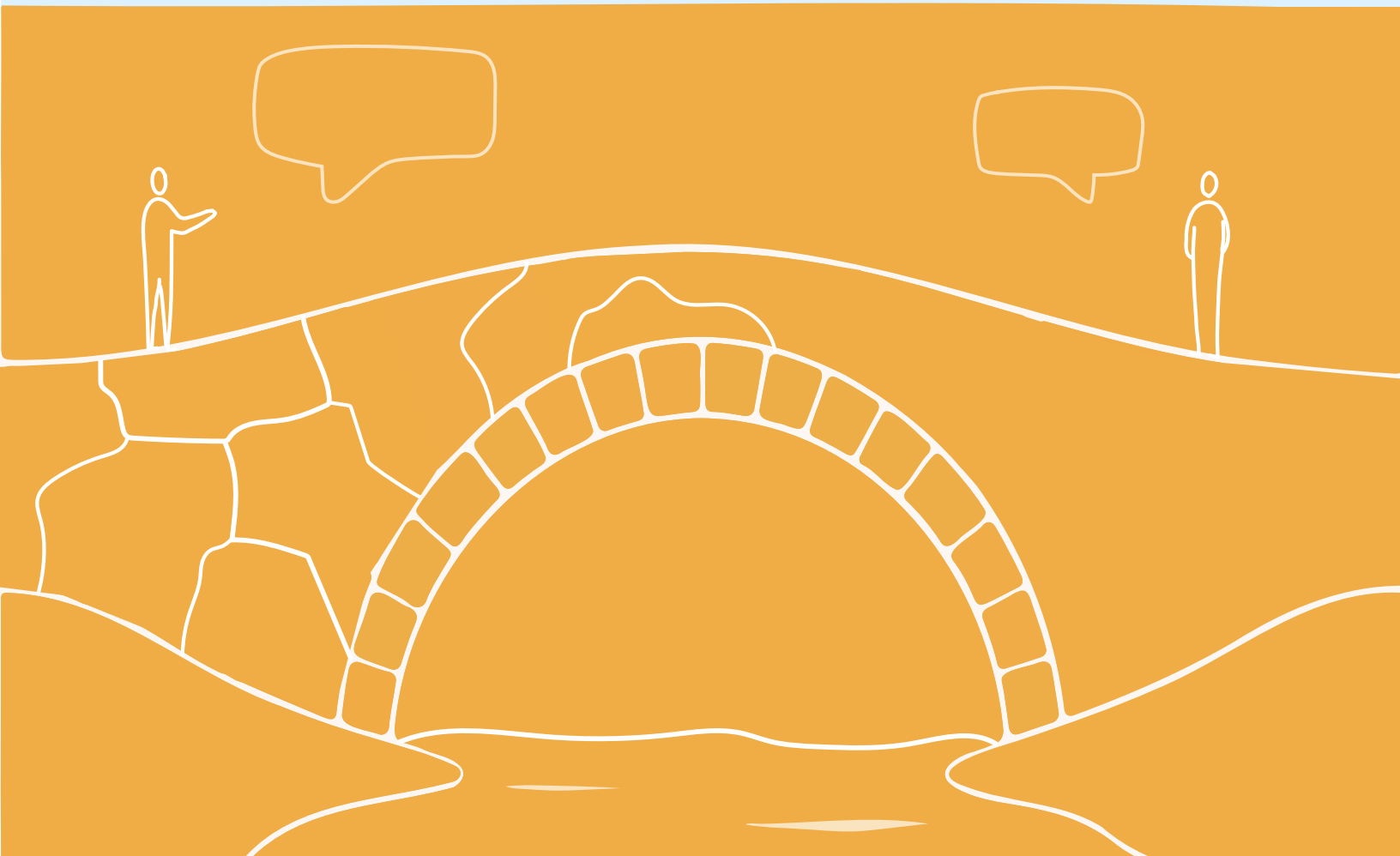
Networked Health

NOVEMBER 2026

OUR INFORMATION, OUR LIVES

Case Studies Supporting Connected Care in Canada



We carry the truth that our son's death was the direct result of non-interoperable health data systems.

- Testimonial 1

REPORT CITATION

Affleck, E., Price, T., Stobart, P. (2026) Our Information, Our Lives. (https://www.networkedhealth.org).

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FOREWORD

Health Information is the essential currency of all decisions in healthcare. Without it, research, public health, digital health innovation, and care can be significantly limited. Similarly, if information is fragmented and not accessible then the quality of health programs and services, including research, innovation and care can be hindered, and the health and wellbeing of Canadians adversely impacted.

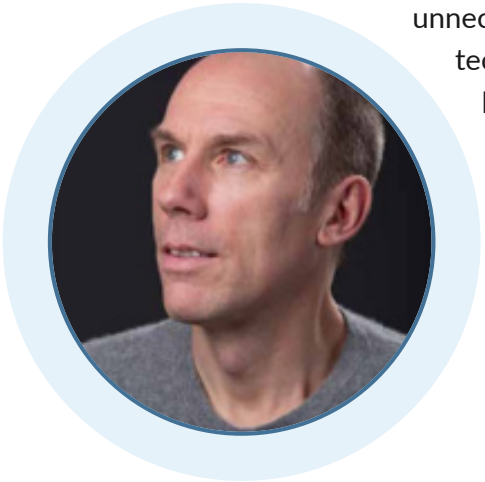
Yet curiously we have not treated this precious resource as a valued asset, but as a risk-bearing commodity. Our approach to assuring health data supports the purpose of healthcare—

the promotion of the health and wellbeing of Canadians—has often been indifferent, if not completely absent. Instead, we have made health information difficult to share and use, institutionalized its fragmentation by jurisdiction and health service, and in doing so have damaged Canadians, healthcare providers and healthcare system function.

The stories in this report point to the folly of not managing health data as a national treasure, to be nurtured and honoured for the insights it can bestow. And this is not a trivial problem. Credible estimates suggest it is costing the country billions of dollars and that harm to patients and providers is widespread.[1] The story of Greg Price[2] cannot be dismissed as an outlier.

So let us listen to the voices of Canadians and act upon the need to reimagine the design and use of health data for collective good. Initiatives like Bill S-5, the Connected Care for Canadians Act, the Shared Pan-Canadian Interoperability Roadmap, and efforts to adopt Pan-Canadian health data content and exchange standards and update health data policies for the digital age signal a new commitment to the proper stewardship of health data in Canada.

May we build upon this momentum and reimagine health data as a resource that is both secure as well as portable, universal, comprehensive and accessible. This can be achieved by embracing person-centred health data architecture, meaning that health data follows the patient wherever that may be, across health services and jurisdictions.



Ultimately the choice should not be too difficult; we can continue to drive unnecessary cost by independently procuring expensive information technology and contorting it to conform to outmoded and archaic health data governance and public policy that harms Canadians, or we can cooperatively reimagine health data design around our shared accountability to quality care. We owe it to each other and the future of Canada to do the latter.

EWAN AFFLECK

October 2026
Yellowknife, Northwest Territories

WITH GRATITUDE: BUILDING A SHARED UNDERSTANDING THROUGH LIVED EXPERIENCE

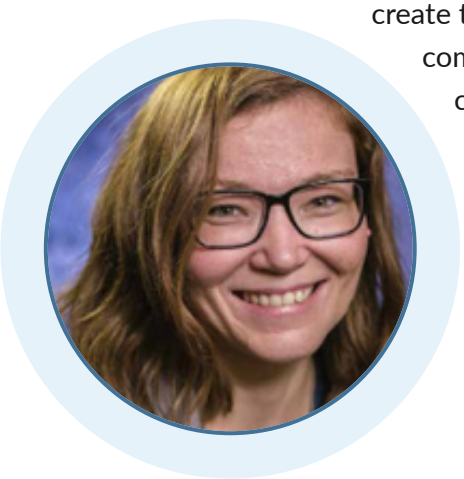
Our family understands intimately how important but difficult it is to share personal stories, and we extend our heartfelt gratitude to the remarkable people who contributed to this report. Honouring such stories matters deeply. It is through the accounts and perspectives of others that our collective understanding of issues like the extent of harm arising from health data fragmentation is deepened. Sharing lived experiences offers an opportunity to reflect and learn, and hopefully these testimonials will be a continual reminder of how vital this work is.

My brother, Greg Price, died on May 19, 2012. Although many factors contributed to his tragic outcome, a lack of timely access to his health information, by both Greg and his care team, was identified as a key contributor to his death. Greg's story has been well documented in our film *Falling Through the Cracks: Greg's Story*,[3] as well as in the *Continuity of Patient Care Study*,[4] a report by the Health Quality Council of Alberta. Both outline how a lack of timely access to Greg's health information critically hindered his care.

Through screenings of the film, my family and I have had the privilege to engage with over 60,000 people. In doing so, we have come to appreciate that although the circumstances that led to Greg's death are not unique, the stories of others who have 'fallen through the cracks' remain largely untold.

This report brings some of them forward. Together, they contribute to a shared understanding of how fragmented health information affects care in Canada, and that shared understanding is where meaningful change begins. When everyone involved in health and care can see the same picture, we can work together toward a health system where information follows each person and supports safe, compassionate care.

Caring for patients requires more than a group of individuals; it requires teams. We know information and communication are required for effective teamwork, and patients need care teams that work effectively together. It is a safety risk if the team doesn't have access to the information they require. Yet we have heard thousands of stories from both patients and members of the health workforce that reflect feelings of frustration and fear arising from a lack of portable and accessible health information. We need to create the conditions where health providers can succeed in providing safe and compassionate care, and one of the essential building blocks is information continuity, so that a person's health information is available to them and their care team wherever and whenever care is provided.



To prevent further harm, we must heed the stories of Canadians, those seeking and providing care alike, and work together in common purpose to achieve health data interoperability across Canada.

TERI PRICE

Greg's Wings | Calgary, Alberta

ACKNOWLEDGEMENT

We would like to acknowledge the contribution of Phoebe Stobart of Networked Health.

Most importantly we want to acknowledge all the members of the health workforce and the public who took the time to contribute stories to this report.

We would also like to thank the Health Everywhere Hub for providing support for this report, as well as the W21C Research and Innovation Centre and the Centre for Health Informatics at the University of Calgary for their assistance on the project.



ABOUT NETWORKED HEALTH

Networked Health is a national collaborative with a mission to advance the responsible design, stewardship and use of health data to foster the health and wellbeing of all people in Canada through research, policy engagement, and collective action.

With a wide range of knowledge and experience from across the public and health sector our members focus on improving health outcomes, supporting the wellbeing of diverse communities, improving healthcare function, and enriching the work experience of healthcare providers.

We follow a Collective Impact model, an approach that recognizes meaningful, lasting social change happens when diverse individuals and organizations come together, align their efforts, and work toward shared goals over time.

For more information, please see: networkedhealth.org

STATEMENT OF ACCOUNTABILITY

The reports of Networked Health are the product of cooperative principle-based collaboration between diverse members of the public and the health and social services sector to promote quality health data design and use that will benefit all people receiving care in Canada. Participation of an individual in a Networked Health 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 Networked Health work is welcomed and encouraged in support of collective accountability to quality health programs and services.

PURPOSE

All healthcare decisions are enriched by information. If information is missing, inaccurate or unavailable, then poor decisions can be made that result in harm to people, populations and the healthcare system.

The intent of this report is to capture stories—first person testimonials from across the health domain—about harm arising from inadequacies in the capacity to appropriately share health information; narratives from both members of the public and the health workforce about the consequences of fragmented health information. Stories that can help inform an effort to improve health data interoperability and benefit the health and wellbeing of Canadians.

