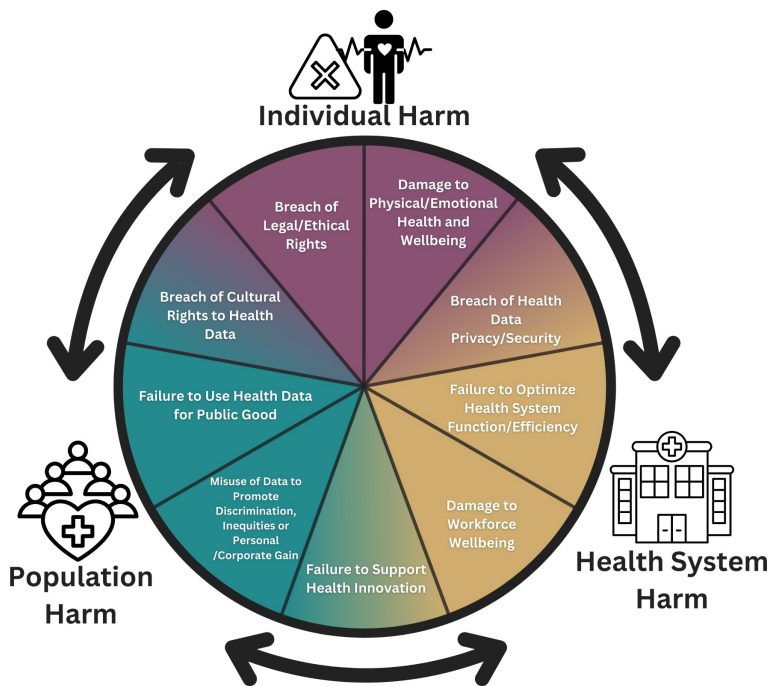
Table 1: Domains and categories of health data-related harm



<b>Domains of health data-related harm</b>	
A.	Individual harm
B.	Population-based harm
C.	Health system harm
<b>Categories of health data-related harm</b>	
1.	Breach of personal health data privacy & security
2.	Damage to physical or emotional health and wellbeing through data misuse, non-use, or lack of integrity
3.	Breach of cultural rights to personal health data
4.	Breach of legal and ethical rights to personal health data
5.	Failure to benefit from science and use health data for public good
6.	Poor design or misuse of data to create misinformation, information, or circumstances that may intentionally or unintentionally promote discrimination, inequities, or seek profit without social license.
7.	Failure to optimize health system function and efficiency due to poor data design, misuse, non-use, or lack of data integrity
8.	Damage to health workforce wellbeing from poor data design and/or misuse, non-use, or lack of data integrity
9.	Failure to support health innovation through health data misuse, non-use, or lack of data integrity

The nine forms of health data-related harm articulated by the AVCCB framework are understood to exist in a matrix relationship (Figure 1), can coexist, and all can lead to individual harm. Some forms of harm contribute more meaningfully to one domain (e.g., damage to physical and emotional wellbeing to individual harm), while others can contribute to multiple domains (e.g., breach of cultural rights to health data to both individual and population-based harm). Health data-related harm can arise both from the under-sharing or over-sharing of data, or from intrinsic deficits in data quality. The Health Data-related Harm Framework can be used to evaluate an instance of operational data use, or the overall integrity of a data system design.

Figure 1: Matrix of forms of health data-related harm



## QUALITY HEALTH PROGRAMS & SERVICES

As an essential ingredient of informed decision-making, the design and use of health data must be framed around its capacity to enable the provision of quality health programs and services. For the purposes of this report, *quality health programs and services* are defined according to the World Health Organization’s seven domains of quality:<sup>28</sup>

- Safe health programs and services
- Efficient health programs and services
- Effective health programs and services
- Equitable health programs and services
- Timely health programs and services
- Person-centred health programs and services
- Integrated health programs and services

<sup>28</sup> Kelly E et al., Quality in primary health care, 2018, (<https://iris.who.int/bitstream/handle/10665/326461/WHO-HIS-SDS-2018.54-eng.pdf?sequence=1>)

## PUBLIC POLICY & HEALTH DATA

Public policy is broadly defined as “an institutionalized proposal or a decided set of elements like laws, regulations, guidelines, and actions to solve or address relevant and real-world problems, guided by a conception and often implemented by programs.”<sup>29</sup> <sup>30</sup> It is thereby the tool used by health system leadership and decision-makers to guide health service design and delivery, including health data design and use.

Public policy is both a determinant of system design, but also a reflection of the *culture or way of being* of the people who oversee a system.

Public policy is not only a determinant of system design - but as a human construct - it is also a reflection of the *culture or way of being* of the people who oversee a system.

Therefore, it follows that an analysis of health data public policy can inform an understanding of both:

- The form and function of health data design and use; and
- The set of beliefs, attitudes, or cultural conventions of health system players, including governments, institutions, health professionals, and the public toward health data design and use.

## CORE ELEMENTS OF HEALTH DATA

Health data is a key constituent of all health service decisions. Health data is inert; it requires context and analysis to guide insight and inform health service decisions. Context and analysis arise from the manipulation of health data by human beings, technology, or both. The capacity of human beings and technology to manipulate health data is enabled by financial and knowledge resources. Therefore together, the resources and infrastructure needed to support a functioning health data ecosystem are:

- Human resources
- Financial resources
- Health information technology
- Data

The provision of quality health programs and services are reliant on evidential decisions arising from health data analysis; decisions that foster the health and wellbeing of people and populations and minimize harm. As such, it follows that to optimize a health data ecosystem, the design and management of its constituent elements – human, financial, technology and data resources and infrastructure – must intentionally foster the provision of quality health programs and services. This is

<sup>29</sup> Wikipedia, Public policy, last updated 2024, ([https://en.wikipedia.org/wiki/Public\\_policy](https://en.wikipedia.org/wiki/Public_policy))

<sup>30</sup> Turgeon J and J-F Savard, Public Policy, in L. Côté and J.-F. Savard (eds.), Encyclopedic Dictionary of Public Administration, 2012, ([https://dictionnaire.enap.ca/Dictionnaire/64/index\\_by\\_author.enap?by=aut&id=14](https://dictionnaire.enap.ca/Dictionnaire/64/index_by_author.enap?by=aut&id=14))

achieved by establishing a clear accountability of the oversight or governance of the health data resources and infrastructure to the delivery of quality health programs and services.

Table 2 summarizes the relationship between the resources, infrastructure, and accountability of the core elements of a functional health data ecosystem.

Table 2: Core elements of health data ecosystem

Core elements of a functional health data ecosystem				
Resources and infrastructure				Governance and accountability
Health data human resources	Health data financial resources	Information and communication technology	Data	
Health sector human resources*	Public Sector	Digital communication technology	Any form of data that impacts health outcomes including but not limited to clinical, social, and demographic data	Those governing health data resources and infrastructure are accountable to design health data workflow and use to foster quality health programs and services and mitigate health data-related harm.
Public human resources	Private Sector	Analogue communication technology		
The patient	Hybrid funding			

\* Includes but is not limited to health professionals, community-based non-professional health service providers, health researchers, health management, health information technology personnel.

### PERSON-CENTERED DATA ARCHITECTURE

In the health context, person-centered data architecture is the *design of health data around the individual as the basic unit of care to assure that their comprehensive and complete health information follows them for the entire course of their health journey*. Person-centered data architecture ties the design of health data technology, public policy, and workflow to the legal right of individuals to their health information. As individuals frequently travel between a variety of health and social services, and across jurisdictions for care, optimizing the capacity for their composite personal health information, including data pertaining social determinants of health, to follow them over time and location demands the harmonization of intra and inter-jurisdictional health data governance, public policy, technology, and workflow.

# METHODOLOGY

This study is a circumscribed and preliminary scan of the impact of public policy on health data design and use in Canada. It is intended to provide a high-level overview to stimulate discourse and prompt more intensive investigation.

For the purposes of this scan, health data public policy is divided into three domains:

1. Public policy in the federal arena.
2. Public policy at the interface between the federal and provincial/territorial arenas.
3. Public policy in the provincial/territorial arena.

The inclusion criteria for content, such as legislation, policy, rulings, agreements, and regulatory standards, were a clear and evident impact on one or more of the core elements of a health data ecosystem described in Table 2.

It is acknowledged that this is not an exhaustive examination, and not all public policy that has an impact on health data has been included.

The analysis of provincial/territorial public policy was restricted to the province of Alberta, given the mandate of the AVCCB that commissioned this work. However, the methodology used can be applied to an analysis of health data public policy in other provinces or territories.

For our analysis, we examined the impact and implications of the following public policy on health data design and use (Figure 2):

## 1. The Federal Arena

- The *Constitution Acts*, 1867 to 1982
- The *Charter of Rights and Freedoms*, 1982
- OCAP / OCAS / Inuit Qaujimajatuqangit
- The Supreme Court of Canada: *McInerny v McDonald*, 1992
- The *Canada Health Act*, 1984
- The *Food and Drugs Act*, 1985
- Bill C-72 – Proposed *Connected Care for Canadians Act*, 2024

## 2. The Federal / Provincial / Territorial Interface

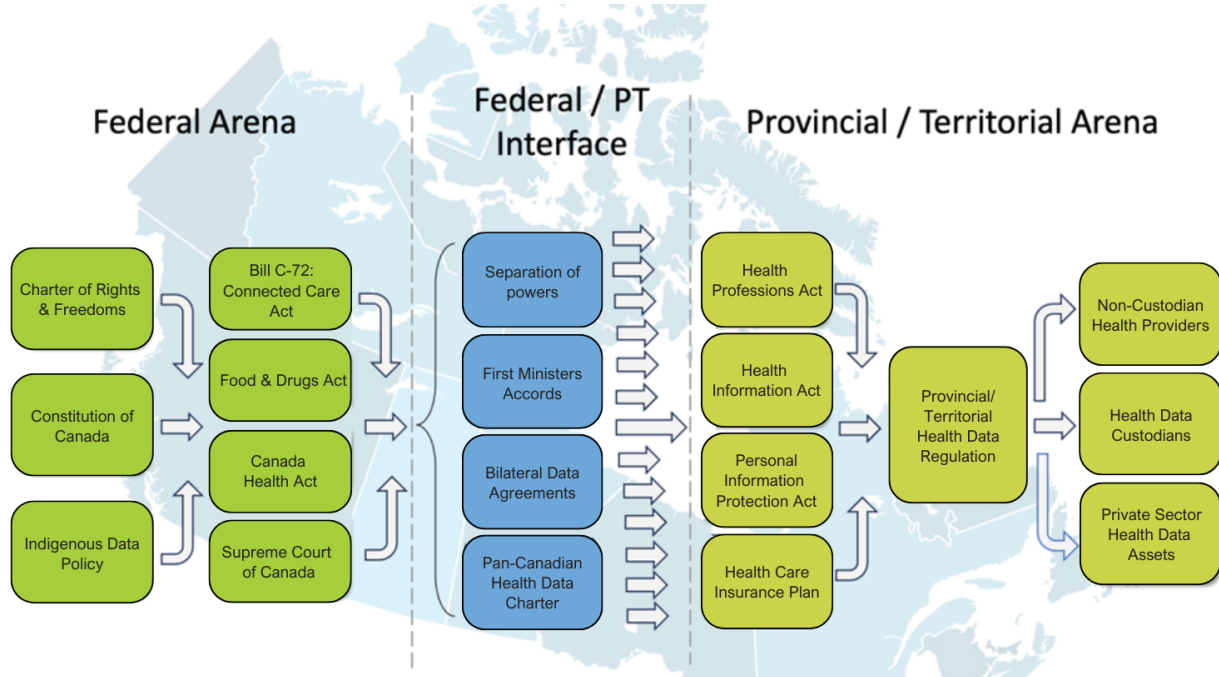
- The impact of separation of powers on health data design and use
- The pan-Canadian *Health Data Charter*, 2022
- The Joint FPT Action Plan on Health Data and Digital Health, 2023
- Bilateral federal – provincial/territorial health data agreements, 2023

### 3. The Provincial / Territorial Arena

- Select jurisdictional legislation:
  - *Health Professions Act*, RSA 2000, c H-7
  - *Alberta Health Care Insurance Act*, RSA 2000, c A-20
  - *Health Information Act*, RSA 2000, c H-5
  - *Personal Information Protection Act*, SA 2003, c P-6.5
- The impact of provincial regulation on:
  - Health data human resources
  - Health data financing
  - Health data technology
  - Health data
  - Governance and accountability of health data design and use to quality care

These domains of public policy exist in a hierarchy of descending influence as depicted in Figure 2, and together help define and reflect the form and function of health data design and use in Canada.

Figure 2: Arenas and domains of public policy impacting health data in Canada



Each of these distinct public policies were evaluated for their impact on health data design and use. In turn, the composite picture that emerged informed an overview of the beliefs, attitudes, or cultural conventions that the Canadian health system holds with respect to health data.



# CURRENT HEALTH DATA PUBLIC POLICY

## FEDERAL ARENA

In this section, we examined the impact of federal or national public policy on health data design and use in Canada. Specifically, we examine seven elements of policy:

- The *Constitution Act*, 1982
- The *Charter of Rights and Freedoms*
- OCAP / OCAS / Inuit Qaujimajatuqangit
- The Supreme Court of Canada – *McInerny v McDonald*
- The *Canada Health Act*
- The *Food and Drugs Act*
- The *Connected Care for Canadians Act*

### THE CONSTITUTION ACT, 1982

The Canadian *Constitution Act*, 1982 (the “*Constitution Act*”) does not explicitly assign “health” as a legislative power to either the federal or provincial / territorial governments.<sup>31</sup> The closest reference to health are the specific designation of accountability for the “establishment, maintenance, and management of hospitals” to the provincial legislature under s. 92(7) of the *Constitution Act*.<sup>32</sup> Additionally, s. 92(13) (Property and Civil Rights in the Province) and s. 92(16) (Generally all Matters of a merely local or private Nature in the Province) speak to provincial jurisdiction over local health matters that are at a provincial level.