This project was undertaken to document harm arising from non-interoperable health data to highlight the importance of the growing effort to mandate the appropriate and timely exchange of health data in Canada. The report offers a small sample of testimonials about harm arising from fragmented or poorly accessible health information. Given the limited scope of this project, testimonials gathered doubtless represent an incomplete picture of a complex and nuanced problem. A more comprehensive survey of the qualitative and quantitative impact of a lack of interoperability on the health and wellbeing of Canadians and the healthcare system is merited.

The testimonials included in this report are shared with the express consent of the contributors. Some details have been changed to protect the identity of the authors.

DEFINITIONS

Health

"A state of complete physical, mental and social wellbeing and not merely the absence of disease and infirmity."[5]

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."[6]

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 socioeconomic, community and health system characteristics."[7]

Health Data Interoperability

"The ability of different information systems, devices and applications (systems) to access, exchange, integrate and cooperatively use data in a coordinated manner to optimize the health of individuals and populations."[8]

Health Data Related Harm

"Damage suffered by individuals, populations, and/or the health system arising from poor health data access, quality or use."[9]

INTRODUCTION

INTEROPERABILITY IN CANADA

A key element of a world-class health data system is the ability to securely access and share accurate health information across healthcare services, settings and jurisdictions to support quality health programs and services.

> *"It is imperative that we unlock the potential of Canadian health data for the benefit of all."*
>
> – Testimonial 18

In Canada, structural barriers hinder the sharing and use of health data. A 2024 survey found only 47% of Canadians reported the capacity to access some of their health information electronically despite a full 89% of respondents wishing to have comprehensive access to their records.[10] Canada significantly lags international peers with only 29% of physicians having the capacity to exchange digital patient summaries with care providers outside their practice.[11] In a 2026 study physicians reported spending an average of *"86 additional minutes per day beyond what they felt should be spent searching for patient information, with over a third spending two or more hours".*[12] According to the Commonwealth Fund's 2023 International Health Policy Survey, compared to international peers Canadian physicians report lower rates of virtual care services including the ability for patients to request appointments online (23% vs 57%), the ability for patients to email their provider (50% vs. 75%), and the ability for patients to renew prescriptions online (24% vs 58%).[13]

The problem is thought to stem in part from a lack of comprehensive and regulated health data interoperability in Canada. Health data interoperability is defined as:

> ***The ability of different information systems, devices and applications (systems) to access, exchange, integrate and cooperatively use data in a coordinated manner to optimize the health of individuals and populations.***[14]

Achieving comprehensive Pan-Canadian health data interoperability will require the coordinated and cooperative design and implementation of health data standards, technology, legislation, policy, regulation and governance; properties of a coherent health data strategy and use that have largely been lacking in Canada.

This is not a new challenge. For decades, experts have been clear: health data in Canada must be interoperable to support quality health services.[15] This has been reiterated in many recent publications,[16] including the reports of the Expert Advisory Group (EAG) of the Pan-Canadian Health Data Strategy, and the seminal report Interoperability Saves Lives which articulated that health data interoperability is a composite of both technical factors (data content and data exchange standards, internet connectivity, common user authentication, etc.) and human factors (harmonized governance, legislation, public policy, regulation, culture and market factors).[17] Achieving interoperability requires both the deployment of integrated health information technologies, and integrated human relationships around health data.

If the way we in Canada choose to behave around health data - as manifest in data governance and public policy - fails to support cooperative interoperability across services and jurisdictions, then the technology we deploy will fail. This is the lived experience in Canada over decades. This pattern of behaviour persists despite acknowledged international precedent demonstrating both the link between interoperability and safe health programs and services and means to achieve interoperability through cooperative governance and legislation; the United States legislated health data interoperability ten years ago,[18] Denmark decades before.[19]

> *"We can continue to throw billions of dollars at new software and technology, but we won't succeed with it until we can remedy these fundamental human and relational problems."*
>
> – Testimonial 29

HEALTH DATA RELATED HARM

Non-interoperable systems and a lack of access to timely and accurate data can adversely impact individuals and impair healthcare system function. The Health Data Related Harm Framework, first proposed in the 2023 report *Interoperability Saves Lives*,[20] articulates a comprehensive and concise continuum of harm that can arise from poor health data access, quality or use. The framework identifies three overlapping domains of harm: individual, population-based, and health system harm. In turn, ten distinct but interdependent categories of health data related harm are described (Table 1).

Table 1: Domains and Categories of health data related harm

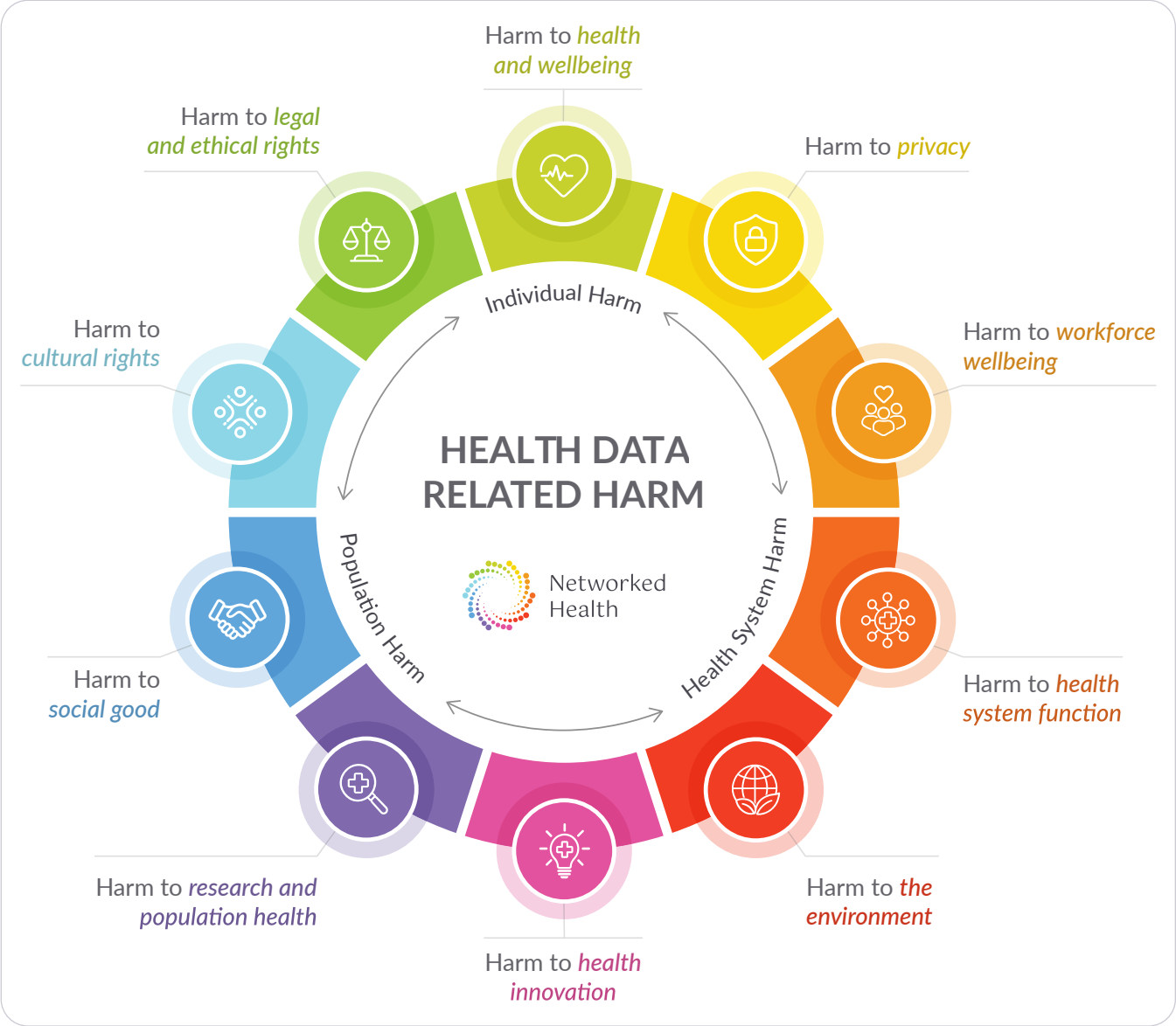
Domains of Health Data Related Harm	
Forms of harm can adversely impact: 1. Individuals 2. Populations 3. The healthcare system Or any combination of the three.	
Categories of Health Data Related Harm	
Harm to health and wellbeing	Harm to the physical and/or emotional health and wellbeing of patients arising from poor health data access, quality and/or use.
Harm to privacy	Harm resulting from the disclosure of sensitive, confidential, or private health data to unauthorized entities arising from poor data access, quality and/or use.
Harm to cultural rights	Harm to the shared beliefs, customs, knowledge, language, way of life, and/or inherent rights of an individual or community arising from poor health data access, quality and/or use.
Harm to legal and ethical rights	Harm to the entitlements granted by a government or legal system, and/or moral principles, arising from poor health data access, quality and/or use.
Harm to research and population health	Harm to public good resulting from the inability to gain insights through research and population health arising from poor health data access, quality and/or use.
Harm to social good	Harm from bias, prejudice, inequities or personal, group, institutional or corporate gain without social license arising from poor health data access, quality and/or use.

Harm to health system function	Harm to efficient and effective health system function arising from poor data access, quality and/or use.
Harm to health workforce wellbeing	Harm to health sector workforce wellbeing, including burnout, arising from poor health data access, quality and/or use.
Harm to health innovation	Harm arising from the inability to develop and apply new health sector ideas, products, services, or care pathways because of poor health data access, quality and/or use.
Harm to the environment	Harm to the natural world that negatively impacts human life, including damage to the climate, water, soil, and/or other organisms arising from poor health data access, quality and/or use.

The ten categories of health data related harm are interdependent and can have a cumulative impact on the integrity of health system function and welfare of individuals and populations. Forms of harm are not hierarchical but are interwoven as a matrix of co-occurring factors that ultimately, either directly or indirectly, impact the health and wellbeing of individuals (Figure 1). Although a lack of health data interoperability is not a unique cause of harm arising from poor health data design and use, it is an important contributor to poor data access and as such a foundational property of health data that can be eliminated to reduce harm.

A comprehensive study validating the Health Data Related Harm framework carried out with partners at the Mount Sinai Hospital System in New York City is to be released in November 2026.

Figure 1: Matrix of Categories of Health Data Related Harm



For more information, please see the Networked Health report *Health Data Harm*.

METHOD

In 2023 Networked Health proposed the Health Data Related Harm framework as a comprehensive tool to identify, understand and measure the adverse outcomes of poor health data design and use. Understanding and measuring the negative repercussions of poor health data access, quality and/or use presents a valuable opportunity to guide the design of safe and effective digital health information systems. However, as the harm framework was strictly a theoretical construct, it required validation to affirm its value and utility. To accomplish this task Networked Health undertook two parallel arms of inquiry:

1. A mixed method study with partners at Mount Sinai Hospital System in New York City that assessed:
    - The measurement of rates of proposed categories of harm in a functioning health system.
    - The validation of the proposed categories of harm in the framework.

    This study has been submitted to NPJ Digital Medicine.

2. The collection of personal testimonials about harm experienced from poor health data interoperability from across a wide spectrum of healthcare parties in Canada. The results of this branch of inquiry are reflected in this report.

    The following method was used to prepare this report:

    - Personal narratives about the negative impact of health data fragmentation (lack of interoperability) were solicited from the public and members of the health sector workforce through the Networked Health collective. Submissions were accepted from any individual or source.
    - Individuals who submitted a testimonial were asked to sign a consent to publicly share their story.
    - All testimonials were anonymized, with identifying names and locations removed.
    - Thematic analysis of testimonials was conducted, and broad inferences drawn.

Personal stories about shortfalls in health system function can be challenging to locate and collect. Establishing a safe space to gather stories—in a manner that protects the privacy and emotional welfare of contributing parties while preserving the integrity of the message—is required to build knowledge about the harm caused by a lack of interoperable health data.

CONTEXT

IMPACT OF HEALTH DATA FRAGMENTATION

Canada does not measure the harm arising from the poor design or use of health data. Similarly, there are no international standards nor quantifiable metrics for the financial or human cost of health data related harm arising from health data fragmentation. The categories of health data related harm outlined above can serve as a comprehensive framework to gather evidence about the impact of an absence of interoperable health data on the health and wellbeing of individuals and health system function to inform system improvement.

There have long been anecdotes from the public and the health workforce that the inability to securely access and share health information (a lack of interoperable health data) can result in harm, including treatment errors, health service inefficiencies, delays in care, barriers to research and innovation, and provider burnout. A cursory review of the literature revealed studies that support these anecdotes indicating that health data interoperability can:

> *"Many Canadians have no idea how chaotic and potentially dangerous the management of their health information can be, until their health is threatened."*
>
> – Testimonial 8

- Reduce medication errors.[21]
- Increase the number of patients who receive treatment for sepsis within the recommended standard of care.[22]
- Foster a decrease in mortality.[23]
- Result in a decrease in readmission rates (associated with improved inter-service health information exchange).[24]
- Support continuity of patient care and improve patient experience in the healthcare system.[25]
- Support patient empowerment by fostering access to personal health information.[26]
- Improve care by providing more timely access to critical information.[27]
- Increase accuracy of diagnosis, quality of care and patient safety, notably through credibility of information.[28]
- Support an increase in the number of care modalities (e.g. virtual, telemedicine) offered to out-patients in the context of follow-up care that support equity and access related benefits for patients (e.g. reduced travel costs; reduced leave from work; reduced dependent care coverage costs; reduced time spent in ERs by patients).[29]

Conversely, evidence from the literature suggests that a lack of, or poor health data interoperability can contribute to:

- Physical harms to patients, including death.[30]
- Lost opportunity cost to Canada of $9.4 billion a year.[31]
- Threats to patient safety emerging from lack of availability of timely information.[32]

- An increasing likelihood of misdiagnosis, unsafe treatment and duplicative utilization of resources or data entry.[33]
- Prescribing inaccuracies arising from a breakdown in the transmission or exchange of information upon admission, transfer and/or discharge.[34]
- Delays in care.[35]
- Lost or siloed health information.[36]

However, experts acknowledge that measurement of the impact of interoperability is hampered by a lack of industry consistency in outcome measures and variation in the approach and quality of studies done.[37]

To supplement existing knowledge about the value of health data interoperability the gathering of narratives about the impact of health data fragmentation on Canadians and the healthcare system was deemed a valuable exercise.

> *"The public usually doesn't know how fragmented their health information is, or how dangerous it is, because we don't talk about it. It is a dirty secret."*
>
> – Testimonial 26

EFFORTS TO IMPROVE HEALTH DATA INTEROPERABILITY IN CANADA

In recent years there has been growing attention to the necessity to achieve comprehensive health data interoperability in Canada. This has taken the form of governmental, organizational and grassroots initiatives.

The federal government's plan for Working Together to Improve Health Care for Canadians announced in February 2023 and confirmed in Budget 2023, underscored the need for a world-class health data system that is timely, usable, open-by-default, connected, and comprehensive.

As part of this plan, federal, provincial and territorial governments committed to five health data priorities outlined in a Joint FPT Action Plan on Health Data and Digital Health. The second commitment, "adopting common interoperability standards to better connect Canada's health system" aimed to link health data systems and enable Canadians and their healthcare providers to securely access electronic health information and mitigate harm arising from non-interoperable health data. This strategy aligned with the Shared Pan-Canadian Interoperability Roadmap released in 2023 by Canada Health Infoway, which outlined a long-term vision to improve health service in Canada through the development and adoption of health data interoperability content and exchange standards. Without such standards, digital health information platforms will not be able to 'speak to each other', and digital health information will remain locked in different platforms. In addition, some provinces and territories have engaged in independent efforts to advance health data interoperability in their respective jurisdictions, notably Québec and Ontario.

Recognizing that timely access to health data is critical to optimizing Canadian health programs and services and looking to accelerate the implementation of the Pan-Canadian adoption of common interoperability standards, on February 4, 2026, the Federal government tabled Bill S-5, the Connected Care for Canadians Act. The intent of the Act is to foster connected care by mandating health data standards to enable the timely sharing of health information across health information platforms. The Act will require all health information technology vendors operating in Canada to adopt common data standards and prohibit the practice of data blocking which hinders health data interoperability.

The introduction of the *Connected Care for Canadians Act* was supported by a public campaign hosted by Networked Health and supported by a diverse group of fifty-eight Canadian health organizations including the Canadian Medical Association, the Canadian Nurses Association, the Canadian Public Health Association, Imagine Citizens Network, Greg's Wings, INOVAIT and many private sector health information technology providers (for more information, please see: connectedcare4canadians.ca). At the time of writing Bill S-5 has been approved by the Senate and is pending a second reading before the House of Commons.

However, despite the increased focus on integrating health data in recent years, on an operational level interoperability is still in its infancy in Canada; functionally a lack of health data interoperability remains the norm, both within and between Canadian jurisdictions.

> *"When I requested access to my own medical record in shareable, electronic format, all I received, after two weeks, was an invoice for printing and postage charges to send me a paper copy."*
>
> – Testimonial 18

TESTIMONIALS ANALYSIS AND RESULTS

A total of 37 testimonials were submitted to Networked Health for publication. A few individuals submitted more than one testimonial. All testimonials were accepted for inclusion in this report and appear below. Testimonials were reviewed, edited and anonymized.

Each testimonial was evaluated for the forms of harm that it references. Most testimonials speak to more than one category of Health Data Related Harm, which aligns with our research that suggests that in practice categories of harm frequently co-occur. We acknowledge that the evaluation of testimonials was not conducted according to a rigorous qualitative analysis methodology. As such the results simply provide a broad approximation of the occurrence of categories of harm in submitted testimonials. A more comprehensive analysis of testimonials using a systematic, rigorous and proven methodology for examining non-numerical data is suggested in the future.

Two categories of health data related harm, harm to health and wellbeing, and harm to health system function were represented in almost all testimonials. Harm to legal and ethical rights and harm to health workforce wellbeing were also represented relatively frequently. All other categories of harm were represented less frequently, overall between 1 and 5 times, other than harm to privacy which was never acknowledged in any testimonial. It is unclear why privacy never appears, however it should be noted that harm to privacy is associated with the 'oversharing' of information, whereas a lack of health data interoperability is associated with an inability to share information.

Table 2 outlines the occurrence of categories of harm in the 37 testimonials.

Table 2: Frequency of categories of harm addressed in testimonials.

Icon	Category of Health Data Related Harm	Number of Testimonials
	Harm to health and wellbeing	33
	Harm to privacy	0
	Harm to cultural rights	2
	Harm to legal and ethical rights	15

	Harm to research and population health	5
	Harm to social good	2
	Harm to health system function	35
	Harm to health workforce wellbeing	11
	Harm to health innovation	5
	Harm to the environment	1

Initially we considered grouping the testimonials under the ten categories of health data related harm. However, because many testimonials spoke to two or more categories of harm it became challenging to group them coherently under individual harm categories. Further some themes that emerged from our analysis of the testimonials represent important features of the Canadian healthcare system that we felt should be highlighted. Consequently, we grouped the testimonials under the following eight themes:

1. Unsafe Care (testimonials 1 - 7)
2. Inter-jurisdictional Interoperability (testimonials 8 – 16)
3. Research and Innovation (testimonials 17 - 22)
4. Cultural and Legal Rights (testimonials 23 - 24)
5. Burnout (testimonials 25 - 28)
6. Human Factor Interoperability (testimonials 29 - 30)
7. Health System Inefficiency (testimonials 31 - 36)
8. Environment (testimonial 37)

Although many testimonials cover concerns across multiple categories of harm, each story has been sorted according to the predominant theme it reflects.

A generic attribution has been assigned to each testimonial that aligns with an author's role or status in the healthcare ecosystem. There were two broad categories of testimonial authors: recipients of care and members of the health sector workforce.

The following categories of recipients of care are represented among testimonial authors:

- Patient
- Wife of Patient
- Mother of Patient
- Father of Patient
- Family Member of Patient
- Friend of Patient

The following roles in the health sector workforce are represented among testimonial authors:

- Digital Health Innovator
- Researcher
- Nurse
- Physician
- Senior Health Information Systems Administrator
- Senior Health Care Administrator

Although not all regions of Canada are represented in testimonials, authors come from a broad constituency of Canadian locations.

> *"You don't realize how important it is to have access to your health information until you need it and can't access it."*
>
> – Testimonial 9

TESTIMONIALS

01 | UNSAFE CARE

Unsafe care resulting in harm to the health and wellbeing of patients is a theme that appeared through almost every testimonial we received. Patient harm varied from minor inconveniences and delays in care to catastrophic outcomes and death. What is evident from the stories is that almost all other categories of health data related harm, from barriers to research and innovation, to health system inefficiencies and cultural harm ultimately trickle down to impact the health and wellbeing of individual Canadians. If the Canadian healthcare system is a treasured asset intended to support the safe delivery of care, then ready and appropriate access to necessary patient information is required to achieve this goal. As the mother of one patient states *"his story shows how Canada's fractured digital infrastructure endangers patients and leaves clinicians without the tools they need to provide safe, timely care."*

> *"While the harm to providers that results from a lack of coherent information design and non-interoperable systems is considerable, it pales in comparison to the harms experienced by patients."*
>
> – Testimonial 27

Testimonial 1 - Mother of Patient

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*

"[Our son] was a determined, bright, and deeply loved eleven-year-old boy who dreamed big, saw possibility everywhere, and refused to live within the limitations set by others. He had a complex but stable neurological history and had received long-term care from [a large provincial pediatric hospital]. When we moved to [a different location in the province], his medical records did not move with us; instead, they remained locked inside a different health authority's medical record system. When [he] suddenly developed severe neurological symptoms, the emergency team at [the local hospital] treated him without access to the history that defined his risks. For nearly five hours they worked without the information they needed, and by the time his full history was obtained by phone, it was too late. [Our son] had already slipped into a coma and required breathing assistance. He suffered catastrophic hydrocephalus and died 10 hours later. His death was not a failure of clinicians; it was a failure of fragmented systems, blocked information, and the absence of real-time access to essential medical records.

We carry the truth that [our son's] death was the direct result of non-interoperable health data systems. His story shows how Canada's fractured digital infrastructure endangers patients and leaves clinicians without the tools they need to provide safe, timely care. [His] experience makes it clear that Canada's current health data environment is causing harm, and in his case, it cost him his life. If our healthcare system learns anything from [his] death, it must be that Canada's health data infrastructure needs strengthened interoperability, the elimination of data blocking, guaranteed meaningful patient and practitioner access, and

governance shaped by lived experience. Had these measures been in place, our son, who dreamed big, loved deeply, and had so much life ahead of him, might still be alive. I speak this in his name, and in the hope that no practitioner and no family will ever endure what we have."