Federal jurisdiction flows from the federal government’s powers under s. 91(3) (The raising of Money by any Mode or System of Taxation), s. 91(27) (The Criminal Law) and the preamble in s. 91 which says:

“It shall be lawful for the Queen, by and with the Advice and Consent of the Senate and House of Commons, to make Laws for the Peace, Order, and good Government of Canada, in relation to all Matters not coming within the Classes of Subjects by this Act assigned exclusively to the Legislatures of the Provinces;”

As such, the federal government’s “peace, order, and good government” (or POGG power) acts as a catch all for anything that is not captured specifically in s. 91 (federal matters) or s. 92 (provincial matters) of the *Constitution Act*.

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<sup>31</sup>Butler M and Tiedemann M, The federal role in health and health care, 2013, ([https://lop.parl.ca/sites/PublicWebsite/default/en\\_CA/ResearchPublications/201191E#:~:text=The%20Constitution%2C%20however%2C%20does%20contain,other%20hospitals%20to%20the%20provinces.](https://lop.parl.ca/sites/PublicWebsite/default/en_CA/ResearchPublications/201191E#:~:text=The%20Constitution%2C%20however%2C%20does%20contain,other%20hospitals%20to%20the%20provinces.))

<sup>32</sup> The Constitution Acts 1867 to 1982, 2024, ([https://laws.justice.gc.ca/PDF/CONST\\_TRD.pdf#page=62](https://laws.justice.gc.ca/PDF/CONST_TRD.pdf#page=62))

The courts have described the division of powers between federal and provincial governments in various cases, including the Supreme Court of Canada in *Canada (Attorney General) v. PHS Community Services Society*<sup>33</sup>, which states:

“[t]he federal role in the domain of health makes it impossible to precisely define what falls in or out of the proposed provincial “core”. Overlapping federal jurisdiction and the sheer size and diversity of provincial health power render daunting the task of drawing a bright line around a protected provincial core of health where federal legislation may not tread.”

In *Schneider v. The Queen*, the Supreme Court acknowledged that jurisdictional powers to regulate health are often exercised through legislation, saying:

“... "health" is not a matter which is subject to specific constitutional assignment but instead is an amorphous topic which can be addressed by valid federal or provincial legislation, depending in the circumstances of each case on the nature or scope of the health problem in question.”<sup>34 35</sup>

Thereby, the division of power over health services between the federal and provincial / territorial governments<sup>36</sup> that we see today is based on historical interpretations of the *Constitution Act* by the different levels of government and by the courts and the resulting federal and provincial legislation that has been developed to date.<sup>37</sup>

## Impact on Health Data

The *Constitution Act* is silent regarding both health data and health information, making no explicit reference to either term. As such, the distribution of legislative power over health data is undefined and open to interpretation, depending on the specific nature and scope of a health data or health information issue.

The interpretation of the *Constitution Act* as directing the distribution of federal or provincial/territorial power over health services in Canada, impacts health data by enabling and promoting distinct jurisdiction-specific approaches to data design and use. The absence of a formal mechanism to harmonize these independent jurisdictional approaches, as well as the historical lack of focus on data standards and interoperability, contributes to data fragmentation.<sup>38</sup>

<sup>33</sup> Supreme Court of Canada, *Canada (Attorney General) v. PHS Community Services Society*, 2011, (<https://www.canlii.org/en/ca/scc/doc/2011/2011scc44/2011scc44.html>)

<sup>34</sup> Supreme Court of Canada, *Schneider v. The Queen*, 1982, (<https://decisions.scc-csc.ca/scc-csc/scc-csc/en/item/2449/index.do>)

<sup>35</sup> An exception is the specific reference made in the Constitution Act that most categories of hospitals are a provincial responsibility.

<sup>36</sup> Minister of Justice, Constitution Act, 1982, ([https://laws.justice.gc.ca/PDF/CONST\\_TRD.pdf#page=62](https://laws.justice.gc.ca/PDF/CONST_TRD.pdf#page=62))

<sup>37</sup> Butler M and Tiedemann M, The federal role in health and health care, 2013, ([https://lop.parl.ca/sites/PublicWebsite/default/en\\_CA/ResearchPublications/201191E#txt1](https://lop.parl.ca/sites/PublicWebsite/default/en_CA/ResearchPublications/201191E#txt1))

<sup>38</sup> Canadian Institute for Health Information, The expansion of virtual care in Canada - New data and information, 2023, (<https://www.cihi.ca/sites/default/files/document/expansion-of-virtual-care-in-canada-report-en.pdf>)

## THE CHARTER OF RIGHTS & FREEDOMS, 1982

The Canadian *Charter of Rights and Freedoms* (the “Charter”) is the section of the *Constitution Act* that defines the rights and freedoms to which all Canadians are entitled as members of a free and democratic society. The right to receive health care is not explicitly enumerated in the Charter, and although other Canadian laws specifically support the provision of publicly funded health services, they fall short of defining health service as a constitutional right.<sup>39</sup> Nonetheless, the diverse fundamental rights outlined in the Charter have been significant drivers of access to medically necessary services and serve as a protectorate of health-related values.<sup>40</sup>

### Impact on Health Data

The Charter makes no reference to either health data or health information. If health data is deemed a necessary constituent of health service, particularly as it relates to the provision of more equitable and timely care, then the Charter could reasonably be construed as supportive of universal and portable health data design and use.<sup>41</sup>

## OCAP, 1988 / OCAS / INUIT QAUJIMAJATUQANGIT

The term “Indigenous data sovereignty” is relatively new and reflects global advancement in the recognition of the rights of Indigenous Peoples to control data from and about their communities and lands.<sup>42</sup> In Canada, there are three distinct Indigenous groups with unique histories, languages, cultural practices, and spiritual beliefs: First Nations, Inuit, and Métis Peoples. All three have invested in articulating principles that assert their inherent right as sovereign Peoples to control their data, including the First Nations principles of OCAP<sup>43</sup>, the Manitoba Métis principles of OCAS<sup>44</sup> <sup>45</sup>, and the Inuit principles of Qaujimajatuqangit.<sup>46</sup>

Global efforts to define a framework for open data and open science (i.e., FAIR: Findable, Accessible, Interoperable, Reusable)<sup>47</sup> fail to fully reflect the health data rights and interests articulated by Indigenous Peoples, which focus on asserting greater community control over data for collective

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<sup>39</sup> Parliament of Canada, The health of Canadians - The federal role final report, n.d., (<https://sencanada.ca/en/content/sen/committee/372/soci/rep/repoct02vol6part2-e>)

<sup>40</sup> Jones D J, Right to health, a comparative law perspective - Canada, 2022, ([https://www.europarl.europa.eu/thinktank/en/document/EPRS\\_STU\(2022\)729444](https://www.europarl.europa.eu/thinktank/en/document/EPRS_STU(2022)729444))

<sup>41</sup> IBID

<sup>42</sup> Global Indigenous Data Alliance, History of indigenous data sovereignty, n.d., (<https://www.gida-global.org/history-of-indigenous-data-sovereignty/>)

<sup>43</sup> First Nations Information Governance Centre, The First Nations principles of OCAP, n.d., (<https://fnigc.ca/ocap-training/>)

<sup>44</sup> Canadian Institute for Health Information, A path forward: Toward respectful governance of First Nations, Inuit and Métis data housed at CIHI, Updated August 2020, 2020, (<https://www.cihi.ca/sites/default/files/document/path-toward-respectful-governance-fnim-2020-report-en.pdf>)

<sup>45</sup> The OCAS principles are quite specific to Manitoba and not more broadly endorsed across other Métis organizations.

<sup>46</sup> IBID

<sup>47</sup> Wilkinson M D et al., The FAIR Guiding Principles for scientific data management and stewardship, 2016, (<https://doi.org/10.1038/sdata.2016.18/>)

benefit grounded in Indigenous world views. As a complement, the CARE principles for Indigenous data governance (i.e., Collective benefit, Authority to control, Responsibility, Ethics) reflect the crucial role of data in advancing Indigenous empowerment and self-determination.<sup>48</sup>

Information about both individual and community health and wellness are included in the data over which sovereign Peoples in Canada have declared a fundamental authority to own and govern.<sup>49</sup> The *pan-Canadian Health Data Charter* reflects this commitment by pledging to “support First Nations, Inuit and Métis data sovereignty and Indigenous-led governance frameworks”.

## Impact on Health Data

The principles of Indigenous data sovereignty have far-reaching implications for health data design and use in Canada and have been untested in large-scale public policy in many jurisdictions.

There are important examples of efforts to establish clear policy and operational frameworks for the promotion of Indigenous data sovereignty. These include British Columbia where the Ministry of Health has identified the First Nations Health Authority as the health data steward for British Columbia (BC) First Nations based on the principles of OCAP.<sup>50</sup> A joint data governance decision-making process is described in the Tripartite Data Quality and Sharing Agreement between the BC government, the federal government and the First Nations Health Authority.<sup>51</sup> British Columbia is undertaking similar health data efforts with the Métis Nation of BC.<sup>52</sup>

Yukon Territory’s *Health Information Privacy and Management Act* explicitly designates Yukon First Nations entities as a particular type of data custodian with independent rights and obligations under the Act. Further, most provinces and territories have implicitly expressed support for First Nations, Inuit, and Métis data sovereignty by endorsing the principles of the pan-Canadian Health Data Strategy.<sup>53</sup>

The Canadian research community, including the Canadian Institutes of Health Research, have “co-developed with Indigenous peoples, an interdisciplinary research and research training model that contributes to reconciliation.”<sup>54</sup> Similarly, the Canadian Institute for Health Information (CIHI) has set

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<sup>48</sup> Global Indigenous Data Alliance, Care principles for Indigenous data governance, 2018, (<https://www.gida-global.org/care>)

<sup>49</sup> Canadian Institute for Health Information, A path forward: Toward respectful governance of First Nations, Inuit and Métis data housed at CIHI, 2020, (<https://www.cihi.ca/sites/default/files/document/path-toward-respectful-governance-fnim-2020-report-en.pdf>)

<sup>50</sup> First Nations Health Authority Province of British Columbia & Indigenous Services Canada, 2019, Data and Information Governance, (<https://www.fnha.ca/Documents/FNHA-BC-Tripartite-Agreement-Case-Study-Data-and-Information-Governance.pdf>)

<sup>51</sup> First Nations Health Authority Province of British Columbia & Indigenous Services Canada, 2021, Tripartite Data Quality and Sharing Agreement, (<https://www.fnha.ca/Documents/TDQSA-2021-Annual-Report-On-Progress.pdf>)

<sup>52</sup> Letter of Understanding, 2023, Métis Nation British Columbia and Office of the Provincial Health Office – British Columbia, (<https://www.mnbc.ca/OPHLOU2023>)

<sup>53</sup> Unofficial Consolidation of the States of Yukon, Health Information and Management Act, 2013, (<https://laws.yukon.ca/cms/images/LEGISLATION/PRINCIPAL/2013/2013-0016/2013-0016.pdf>)

<sup>54</sup> Government of Canada, setting new directions to support Indigenous research and research training in Canada, 2023, (<https://www.canada.ca/en/research-coordinating-committee/priorities/indigenous-research/strategic-plan-2019-2022.html>)

out to co-develop “a respectful approach to the governance of First Nations, Inuit and Métis data” by working to “align policies, practices, and procedures with Indigenous data sovereignty principles.”<sup>55</sup>

The federal government, while reviewing the *Access to Information Act* in 2019, convened an “Indigenous-specific engagement process” aimed at “unique issues and concerns with access to information.” The government stated in conclusion that the effort “marks only the beginning of the discussions and collaborations needed between the Government of Canada and Indigenous governments, organizations, and Peoples.”<sup>56</sup>

However, creation of comprehensive health public policy to establish Indigenous data sovereignty is not uniform in Canada. Further, to our knowledge, the deployment of health information technologies in Canada are not bound by any regulatory standards that uphold the right of sovereign Peoples to control their health data. Most health professions in Canada are in their infancy in integrating health data literacy into their professional training, including acknowledgement of Indigenous data sovereignty.

## SUPREME COURT OF CANADA – *McINERNEY V. McDONALD*, 1992

In 1992, the Supreme Court of Canada ruled in *McInerney v. McDonald*<sup>57</sup> that an individual is entitled to a copy of their complete medical record from a treating physician, including all content in the possession of the physician from other health sources. It qualified this ruling by asserting that the original medical records must remain in the possession of the treating physician and that an individual’s right of access to their health information is not absolute but can be denied if disclosure is deemed a danger to their emotional or physical wellbeing. The refusal of access to personal health information can be subject to a court challenge.<sup>58 59 60</sup> Although this ruling spoke specifically to physicians, it has been applied in practice to personal health information in all clinical contexts.

### Impact on Health Data

The Supreme Court ruling in *McInerney v. McDonald* does not delineate how patient access to personal health information is to be achieved, simply that it must occur. Despite this landmark decision, patient access to health information in digital format remains limited to approximately one third of Canadians.<sup>61</sup> Although comprehensive digital access to personal health information is

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<sup>55</sup> Canadian Institute for Health Information, A path forward: Toward respectful governance of First Nations, Inuit and Métis data housed at CIHI, 2020, (<https://www.cihi.ca/sites/default/files/document/path-toward-respectful-governance-fnim-2020-report-en.pdf>)

<sup>56</sup> Government of Canada, Access to information review Indigenous-specific what we heard report, 2024, (<https://www.canada.ca/en/treasury-board-secretariat/services/access-information-privacy/reviewing-access-information/the-review-process/indigenous-specific.html>)

<sup>57</sup> Supreme Court of Canada, *McInerney v. MacDonald*, 1992, (1992 CanLII 57 (SCC) | *McInerney v. MacDonald* | CanLII)

<sup>58</sup> Sheppard G, Notebook on ethics, standards, and legal issues for counsellors and psychotherapists - A much-quoted decision of the Supreme Court of Canada regarding medical records, n.d., (<https://www.ccpa-accp.ca/wp-content/uploads/2016/02/NOE.A-Much-Quoted-Decision-of-the-Supreme-Court-of-Canada-Regarding-Medical-Records.pdf>)

<sup>59</sup> Supreme Court of Canada, *McInerney v. MacDonald*, 1992, (1992 CanLII 57 (SCC) | *McInerney v. MacDonald* | CanLII)

<sup>60</sup> Rotino L, Ownership of patient files, 2023, (<https://blackburnlawyers.ca/blog/ownership-of-patient-files/>)

<sup>61</sup> Canada Health Infoway, Connecting the health system - Connected Care. A healthier Canada, n.d., (<https://www.infoway-inforoute.ca/en/component/edocman/6413-connecting-the-health-system-connected-care-a-healthier-canada/view-document>)

technologically possible, it is not required or enforced in legislation at most levels of government. Certain provinces, such as Quebec and Ontario, have recently introduced legislative changes that provide for varying degrees of digital access to personal health information<sup>62 63</sup>.

## CANADA HEALTH ACT, 1984

The purpose of the *Canada Health Act* (CHA) is to promote “continued access to quality health care”<sup>64</sup> by defining the conditions between federal, provincial, and territorial governments for the public funding of health services. This is achieved by defining what *medically necessary* services will be funded for the “purpose of maintaining health, preventing disease, or diagnosing or treating an injury, illness, or disability.”<sup>65</sup>

The division of authority for health services in Canada is outlined in the CHA. The principal responsibilities of the federal government are:

- Setting and administering national standards for the health care system, including defining what health services are publicly funded.
- The transfer of funds to provincial and territorial governments to support *insured* health services based on set conditions.<sup>66</sup>

In turn, provincial and territorial governments are responsible for the management, organization, and delivery of insured health services for their residents. This includes administering the funding and delivery of medically necessary services by physicians, hospitals, and a subset of dental services. Other regulated or lay caregivers are not acknowledged in the CHA, nor is there specific reference made to the management of health data, information, or communication technologies.

The CHA is explicit in stating that the “objective of health care policy in Canada” is to ensure “continued access to *quality health care* without financial or other barriers” to maintain and improve “the *health and well-being* of Canadians.”<sup>67</sup> To receive federal transfer payments to fund insured services, it cites five requirements of health service design that need to be met:

- Public administration
- Comprehensiveness
- Universality
- Portability
- Accessibility

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<sup>62</sup> Gouvernement du Québec, p-39.1 - Act respecting the protection of personal information in the private sector, 2024, (<https://www.legisquebec.gouv.qc.ca/en/document/cs/p-39.1>)

<sup>63</sup> Government of Ontario, Personal Health Information Protection Act, 2004, (<https://www.ontario.ca/laws/statute/04p03>)

<sup>64</sup> Government of Canada, Canada Health Act, 1985, (<https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>)

<sup>65</sup> IBID

<sup>66</sup> Government of Canada, Canada’s health care system, 2023, (<https://www.canada.ca/en/health-canada/services/canada-health-care-system.html>)

<sup>67</sup> Government of Canada, Canada Health Act, 1985, (<https://laws-lois.justice.gc.ca/eng/acts/c-6/page-1.html>)

## Impact on Health Data

The CHA was enacted in 1984, soon after the launch of the early internet,<sup>68</sup> but before the emergence of digital health as a ubiquitous concept or practice. The CHA is silent on the topic of health data, except for the stipulation that provinces and territories must provide information on the operation of their health systems to the federal government. Therefore, guidelines directing how health data should be designed and managed to support the provision of quality health programs and services are absent.

A principal mechanism the CHA uses to foster the “continued access to quality health care” is by assuring provincial and territorial compliance to the five program requirements – public administration, comprehensiveness, universality, portability, and accessibility – by tying them conditionally to federal financial support. What is absent from this approach is an understanding of the role health data plays in supporting the delivery of these five criteria. This relationship was highlighted in the *pan-Canadian Health Data Charter* (the “*Health Data Charter*”) proposed by the Expert Advisory Group of the pan-Canadian Health Data Strategy which intentionally frames optimized health data design around “*the five principles of public administration, comprehensiveness, universality, portability, and accessibility (Canada Health Act)*.”<sup>69</sup>

Although the *Canada Health Act* is silent on the oversight of health data, the collective path chosen in Canada has been to regionalize data design and use without evident thought to the repercussions of this strategy.

The absence of reference to health data in the CHA results in a lack of clarity about the inclusion of digital health services, such as virtual care or advanced analytics (e.g., artificial intelligence) in the envelope of publicly funded, medically necessary care provided by physicians, dentists, or hospitals. This uncertainty has been displayed in the inconsistent and shifting provincial and territorial public funding of virtual care services before, during, and after the COVID-19 pandemic.<sup>70</sup> The resulting confusion triggered a rise in the number of private virtual care companies offering health services for a fee, and led the federal government to warn provinces and territories that if they did not halt patient charges for “medically necessary care,” federal transfer payments would be clawed back.<sup>71</sup>

In the same vein, the lack of comprehensive, portable, universal, and accessible health data can arguably have manifold negative impacts, including:

<sup>68</sup>Online Library Learning Center, A brief history of the Internet, n.d., ([https://www.usg.edu/galileo/skills/unit07/internet07\\_02.phtml#:~:text=January%201%2C%201983%20is%20considered.Protocol%20\(TCP%2FIP\).](https://www.usg.edu/galileo/skills/unit07/internet07_02.phtml#:~:text=January%201%2C%201983%20is%20considered.Protocol%20(TCP%2FIP).))

<sup>69</sup> Government of Canada, Pan-Canadian Health Data Charter, 2023, (<https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>)

<sup>70</sup> Watts M, The evolving regulatory landscape of virtual care in Canada, 2023, ([The evolving regulatory landscape of virtual care in Canada - Osler, Hoskin & Harcourt LLP](#))

<sup>71</sup> CBC News, Ottawa plans to crack down on doctors charging for medically necessary health care, 2023, (<https://www.cbc.ca/news/politics/fees-virtual-doctor-physician-canada-health-act-1.6773607>)

- A lack of health data interoperability between data custodians and across jurisdictional boundaries.
- Health information that fails to follow a patient over the course of their care journey.
- Attenuated patient access to personal health information.
- Informationally fragmented health care teams and services.

As evidence suggests that data fragmentation can contribute to the promotion of health data-related harm - including increased morbidity and mortality, health system cost, provider burnout, and present barriers to health equity, innovation, and research<sup>72</sup> - the absence of comprehensive, portable, universal, and accessible health data arguably circumvents the spirit and intent of the CHA to assure the provision of quality care.

The absence of comprehensive, portable, universal, and accessible health data arguably circumvents the spirit and intent of the *Canada Health Act*.

The application of the five CHA criteria to health data design and use would appear to challenge current provincial and territorial-centered health data design practices. Enforcing health data portability, universality, comprehensiveness, and accessibility would necessitate that information follow a patient seamlessly across institutional and jurisdictional boundaries, both within and between provinces and territories; thereby necessitating a harmonized approach to both intra and extra-provincial and territorial health data flow. This would be a significant challenge to health data governance orthodoxy in Canada as it exists today.

## FOOD AND DRUGS ACT, 1985

The Canadian *Food and Drugs Act* is federal legislation that governs how food and drugs are managed to assure the safety and wellbeing of Canadians. The *Food and Drugs Act* also sets regulatory standards that govern the safe and effective use of certain medical devices, which are defined as “instruments used to treat, reduce, diagnose, or prevent a disease or abnormal physical condition.”<sup>73</sup> This definition covers a wide range of devices (e.g., hip implants, pacemakers, synthetic skin, artificial heart valves, test kits for diagnosis, contraceptive devices, medical laboratory diagnostic instruments).<sup>74</sup> Any new drug or medical device fitting into these categories must go through a rigorous evaluation process to assure it is safe and effective for use by humans.

Although there is emerging guidance from Health Canada on the potential future inclusion of Software as a Medical Device (SaMD) as regulated technology under the *Food and Drugs Act*, many health information technologies are not considered.<sup>75</sup> Reflecting the current state, a March 2023 review by the Institute for Health Economics states that “while some countries have proposed national frameworks for the evaluation of digital health technologies, no such framework has been developed

<sup>72</sup> Affleck E et al., Interoperability Saves Lives, 2023, ([https://www.albertavirtualcare.org/files/ugd/efde1a\\_43101bc906434781a6d497cd576602c1.pdf](https://www.albertavirtualcare.org/files/ugd/efde1a_43101bc906434781a6d497cd576602c1.pdf))

<sup>73</sup> Government of Canada, Food and Drugs Act (R.S.C., 1985, c. F-27), (<https://laws-lois.justice.gc.ca/eng/acts/F-27/>)

<sup>74</sup> Government of Canada, Safe medical devices in Canada, 2022, (<https://www.canada.ca/en/health-canada/services/drugs-health-products/medical-devices/activities/fact-sheets/safe-medical-devices-fact-sheet.html>)

<sup>75</sup> The Office of the National Coordinator for Health Information Technology, Health IT: Advancing America’s health care, n.d., (<https://www.healthit.gov/sites/default/files/pdf/health-information-technology-fact-sheet.pdf>)



in Canada.”<sup>76</sup> This means that despite their undeniable use to “treat, reduce, diagnose, or prevent a disease or abnormal physical condition,” electronic medical records, virtual care technologies, picture archiving, and communication technologies and other health information technology applications can be developed and deployed in the health care system without assurance that the health information they gather, store, and exchange will be managed in a manner that assures the health and wellbeing of Canadians and mitigates potential harm.<sup>77</sup>

## Impact on Health Data

There is a growing recognition that shortfalls in the design and use of health information technology can result in harm to individuals, populations, and the health care system.<sup>78</sup> The absence of national regulatory standards and processes to mitigate potential harm arising from poorly designed, deployed, and integrated information technology appears to put the health and wellbeing of Canadians at risk.

## BILL C-72 – PROPOSED CONNECTED CARE FOR CANADIANS ACT - 2024

On June 6th, 2024, the federal government tabled Bill C-72 - the *Connected Care for Canadians Act* - before parliament. The proposed legislation aims to “ensure that health information technology that is licensed, sold or supplied as a service by a vendor is interoperable and to prohibit data blocking by the vendor in order to promote a connected, secure and person-centered health system”.<sup>79</sup> The *Connected Care for Canadians Act* will apply to any province or territory that does “not have requirements that are substantially similar to or exceed those established under this Act”<sup>80</sup>.

Importantly the *Connected Care for Canadians Act* links the design and use of health data to:

- Patient safety, equity, and the promotion of health outcomes.
- Patient access to digital personal health information.
- Informed health service decision-making.
- Optimized health system oversight, administration, research, and innovation.

The *Connected Care for Canadians Act* suggests it aspires to promote a cooperative approach between federal, provincial, territorial governments, and Indigenous Peoples to “establish common interoperability standards in order to create a connected health system”.<sup>81</sup>

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<sup>76</sup> Lopatina E., Regulation, assessment, and adoption of digital health technologies in Canada, 2023, (<https://policycommons.net/artifacts/3528026/regulation-assessment-and-adoption-of-digital-health-technologies-in-canada/4328862/>)

<sup>77</sup> IBID

<sup>78</sup> Affleck E et al., Interoperability Saves Lives, 2023, ([https://www.albertavirtualcare.org/files/ugd/efde1a\\_43101bc906434781a6d497cd576602c1.pdf](https://www.albertavirtualcare.org/files/ugd/efde1a_43101bc906434781a6d497cd576602c1.pdf))

<sup>79</sup> House of Commons of Canada, Bill C-72: An Act respecting the interoperability of health information technology and to prohibit data blocking by health information technology vendors, 2024, ([https://www.parl.ca/Content/Bills/441/Government/C-72/C-72\\_1/C-72\\_1.PDF](https://www.parl.ca/Content/Bills/441/Government/C-72/C-72_1/C-72_1.PDF))

<sup>80</sup> IBID

<sup>81</sup> [https://www.parl.ca/Content/Bills/441/Government/C-72/C-72\\_1/C-72\\_1.PDF](https://www.parl.ca/Content/Bills/441/Government/C-72/C-72_1/C-72_1.PDF)

The *Connected Care for Canadians Act* does not articulate specific interoperability standards, and states that these will be established in the context of “regulations for carrying out the purposes of the Act.”<sup>82</sup>

**Impact on Health Data**

If passed by parliament, the *Connected Care for Canadians Act* will be the first federal legislation that binds a property of the design and use of health data to the provision of quality care. This is symbolically and functionally a very important statement that signals a new direction for health data design and use in Canada, and points to a link between the use of health data to the conditions of the CHA. The *Connected Care for Canadians Act* also explicitly acknowledges the importance of person-centred health service but falls short of calling for person-centred health data architecture. This Act is also significant as it represents the first introduction of federal health information technology regulatory standards.

The details of the regulatory standards and oversight required to operationalize the *Connected Care for Canadians Act* remain to be established, but this bill appears to signal a watershed moment when the design and use of health data in Canada has finally been acknowledged as a determinant of the health and wellbeing of Canadians and health system optimization.