Testimonial 2 - Physician

Categories of harm: *Patient Health and Wellbeing, Health System Function*

"I had a patient who had a routine surgery. Postoperatively, I asked her to complete some lab work. The labs never came back to me, so I assumed that she never completed the lab work. Then a few weeks later I met her while I was on call. She had come into the emergency room at two in the morning, hemorrhaging, pale, needing emergent surgery and blood transfusions. Afterwards, I dug through the available systems, it turned out she had completed her labs, but the lab result never came back to me. Had it come back to me, it would have been obvious that she needed a repeat procedure, and we could have arranged for it on a routine basis instead of doing it in an emergent and life-threatening circumstance. So much harm and distress occurred, all because a lab result wasn't routed back to me properly. She could have died because a lab result wasn't routed properly. This isn't new technology. The file format the lab result was in has been around since 1989. The protocol to deliver the lab result has been around, in various forms, since 1971, and in its most current iteration since 1997. That is decade, after decade, after decade, and we still have unacceptable errors like this."

In 2024 Alberta Health Services (AHS) identified approximately 14,000 referrals between AHS providers and non-AHS specialists that were misprocessed, delayed or never sent. Among its many recommendations the investigation into this event by Health Quality Alberta recommended that "the Minister of Health should mandate health data interoperability between health information systems," and "Alberta Health should continue efforts to align interoperability standards with the Pan-Canadian Health Data Charter"

For more information, please see: Outgoing Referrals Review

Testimonial 3 - Mother of Patient

Categories of harm: *Patient Health and Wellbeing, Health System Function*



"Our 17-year-old son, Dan[1] had just finished his university applications. He seemed to have a severe flu and had been vomiting for a couple of days. We took him twice to an ER at our local children's hospital over a couple of days. He did not survive the care that he received. Access to his personal health data in this acute care facility would have helped us to be more effective advocates for [his care] and also to be more effective partners with the healthcare providers involved in the care he received. We would have been able to draw attention to reports posted on his file [...] Patients and families would have a complete view of the care that is being provided and also have an in-depth understanding of their family member."

Testimonial 4 - Physician

Categories of harm: *Patient Health and Wellbeing, Health System Function*



"About once every couple of months we have documents from the provincial cancer center that never come back to us. We send a patient down to the cancer center, the patient gets seen, a report gets created, but it never comes back to us. They just sit on a server—floating in digital purgatory. We keep a list of patients we have referred down to the cancer center, and manually double check that documents are not getting lost, and nothing is falling through the cracks—but despite our best efforts, we know that things do fall through the cracks. Eventually something will fall through the cracks with disastrous results. Someone's cancer care is going to be negatively affected: they are going to have a recurrence of their cancer that gets missed because nobody followed up with them or some other untoward harm will occur just because documents failed to go where they were supposed to. It is unfathomable to me that this is the current state in 2026. It is unfathomable to me that this was ever the current state. But what is more concerning is that when I mention this to colleagues, none of them find this astonishing or egregious, because it is so common and so normal across all settings, that nobody can even imagine it being any other way."

> *"It is unfathomable to me that this is the current state in 2026. It is unfathomable to me that this was ever the current state."*
> – Testimonial 4

[1] The family of the patient requested that his name appear in this testimonial.

Testimonial 5 - Friend of Patient

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*

"He was a 21-year-old rising star. And, at 21, he was still a kid. His life was tough—he was being raised by a single mother, he was the eldest of 5 siblings, and he only had the comforts that his part-time, minimum wage job could offer to him. He had a pain in his stomach that he had been ignoring for a while. And then, there was blood in his urine that he couldn't ignore.

Somewhere between college classes and evening shifts, he took himself to a walk-in clinic. They saw him eventually, for a few minutes, just enough time to write a referral for some tests. The results that came back were not good. It was cancer. He found himself navigating complex tertiary centers, in and out of specialists' clinics and CT scanners. An oncologist he barely knew drew up a care plan for him. This doctor didn't have any information about [him] beyond his test results and diagnosis. His economic situation, his family situation, all of the fundamental pieces about his life that make him the whole person he is. Not even a summary of the necessary information, as a starting point. The doctor prescribed a drug that he could not afford and didn't provide any of the supports we have available in our health system for situations like this because the data that doctor needed was not available.

All because the healthcare system hasn't designed its data and information flow to make the solutions to these problems easily accessible not just to clinicians, but also to patients and policy makers. We haven't made the basic data available in a consumable way for all these people to do their jobs effectively.

This story is based on an experience a friend of mine went through recently. But there are no more degrees of separation, this could easily be anyone's story. It's time for us to come together around our common goals and design a better health system for all of us. Data saves lives. No one in this situation wanted to create harm; no one wanted to create hardship. It happened because the right information was not available to the right person at the right time. This is entirely fixable—we have the tools, the smarts, and the will to correct this problem in Canada. It's time to envision and build a healthcare system, supported by data and digital tools, that will provide wholistic, compassionate and connected care. We must come together to ensure we no longer leave anyone behind. We must strive for a world in which [my friend's] transitions across the various healthcare settings he visits are seamless; where the clinicians he interacts with have the data they require to provide him with the personalized care he deserves; and where he not only had access to his data, but also the tools and supports to understand that data and advocate for his own health. This is about humanizing healthcare again."

Testimonial 6 - Physician

Categories of harm: *Patient Health and Wellbeing, Health System Function, Health Workforce Wellbeing*



"[As an on-call specialist] I was contacted by phone by an emergency room physician in [a nearby community] about 11:30 PM on a Friday about a patient brought in by the RCMP with psychotic symptoms and possible threats of suicide though the patient vehemently denied this. The report provided to me was that the patient was already in care, had a regular outpatient team and psychiatrist, and was already on treatment, although they had recently been switched from one medication to another. The emergency room doctor did not feel there were any grounds to certify the patient or even to hospitalize them, and after discussion it was determined that they should be discharged home. [After the weekend] I contacted the local psychiatrist on Monday to let them know their patient had been at the hospital. She informed me that the patient was in fact not compliant with outpatient care and the [psychiatric service] had been attempting to get the patient certified and involuntarily hospitalized, but had not had sufficient grounds to do so. The patient's presentation on Friday would, of course, have been exactly the opportunity to make that happen, but, none of the patient information was available to the treating emergency room doctor in [the nearby community], or to myself as the consulting psychiatrist. I would have provided different advice if I had had access to the patient's information. The lack of access to the patient's chart put them at risk."

Testimonial 7 - Senior Health Care Administrator

Categories of harm: *Patient Health and Wellbeing*



"When patients and healthcare providers don't have timely access to information they need to make good healthcare decisions, the impact can range from a minor annoyance to an extremely [dangerous] patient safety issue. I've seen both.

A GP not having access to screening mammography results in a timely way when there were no significant findings on the test wastes time and causes extra effort. But ultimately, there was no change to the outcome for that patient.

A physician not having timely access to medication information for a patient experiencing severe side effects, including delirium, has the potential to be life-threatening. In the case that I'm thinking of, the patient's partner was fortunately present and able to inform the physician of the patient's pharmacy, which enabled follow-up. If they had not been, the outcomes could have been much worse as the physician's initial assumption was that the patient had taken street drugs, which would have led to a different treatment plan."

02 | INTER-JURISDICTIONAL INTEROPERABILITY

A theme that appeared commonly across testimonials was the challenge that patients and the health workforce encounter trying to mobilize required health data across provincial and territorial boundaries. Testimonials speak to jurisdictional barriers to health information exchange that result in a host of negative outcomes including emotional stress, delayed diagnoses, poor health outcomes, repeated tests and avoidable system cost. Some patients relate that they do not trust that their health information will get to where it needs to be, so they compensate by both carrying paper copies of their own records to share with providers and relying on their "memory" to inform caregivers not able to access their prior health information. Testimonials speak of the continued reliance on fax and Canada Post to transfer medical information across jurisdictions. Commenting on jurisdictional barriers to health information exchange one author reflected *"when you think about it this seems completely crazy; publicly funded health care in Canada is supposed to be portable across jurisdictions. That is what the Canada Health Act says. Yet the information needed to provide that care is not portable."*

Testimonial 8 - Father of Patient

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*

"Many Canadians have no idea how chaotic and potentially dangerous the management of their health information can be, until their health is threatened. Consider the diagnostic odyssey of [my daughter], who was studying out of province. In January 2026, she was found to have a suspicious breast mass on a visit to a drop-in clinic in [a large Canadian city] where she is studying. A breast ultrasound ordered by the drop-in clinic physician was found to be concerning for possible cancer. She was told her family doctor would need to arrange a breast biopsy. However, her family GP in [our home province] was unable to view the image electronically due to a lack of interprovincial health data interoperability, so could not immediately initiate a request for a breast biopsy. When my daughter requested the report be sent to her GP and asked about the status of the image, she was told the report had been mailed by Canada Post (regular mail, no less), to her [home-province] GP. Fortunately, a family friend [in the province] where my daughter is studying is an interventional radiologist and had access to [her] images on the provincial Digital Imaging system but could not refer her as he is not a GP. At one point my daughter had 3 separate fax numbers she was tracking to navigate her care and results amongst provider organizations and physicians, across two provinces.

The stress of wrangling health professionals and informational uncertainty is a burden Canadians, like [my daughter] should not have to bear. Ultimately, [my daughter] had the biopsy in [the province where she is studying] and all is fine. Not only did the added stress of potentially having breast cancer weigh on [her] mind, but she also had to stress (unnecessarily) about multiple providers and their limited visibility into her images and results."

Testimonial 9 - Mother of Patient

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*

"My son recently struggled to navigate through the healthcare system in part because he moves back and forth between two provinces. He has a [provincial] health card, and a [provincial] family physician but attends university out of province. When he became suddenly [sick] while away at school, without a local family physician, he went to a walk-in clinic near campus. The physician was concerned and sent him for urgent blood tests and abdominal ultrasound. Because he could not access his results online [it] necessitated another long wait at the walk-in clinic to get results from a different doctor as the original walk-in doctor was off that day.

The tests ruled out a few things, but the cause of his [sickness] was still unclear, so the 2nd doctor sent him for more blood tests. Again, due to lack of access to his health information he had to go back to walk-in a third time for results which were still inconclusive, so they sent him for more tests saying only that a few of his liver tests were still abnormal and getting worse. After his 4th visit to the walk-in, they decided to send a referral to a liver specialist. After weeks of waiting, he called and was told to see walk-in again for a status update on his referral. At this appointment he was told his referral was denied as he didn't meet the criteria, and that they were going to send a referral to the GI pathway instead. This process took from February to mid-April. During this time, he had no access to his lab or ultrasound results because healthcare information does not upload to an out of province health card. This is not something we had thought about or considered before he became ill.

You don't realize how important it is to have access to your health information until you need it and can't access it. He asked the walk-in clinic to send his test results to his family doctor [in his home province] as he would be coming back [to the province] for the summer and wanted to follow up with his doctor when he got home. Only one set of blood tests and no imaging reports were received by his family doctor. This necessitated his family physician to reorder many of the same tests all over again which not only delayed possible diagnosis and treatment but also wasted valuable healthcare resources. Four months after becoming ill, he has yet to hear if his 2nd referral was accepted in [the province where he goes to school]. He has no definitive diagnosis. And still doesn't have access to any of the testing done [while away at school]."

> *"These borders and subsequent disparate information landscapes create significant inequalities and inequities in the care that people receive, and in many cases cause indirect and direct harm."*
>
> – Testimonial 14

Testimonial 10 - Patient

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*

"I am a 61-yr old woman currently living in [a community in Canada's north]. My health journey has taken me across [our territory] to [two provinces] where I have received care for pulmonary embolisms, breast cancer, a gastro-intestinal stromal tumour and life-threatening complications. Along the way, I experienced compassionate healthcare professionals and cancer navigation services that helped me find my way through the system. At the same time, moving between jurisdictions [provinces and territories] revealed how difficult it can be when health information is not available across jurisdictions and does not travel with the patient. During one trip to [one province], I landed in an emergency room at one hospital and was subsequently admitted for 8 days at another hospital, including numerous medical tests, scans and assessments. Follow-up treatment, which included surgery, was provided in [a second province]. The two hospitals [in the first province] where I was treated provided me online access to my own blood test results (along with various consultations, discharge summaries, etc.). Being able to access my results was empowering; it gave me a greater sense of understanding and involvement in my care, but the information was not visible to my healthcare providers back home in [my territory], nor in the second province. I found myself carrying my own paper records, sharing results between various providers, and relying on my memory while navigating systems and caregivers that could not readily see what had already been done elsewhere. As I moved between the jurisdictions, I often found that pieces of my health record existed in different systems, requiring me to carry the burden of filling in the gaps. I also experienced varying levels of access to my own health information depending on the jurisdiction and healthcare service providing my care. For example, as a resident of [my northern territory], I did not have online access to medical care received in Alberta, even though it was available to Alberta residents. Having access to my own information helped, but access alone wasn't enough. What I needed was for my health information to follow me, so that every provider involved in my care could see the same complete picture without relying on me to connect the dots. My experience showed me that while patient access to health information is important, true continuity of care depends on information being available to both patients and providers, regardless of where care is received."

Testimonial 11 - Patient

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*



"I required an expert opinion from a radiation oncologist in [another province] (I am a cancer patient in [my home province]). I needed to send the actual MRI images to them. I arranged with [a hospital] in [my home province] to send the images, which they claimed could only be done if I drove [there] to get a CD of the images and mail it myself. It was COVID times, so I persuaded them to send the CD directly, which they only do by regular mail. A month later, [the other province's hospital] did not have the CD. I asked that it be sent again. A month later, and [the other province's hospital] still did not have it—it seems the CD was lost a second time. This time, I asked the Quality branch to help me locate the source of the problem. The Quality officer who investigated my situation was new to the post and younger. She confessed that they do have the capacity to send the images electronically, but do not use it. She told me when she heard about the CD business, she actually asked "What is a CD?" That is how outdated we are—using CDs mailed by ordinary mail when we have a safer, more prompt, and more secure option denied to patients. The [other province's hospital] expert was forced to give his second opinion without the aid of the MRI images. My cancer care was significantly delayed and compromised by this bungling."

Testimonial 12 - Family Member of Patient

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*



"An elderly family member had a COVID exposure and symptoms when visiting us in [our home province]. He was recommended antiviral treatment, but his care provider required a lab test to ensure it was a safe choice. This test had been conducted a week earlier but in [a different province], and there was no way to share those results with his provider here. He was unable to have the necessary tests conducted here in [our home province] in a sufficiently timely fashion and had to forego the antiviral treatment. Thankfully, he recovered fully regardless, but it was a frustrating and stressful experience."

Testimonial 13 - Patient

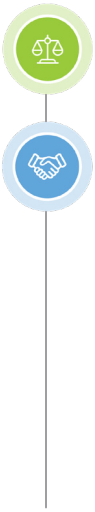
Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*



"Although I am from [my home province], I required hospitalization at [an out-of-province hospital] for a major pelvic surgery. Due to a series of errors there (a poorly placed IV led to the fluid going interstitial) they could not access a vein. They refused to use my in-chest Port-a-Cath, saying they did not place it originally and therefore did not trust it. They were unwilling or unable to get information from [my home province] showing that the porta Cath was safely placed and routinely accessed here. I went without pain medication, hydration, or blood collection for three days after a major surgery due to these communication problems."

Testimonial 14 - Physician

Categories of harm: *Legal and Ethical Rights, Social Good*



"I have had the opportunity (and privilege) to work in healthcare in different capacities and in multiple regions in Canada. Despite a publicly funded, single-payer system, there are marked differences in the ways that we collect, access, and store health information. Each border you cross—be that a provincial border, health region border, or imagined border between a "private" clinic and the acute care hospital across the street—lands you in a completely different information landscape. These borders and subsequent disparate information landscapes create significant inequalities and inequities in the care that people receive, and in many cases cause indirect and direct harm."

> *"Information here is stored in so many different silos and there are so many barriers to accessing them that it is impossible to provide the same quality of care to patients that I am used to providing."*
>
> – Testimonial 27

Testimonial 15 - Physician, Digital Health Innovator

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Social Good, Health System Function*



"My passion lies with virtual care and how to best utilize it to expand access to care. In my opinion, effective virtual care demands interoperability to be safe. I may see a patient for the first time, not know anything about them, and will have 10-15 minutes to make a decision as to whether they need outpatient or inpatient management. Such direction of care, in the era of complex patients, is only possible in environments where a patient's information is following them where they are seeking care. Can you imagine trying to treat an elderly patient who is dizzy, not knowing anything about them, and then directing them to an ER which also doesn't know anything about them? That is the current standard.

I am incredulous that a patient could go to a clinic down the street from their usual place of care and have to start from scratch with a combination of PDFs and paper [records] to help build a summary. We are laggards in digital health innovation as our data is inaccessible, inoperable, and inadequate. From my experience, any attempts at being collaborative are blocked by vendors seeking to protect their monopolies and limiting [data] access. It should not be their data to hold hostage—it should belong to patients and follow them along their care pathway."

Testimonial 16 - Physician

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function*



"I have a patient with chronic disease who drives a truck for a living: he resides— formally—in [one province] but is rarely actually [there]. His narrative unmasks the inconsistencies that plague jurisdictional boundaries in Canada. For example: his pharmacy can freely move prescriptions between provinces, but I—as his family doctor—must erect obstructions based on provincial licensing and reasonable expectation of follow-up care. Where is he when I call him, and how much does that matter? Where and when should he get lab work done, and how will the results reach me? To whom—and in which province—should (or may) I fax a prescription? Together, we manage, but it feels like different parts of the system follow different rules. There is no immediate or catastrophic harm to the patient, but he doesn't seek care as often as he ought to. I believe his care suffers as a result."

03 | RESEARCH AND INNOVATION

Health data is required by all branches of health service including research and innovation. A series of testimonials from digital health innovators and health researchers paint the picture of a fragmented and cumbersome health data ecosystem that hinders research and innovation. Testimonials relate that health data fragmentation is resulting in *"treatments that go undeveloped, discoveries that never get made, dollars spent on care we can't measure or improve, and patients who suffer in the gap"*. The economic impact of failed health research and innovation is highlighted; *"an entire generation of homegrown health technology and the jobs, companies, and savings that would come with it, [are] left on the table."* One senses a collective level of frustration from this constituency with the state of health data interoperability in Canada.

Testimonial 17 - Digital Health Innovator

Categories of harm: *Patient Health and Wellbeing, Research and Population Health, Health System Function, Health Workforce Wellbeing, Health Innovation*



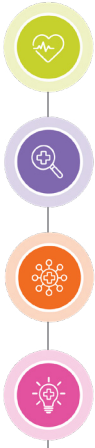
"As part of a nationally funded AI Scribe project we are running at [a large provincial health authority] we created a benchmark and protocol for measuring the accuracy and hallucination of any AI scribe. The input data are doctor-patient encounter transcripts generated using data collected by [our AI scribe] users within the [local health authority] who have consented to using the data for research purposes and to improve the tool. In cooperation with [the local university] and the [associated AI institute] we have access to world class researchers working on these types of problems. Despite multiple requests, escalations, and advocacy,

> *"The lack of clear public policy supporting health data sharing for this type of work is hampering much needed Canadian health research and innovation and becomes deeply frustrating for those of us trying to improve health system function."*
>
> – Testimonial 17

[the health authority] has been unable to grant even de-identified data access to [non-health authority] researchers. This remains a significant roadblock for our [AI scribe project], as these researchers are confined to an advisory role, leaving the actual benchmarking and optimization work to [health authority] analysts. While our [health authority] analytics colleagues are skilled, they are not Machine Learning specialists and carry substantial competing workloads. This lack of access to data has hampered our ability to evaluate and improve not only [our AI scribe], but other commercial tools as well. Eliminating AI scribe hallucinations will help improve the accuracy of these tools and increase patient safety. The lack of clear public policy supporting health data sharing for this type of work is hampering much needed Canadian health research and innovation and becomes deeply frustrating for those of us trying to improve health system function."

Testimonial 18 - Physician, Digital Health Innovator

Categories of harm: *Patient Health and Wellbeing, Research and Population Health, Health System Function, Health Innovation*



"I am a physician and AI designer, and I am committed to improving health care function through the development of AI tools that improve system efficiency and patient care. Most of my work centres on the development of a robust AI scribe. To support the scribe, I have created an AI agent that talks to a patient autonomously, takes a complete history, and returns a resident-level summary to the attending physician. This 'agential intake' workflow offers the promise of giving patients more time to tell their story, and physicians more time to discuss plans and concerns with patients. It could dramatically improve the delivery of care in the emergency department and beyond. In addition to taking a history, [the tool] is theoretically able to review a patient's chart and integrate that into its questions and summary, compounding the utility to the patient and physician. Unfortunately, there is a big obstacle to its use, the lack of easy, but appropriate access to patient health records. Patient information is siloed across a variety of databases including the [provincial Electronic Health Record], the health authority digital health platform, and multiple community-based clinic records. The principal agencies overseeing this data will not allow appropriate, but easy access for innovators or patients, so [this innovation] remains neutered in its capabilities. While patients can technically access some of their health data via [the provincial patient portal], the data available in practice is incomplete, not easily machine-consumable, and certainly not accessible to third-party applications without significant institutional negotiation. To put this in context when I requested access to my own medical record in shareable, electronic format, all I received, after two weeks, was an invoice for printing and postage charges to send me a paper copy. As the amount of electronic health data accumulates so will its latent value to patient wellbeing and the effectiveness of digital systems needed for care. It is imperative that we unlock the potential [of Canadian health data] for the benefit of all."

Testimonial 19 - Physician, Researcher, Innovator

Categories of harm: *Patient Health and Wellbeing, Research and Population Health, Health System Function, Health Workforce Wellbeing, Health Innovation*



"I've spent nearly a decade now as an emergency physician and health researcher at [a large Canadian university], and for most of that time I've been chasing a goal to take the AI and digital health innovations we build in the lab and put them to work at the bedside. The hardest barrier hasn't been the science or the clinical appetite for change. It has been our collective inability to move health data from one place to another.

It has taken five or more years to claw out even the minimal degree of interoperability needed to deploy a tool like an AI clinical scribe (which depends on very little if any data linkage). We have still never genuinely realized the ability to implement our tools inside the EMR itself, which would unlock enormous value. If it takes five years to gain a small toehold, then across a thirty- or forty-year career I will be lucky to see a handful of innovations cross the gap from bench to bedside. Data bottlenecks preclude real healthcare innovation and knowledge discovery.

There is an enormous economic opportunity going unrealized in this province and this country. An entire generation of homegrown health technology and the jobs, companies, and savings that would come with it, are being left on the table. There is a vast reservoir of real-world evidence that we are simply failing to generate: evidence that would tell us which treatments work, for whom, and at what cost. Because we cannot generate that evidence at home, we are forced to lean on open and semi-open datasets from the United States to answer questions about our own patients — an absurd position for a country with universal, publicly funded health care and some of the richest longitudinal data in the world.