**SUMMARY: FEDERAL ARENA**

Table 3: Summary of the impact of federal public policy on the core elements of health data ecosystem

Core elements of health data ecosystem	The federal arena
Human resources	<ul style="list-style-type: none"> <li>• There is no federal legislation that stipulates whether health data related services by physicians and dentists are considered “essential” or publicly funded health services.</li> </ul>
Financial resources	<ul style="list-style-type: none"> <li>• There are no provisions in federal legislation for the financial support of health data design and use, nor legislated funding for data governance and stewardship in relation to health information and communication technology.</li> </ul>

<sup>82</sup> [https://www.parl.ca/Content/Bills/441/Government/C-72/C-72\\_1/C-72\\_1.PDF](https://www.parl.ca/Content/Bills/441/Government/C-72/C-72_1/C-72_1.PDF)

<p><b>Information and communication technology</b></p>	<ul style="list-style-type: none"> <li>• Federal legislation does not recognize health information technologies as medical devices subject to regulation.*</li> <li>• There is no federal legislation, nor regulatory standards or processes, that bind the design and use of health information technology and the data captured, stored, and processed by such technology to principles of Indigenous data sovereignty.</li> <li>• The proposed <i>Connected Care for Canadians Act</i> mandates standards for health data interoperability and data unblocking.</li> </ul>
<p><b>Data</b></p>	<ul style="list-style-type: none"> <li>• The only reference to health data in the CHA states that provinces and territories must provide information on the operation of their health systems to the federal government.</li> <li>• The CHA makes no reference to health data or information in the list of services to be administered under the authority of provinces and territories.</li> <li>• The Supreme Court of Canada ruled that an individual is entitled to a copy of their complete medical record from a treating physician, including all content from other health sources.</li> <li>• There is limited integration of Indigenous concepts of data ownership and control into federal (or provincial/territorial) health data public policy.</li> <li>• If health data is deemed a necessary constituent of quality health service, then the Canadian <i>Charter of Rights and Freedoms</i> as a driver of the right of access to medically necessary services could reasonably be construed as supportive of universal and portable health data design and use.</li> </ul>
<p><b>Governance and accountability to quality health programs and services</b></p>	<ul style="list-style-type: none"> <li>• There is no clear governance and accountability structure, whether at the federal or provincial level, for the design, use, and overall stewardship of health data.</li> <li>• The CHA does not indicate how health data is to be managed to support “quality health care” and promote the “health and wellbeing of Canadians.”</li> <li>• There is no indication how health data should be used to meet the five conditions of the CHA.</li> <li>• There is an absence of public policy that dictates the meaningful inclusion of the public and Indigenous representation in the oversight of health data design and use.</li> <li>• The recent tabling of Bill C-72 (the <i>Connected Care for Canadians Act</i>) signals the first time there is proposed federal legislation aimed at: <ul style="list-style-type: none"> <li>◦ binding the design and use of health data and information technology to the promotion of quality health programs or services.</li> <li>◦ minimizing forms of potential harm arising from the under-sharing of health data.</li> </ul> </li> </ul>

\* If the *Artificial Intelligence and Data Act* (tabled November 2022 as part of federal Bill C-27) is passed, then AI systems relating to health care will likely be considered medical devices subject to regulation. See: <https://www.parl.ca/legisinfo/en/bill/44-1/c-27>

## FEDERAL - PROVINCIAL/TERRITORIAL INTERFACE

The federated approach to health service in Canada designates oversight for select health care functions to distinct federal, provincial, and territorial governments. However, the oversight of health data design and management is not clearly assigned in defining federal health legislation.

In this section, we examine the interrelationship between the health data efforts of federal, provincial, and territorial governments; alignment between respective approaches to the design and use of health data; and what level of cooperation is enlisted to promote data-driven quality health programs and services. Specifically, we examine four elements of this relationship:

- The impact of separation of powers on health data design and use

- The *pan-Canadian Health Data Charter* - 2022
- The Joint FPT Action Plan on Health Data and Digital Health - 2023
- Bilateral federal – provincial/territorial health data agreements - 2023

## IMPACT OF SEPARATION OF POWERS ON HEALTH DATA DESIGN AND USE

As described above, the division of power over health services between federal and provincial/territorial governments is based principally on the historical interpretation of the *Constitution Act* by different levels of government and by the courts, which is reflected in the CHA. The division of power is a canon of the federated approach to Canadian health care; a way of being that impacts the form and function of most aspects of health system design and service, including health data design and use.

There is no formal mechanism or process for harmonizing distinct jurisdictional health data legislative and regulatory approaches in Canada.

Operational health data public policy is primarily managed on a provincial and territorial basis. This principally takes the form of legislative acts dictating the rules governing the access to and protection of personal health information. Provinces and territories have either a jurisdictional statute specific to health information, or a generic personal information privacy statute that applies to health data in the absence of specific

legislation, or a combination of both. Generally, health data legislation designates the role of “custodian” to specific health institutions, such as health authorities or hospitals, and to specific health care professions, either individually or as an entity comprising a clinical practice. Custodians have clear accountabilities for the trusted management and protection of personal health information. The regulatory oversight of health data is largely consistent across jurisdictions. All provinces and territories safeguard the access, privacy, and security of health data through the offices of a legislated privacy commissioner or ombudsman.<sup>83</sup>

Importantly, there is no formal mechanism or process for harmonizing these distinct jurisdictional legislative and regulatory approaches. Across the country, legislation concerning personal information focuses almost exclusively on personal access, privacy, and security of health data. The oversight and regulation of other properties of health data use that could promote quality of care or result in 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.

Similarly, the regulation of health information technology to assure that the data it manages is interoperable or designed to afford uniform patient access to personal health information is omitted from legislation and regulation at almost all levels of government in Canada. The exceptions are Ontario which in 2021 introduced nascent health data interoperability regulatory standards under the

<sup>83</sup> Office of the Privacy Commissioner of Canada, Provincial and territorial privacy laws and oversight, 2020, (<https://www.priv.gc.ca/en/about-the-opc/what-we-do/provincial-and-territorial-collaboration/provincial-and-territorial-privacy-laws-and-oversight/>)

*Personal Health Information Protection Act*,<sup>84</sup> and Quebec where Bill 3 requires that patients have access to their health records in a “structured and commonly used technological format.”<sup>85</sup>

## Impact on Health Data

Two principal themes emerge from this comparative analysis of the provincial/territorial approaches to health data public policy which have repercussions for health system function and the health and wellbeing of Canadians.

The first observation is that although the *Canada Health Act* is silent on the oversight of health data, the collective path chosen in Canada has been to regionalize data design and use without evident thought to the repercussions of this strategy. The fragmentation of health data public policy by jurisdiction results in an approach that is disjointed, lacks coordination, hinders the sharing of health data across health institutions and jurisdictions, hampers the delivery of quality care, and fosters individual, population, and health system harm. Jurisdictional health data policy fragmentation does not support person-centric health data architecture.

*It is odd that a health care system with the stated mission of promoting the health and wellbeing of Canadians dedicates more policy time and resources to preventing health data privacy breaches than to assuring data is used to foster quality care, research, population and public health, and health system efficiencies.*

The second observation is that across all provinces and territories, there appears to be a propensity to establish public policy to prevent privacy breaches while almost completely neglecting policy to mitigate other forms of health data-related harm. It is odd that a health care system with the stated mission of promoting the health and wellbeing of Canadians dedicates more data policy time and

resources to preventing privacy breaches than to assuring data can be used to foster health and wellbeing, research, population and public health, and health system efficiencies.

The recent tabling of Bill C-72 (the *Connected Care for Canadians Act*), which explicitly calls for the cooperative harmonization of health information technology data standards signals a meaningful shift toward strategic health data oversight both within provincial jurisdictions and between provinces and territories. It also represents the first unifying health data management legislation in Canada that would appear to go beyond the traditional focus on privacy and data protection, as it introduces the concept of “anti-data blocking”, which promotes access to and flow of health information between parties. Quebec’s Bill 3 (*An Act respecting health and social services Information and amending various legislative provisions*)<sup>86</sup>, which recently came into force on July 1, 2024, is also notable as provincial health information privacy legislation that specifically seeks to optimize the use of health data with the express intent “to improve the quality of services offered to the population”. The Act

<sup>84</sup> Ontario Health, Digital health information exchange standard, 2022, (<https://www.ontariohealth.ca/system-planning/digital-standards/digital-health-information-exchange>)

<sup>85</sup> [National Assembly of Quebec, 2023. An Act Respecting Health and Social Services Information and Amending Various Legislative Provisions.](https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF)

<sup>86</sup> [IBID](https://www.publicationsduquebec.gouv.qc.ca/fileadmin/Fichiers_client/lois_et_reglements/LoisAnnuelles/en/2023/2023C5A.PDF)

contains various novel provisions that place certain accountabilities on data custodians for the sharing of health data to support care as well as research.

## PAN-CANADIAN HEALTH DATA CHARTER - 2022

In 2022, the Expert Advisory Group of the of the pan-Canadian Health Data Strategy published the *pan-Canadian Health Data Charter* (“Health Data Charter”), a set of principles intended to harmonize the design and use of health data in Canada. The *Health Data Charter* states it is “*inspired by the universal human right to health, to benefit from science, and to non-discrimination and equity, and founded on the five principles of public administration, comprehensiveness, universality, portability, and accessibility (Canada Health Act)*”<sup>87</sup> The *Health Data Charter* is explicit in calling for the adoption of “person-centric” health data architecture and the “harmonization of health data governance, oversight, and policy” across federal, provincial and territorial governments.<sup>88</sup>

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<sup>87</sup> Government of Canada, Pan-Canadian Health Data Charter, 2023, (<https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>)

<sup>88</sup> IBID

## Pan-Canadian Health Data Charter

The Charter is based on advice from the Expert Advisory Group of the pan-Canadian Health Data Strategy, which recommended establishing common principles "*inspired by the universal human rights to health, to benefit from science, and to non-discrimination and equity, and founded on the five principles of public administration, comprehensiveness, universality, portability, and accessibility (Canada Health Act).*" This Charter highlights Canada's commitment to respecting Indigenous data sovereignty and Indigenous-led health data governance.

*To honour the duty to put people and populations at the core of all decisions about the disclosure, access and use of health information, the Pan-Canadian Health Data Charter requires:*

- 1. Person-centric health information design to ensure that health data follows the individual across points of care to support individual, clinical, and analytical access and use while respecting individual privacy with regard to the handling of their information under existing privacy legislation.*
- 2. Inclusion of diverse members of the public, patients, communities and other partners in culturally integrated health information system development and oversight.*
- 3. Commitment to support First Nations, Inuit and Métis data sovereignty and Indigenous-led governance frameworks.*
- 4. Common standards for terminology, health data design, stewardship, interoperability, access, and portability.*
- 5. The quality, security, and privacy of health data to maximize benefits, build trust, and reduce harm to individuals and populations.*
- 6. Timely availability and accessibility of meaningful and comprehensive health data to individuals, decision makers, the health workforce, and researchers to support an individual's health needs, quality health programs and services, population and public health, and research.*
- 7. The ethical use of health data to support decision making, policies, programs, services, statistics, and research for better health outcomes, while respecting the importance of open science and being open-by-design.*
- 8. Data-driven social and technological innovation through partnership, invention, discovery, value creation and international best practice.*
- 9. Literacy regarding health data, health data analysis and digital methods for the public, decision-makers, the health workforce, and researchers.*
- 10. Harmonization of health data governance, oversight, and policy in areas jointly agreed to by FPT governments for pan-Canadian coordination.*

At a meeting of health ministers in October 2023, the *Health Data Charter* was endorsed in principle by all provinces and territories, other than Quebec.<sup>89</sup> Subsequently, in bilateral agreements negotiated between the federal government and individual provinces and territories, advancing the “person-centered principles” of the *Health Data Charter* were tied to the transfer of funds to jurisdictions for health data-related work.

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<sup>89</sup> Government of Canada, Pan-Canadian Health Data Charter, 2023, (<https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements/pan-canadian-data-charter.html>)

## Impact on Health Data

At this early juncture, it is unclear if the endorsement of the *Health Data Charter* by provinces and territories or tying its principles to the transfer of funds will meaningfully foster optimized health data design and use. The *Health Data Charter* presents an aspirational vision; achieving true person-centred health data architecture will require a wholesale shift in the traditional jurisdictional and custodian-centered approach to health data governance, management, and use in Canada. To achieve this will demand a level of data literacy, institutional and jurisdictional selflessness, and collective cooperation and action that has traditionally been lacking among health data powerbrokers in Canada. Bill C-72, the proposed *Connected Care for Canadians Act*, borrows much language from the *Health Data Charter*, but does not explicitly cite it. The *Health Data Charter* serves as an important point of reference, a measure of accountability, and a common vision for those aspiring to join forces to promote health data optimization in Canada.

Achieving true person-centred health data architecture will require a level of data literacy, institutional and jurisdictional selflessness, and collective cooperation and action that has traditionally been lacking among health data powerbrokers in Canada.

## JOINT FPT ACTION PLAN ON HEALTH DATA AND DIGITAL HEALTH - 2023

In November 2022, in response to COVID-19 and the ascendancy of public health and virtual care as essential and information-dependent health services, federal, provincial, and territorial Ministers of Health agreed that the optimization of health data was a priority for the Canadian health care system.<sup>90</sup> One year later, this culminated in the approval of the Joint FPT Action Plan on Health Data and Digital Health.<sup>91</sup> The plan articulated a shared commitment by federal, provincial, and territorial governments to promote:

- The collection and sharing of high-quality and comparable depersonalized information.
- Common interoperability standards.
- The alignment of provincial and territorial health data policies and legislative frameworks.
- Common principles for the management of health data.
- The capacity to collect and share public health data.<sup>92</sup>

## Impact on Health Data

The unprecedented interest and investment in health data demonstrated by federal, provincial, and territorial governments since the COVID-19 pandemic engenders optimism for the future of health

<sup>90</sup> Government of Canada, Federal statement on the federal, provincial, territorial health ministers' meeting, 2022, (<https://www.canada.ca/en/health-canada/news/2022/11/federal-statement-on-the-federal-provincial-territorial-health-ministers-meeting.html>)

<sup>91</sup> SAMTIS, Rapid recap: 2023 health ministers' meeting, 2023, (<https://santishealth.ca/insights/rapid-recap-2023-health-ministers-meeting/>)

<sup>92</sup> IBID



data design and use in Canada. The establishment of the Joint FPT Action Plan on Health Data and Digital Health prompted the negotiation of bilateral agreements between the federal government and individual provinces and territories which tie the transfer of funds to specific health data deliverables.

## WORKING TOGETHER BILATERAL AGREEMENTS – 2023-24

In the 2023 federal budget, the Government of Canada directed \$200 billion dollars to support the Working Together to Improve Health Care for Canadians Plan.<sup>93</sup> One of the four pillars of this plan, the “Modernization Aim”, was intended to foster the standardization of health “information and digital tools so health care providers and patients have access to electronic health information.”<sup>94</sup> Funding to support this pillar was offered individually to each province and territory through bilateral agreements “intended to be flexible and tailored, so that provinces and territories can address the unique needs of their populations and geography.”<sup>95</sup>

The conditions to receive funding for the health data pillar included:

- “Collecting and securely sharing comparable information needed to improve health care for people in Canada.
- Adopting common standards to better connect Canada's health care system, including with the implementation of the Shared Pan-Canadian Health Data Interoperability Roadmap.<sup>96</sup>
- Aligning policies and legislative frameworks to support the use of health information for public good.
- Advancing in person-centered principles outlined in the *pan-Canadian Health Data Charter* for the management of health information.
- Helping better manage public health emergencies.”<sup>97</sup>

All provinces and territories have signed a bilateral agreement with the federal government between October 10, 2023, and March 27, 2024. The statements of work differ significantly due to customization to jurisdictional projects and needs.<sup>98</sup>

### Impact on Health Data

The intent of the Working Together health data modernization program is to foster harmonized health data public policy and legislation, advance person-centric data design, and promote the use of data

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<sup>93</sup> Government of Canada, Working together to improve health care in Canada: Overview, 2024, (<https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities.html>)

<sup>94</sup> IBID

<sup>95</sup> IBID

<sup>96</sup> Canada Health Infoway, Connecting you to Modern Health Care: Shared Pan-Canadian Interoperability Roadmap, 2023, (<https://www.infoway-inforoute.ca/en/component/edocman/resources/interoperability/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap?Itemid=103>)

<sup>97</sup> Government of Canada, Working together to improve health care in Canada: Working Together bilateral agreements, 2024, (<https://www.canada.ca/en/health-canada/corporate/transparency/health-agreements/shared-health-priorities/working-together-bilateral-agreements.html>)

<sup>98</sup> IBID

for public good across the continuum of provinces and territories. This intention is meritorious, but may be attenuated by variable jurisdictional uptake and program customization. The habit of customizing health data design and standards to pre-existing jurisdictional conditions suggests that the fragmentation of health data across provinces and territories may remain a persistent challenge. If passed as an Act of parliament, the *Connected Care for Canadians Act* should improve the variable approach of jurisdictions to health information technology data standards design and use.

**SUMMARY: FEDERAL – PROVINCIAL/TERRITORIAL INTERFACE**

Table 5: Summary of Impact of Federal / Provincial-Territorial Interface on Core Elements of Health Data Ecosystem

Core elements of health data	Federal - provincial/territorial interface
<b>Human resources</b>	<ul style="list-style-type: none"> <li>• Nothing to note.</li> </ul>
<b>Financial resources</b>	<ul style="list-style-type: none"> <li>• In 2023, the federal government offered one-time provincial and territorial funding for health data initiatives to advance person-centered data design and care, and to align jurisdictional health data policy and legislation. There has been significant uptake of health data funding across provinces and territories, but with project customization based on the specific needs and priorities of each jurisdiction.</li> </ul>
<b>Information and communication technology</b>	<ul style="list-style-type: none"> <li>• There is currently no binding process or mechanism to achieve harmonized health information technology public policy across federal/provincial/territorial governments in Canada.</li> <li>• If passed into law the <i>Connected Care for Canadians Act</i> will constitute the first public policy to mandate a common approach to health information technology data standards design in Canada.</li> </ul>

## Data

- Responsibility for health data design and use has largely defaulted to provincial and territorial authority, but without significant coordination even within each jurisdiction. The regionalization and decentralization of data design and use has evidently occurred without manifest thought to the repercussions of this non-harmonized approach.
- There has been greater interest and investment in health data demonstrated by federal, provincial, and territorial governments since the COVID-19 pandemic. This interest is in part exemplified by:
  - the endorsement of the *Health Data Charter*.
  - the establishment of the Joint FPT Action Plan on Health Data and Digital Health.
- The tendency to customize jurisdictional approaches to health data design and standards suggests that the fragmentation of health data across provinces and territories may be perpetuated.
- If passed into law, the *Connected Care for Canadians Act* will help mitigate regional health data fragmentation.
- There is currently no binding mechanism or process for harmonizing distinct provincial and territorial health data legislative and regulatory approaches.
- The legislative and regulatory oversight of health data is generally consistent across provinces and territories in the sense that it focuses almost exclusively on personal access, privacy, and security of health information.
- There is a uniform and almost complete absence of any legislative or regulatory approach to minimize most forms of health data-related harm, aside from privacy and security, across all provinces and territories, including assuring the health and wellbeing of Canadians.

## Governance and accountability to quality health programs and services

- Jurisdictional health data policy fragmentation does not support person-centric health data architecture and the delivery of quality health programs and services.
- There is an almost uniform absence of coordinated governance, accountability, and public policy across federal, provincial, and territorial governments that binds the design and use of health data to the delivery of quality health programs and services.

## PROVINCIAL ARENA

For this report, provincial/territorial public policy analysis will be limited to an examination of Alberta legislation, regulation, and policy. However, the methodology used can be applied to examine health data public policy in other provinces and territories.

The analysis of the impact of Alberta legislation on health data will include an evaluation of the following four acts:

1. *Health Professions Act*, RSA 2000, c H-7.
2. *Alberta Health Care Insurance Act*, RSA 2000, c A-20.
3. *Health Information Act*, RSA 2000, c H-5.
4. *Personal Information Protection Act*, SA 2003, c P-6.5.

Further, as the federal *Food and Drugs Act* does not regulate the safety of digital health information technologies, the provincial approach to digital health information technology regulation will be examined.

An evaluation of provincial regulatory oversight of health data design and use will follow.

## HEALTH PROFESSIONS ACT, 2000

The Alberta *Health Professions Act* (HPA) governs the “practice of regulated health professions, sets out standard processes for colleges for registration, continuing competence, complaints and discipline and establishes a board that advises the Minister”.<sup>99</sup> The Alberta HPA names 29 provincial regulated health professions, and defines how:

- They are governed by independent regulatory bodies called “colleges”.
- Colleges are obligated to ensure that all registered health professionals under their supervision provide safe, competent, and ethical care.
- Colleges carry out governance and regulatory responsibilities in a way that protects and serves the public interest, by:
  - Maintaining and enforcing professional regulations, standards of practice, and codes of ethics; and,
  - Investigating complaints and imposing disciplinary sanctions when appropriate.
- The scopes of practice of respective regulated professions are non-exclusive and can overlap.<sup>100</sup>

### Impact on Health Data

Alberta health profession regulatory colleges do not have a mandate to oversee or regulate the health data captured, stored, or managed by their members. Standards of practice set by colleges establish professional benchmarks to ensure members deliver safe, competent, and ethical care, including duties of confidentiality to patients and their data. Some professional standards dictate how members are expected to interact with health data in the context of their professional duty to serve the public interest; notable examples being virtual care, continuity of care, and episodic care. However, direct features of health data design and many aspects of its use by health professionals are not addressed through professional regulatory standards; nor are there data literacy standards that must be met to qualify for a particular health profession designation. Further, there is no process for aligning the standards of respective colleges that touch on health data use or management, which can adversely impact the function of team-based health service.

## ALBERTA HEALTH CARE INSURANCE ACT, 2000

In alignment with the *Canada Health Act*, the *Alberta Health Care Insurance Act* establishes the Alberta Health Care Insurance Plan (AHCIP), which provides eligible Alberta residents with full coverage for *medically necessary physician* services, and some dental and oral surgical health

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<sup>99</sup> Government of Alberta, Health Professions Act, 2024, (<https://open.alberta.ca/publications/h07>)

<sup>100</sup> Government of Alberta, Regulated health professions and colleges, n.d., (<https://www.alberta.ca/regulated-health-professions#:~:text=The%20HPA%20was%20developed%20to,provide%20the%20same%20health%20services>)

services.<sup>101</sup> The Alberta government also funds Alberta Health Services (AHS) to deliver hospital-based services, including mental health and addiction, physiotherapy, midwifery, cancer care, and home care services.<sup>102</sup>

## Impact on Health Data

The AHCIP does not acknowledge health data, health information technology, nor specific data-related services like virtual care.

The principal costs associated with health data have historically been associated with the technology used to capture, hold, and exchange it, and the human resources to manage it. The approach to the funding of health information technology in Alberta is context specific. While health care providers in 'private practice' are accountable for covering the cost of the health information technology they use to manage clinical data, the same categories of information technology that health care providers and support staff use in hospitals are publicly funded.

This inconsistency is also manifest in the funding of virtual care, a health information and communication technology dependent service. Prior to 2020 and the COVID-19 pandemic, the funding of virtual care services by physicians in Canada was limited. The absence of public funding for virtual care meant that this form of care, when available, was largely provided by private sector agencies, corporations, and privately funded physicians. This changed suddenly in early 2020, when most provinces and territories, including Alberta, adopted virtual care insurance plans. This has continued to evolve since the end of the pandemic in an inconsistent way across jurisdictions, with some provinces repealing or altering coverage.<sup>103</sup> In Alberta, virtual care financial coverage has continued for select physician services, including the assessment of a patient's condition by telephone or secure videoconference.<sup>104</sup>

## HEALTH INFORMATION ACT, 2000

The Alberta *Health Information Act* (HIA) articulates the rules governing the protection of personal health information under the control of health data custodians. Custodians include various organizations and entities that collect, use, and disclose personal health information while carrying out their duties and responsibilities as part of the Alberta health care system.<sup>105</sup> Organizations that are listed as custodians include Alberta Health Services and Alberta Health. Of the 29 regulated health professions in Alberta, 11 are designated as custodians, including physicians, pharmacists, and denturists. Psychologists, physiotherapists, and licensed practical nurses are among the 18 regulated professions that are not custodians (Table 6).

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<sup>101</sup> Government of Alberta, Health care services covered in Alberta, n.d., (<https://www.alberta.ca/ahcip-what-is-covered>)

<sup>102</sup> IBID

<sup>103</sup> Watts M et al., The evolving regulatory landscape of virtual care in Canada, 2023 (<https://www.osler.com/en/insights/updates/the-evolving-regulatory-landscape-of-virtual-care-in-canada/>)

<sup>104</sup> Alberta Medical Association, Virtual care, 2024, (<https://www.albertadoctors.org/leaders-partners/ehealth/virtual-care#codes>)

<sup>105</sup> Government of Alberta, Health Information Act, n.d., (<https://www.alberta.ca/health-information-act>)

Table 6: Alberta health professions by custodial status

Custodians - Governed by HIA	Non-Custodians - Governed by PIPA
<ul style="list-style-type: none"> <li>• Chiropractors</li> <li>• Optometrists</li> <li>• Pharmacists &amp; Pharmacy Technicians</li> <li>• Dentists</li> <li>• Registered Nurses</li> <li>• Denturists</li> <li>• Midwives</li> <li>• Opticians</li> <li>• Physicians</li> <li>• Podiatric Physicians</li> <li>• Dental Hygienists</li> </ul>	<ul style="list-style-type: none"> <li>• Acupuncturists</li> <li>• Dental Technologists</li> <li>• Laboratory and X-ray Technologists</li> <li>• Dietitians</li> <li>• Medical Diagnostic and Therapeutic Technologists</li> <li>• Hearing Aid Practitioners</li> <li>• Occupational Therapists</li> <li>• Licensed Practical Nurses</li> <li>• Paramedics</li> <li>• Physiotherapists</li> <li>• Social Workers</li> <li>• Respiratory Therapists</li> <li>• Speech-Language Pathologists and Audiologists</li> <li>• Medical Laboratory Technologists</li> <li>• Naturopathic Doctors</li> <li>• Dental Assistants</li> <li>• Psychologists</li> <li>• Psychiatric Nurses</li> </ul>

The HIA is essentially privacy legislation that seeks to strike a balance between the protection of privacy by limiting health information sharing to what is considered necessary and supporting health service delivery by permitting the appropriate sharing of health information.<sup>106</sup> The HIA does not purport to be all-encompassing health data legislation that governs all facets of data use.

As such, most other forms of health data-related harm (Figure 1) that arise from the poor design and use of health data – including damage to patient health and wellbeing, health system inefficiencies, cultural harm, and health provider burnout – are not addressed by the HIA. One exception is that the HIA affirms the right of patients to access their personal health information. The HIA outlines a process for individuals to access their health records – historically paper-based – through the submission of an access request form that includes a fee for receiving a printed copy of the information. There is no specific mention of digital access to personal health information.

Importantly, although the HIA is permissive of health data sharing for appropriate clinical purposes, there is no *duty to share* information on the part of custodians. As such, there appear to be no consequences, to our knowledge, for a custodian whose choice not to share health information or whose failure to adopt processes and systems to facilitate data sharing leads to the death or other adverse health outcomes of a patient. Health data-related harm arising from under-sharing health information is not addressed in any other provincial legislation.

<sup>106</sup> IBID

The HIA is focused on health data and was not intended to consider the impact of, nor set regulatory standards for the design and use of health information technology. This includes the absence of assurances that the health information technology functions in a manner that safeguards the health and wellbeing of individuals and populations. The HIA only impacts health information technology by defining privacy and security standards for the health data it manages. This reflects that the HIA is principally privacy legislation and underscores a gap in health data and information technology public policy that addresses other forms of health data-related harm.

## Impact on Health Data

The impact of the HIA on health data will be addressed below in conjunction with the impact of the *Personal Information Protection Act*.

### PERSONAL INFORMATION PROTECTION ACT, 2003

The Alberta *Personal Information Protection Act* (PIPA) defines the right of access and protection of personal information for provincially regulated private sector organizations, businesses, and, under limited circumstances, non-profit organizations.<sup>107</sup> PIPA is not designed specifically for health information, but applies broadly to all forms of personal information. Parties that play a role in the health sector, but which are governed by PIPA for the management of health information in their custody or control include:

- Organizations, entities, or individuals not defined as custodians under the HIA, including regulated health professionals such as psychologists, physiotherapists, and licensed practical nurses (Table 6).
- Health information technology vendors that hold personal health information on their proprietary technology.