In the end, this is what fragmentation costs us: treatments that go undeveloped, discoveries that never get made, dollars spent on care we can't measure or improve, and patients who suffer in the gap. We cannot innovate, we cannot generate the real-world evidence that improves how care is delivered, and we cannot save the money or the lives that better information would let us save."

Testimonial 20 - Digital Health Innovator

Categories of harm: *Patient Health and Wellbeing, Research and Population Health, Health System Function, Health Workforce Wellbeing, Health Innovation*



"In my work building digital patient engagement programs over the last 15 years, I have seen how the lack of interoperability in Canadian (public) health can turn good ideas into slow, expensive, one-off projects and failed pilots. The technology to support patients between visits exists. We can send reminders, collect patient-reported information, tailor education, and help people navigate care. But when data cannot move securely and predictably between systems, everything gets bogged down in one-off discussions, narrow expensive pilots with punishing inclusion/exclusion criteria, custom integrations and manual workarounds that impact success.

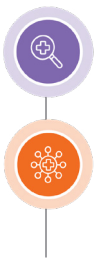
That has a direct impact on patients who are most likely to benefit from low-burden digital support; individuals managing chronic illness, mental health challenges, medication adherence, language barriers, or complex care. One such example is a pilot of a novel platform with a [provincial] hospital which shall remain nameless that cares for a population at-home (hospital at home programming for a particularly vulnerable population). The lack of interoperability [of health data] precluded the accessibility of a proven technology beyond more than a singular clinic setting for a narrow fraction of the population that needed to be addressed. As a result, less than 10 patients were recruited for the pilot program, and the pilot was deemed a failure. To be clear, in other settings the system is flourishing showing significant readmission reduction benefits and outcomes for the population in need.

In practice, poor interoperability means fewer programs reach scale, fewer patients receive personalized support, and innovators spend scarce research and implementation dollars overcoming system barriers instead of improving outcomes. I have come to see interoperability as a patient safety and access issue, not just an IT issue."

> *"It's time for us to come together around our common goals and design a better health system for all of us. Data saves lives."*
>
> – Testimonial 5

Testimonial 21 - Nurse, Researcher

Categories of harm: *Research and Population Health, Health System Function*



"I am a nurse and a health researcher with a focus on digital health information systems. We once spent a little over a year just trying to get access to Electronic Health Record data for a study that had already been ethics approved. A year. And that was the best-case scenario: we knew exactly who to ask, we knew the processes required, and we had existing relationships and partnerships in place. Not collecting data, not analyzing it, just waiting for permission to see it. By the time it came through, the context had shifted, the questions we

were asking were no longer timely, and our research team lost momentum we never really got back. Multiply that across every [Canadian] researcher hitting the same wall, and you start to see how much potential insight just evaporates while we wait. It's not that the data doesn't exist. It's that getting to it costs more than most people realize."

Testimonial 22 - Senior Health Care Administrator, Physician

Categories of harm: *Health System Function, Health Innovation*



"The second half of my medical career includes various roles (e.g. CMIO of a provincial health authority) trying, mostly unsuccessfully, to fix [problems related to a lack of health data interoperability]. It has been clear for over a decade what can work here for interoperability as it currently does in various global jurisdictions. Yet, in some instances, we seem to be going backwards, hellbent on limiting the number of products in a bid to improve interoperability using shrink wrapped solutions which miss the mark while also stifling the innovation that we need to advance faster and further. It's gratifying to see an increasing number of providers calling out these issues but to get meaningful action will take a serious reboot in thinking and strategy. Clearly what is happening now is not working."

04 | CULTURAL AND LEGAL RIGHTS

Ideally, the management of health data in Canada would be guided by rights-based and ethical standards arising from Canadian legal precedent and international convention. These include the United Nations Declaration of the Rights of Indigenous Peoples and aligned policies adopted federally and in some Canadian provinces that support the rights of Indigenous Peoples to control their health data, and a 1992 ruling from the Supreme Court of Canada that established the right of access of Canadians to their health information. Unfortunately, digital age health data design and use in Canada often falls short of these standards. This is borne out in many testimonials that describe shortfalls in the ability of individuals, including Indigenous people, to access their health information, and the implications this has for their health and cultural wellbeing.

Testimonial 23 - Wife of Patient

Categories of harm: *Patient Health and Wellbeing, Cultural Rights, Legal and Ethical Rights, Health System Function*



"My husband, an Indigenous [First Nations] man from [a community in a province], where he was a Chief in his House clan, was diagnosed with advanced esophageal cancer after experiencing difficulty swallowing. Throughout his treatment, we travelled between multiple communities and cancer centres, relying on healthcare providers across the province to coordinate his care. Throughout his care journey, we encountered repeated breakdowns in communication. Referrals were delayed, clinicians often appeared unfamiliar with his medical history, critical imaging was missed, and important symptoms, including changes in his vision and severe headaches, were not connected across his care team. We found ourselves reading his medical records, tracking appointments, questioning inconsistencies,

and advocating for investigations that should have been routine.

Although many individual providers showed compassion, they often worked in isolation rather than as a coordinated team. After my husband passed away, we participated in a healing process where healthcare leaders acknowledged that racism may have influenced aspects of his care, an admission that was painful to hear but validated some of our concerns. His case has since become part of an Indigenous health case study to help improve care. More than anything, our experience showed us that disconnected health information can have devastating consequences, and that Indigenous patients and families should not have to navigate fragmented systems or carry the burden of coordinating care themselves."

"Our experience showed us that disconnected health information can have devastating consequences, and that Indigenous patients and families should not have to navigate fragmented systems or carry the burden of coordinating care themselves."
– Testimonial 23

Testimonial 24 - Mother of Patient

Categories of harm: *Patient Health and Wellbeing, Cultural Rights, Health System Function*

"I am a Cree First Nation woman originally from [a First Nation] in Treaty 4 Territory. I moved to [a Canadian territory] with my family when I was 10 years old. We have residential schools deeply embedded in our family history. All my family members ahead of me went through residential school and they were impacted by the intergenerational trauma. I have been deeply impacted in my life by that trauma and during my daughter's diagnosis and our journey.

When my daughter was diagnosed with Rett syndrome (a complex, multi-symptomatic diagnosis caused by a gene mutation (MECP2) at 18 months of age, our lives became a series of appointments, assessments, hospital visits, and trips between [two jurisdictions]. Over the years, we worked with many different providers and community services, all of whom needed information about her condition and care. At almost every appointment, I was asked to tell the story again, from pregnancy and early development to diagnoses, surgeries, medications, feeding challenges, and specialist recommendations. I quickly realized that if I did not carry the information forward, no one else would.

As my daughter's needs became more complex, so did the role I played in coordinating her care. I am a single mother managing my daughter's complex daily needs, my family's needs and my own health condition. I became the person responsible for connecting information across providers, organizations, and jurisdictions. I relayed updates from specialists to local care teams, shared reports between services, attended meetings, and ensured that important details were not lost between appointments. Much of my daughter's care

management depended on my ability to remember, organize, and communicate information accurately. While the care teams changed over time, I remained the one constant in her journey. Looking back, it often felt as though I was functioning as the bridge between disconnected parts of the health system. My experience showed me that when health information does not follow the person, families are left carrying not only the caregiving, but also the responsibility for ensuring continuity of information and care."

05 | BURNOUT

There is a great deal of research linking the use of digital health information technology to provider burnout,[38] but in general the focus has been on technical interfaces and less on issues of health data interoperability. Yet, running through many health workforce testimonials is an undercurrent of frustration with the current state of health data fragmentation. Stories from members of the health workforce include words like "fear", "incredulous", "unfathomable" and "exasperatingly"; the word frustration appears seven times. A few testimonials call the issue out specifically, one physician stating that the chaotic state of health data led them to the point where, *"only 6 months out of training [...] I was very seriously considering quitting clinical medicine altogether."* Another physician observes *"I would say that frustration with the fragmentation of health information is very common among my colleagues—almost a given that we accept wearily as a way of being that cannot be changed."* The theme of a complacent or passive acceptance of the state of dysfunction of health data in Canada is touched on a few times, pointing to a potential undercurrent of burnout or moral injury in the workforce.

Testimonial 25 - Physician

Categories of harm: *Patient Health and Wellbeing, Health System Function, Health Workforce Wellbeing*

"It's a gong show out there right now, with respect to interoperability. Fear in the community—in the workforce—about if information is getting to where it's supposed to. Results routing, patient communication through portals, our accountability for information that does or even does not come to us (that the patient thinks does). Honestly, it feels like it's just one thing after another. We are playing whack-a-mole with volatile issues. Working around one, and another one pops up. None of the workarounds are particularly satisfactory, but maybe they close the gap a bit. It is impossible to build a high-functioning system when you are constantly in damage control mode. But it's where we are at and it's where we will be for quite a while."

"It's a gong show out there right now, with respect to interoperability. Fear in the community—in the workforce—about if information is getting to where it's supposed to."

– Testimonial 25

Testimonial 26 - Physician

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function, Health Workforce Wellbeing*

"I work at a hospital in a regional center. We accept patients for care in transfer from within our jurisdiction and adjoining provinces and territories. Routinely patients who are transferred from across this provincial boundary are very ill and arrive with photocopied information that pertains to their health concern, as there is no means for digital health communication across the jurisdictional boundary. This is routine in Canada as digital health information technology almost never operates across provincial or territorial boundaries. This means that a patient's digital health information does not follow them on their care journey.

The quality of the photocopied information that accompanies the ill patients is highly variable. Sometimes the information is quite comprehensive, with a proper transfer note, orders, and medication list. However sometimes the information is incomplete. Comprehensive transfer notes that describe the patient's health concerns, recommended course of treatment, and follow-up plans can be piecemeal or completely missing. As there is no consistency in the information that accompanies a patient, one never knows if what one has received is complete, and what is missing. The uncertainty about the quality of the patient information can be very stressful and time consuming. Trying to track down accurate information from the point of transfer can be very challenging and caring for an acutely ill individual when one cannot rely on the integrity of the health information upon which decisions about their care are based is a very poor way to manage health service. Healthcare providers in Canada are well trained and committed to providing quality patient care. Working in an environment that impairs one's capacity to provide excellent care is very discouraging and can be frightening.

Furthermore, there is really no one to complain to about this mess; it is nameless faceless people and processes that seem to have set up these terribly fragmented information systems. Who are we to talk to get provinces and territories to set up harmonized health data systems? Most of us just accept that it is deeply broken and dangerous and try and do our best. I would say that frustration with the fragmentation of health information is very common among my colleagues—almost a given that we accept wearily as a way of being that cannot be changed. This state contributes significantly to stress and burnout and promotes unsafe care and harm to both patients and the health workforce. And the public usually doesn't know how fragmented their health information is, or how dangerous it is, because we don't talk about it. It is a dirty secret."

Testimonial 27 - Physician

Categories of harm: *Patient Health and Wellbeing, Legal and Ethical Rights, Health System Function, Health Workforce Wellbeing*

"I recently started working as a staff physician in a new province. It is a wealthy and populous province that has committed significant financial and human resources to the development and implementation of clinical information systems. When I started to provide care to patients, I started to use the clinical information systems available to me to help me guide them through their decision making and healthcare journey. I would look up historical labs, I would review current and prior imaging reports and the images themselves, I would review historic pathology reports, and I would read notes from other colleagues in primary care, various specialties, and allied health disciplines. Or at least, I tried to. Instead, I have found myself in an information vacuum where I can't provide the level or quality of care I can elsewhere. By crossing a provincial border, then a few health region borders, and finally borders between facilities I have landed in an extraordinarily fractured information landscape. It is so fractured, that it was more or less an information vacuum. The common practices that I had in other places are impossible to operationalize in clinical practice here. I tried to look up prior labs and imaging only to find that they weren't collected, were unavailable in one information system, required significant paperwork to request access to, or were otherwise not accessible. When I tried to access colleagues' clinical documentation, I found it next to impossible.