Although PIPA does address the right of access to an individual's personal information, it does not address issues specific to personal health information, nor forms of health data-related harm, other than the breach of privacy or access to personal health information.<sup>108</sup>

## Impact on Health Data (HIA & PIPA)

Quality health programs and services are wholly dependent on the comprehensive exchange of health data. If pertinent health data is missing or unavailable, either at the point of care or for secondary use, errors can occur and insights can be lost, thus putting the health and wellbeing of patients and populations at risk. Consequently, the sharing of health information becomes a necessity

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<sup>107</sup> Government of Alberta, Personal Information Protection Act – Overview, n.d., (<https://www.alberta.ca/personal-information-protection-act-overview#jumplinks-0>)

<sup>108</sup> Government of Alberta, Personal Information Protection Act – Overview, n.d., (<https://www.alberta.ca/personal-information-protection-act-overview>)

to assure that it minimizes harm to patients, populations, and the health care system, and promotes quality health programs and services.

### *Custodianship*

The custodial model of health data oversight dictated in the HIA unintentionally fosters the fragmentation of health data and promotion of health data-related harm in several ways. First, the HIA places a relative emphasis on one form of health data-related harm – breaches of privacy – relative to most other forms of harm. It assigns accountability to data custodians to assure the privacy and security of the health information that they manage without any countervailing duty to assure the sharing of that data across health personnel collaborating in direct patient care, research, management, or population and public health.

There is also no countervailing legislation to the HIA that dictates health data, or the technology that manages it, must be interoperable to permit appropriate data exchange. Consequently, the HIA obliges custodians to procure technology platforms that are secure, but in no way expects these technologies to interoperate. The result is the unintentional, yet pervasive custodian-centric fragmentation of individual and population-based health data. This has a deeply negative impact on the integrity of all health programs and services, which are wholly dependent on the appropriate sharing of health information across services, custodians, and jurisdictions to function safely and effectively.

### *Duty to Share Data*

Although the HIA is permissive of data sharing, it does not obligate it. This means that the decision to not share health information has no repercussions, irrespective of the impact on the health and wellbeing of patients and populations. Like the HIA, PIPA also focuses almost exclusively on harm arising from sharing information, neglecting to address forms of harm that arise from a lack of information sharing, such as poor health outcomes. The by-product is that entities, including health professions not deemed custodians, can be similarly disincentivized to appropriately share health data in support of quality health programs and services.

As privacy legislation, the HIA and PIPA were not designed to safeguard the public from many core categories of health data-related harm. Failing to adopt laws – whether within or outside privacy legislation - that uphold a duty to share data for the express support of health and wellbeing, results in an overemphasis on the importance of privacy and a health workforce that can be disincentivized to share health information for fear of privacy repercussions. This imbalance reflects the odd status of the Canadian health sector, which exhibits a significant legislative focus on data privacy in the face of an almost complete absence of data policy mitigating other forms of harm, including illness and death.



## *Legislated Division of Data Oversight – Regulated Health Professionals*

The fact that the scope of application of the HIA results in the division of health care professionals into two distinct health information management groups – custodians and non-custodians – is problematic. This separates a patient’s team of providers into two legislatively distinct groups: those governed by the HIA and those governed by PIPA. Not only does this amplify the custodian-based fragmentation of personal health information, but it can adversely impact the exchange of health information across a care team by creating functional complications for some health professions and technology vendors.

For health professionals that are not designated custodians (18 in Alberta), such as psychologists and physiotherapists, their accountability for the personal health information they manage can shift based on the location of their work. When working for a public sector health institution, such as a hospital, they are designated as an affiliate of the hospital as custodian and the personal health information they manage is therefore subject to the HIA. Whereas when working in their private clinic, the information they manage is governed by PIPA. To further complicate matters, non-custodian health professionals working at a non-health public institution, such as a university, must comply with the *Freedom of Information and Privacy Protection Act* (FOIP).<sup>109</sup> This means that non-custodian health professionals may be subject to compliance with three distinct privacy acts depending on where they might be working. The sharing of health information they generate in these distinct locations can be cumbersome, even as it relates to caring for the same patient. Further, non-custodian health professionals working in the private sector are not eligible to access patient information on the provincial electronic health record, Netcare, which impairs their capacity to view relevant health information and adversely impacts continuity of care.<sup>110</sup> The very same health professional is entitled to access Netcare if they are working as an affiliate at a custodian health institution.

## *Health Information Technology Vendors*

Health information technology vendors that function by exchanging health data between custodian and non-custodian members of a patient’s care team face similar issues. They must configure their software to adjust protocols for exchange of information to the legislative status of the health professional in question, which is a complex and expensive proposition that disincentivizes digital health innovation, team-based interoperability, and ultimately promotes personal health information fragmentation. Adding to the complexity, in some cases, the vendors are only entitled to collect and retain data based on the authority of the custodian under the HIA. This limits the functionality and value of the vendor’s systems and data holdings for the public good, while contributing to patient data

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<sup>109</sup> Government of Alberta, Freedom of Information and Protection of Privacy Act, FIOP: A guide, 2006, (<https://open.alberta.ca/dataset/8427c023-5df1-4003-a504-f1463013e7c2/resource/2aec33df-5b57-42ee-b690-609bab99baca/download/foipguide.pdf>)

<sup>110</sup> Government of Alberta, Privacy and security for Alberta Netcare, n.d., (<https://www.albertanetcare.ca/patientprivacy.htm>)

fragmentation and discontinuity, as the vendor has no authority to retain data for the benefit of the patient if the custodian elects to stop using the vendor's platform.

Health information technology vendors are governed by PIPA and have different accountabilities for the health information they hold in their proprietary software compared to custodian health professionals who use their platforms. Nurses, physicians, and other custodian providers working on proprietary software platforms hosted by a digital health technology vendor must comply to the HIA, yet frequently lack any authority over how the technology platform they are using manages personal health data. As custodians, they can bear responsibility for how the technology platform that they use manages personal health information and may be liable for any data breaches that occur.

Information management agreements that bridge different legislated data accountabilities are often entered into between custodians and technology vendors in which each party attempts to limit their own responsibility and liability. This may promote an adversarial mindset which sets parties against each other instead of encouraging data collaboration and innovation. This disjointed legislative approach to health data contributes to regulatory complexity for technology vendors that can exacerbate health data fragmentation<sup>111</sup>, impair collaboration between public and private sector entities, and impede the advancement of research, innovation, and a robust, vibrant digital health care technology industry.

### *Access to Personal Health Information*

In a 2017 report, the Auditor General of Alberta stated, "patients do not have [digital] access to their own health information."<sup>112</sup> This is reflected in the approach of both the HIA and PIPA to personal health information access; there is no reference to digital access, only to a paper-based process, which reflects the age of the legislation. Further, the accountability for assuring patient access to personal health information rests with custodians, which means digital access to personal health information tends to occur at the discretion of a specific custodian, technology, or health service, rather than being a system-wide principle of health data design. This is reflected in the proliferation of custodian-centered patient portals in Canada.<sup>113</sup>

Significant headway has been made with digital personal health information access in Alberta since 2017 with the implementation of two patient portals by Alberta Health Services,<sup>114</sup> and Alberta Health<sup>115</sup>, although these platforms only provide a subset of a patient's overall health information.

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<sup>111</sup> Spithoff, S., McPhail, B., Grundy, Q., Vesely, L., Rowe, R., Herder, M., Allard, B., & Schumacher, L. (2022). Commercial virtual healthcare services in Canada: Digital trails, de-identified data and privacy implications. Health Tech and Society Lab. <https://www.healthtechandsocietylab.org/new-page>

<sup>112</sup> The office of the auditor general of Alberta, Better healthcare for Albertans, 2017, (<https://www.oag.ab.ca/wp-content/uploads/2020/05/2017 - Better Healthcare for Albertans Report - May 2017.pdf>)

<sup>113</sup> Canada Health Infoway, Access to Personal Health Information (PHI), n.d., (<https://insights.inforoute.ca/2023-access-to-phi/>)

<sup>114</sup> Alberta Health Services, Find healthcare, n.d., (<https://www.albertahealthservices.ca/findhealth/Service.aspx?id=1082056&serviceAtFacilityID=1128770>)

<sup>115</sup> Government of Alberta, MyHealth records, n.d., (<https://myhealth.alberta.ca/myhealthrecords>)

## *Team-Based Quality Care*

Today's reality is that the sharing of personal health information across a care team is not guided by legislation aimed at fostering an individual's health and wellbeing, but rather is impeded by a complex and dated suite of public policy focused almost exclusively on access, privacy, and security, and centered around providers and services, not the patient. Health care providers, researchers, public health providers, management, and innovators alike must attempt to navigate this cumbersome policy environment to advance health sector function and support the health and wellbeing of the public. Together, the HIA, PIPA, and the absence of countervailing legislation addressing the means and the duty to share health data contribute to the cultivation, or at minimum the absence of mitigation, of the many forms of health data-related harm that occur in the context of poor health data design and use. Ultimately all these factors hinder person-centric team-based care, despite this being a priority expressly identified in the government's Modernizing Alberta's Primary Care System (MAPS) initiative.<sup>116</sup>

## **ABSENCE OF HEALTH INFORMATION TECHNOLOGY LEGISLATION**

As noted above, until the recent introduction of the *Connected Care for Canadians Act*, health information technologies have been excluded from federal regulatory oversight as they are not defined as medical devices in the federal FDA. The historical absence of health information legislative or regulatory oversight at the federal level is replicated at the provincial and territorial level. Although the data captured, held, and exchanged by health information technologies is subject to the provisions of multiple acts, including the HIA and PIPA, the health information technology itself has traditionally had no dedicated regulatory oversight. This means that to date there has been no public policy framework for assuring the safety of health information technologies used in Canada. The *Connected Care for Canadians Act* changes the landscape in this respect by taking the first step towards laying the foundation for better data portability and interoperability, such as mandatory data content and exchange standards, anti-data blocking requirements, and a regulatory process for upholding these provisions.

### **Impact on Health Data**

The historical absence of legislation to assure that health information technologies capture, manage, and exchange health data in a manner that promotes the health and wellbeing of Albertans and Canadians adversely impacts the provision of quality health services and programs and exacerbates some forms of health data-related harm.

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<sup>116</sup> Government of Alberta, Modernizing Alberta's Primary Health Care System (MAPS) Engagement, 2024, (<https://www.alberta.ca/modernizing-albertas-primary-health-care-system-engagement>)

## PROVINCIAL REGULATION

The regulatory oversight of health data in Alberta is addressed by considering the regulatory approach to core elements of a health data ecosystem:

- Human resources
- Financial resources
- Information technology
- Data
- Governance and accountability to health and wellbeing

### *Human Resources Regulation:*

There are 29 regulated health professions in Alberta, each of whom have a regulatory college mandated to ensure that all registered health professionals under their supervision provide safe, competent, and ethical care. To our knowledge, none of Alberta's regulatory colleges have a dedicated standard of practice that dictates how members must interact with health data to uphold public good. Rather, member accountabilities to health data are distributed in a variety of disparate standards of practice and the approach taken is inconsistent from college to college. For instance, as of 2023, only 50% of Alberta's colleges had a standard of practice for virtual care – a data dependent health service.<sup>117</sup> A further 20% had such a standard in development.<sup>118</sup> There is no framework, benchmark, or process across colleges to assure that these standards are harmonized and support health data exchange across a patient's care team.

Many of the health sector human resources involved in the design and use of health data – including private sector technology vendors, many health information technology consultants, and health care providers not listed in the *Health Professions Act* – are unregulated and bear no clear accountability to promote health data use that fosters public good. Moreover, none of the health professional colleges have data literacy standards that must be met to qualify as a particular health professional.

### *Financial Resources Regulation:*

There is no regulatory oversight of the financial management of health data in Alberta.

### *Health Data Regulation:*

Health data in Alberta is subject to the regulatory oversight of the Office of the Information Privacy Commissioner (OIPC). The mandate of the OIPC is to advocate “for the access and privacy rights of

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<sup>117</sup> Report not yet published, for more information contact the Alberta Virtual Care Coordinating Body

<sup>118</sup> IBID

Albertans,” and ensure that “public bodies, health custodians and private sector organizations uphold the access and privacy rights contained in the laws of Alberta.”<sup>119</sup> The Privacy Commissioner (“Commissioner”) is appointed under the *Freedom of Information and Protection of Privacy Act* and has broad accountabilities for information privacy as dictated by multiple acts, including the HIA.

The Commissioner is charged with interpreting and enforcing the provisions of the HIA through a set of regulatory processes and powers that include Privacy Impact Assessments (PIAs), the right to conduct investigations to ensure compliance with the HIA, and the capability to advise custodians on their obligations under the Act.<sup>120</sup>

When deploying new information systems or making substantial changes to existing systems which involve the collection, use, and disclosure of individually identifying health information, all custodians must prepare and submit a PIA to the OIPC. Submission of the PIA to the OIPC must occur prior to the implementation of any changes in information management. There is currently a significant delay in the processing of PIAs in Alberta.<sup>121</sup> The scope of health-related responsibilities of the OIPC does not extend beyond harm arising from privacy-related concerns or access to information. Other than the duties assigned to the OIPC through the HIA, there are no other provincial regulatory mechanisms or processes dedicated to assuring that health data is used in a manner that promotes quality health programs and services while minimizing health data-related harm.

### ***Health Information and Communication Technology Regulation:***

There is no direct regulatory oversight of health information technologies in Alberta.

There is indirect regulatory oversight in that health information technology vendors and custodians deploying new technologies must assure that the digital solution they are implementing manages health data in compliance with the privacy requirements of the HIA and PIPA.

Across jurisdictions, Ontario is an exception to this rule as it is in the process of establishing provincial regulatory standards for virtual visit solutions, digital health information exchange, online appointment booking, and patient portals.<sup>122</sup>

### ***Regulation of Governance and Accountability to Health and Wellbeing:***

There are no provincial regulatory oversight or governance and accountability mechanisms in Alberta to assure that health data is used to promote quality health programs or services that support the health and wellbeing of the public.

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<sup>119</sup> Office of the Information and Privacy Commissioner of Alberta, About the OIPC, n.d., (<https://oipc.ab.ca/about-us/about-the-oipc/>)

<sup>120</sup> IBID

<sup>121</sup> Alberta PIA, Frequently asked questions, n.d., (<https://www.albertapia.ca/faq>)

<sup>122</sup> Ontario Health, Digital standards in health care, 2023, (<https://www.ontariohealth.ca/system-planning/digital-standards>)

### Impact on Health Data

While the regulation of health data to prevent breaches of privacy and security and assure patient access to personal health information are present, provincial regulatory oversight is perhaps most notable for unregulated aspects of the data ecosystem. The absences include:

- The regulation of health information technologies to protect the safety and wellbeing of the public, health workforce, and health system.
- The regulation of health data to prevent most forms of health data-related harm, other than issues related to data access, privacy, and security.
- The regulation of the design and use of health data to uphold the health and wellbeing of Albertans.
- The regulation of many of the health sector human resources involved in the design and use of health data.

This piecemeal and imbalanced approach to health data regulation places the welfare of the public, the health care workforce, and the health care system at risk.

### SUMMARY – PROVINCIAL/TERRITORIAL ARENA

Table 7: Summary of Impact of Provincial Public Policy (Alberta) by Core Elements of Health Data Ecosystem

Core elements of health data ecosystem	The provincial/territorial (Alberta) arena
Human resources	<ul style="list-style-type: none"> <li>• Only 11 of the 29 (37.9%) regulated health professions in Alberta are designated as custodians. Custodian and non-custodian health professions are subject to different provincial privacy legislation, but can belong to the same care team.</li> <li>• None of Alberta’s regulatory colleges have data literacy standards or a dedicated standard of practice that dictates how members must interact with health data to uphold quality of care and public good. There are regulatory standards of practice that touch upon the accountability of members to certain aspects of health data use, primarily in relation to access, privacy, and confidentiality.</li> <li>• There is no framework, benchmark, or process across health profession regulatory colleges to achieve a harmonized person-centred approach to data use across a patient’s care team.</li> <li>• Health sector human resources involved in the design and use of health data systems are not subject to professional regulation or required to possess any set educational requirements, such as data literacy.</li> </ul>

<p><b>Financial resources</b></p>	<ul style="list-style-type: none"> <li>• There is inconsistency in the financial coverage of health information technology: <ul style="list-style-type: none"> <li>◦ Publicly-funded physicians in ‘private practice’ are accountable for covering the cost of the health information technology that they use to manage clinical data.</li> <li>◦ The cost of information technology used by publicly-funded physicians in hospitals is covered by the provincial government.</li> </ul> </li> <li>• There is no regulatory oversight of the financial management or investment in health data governance, design, and use in Alberta.</li> </ul>
<p><b>Information and communication technology</b></p>	<ul style="list-style-type: none"> <li>• Despite the Supreme Court of Canada decision of <i>McInerney v. MacDonald</i> and applicable provisions of the Alberta HIA, patient access to comprehensive digital personal health information remains cumbersome in Alberta.</li> <li>• An absence of legislation to assure that health information technologies capture, manage, and exchange health data in a manner that promotes the health and wellbeing of Albertans adversely impacts the provision of quality health services and programs, and the health and wellbeing of the public and health system.</li> <li>• There is no direct regulatory oversight of health information technologies in Alberta.</li> </ul>
<p><b>Data</b></p>	<ul style="list-style-type: none"> <li>• The custodial model of health data oversight dictated in the Alberta HIA unintentionally fosters the fragmentation of health data and promotion of health data-related harm.</li> <li>• Most forms of health data-related harm that arise from the poor design and use of health data – including damage to patient health and wellbeing, health system inefficiencies, cultural harm, and health provider burnout – are not directly addressed in provincial legislation or regulations.</li> <li>• There is no provincial legislation that dictates that health data, or the technology that manages it, must be interoperable to permit appropriate data exchange and foster quality care.</li> <li>• Although the Alberta HIA is permissive of data sharing, it does not obligate it, meaning that the decision to not share health information has no repercussions, irrespective of the impact on the health and wellbeing of patients and populations.</li> <li>• Although Alberta has recently endorsed the <i>Health Data Charter</i>, there has been limited operationalization of the ten <i>Health Data Charter</i> principles, including: <ul style="list-style-type: none"> <li>◦ The support of “First Nations, Inuit, and Métis data sovereignty and Indigenous-led governance frameworks.”</li> <li>◦ “Person-centric health information design to ensure that health data follows the individual across points of care.”</li> </ul> </li> </ul>
<p><b>Governance and accountability to quality health programs and services</b></p>	<ul style="list-style-type: none"> <li>• The only dedicated provincial health data legislation, the HIA, places a relative emphasis on two forms of health data-related harm – lack of legal access to information and breaches of privacy - relative to most other forms of harm. <ul style="list-style-type: none"> <li>◦ An overemphasis on the importance of privacy promotes a health workforce that is disincentivized to share health information for fear of privacy repercussions.</li> </ul> </li> <li>• PIPA also neglects to safeguard the health and wellbeing of the public from many core categories of health data-related harm.</li> <li>• The sharing of personal health information across a care team is not guided by legislation aimed at upholding quality health programs and services or an individual’s health and wellbeing.</li> <li>• There are no other provincial regulatory mechanisms or processes dedicated to assuring that health data is used in a manner that promotes quality health programs and services and minimizes health data related harm.</li> <li>• The oversight of health data design and use in Alberta is functionally fragmented between custodians, the government, and private sector interests. Largely excluded from meaningful oversight are public and Indigenous representation.</li> </ul>

# CANADIAN HEALTH DATA PUBLIC POLICY - SUMMARY

Based on a distillation of the three arenas of Canadian health data public policy - federal arena, FPT interface, and provincial/territorial arena - a summation of findings was conducted to elucidate crosscutting themes. These themes were organized into three categories:

- Governance
- Existing legislation and regulation
- Policy gaps

These themes are predicated on an understanding that health data or information (contextualized data) is a key ingredient - or currency - of all informed decisions in health service.

## GOVERNANCE

### 1. **IT IS UNCLEAR WHO OVERSEES THE DESIGN AND USE OF HEALTH DATA IN CANADA, THE PROVINCES, AND TERRITORIES.**

The oversight of health data design and use is not identified in the *Canada Health Act*, nor in any other federal legislation. The federal government does assert control over some data assets arising from federally-funded health services, including the armed forces, and Non-Insured Health Benefits for First Nations and Inuit peoples.<sup>123</sup> There is presumptive provincial/territorial oversight of most other categories of health data as manifest in practice, including jurisdictional information acts which assert this power by ascribing to local data custodians and non-custodians independent control over the technologies they select to manage health data, without any accountability to a grander strategic plan. Functional application of Indigenous data sovereignty is largely absent, as is meaningful inclusion of public representation in data oversight. Further, health technology vendors, which are subject to different data legislation than health data custodians, also exert control over some categories of health data.

Taken together, this results in the compound fragmentation of health data oversight across nested levels of authority including federal, provincial, territorial governments, custodians, and non-custodians, including private sector technology vendors. The result is that there is no clarity about data oversight and a resulting absence of a harmonized approach to health data design and use in Canada. The recent tabling of the *Connected Care for Canadians Act* signals the first time the federal government is asserting its right to dictate national health information technology standards and may mark a sea change in historical data governance practice. Lost in this

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<sup>123</sup> Government of Canada, Non-insured health benefits for First Nations and Inuit, 2023, (<https://www.sac-isc.gc.ca/eng/1572537161086/1572537234517>)



governance fragmentation - functionally and in public policy - is the capacity of the public and Indigenous Peoples to assert control over their personal health information, particularly as it relates to their ability to access their comprehensive digital health information.

**2. HEALTH DATA OVERSIGHT HAS LARGELY DEFAULTED TO THE PROVINCES AND TERRITORIES BUT IS NOT MANDATED IN PUBLIC POLICY.**

Neither the *Constitution Act* nor the *Canada Health Act* dictate that health data oversight is a mandated provincial and territorial power; rather, provincial and territorial governments have assumed the oversight of health data assets in their jurisdictions. Combined with the absence of a formal mechanism for assuring public policy harmonization (see number 3 below), the presumption of jurisdictional health data oversight promotes the structural fragmentation of patient and population-based information, thereby negatively impacting the effective and safe use of health data in Canada. The tabling of the *Connected Care for Canadians Act* may be interpreted as challenging traditional jurisdictional data oversight practices, although it explicitly provides the option for provinces and territories to develop similar and equal legislation.

**3. THERE IS NO ESTABLISHED MECHANISM FOR HARMONIZING HEALTH DATA PUBLIC POLICY ACROSS HEALTH SYSTEM STAKEHOLDERS AND JURISDICTIONS.**

Although the requirements of the *Canada Health Act* dictate that health service should be portable, comprehensive, accessible, and universal, these conditions are not routinely met in the management of health data. The failure to ensure health data is where it needs to be to inform primary and secondary uses undermines quality health programs and services and cultivates health data-related harm. Yet there are limited governance or policy mechanisms to foster alignment of health data public policy both nationally or within provinces and territories. Although, the *pan-Canadian Health Data Charter* and recent FPT bilateral agreements have the stated aim of fostering health data public policy harmonization, on a functional basis, policy alignment is not binding and has been largely attenuated by jurisdiction-specific priorities and agendas.

## EXISTING LEGISLATION AND REGULATION

**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.**

The ubiquitous jurisdictional custodial model of health data oversight ascribes to custodians an accountability to assure that the health information technology they select ensures the privacy and security of health data, without any expectations that this technology can share information with other platforms to support quality health programs and services. The unintended by-product of this policy approach is the creation of custodian-centric silos of health data that do not interoperate. This has significant negative repercussions on health system function. Further the

segmentation of health data by differential privacy legislation that can vary depending on the status or location of the health professional further fragments continuity of patient information and team-based care. Ultimately, although a service and location specific approach to health data can support privacy, it can also promote other forms of health data-related harm and hinder the delivery of quality health programs and services.

**5. THE SCOPE OF LEGISLATIVE AND REGULATORY OVERSIGHT OF HEALTH DATA IS LARGELY CONSISTENT ACROSS PROVINCES AND TERRITORIES, FOCUSING ALMOST EXCLUSIVELY ON ACCESS, PRIVACY, AND THE SECURITY OF HEALTH INFORMATION.**

The scope of regulatory oversight of health data in Canadian jurisdictions is almost exclusively focused on defining appropriate, and preventing inappropriate access to, or disclosure of health information. With perhaps the exception of Quebec's recent Bill 3, there is a consistent absence across provinces and territories of regulatory efforts to assure the design and use of health data promotes quality health programs and services while mitigating other forms of health data-related harm. Despite the thematic consistency of scope, each jurisdiction's approach to health data regulation has differences, which results in legal compliance complexities that hinder beneficial data sharing across jurisdictions.

**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.**

There is no duty to share health data to support health and wellbeing at any level of public policy in Canada. This absence means that there is no countervailing impetus to the legislated duty to protect health data as dictated by jurisdictional privacy legislation. This imbalance in legislative and regulatory accountability encourages a conservative reluctance to share data. In turn this promotes data fragmentation and health data-related harm.

**7. PATIENT ACCESS TO HEALTH INFORMATION IS GENERICALLY ENABLED IN LEGISLATION BUT NOT ENFORCED IN DIGITAL HEALTH TECHNOLOGY DESIGN AND REGULATION.**

Both Supreme Court of Canada jurisprudence and Alberta legislation enable patient access to their personal health information, but these policies make no reference to digital modalities of communication. Accessing a complete suite of personal health information through a single channel is still not possible, and the design of digital health technology to enable comprehensive patient access to personal health information is neither mandated in legislation nor enforced. The proposed *Connected Care for Canadians Act* aims to foster comprehensive digital personal health information access for patients, but its effectiveness will depend on public policy pertaining to health data design, use, and governance that have yet to be established.

## 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.**

Until recently, the relationship between health data and the delivery of quality health programs and services has not been acknowledged or defined in almost any Canadian public policy. Health data flow has been a by-product of technology procurement and deployment processes lacking in regulatory accountability to the health and wellbeing of the public. The publication of the *pan-Canadian Health Data Charter* in 2022 changed this custom by tying the principles of optimized health data design to the *Canada Health Act* and its stated purpose to foster health and wellbeing. It remains to be seen if the *pan-Canadian Health Data Charter* will meaningfully impact federal, provincial, or territorial health data practices. The tabling of the federal Bill C-72 (the *Connected Care for Canadians Act*) and the recent coming into force of Quebec's Bill 3 are the first significant public policy instruments to link health data design and use to quality care.

### 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.**

The accessibility, portability, universality, and comprehensiveness of health data has a bearing on its capacity to enable quality health programs and services. Shortfalls in any of these properties of health data can contribute to the harm of individuals, populations, and the health system. A lack of consideration of most forms of health data-related harm in Canadian health data public policy is a recurring oversight that has costly human and financial implications. The two forms of harm that are consistently addressed in public policy are the legal right of individuals to access personal health information and health data privacy. The problem is not the policy attention to health data access and privacy, but rather the consistent absence of a similar awareness and attention at all levels of public policy in Canada to simultaneously minimize almost all other forms of health-data related harm. The proposed *Connected Care for Canadians Act* does aim to mitigate some forms of harm associated with the under-sharing of health data. Quebec's Bill 3 also offers an example of provincial health information privacy legislation that has novel provisions to support better data interoperability and sharing to mitigate some forms of harm.

### 10. **THE INTEGRATION OF PRINCIPLES OF INDIGENOUS DATA SOVEREIGNTY INTO HEALTH DATA DESIGN AND USE ARE OFTEN ABSENT IN GOVERNMENTAL PUBLIC POLICY.**

Despite efforts in some jurisdictions, there is an absence of harmonized and comprehensive legislation in Canada that addresses the rights of Indigenous Peoples to control health data from

and about their communities and lands. Indigenous communities have established data sovereignty principles, and these are beginning to gain traction with some governments and health organizations. However, a more fulsome framework for the meaningful integration of Indigenous data sovereignty into functional health data design and use is lacking.