Information here is stored in so many different silos and there are so many barriers to accessing them that it is impossible to provide the same quality of care to patients that I am used to providing elsewhere in the country. (To be clear, I don't want to paint the picture that what we are doing in other provinces or locations in the country is good, only that it is different. Similar problems exist in other parts of the country, they are just exponentially magnified here). The first six months that I started to practice, I tried to provide the same quality of care that I was used to providing, but doing so quickly proved to be impossible. The time and energy required to access the type and amount of information that I was accustomed to accessing and then trying to disseminate information to the correct places, would keep me in clinic until well into the evening or even longer. After months of exasperatingly trying to sort out issues I was having with document distribution, I resolved to stay at work until I made some headway on a specific aspect of the problem—I didn't leave [the] clinic until 02:00 the next morning, and the problem remained largely unsolved.

I got to the point where only 6 months out of training, that I was going to quit, pack up, and move elsewhere in the country to work. I was very seriously considering quitting clinical medicine altogether—and had it not been for my student loans, I might have. I quickly recognized the way I was trained and accustomed to practice medicine was not sustainable and that I couldn't keep doing it, but changing what I was doing would mean that I would be delivering a lower standard and quality of care than I had previously. There

is an extraordinary amount of distress and moral injury that arises when you realize that you can't provide good care simply because of system issues that have led to fractured and inaccessible information. Now that I am almost two years into working here the level of distress I feel is no less than it was when I started, but at least I am able to put boundaries around what I can reasonably expect to accomplish and the quality of care that I can provide within the context I am working and keep the level of burnout lower than it could be.

"There is an extraordinary amount of distress and moral injury that arises when you realize that you can't provide good care simply because of system issues that have led to fractured and inaccessible information."

– Testimonial 27

Nevertheless, there are still a few patients every week for whom I feel compelled to dig through the information systems available (and unavailable) to me to attempt to provide an appropriate level of care, because they deserve a system that serves them better. ...but those hours quickly add up, and so does the personal and professional toll. What has kept me from quitting or moving has been connecting with a few colleagues who work in the health informatics space who shared the same frustrations as I do, and slowly but surely are working to try to solve the root causes to these problems. Thus, I feel privileged to provide this testimonial and thank you for the opportunity to do so. While the harm to providers that results from a lack of coherent information design and non-interoperable systems is considerable, it pales in comparison to the harms experienced by patients."

Testimonial 28 - Physician

Categories of harm: *Patient Health and Wellbeing, Health System Function, Health Workforce Wellbeing*

"I was texted from the emergency room in our community by the Mental Health Services Unit nurse about a patient post suicide attempt by overdose. She stated that the patient "describes Borderline Personality Disorder traits, but she has a bipolar II diagnosis." These, of course, would be very different scenarios as Borderline patients make suicide attempts quite regularly and routinely, whereas for a bipolar patient, it might indicate bipolar depression, and they have a much higher lethality rate. I saw the patient in person the next morning. I concurred with the diagnosis of probable Borderline Personality Disorder in addition to or maybe even instead of bipolar disorder. On Monday, I let the outpatient psychiatrist know about the patient's presentation. She proceeded to send me her outpatient notes, which indicated that this individual had already been diagnosed with Borderline Personality Disorder. Those notes, of course, were not available to the emergency room physician, the Mental Health Services Unit liaison nurse or myself because they are on a separate Electronic Medical Chart system."

06 | HUMAN FACTOR INTEROPERABILITY

Traditionally, health data interoperability has been considered a technical issue focused on the ability of different computer systems, software, and platforms to exchange, interpret, and use data together. Networked Health introduced the concept of Human Factor Interoperability in the 2023 report *Interoperability Saves Lives*[39], positing that the ability of health data to interoperate is also deeply dependent on human relationships; the ability of the human beings overseeing digital health technology to agree on governance, legislation, policy and regulations that support the interoperability of technical systems. A theme that emerges from testimonials is that the perceived obstacles to interoperability are often not technical. The author of one testimonial clearly articulates how their understanding of health data interoperability has evolved from a set belief that it is strictly a technical domain, to an understanding that if the technology is not properly governed interoperability can fail. Another testimonial relates a story of failed health data interoperability and concludes *"I think it is an example of how little of this is dependent on technology. It is all dependent on human beings and how we work together. We can continue to throw billions of dollars at new software and technology, but we won't succeed with it until we can remedy these fundamental human and relational problems."*

Testimonial 29 - Physician

Categories of harm: *Patient Health and Wellbeing, Health System Function, Health Workforce Wellbeing*

"A few years ago, we had an expansion of subspeciality surgical cancer care in our province. A new program with several surgeons that will significantly bolster an under resourced service with long wait times. I was talking to one of the new surgeons and by happenstance they mentioned that imaging and labs done in the northern half of the province were not coming back to them. Not digitally in their information, not by fax, not by physical letter. Can you imagine what it would be like to have that CT scan show new metastasis of disease? Can you imagine what might get missed in this scenario? Because I happen to do some work with our information systems in the north, I was able to direct the surgeon and their admin staff down the correct path to get connected. They needed to fill out a form, and then 24 hours later, things were connected. Today, information is flowing as it should. But no data flowed for almost 2 years, and the situation was only corrected by happenstance. In other provinces I have worked in, this sort of thing doesn't happen - or at least, doesn't happen often. In those settings, the College, Ministry, Physician organization, IT, and informatics teams all coordinate to make things work. Unfortunately, that is not how things work here. I have been told there have been multiple attempts to get the College, Ministry, Physician Organization, IT, and informatics teams all together at the same table to start coordinating, only to have it all fall apart and go nowhere because they could not find any way to work together. Everyone blames everyone else. Nobody takes responsibility. Nobody is accountable. I think it is an example of how little of this is dependent on technology. It is all dependent on human beings and how we work together. We can continue to throw billions of dollars at new software and technology, but we won't succeed with it until we can remedy

these fundamental human and relational problems. And until we do, how many missed labs and imaging reports will go unread? What is the human cost to this problem?"

Testimonial 30 - Senior Health Information Systems Administrator

Categories of harm: *Patient Health and Wellbeing, Health System Function*



"I am a senior health information systems leader at a large hospital in one of Canada's major urban centers. A few months ago, one of our physicians casually mentioned that he hadn't seen pathology results for several patients in quite some time. These weren't routine tests; they were pathology reports used to confirm cancer diagnoses. That comment triggered an investigation, and what we found was alarming: hundreds of completed lab results were sitting undelivered in a broken interface between our hospital's electronic medical record and an external laboratory system. The tests had been ordered, the specimens analyzed, and the results generated. But because two systems stopped communicating properly, the information never reached the clinicians who needed it.

After we cleared the backlog, a physician called me. One of his patients had a confirmed cancer diagnosis that had been delayed for months because the result had been trapped in that interface. He asked me a question I couldn't answer: "How am I supposed to explain to my patient that their treatment was delayed because of a broken interface?"

That experience fundamentally changed the way I think about interoperability. We often talk about interfaces, standards, and data exchange as technical problems. But interoperability failures in healthcare are not simply IT issues – they are patient safety issues. When governance is weak, accountability is unclear, or monitoring is absent, failures can remain invisible for weeks or months. The consequences aren't measured in system downtime or support tickets; they're measured in delayed diagnoses, delayed treatment, and harm to patients.

Interoperability only improves care when it is actively governed, continuously monitored, and treated as a critical clinical safety function, not simply a technology project."

07 | HEALTH SYSTEM INEFFICIENCY

Almost every testimonial either directly or indirectly raises issues about the significant operational barriers to almost all branches of health service posed by a lack of ready and appropriate access to health data. Across the board testimonials tell of delays in health services caused by inaccessible or untimely health data; delays that translate into missed diagnoses, redundant use of resources, and overdue or shelved research and innovation. Taken together these culminate in failed opportunities to optimize health system function resulting in a degradation of quality health services, poor patient outcomes and workforce attrition. Collectively this results in significant and avoidable financial cost to governments and

the public. Reflecting on their experience with the healthcare system one author writes *"this experience showed me how gaps in health data interoperability can place unnecessary burdens on families and create missed opportunities for more efficient, safe and coordinated care."*

Testimonial 31 - Physician

Categories of harm: *Patient Health and Wellbeing, Health System Function*



"We recently had a patient present to the emergency room. They were diagnosed with cancer. They had no family doctor, but the emergency room physician also had a family practice and agreed to add them to her already overfull panel. Together they had extensive conversations about end-of-life care and goals. Goals of care and an advance directive were documented and were distributed to the patient, the physician, and to health records at the hospital. Significant work went into planning goals of care with this patient, their family, and palliative care professionals in the community.

> *"Can you imagine trying to treat an elderly patient who is dizzy, not knowing anything about them, and then directing them to an ER which also doesn't know anything about them? That is the current standard."*
>
> – Testimonial 15

The cancer progressed rapidly enough that one evening the patient's airway compromised, and although they managed to get to [the] hospital [they were] unable to breathe and unable to talk. This was the natural course of the patient's cancer. They knew this eventually would happen, which is why they made a plan for what they wanted at the end of life. Per the patient's prior wishes and plan, they wanted palliation— management of symptoms so that they could die peacefully, in their home community.

Unfortunately, nobody was aware of the plan. The plan was documented in the physician's "private office" medical record system and inaccessible to anyone else [including the emergency room staff], even though that office is literally across the street from the hospital. There was no ability to document the patient's wishes in any of the larger information systems deployed in the hospital or acute care setting—because despite spending decades and billions (that is billions, starting with a "B" and ending with an "S"), nobody thought a mechanism to make this patient's information available to them across the different settings of hospital and physician office (which I reiterate, are directly across the street from each other) might be important. The paper copy of the patient's advance directive and wishes that was faxed to health records so it could be part of the patient's chart? ... to this day, it is still missing.

General surgery was consulted. Otolaryngology was consulted. Emergent CT scans, an MRI, and labs were arranged. A plan was set in motion to transport them to a major urban tertiary care center for surgery. A surgery that the patient expressly did not want. But as they lay in

the emergency, unable to talk, their ability to breathe slowly dwindling, they were unable to communicate that to anyone. The information systems available that could and should have been designed to communicate this information on their behalf instead failed them. By happenstance, their family doctor was scheduled to work in the emergency room that morning. They came in, recognized the patient, clarified their wishes, and averted flying the patient out for emergent surgery. They died peacefully in their home community per their wishes. But only because of happenstance."

In a 2025 study health economists estimated that fragmentation of health data systems and downstream impairment of secondary uses arising from a lack of health data interoperability is costing Canadian health services $9.4 billion annually. The authors estimated that a similar annual cost is borne by the public bringing the total estimated Canadian price tag to nearly $19 billion annually.

For more information, please see: https://pubmed.ncbi.nlm.nih.gov/41084200/

Testimonial 32 - Father of Patient

Categories of harm: *Patient Health and Wellbeing, Health System Function*

"My son was born a few weeks early and weighed less than five pounds. Following discharge from hospital we attended a public health clinic for follow-up assessments during his first days at home. The care we received was excellent, and the nurses provided invaluable support during an overwhelming time. What surprised me was learning that the information collected during several hours of assessments could not be directly shared with my son's pediatrician, who would assume responsibility for his care the very next day. Instead, I was encouraged to take a photo of a handwritten note containing some of his measurements and share it [with the pediatrician] myself. As a parent, I couldn't help but wonder why important health information could not move seamlessly between members of the same care team. This experience showed me how gaps in health data interoperability can place unnecessary burdens on families and create missed opportunities for more coordinated care."