**11. HEALTH INFORMATION TECHNOLOGY IS ALMOST WHOLLY UNREGULATED WITH RESPECT TO ITS CAPACITY TO PROMOTE THE HEALTH AND WELLBEING OF CANADIANS, MITIGATE HARM, AND FOSTER INNOVATION.**

Most technologies used in health care including drugs and medical devices are regulated to assure their safe use and protect public good. Curiously health information technologies are largely exempt from regulatory oversight and can be deployed freely on the market, except for mandatory compliance to privacy and security standards. This practice is consistent across the country and at all levels of government. It is odd that if the purpose of health service in Canada is to promote health and wellbeing that there is no effort in public policy to assure that health information technology supports this aim. This is akin to the airline industry deploying airplanes without assuring they are safe for passengers and pilots. The recent tabling of Bill C-72 (*Connected Care for Canadians Act*) may signal a watershed moment where accountability for the design and use of health Information technology is tied to the health and wellbeing of Canadians.

**12. INDIVIDUALS WHO DESIGN AND USE HEALTH DATA SYSTEMS IN CANADA DO NOT REQUIRE ANY DATA LITERACY TRAINING, DEFINED CREDENTIALS, OR KNOWLEDGE ASSETS.**

The design of health data systems, both from policy and technical perspectives, has a great bearing on the functional usability of health data to support quality health programs and services. Yet there is an absence of regulatory oversight of individuals involved in the design of health data systems and technology at all levels of health sector function, meaning that the personnel designing data systems lack any pedagogic requirements or membership in a regulated profession. Similarly, regulated health professionals also are not currently required to achieve any standard of practice when it comes to data literacy and the appropriate use and sharing of data to support quality of care and health and wellbeing of patients.

Table 8: Summary of Canadian Health Data Public Policy Themes by Domain

**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 established mechanism for harmonizing health data public policy across health system stakeholders and jurisdictions.

## EXISTING HEALTH DATA LEGISLATION AND REGULATION

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 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, 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.

# A CANADIAN HEALTH DATA CULTURE

In a 2014 systematic literature review by the Australian National University that examined the impact that national culture has in “shaping public policy”, the authors concluded that “the weight of evidence from the literature, clearly supports the hypothesis that national culture has a significant influence on public policy.”<sup>124</sup> This suggests that current state health data public policy reflects the foundational beliefs and attitudes about health data held by the Canadian health sector. Hence, an understanding of these beliefs can inform an approach to the reimagination of data policy that supports the health and wellbeing of Canadians.

An examination of what current public policy reveals about the attitude of Canada, its jurisdictions, and the health sector to health data and how these attitudes manifest a *Canadian health data culture*, is a complex endeavor. Recognizing that a proper treatment of this topic requires a fulsome

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<sup>124</sup> Australian National University, The role of national culture in shaping public policy: A review of the literature, 2014, ([https://coombs-forum.crawford.anu.edu.au/sites/default/files/publication/coombs\\_forum\\_crawford\\_anu\\_edu\\_au/2014-08/daniell\\_2014\\_the\\_role\\_of\\_national\\_culture\\_in\\_shaping\\_public\\_policy\\_final.pdf](https://coombs-forum.crawford.anu.edu.au/sites/default/files/publication/coombs_forum_crawford_anu_edu_au/2014-08/daniell_2014_the_role_of_national_culture_in_shaping_public_policy_final.pdf))

investigation that is beyond the scope of this report, we will restrict commentary to a rudimentary overview of perceived cultural trends.

Our analysis of health data public policy offers three summary findings:

1. That health data public policy is largely divorced from an accountability to the delivery of quality health programs and services.
2. That most forms of health data-related harm are not addressed in health data public policy.
3. That health data public policy is not person-centred, but fosters location and service-specific data fragmentation.

A Canadian health data culture is examined through these three findings.

## HEALTH DATA AND QUALITY HEALTH PROGRAMS AND SERVICES

Recognizing that the health industry is wholly dependent on data to optimize all domains of service, why would Canada - which places great cultural value on its pioneering health system - fail to effectively harness such an elemental component of health service function? Health public policy

The way health data is governed and regulated in Canada impairs the very capacity of health service to achieve its legislated goal to promote the health and wellbeing of Canadians.

often fails to support or overtly hinders the portability, universality, comprehensiveness, and accessibility of health data, meaning that accountability to the core conditions of the *Canada Health Act* seem not to be considered in the design and oversight of health data. Therein lies a fundamental contradiction, that the way health data is governed and regulated in Canada appears to impair the capacity of the health system to achieve its legislated goal. It is difficult to believe that data as a core constituent of informed health decisions has been intentionally or

neglectfully overlooked to the detriment of all. Rather, what this implies is a widespread failure to perceive or understand the foundational importance of health data to the health and wellbeing of Canadians. Limited understanding of the key role health data plays in the provision of health service – a manifest and widespread ‘health data illiteracy’ - may be a central contributor to Canada’s health data dysfunction.

A lack of data literacy may also reflect that health data is not a compelling topic for most; it is opaque and perceived as dull and administrative in nature - a niche pursuit perhaps best left to technophiles, data geeks, and academics. Perhaps most members of the public, health workforce, and leadership alike do not expressly link health data to health and wellbeing or perceive optimized data as an essential ingredient of optimal health system function.

## HEALTH DATA PUBLIC POLICY AND HARM

The discrepancy manifest in vigorous efforts to limit health data privacy-related damage compared to a dearth of effort to mitigate almost all other forms of health data-related harm is a curious phenomenon. Why would a health care system with the express purpose of promoting health and wellbeing adopt public policy that appears to value personal privacy more than preventing other potential detrimental impacts of health data misuse? These detrimental impacts include damage to physical and mental health, public health, provider wellbeing, cultural wellbeing, health innovation, and health system function, the prevention of which are conspicuously absent in almost all health data public policy. Health data public policy seems manifestly focused on data as a risk-bearing commodity, the use of which is tolerated rather than celebrated. Arguably, at an extreme the approach of health data public policy steps beyond that of benign neglect and can actively promote, albeit unintentionally, harm to health, wellbeing, and health system function.

The perception of privacy as an almost exclusive risk arising from health data is perhaps best understood not as a peculiar flaw in evidential thinking, but as an entrenched cultural truism born of longstanding practice. Challenging such a truism can be difficult, particularly if there are established conventions, structures, and protocols associated with that way of thinking. The privacy industry in Canada is buffered by longstanding investment in ubiquitous human resources, policy, and infrastructure. The suggestion that other forms of harm arising from health data require attention may be interpreted as a threat to the status quo, even when privacy mitigation is acknowledged as a legitimate concern. Further, this unifocal approach to one form of health data-related harm is likely also sustained by aforementioned shortfalls in health data literacy.

It is the dissonance between these two traditions, location-agnostic digital data and location-specific analogue data policy that has sown many of Canada's health data woes.

## PERSON-CENTERED HEALTH DATA ARCHITECTURE

Canada's health data public policy construct evolved within a longstanding federated model of health governance. Although health data is not included among the mandated domains of provincial and territorial oversight, jurisdictional oversight has been assumed. In a pre-digital era, health data public policy directed local health service providers or custodians to hold physical copies of portions of a patient's information in trust. For patients requiring care across custodial or jurisdictional boundaries, information sharing was achieved through the transfer of physical copies of health information, or with the tacit expectation that the patient themselves would carry knowledge of their health history. This policy approach worked well as it was congruent with the capacity of contemporary analogue technology.

The advent of digital technology and remotely accessible cloud-based data storage eliminated the necessity to physically segment patient information by location and service, offering the opportunity to house an individual's complete record in a common virtual database. Yet health data public policy

and regulation did not evolve to support this shift; custodial and location-based health data public policy has remained largely intact in the digital era. The effort to deploy digital data solutions in an analogue policy environment has proven an incompatible marriage, resulting in the fragmentation of digital platforms, patient data, and the elimination of the high value proposition of interoperability. It is the dissonance between these two traditions - location-agnostic digital data and location-specific analogue data policy - that has sown many of Canada's health data woes.

The lack of recognition that health data public policy needed to evolve in lockstep with the deployment of digital health solutions speaks again to a lack of data literacy, as well as a perception that the value proposition of digitizing health information lies in the deployment of technology, not in how human beings can use that technology to foster improved communication and knowledge. Improved human communication and knowledge are dependent on optimized data exchange and analysis, factors not fostered by public policy that segments data by location and service and promotes decentralized authority over health data across a variety of actors, including governments, custodians, and information technology vendors. The vested interests of these entities, including monetary, political, and professional agendas, combined with a lack of incentives to cooperate around common data standards and processes, serve to perpetuate health data public policy fragmentation and hinder

evidential system reform.

Conspicuous principle-based cooperation across health sector stakeholders is the essential ingredient required to achieve optimized health data use in Canada.

Lost in this entrenched data regionalism and protectionism is the impact on the beneficiary of care - the patient - whose data is fragmented causing increased risk to them largely without their knowledge and outside of their control. The notion of person-centred health data, where a patient's health information follows them over

time and location - a core principle of the pan-Canadian *Health Data Charter* - demands levels of trust and cooperation around harmonized data standards, public policy, and workflow for which there is no precedent nor mechanism in Canada. Conspicuous principle-based cooperation - human cooperation - across health sector stakeholders is the essential ingredient required to achieve optimized health data use in Canada. A keystone of this cooperative approach is the rightful inclusion of meaningful public and Indigenous representation in the oversight of health data design and use. The absence of these constituencies from most health data oversight speaks to an enduring failure of health system powerbrokers to understand and honor just health data ownership and accountability.

### CANADIAN HEALTH DATA CULTURE

The American psychologist Edgar Schein suggested that an unwritten code of conduct, or *organizational culture* defines the accepted functional behavior of every industry. He defined organizational culture as:

“The pattern of basic assumptions that a given group has invented, discovered, or developed in learning to cope with its problems of external adaptation and internal integration - a pattern of



assumptions that has worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think, and feel in relation to those problems.”<sup>125</sup>

Indeed, a Canadian health data culture seems more easily understood as a “pattern of assumptions” that “worked well enough to be considered valid and, therefore, to be taught to new members as the correct way to perceive, think, and feel”. The assumptions considered valid appear not to have adjusted to the disruption of digital information technology, but have remained tethered to an analogue era when regional fragmentation was defined by a lack of appreciation for the foundational relationship between health data and health and wellbeing, a failure to appreciate the breadth of harm that can arise from fragmented health data, and a perception that technology, not the novel use of data by cooperating human beings, is the true value proposition of the digital revolution.



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<sup>125</sup> Schein E H, The role of the founder in creating organizational culture, 1983, ([https://doi.org/10.1016/0090-2616\(83\)90023-2](https://doi.org/10.1016/0090-2616(83)90023-2))

# EUROPEAN HEALTH DATA SPACE

The European Union (EU) is the supranational political and economic union of twenty-seven European states. Akin to the portability of health services between Canadian provinces and territories, all EU countries offer their citizens reciprocal emergency health services when visiting other participating countries. To support this program, the member states of the EU have recognized that portability of citizen health information is required. To this end, the EU has established the *European Health Data Space* (EHDS) to safely and securely “exchange, use and reuse health data to benefit patients, researchers, innovators, and regulators”<sup>126</sup>

The EHDS is designed to:

- Empower patient control of personal health data.
- Foster the safe and secure exchange of data for the delivery of health care across the EU (primary use data).
- Foster a single market for health information technologies.
- Enable the efficient and trustworthy reuse of health data for research, innovation, policy-making, and regulatory activities (secondary use data).<sup>127</sup>

Importantly, the EU acknowledges that “trust is a fundamental enabler for the success of the EHDS”. This is achieved by establishing a robust and collaborative public policy suite that guides all facets of data governance, security, protection, regulation, and technology. Public policy resulted from a process that included open public consultation and impact assessments. Further, the EHDS includes provisions that allow member states to opt out of both primary or secondary use of data opportunities.<sup>128</sup>

The alignment between the optimization of portable health services and data in the EU and similar opportunities across Canadian provinces and territories seems evident. If independent nations can craft public policy that enables efficient and trustworthy health data use in support of optimized primary and secondary health services, surely jurisdictions in the same country can do likewise. The EHDS provides an excellent model for how Canadian health data public policy can be reimaged to support excellence in health service.

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<sup>126</sup> European Commission, European health data space, n.d., ([https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space\\_en](https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en))

<sup>127</sup> IBID

<sup>128</sup> IBID

# RECOMMENDATIONS

## 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 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.<sup>129</sup>
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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.

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<sup>129</sup> 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.

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**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.

# CONCLUSION

A growing list of thought leaders suggest that health data design and use in Canada is deeply troubled, contributing to health system dysfunction and preventable harm to Canadians. A high-level examination of public policy reveals an approach to health data design and use that fails to uphold core accountabilities to the health and wellbeing of Canadians and minimize preventable health data-related harm. Our collective approach to health data policy hinders the capacity to honor the tenets of the *Canada Health Act* (portable, comprehensive, universal, and accessible health care) and fails to recognize the rights of Indigenous Peoples to control data from and about their communities. Individual Canadians continue to struggle to access their comprehensive health information in digital form and have little license to participate in the oversight of the design and use of health data. A unifocal fixation with data privacy stands in stark contrast to the neglect of public policy aimed at assuring the use of data to benefit individual and population health and wellbeing.

We asked the question in the introduction, “why are we in Canada taking an approach to health data that harms people?” Upon reflection, perhaps this question was poorly worded. Our findings suggest that Canada has not intentionally “established” a harmful approach to health data, rather it has simply allowed a harmful approach to evolve in the absence of a cogent plan. The underperformance of health data in Canada is framed by policy neglect rather than intentionality.

This neglect appears to 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 has 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 seemed a fanciful impossibility before a resolute will to preserve jurisdictional, organizational, and professional data autonomy. Ultimately, the needs of the patient, whose data it is, has not been heard.

Yet there is reason for optimism. The *pan-Canadian Health Data Charter* is the first systemic public policy to link health data design and use to the health and wellbeing of Canadians. Should Bill C-72 pass into legislation, this will mark a defining moment when public policy in Canada finally mandates the intentional design of data to support health and wellbeing and minimize health data-related harm. Quebec’s Bill 3 represents an example of the type of improvement to provincial health information legislation that can foster a transition to a stewardship model. Together, these developments represent a shift in data public policy that may signal a meaningful redefinition of Canadian health data culture.