Testimonial 33 - Family Member of Patient

Categories of harm: *Patient Health and Wellbeing, Health System Function*

"A family member received excellent care for breast cancer in [a province in Canada], which was thankfully caught early. She was discharged from the cancer program, with the expectation her primary care provider would provide the necessary follow-up treatment and monitoring. Her primary care provider retired during the course of her treatment, however, and it took some time to find a new one. Unfortunately, the new provider was unable to access her care records and was reluctant to provide the follow-up care, instead

recommending she return to the cancer center. Significant effort was required to ensure the information was shared and demand the new provider fulfill their role."

Testimonial 34 - Patient

Categories of harm: *Patient Health and Wellbeing, Health System Function*



"In 2010, I was diagnosed with a rare non-malignant brain tumor in the Emergency Room (ER) at the age of thirty-three. Our son was four-years old. I walked out of the ER with no information other than the name of my brain tumor and that I would have yearly MRIs to monitor its growth. Overnight, I went from being a routine patient to one who had multiple specialists, multiple medications and appointments. I quickly learnt to ask for paper copies of all my imaging and reports from my specialists. My health information was not easily accessible but vital to the understanding of my condition. Later in my patient journey, lack of communication integrity of my health data almost cost me my life. This is why and how.

Two years after my diagnosis, a sudden change and increase in my vertigo and migraine symptoms prompted a visit to my GP. My GP added additional medications to my prescriptions and immediately referred me to my neurologist for assessment. The locum neurologist assessed me and said I had [a benign condition called] labyrinthitis. One week later, I saw my GP again due to no resolution, despite increased medications, of my weeklong migraine. She advised me to go to my local emergency room. I had a paper referral letter from her stating "increased migraines and vertigo, history of brain tumor, imaging requested". The ER doctor called the locum neurologist who had assessed me previously. The locum neurologist did not recommend imaging and did not document any of the conversation with the ER doctor in my neurology chart. I was given IV migraine medications in the ER and sent home. I continued to do poorly. By this point as a patient and family, we felt the standard of care was lacking and arranged for a private MRI for a sense of comfort. It showed my brain tumor had doubled in size and I had obstructive hydrocephalus. I needed urgent brain surgery to remove the tumor.

By then, we had lost faith and trust in our local healthcare system. I had surgery [in the United States soon after]. On arrival, I was immediately transferred to the ICU. As a result of the prolonged hydrocephalus, surgery and aseptic meningitis, I live with a brain injury. I was diagnosed with PTSD nine months after my brain surgery as a result of the trauma and challenges I faced in accessing care when I needed it most. I had counselling for over 2 years to help me with my PTSD.

I learned that the ability for my healthcare team to communicate information about my health status between them in a timely and accurate manner is crucial to the assessment of my health and outcome. Accessing care in a safe and timely manner remains one of my biggest challenges today along with accessing my health data information."

Testimonial 35 - Physician

Categories of harm: *Patient Health and Wellbeing, Social Good, Health System Function*



"As an ER physician, I had a recent case highlighting the challenges of fragmented healthcare data. A patient came to our emergency department, extremely unwell. She had visited another hospital twice in the previous week with severe abdominal pain, nausea, vomiting, diarrhea, and fatigue. Despite an exhaustive series of CT scans and blood tests, the cause was unclear, and she was discharged with a presumptive diagnosis of gastroenteritis. But the physicians at the other hospital were missing critical information. The patient had recently been diagnosed with ulcerative colitis at an offsite, community clinic. She had forgotten to mention this new diagnosis herself to the team, but the problem was compounded by the fact that hospital EMRs do not communicate readily with outpatient clinics. As such, this key detail was not available to the team.

By the time she reached us, she had become much sicker. She was dehydrated, which caused significant kidney damage, and her diarrhea had evolved into multiple bloody stools per day. Fortunately, a family member accompanied her and relayed her recent diagnosis of ulcerative colitis. This critical information saved time and resources and allowed us to focus on key interventions. The patient was resuscitated with fluids, and steroid therapy. An urgent colonoscopy was completed, which showed the extent of her colitis flare, and helped guide further treatment. Although the patient recovered well, she required a lengthy stay in hospital.

It's clear that the prior ER teams' unawareness of her ulcerative colitis diagnosis led to unnecessary testing, such as CT scans, which are costly to the healthcare system and exposed the patient to avoidable radiation. It also resulted in delays to critical treatment, which could have saved the patient days of suffering and a prolonged hospital admission that separated the patient from her young children and husband. Further, as the family's primary income generator, her protracted illness and hospitalization limited her from working and created obvious financial strain for the family—an often-overlooked consequence.

This case epitomizes the challenges of fragmented health data and its associated harms. Had there been easier access to the patient's health records, her trajectory could have been dramatically different. Early recognition of her underlying disease could have resulted in less testing, earlier treatment, and thus less suffering and reduced resource utilization."

Testimonial 36 - Physician, Digital Health Innovator

Categories of harm: *Patient Health and Wellbeing, Health System Function*



"For 38 years I've been actively pursuing health information interoperability. The first half of that time was while in active clinical practice where I was continuously frustrated with the huge gap between what was available and what was needed. Even today, if one wants to take advantage of a well-designed EMR, it is necessary to manually transform so much unstructured data locked in various documents to a structured form which can be used for functions like decision support and QI. One even has to code common documents such as medical imaging reports that aren't coded at source to a standard nomenclature. Even if one takes the time to do all this entry and coding, there are still volumes of information that are never sent to you either by mistake or by system design such as not routinely sending immunization administration information to primary care. Also, because something you thought was going to happen like an important consultation or test never happened and for lack of closed loop ordering, you weren't aware of it ("Greg's Wings" nicely exposes that travesty). It was interesting to see how many business-smart physicians have taken on the administrative burden of manual entry or top up of information because they see the immense value to quality of patient care and even a hint of improved office/care efficiency despite this burden. This is a testament to professionalism but also to a failed system that they have to divert their time and energy to do this."

> *"I found myself carrying my own paper records, sharing results between various providers, and relying on my memory while navigating systems and caregivers that could not readily see what had already been done elsewhere."*
>
> – Testimonial 10

08 | ENVIRONMENT

Harm to the environment is perhaps the least intuitive of all categories of Health Data Related Harm. Initially our framework was composed of nine categories; we only added harm to the environment based on the results of our validation study with Mount Sinai in New York City. Many respondents to that study observed that environmental damage is a leading cause of human health degradation and that the way we use health data can be linked to environmental degradation. The most compelling current example is the excessive use of water to cool AI data centers that is depleting water reserves needed for people, depriving communities of natural resources required to grow food and sustain human beings. The Lancet has famously called climate change the greatest global health threat of the 21st century. [40] Our relationship with health data and how we manage energy and water resources required to manipulate it have a great bearing on climate change and the sustainability of other resources needed for human health.

Testimonial 37 - Physician

Categories of harm: *Legal and Ethical Rights, Health System Function, Environment*



"I live in a northern territory where in recent years we have witnessed a sharp increase in forest fires. 2023 was a particularly bad wildfire season resulting in the evacuation of almost 70% of the population of our territory to provinces in the south. This included the evacuation of all patients from the territorial hospital to hospitals in other jurisdictions. Unfortunately, the digital records of all residents of the territory that were evacuated – including hospitalized patients - were not accessible to the provincial health care providers caring for them in the south. Unless patients were sent with a printed paper copy of their chart, southern health services could not see their historical health information. The same was also true for residents of the territory seeking care while evacuated south. When you think about it this seems completely crazy; publicly funded health care in Canada is supposed to be portable across jurisdictions. That is what the Canada Health Act says. Yet the information needed to provide that care is not portable. I do not know if there were any bad outcomes because of this, but surely there must be a better way to design the healthcare system.

The other irony of this situation is the significant reliance northern Canada continues to have on the physical transportation of patients for care, when at times that care can be provided just as effectively virtually through interoperable health information technology. Unfortunately, virtual care technologies are still underutilized and often not interoperable, meaning that the reliance on transporting patients by fossil fuel driven planes and ambulances in the north has not been reduced significantly. While clearly the contribution of carbon emissions to greenhouse gases from northern patient transportation is relatively small, this still contributes to an increase in the incidence of forest fires which in turn negatively impact human health. So, there is a link between the lack of interoperable health data technologies in Canada, continued reliance on patient transportation, the burning of fossil fuels and an increase in forest fires and other climate disasters."

CONCLUSION

The testimonials in this report, from patients, families and members of the Canadian health workforce, suggest that a lack of health data interoperability can adversely impact individuals and the health care system. However, as testimonials constitute a very small sample size and were not gathered, nor analyzed according to rigorous scientific methodology, our ability to draw comprehensive or definitive conclusions is limited. Nonetheless the thematic consistency found in testimonials does suggest that the evaluation of harm arising from poor health data access, quality and use merits further investigation, ideally on a larger scale framed by more rigorous methodology. In doing so an effort should be made to hear from all health ecosystem constituents including those voices not captured in this report including government, public health, population health and many categories of health care providers. Similarly, testimonials from across Canada that cover all contexts including urban, rural and remote services are suggested.

An important observation arising from the thematic analysis of our data is that all domains of the health ecosystem that submitted testimonials – patients and families, health care providers, researchers, innovators and health care administrators - appear to share a common perception that the current lack of health data interoperability is damaging health system function and harming the health and wellbeing of Canadians. This suggests that a lack of health data access is a shared problem and may have a common root cause. The functional separation of strategic data design and use by custodian, health service and location that has typified the Canadian approach – data for research, data for innovation, data for management, data for public health, data for hospital-based services, data for community-based services, data for a jurisdiction – appears to exacerbate the fragmentation of health data by creating functional silos. Common reports across testimonials of the harm arising from province and territory-specific data fragmentation, or a lack of health data exchange across neighbouring health services drives home the point. The functional fragmentation of health data across services and jurisdictions is a choice that health leaders and provincial and territorial governments have made, not a necessity; a choice that violates – as one testimonial points out – the spirit and intent of the Canada Health Act and creates unsafe conditions for Canadians.

The word safe and its various derivatives (unsafe, safer, safety, safely) appears 18 times across testimonials. Understanding that the purpose of Canadian health service is to support the health and wellbeing of Canadians, deploying fragmented data systems that result in unsafe conditions for Canadians surely violates the core accountability of Canadian health service. Yet curiously health data interoperability has not been a priority in Canada. Only now, with Bill S-5 before the House of Commons is Canada considering taking preliminary steps toward the legislation of health data interoperability, many years after comparable nations have gone down this road.

The passage of Bill S-5 is simply a first step. Achieving mature health data interoperability is a complex longitudinal task that will not occur without a long-term cooperative Pan-Canadian effort. Piecemeal approaches will lead to uneven progress and perpetuate preventable harm to Canadians and the healthcare system.

Why has it taken us so long to address this foundational function of a safe healthcare system? Legislating interoperability is a choice. Harmonizing interoperability legislation, policy, regulation and technology is a choice. Cooperating across health services and jurisdictions is a choice. If we choose not to harmonize our approach, choose not to cooperate, then we are choosing to harm the Canadian health care system, and harm our fellow Canadians. Let us listen to the courageous individuals who submitted testimonials for this report and make the right choice. Let us choose a safe and interoperable health system. To achieve this all we need do is choose to cooperate.

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