Human Factor
Health Data Interoperability

COMMENTARY

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ABSTRACT

Comprehensive health data interoperability is recognized as an essential element of high-functioning and accountable health service. Canada is lagging in health data interoperability compared to international comparators, and lacks a comprehensive approach to human factor interoperability, *defined as system-level relationships that impact the capacity of health sector stakeholders to adopt harmonized health data standards and technology. Without addressing these system-level relationships, the adoption of harmonized health data standards and technology will be obstructed and Canadians will be underserved. The proposed health data interoperability framework articulates the factors that Canada needs to address to optimize health data design to support quality health programs and services.*

Introduction

The *Canada Health Act* (1985) states that the core accountability of health service is "to protect, promote and restore the physical and mental well-being of residents of Canada." The Medical Council of Canada (2022) links the purpose of digital health to this core accountability by defining it as "the use of information technology/electronic communication tools, services and processes to deliver health care services or to *support better health*." In the context of the focus of this series of papers – "essential digital health for the underserved" (Ho et al. 2024: 5) – the following question can be asked: Are there Canadians who are not well served by digital health because of its failure to uphold its core accountability to support better health? Let us consider this question in the context of one of the foundational properties of optimized digital health: health data interoperability.

Comprehensive health data interoperability is shown to improve the safety, efficiency and effectiveness of health programs and services and contribute to significant long-term health sector cost savings (Canada Health Infoway 2022; Li et al. 2022). Conversely, fragmentation of health data resulting from a lack of health data interoperability can adversely impact the quality of individual care, population health and health system function (Cresswell et al. 2017; Public Health Agency of Canada 2022). Yet there is not a single systematic framework for health data interoperability that considers *all determinants* of optimized system design. Broad industry accord posits that *health data interoperability* involves three principal features: the secure access and integration of electronic health data; its transmission across disparate health technologies in a format that enables its meaningful use; and the application of that data to optimize health outcomes (HIMSS n.d.; IBM n.d.). Interoperability is often divided into progressive tiers that describe the increasing levels of computer-to-computer data exchange and meaning. It is notable that the focus of this definitional approach is on *technical* and *ontological* factors that concern the bridging of data across disparate digital systems, revealing a technological bias in the definition of health data interoperability. This bias was noted in "A Network Model for Human Interoperability," a paper published in the journal *Human Factors*, in which Handley (2014) set out a framework for human interoperability, defined as the "system-level relationships that affect collaboration among operators interacting through technology." Handley (2014) observed that human considerations are often "poorly specified, and the focus of the system engineering effort is on the technology component" (p. 349) and asserted that incorporating human interoperability into networked technology design may improve system function.

We suggest that Handley's (2014) insights could meaningfully inform Canada's approach to health data interoperability, which arguably has demonstrated a relative absence of attention to human or system-level relationships around the use of health information technology. Following Handley's domains, we propose a pragmatic framework for health data interoperability that considers both *human* and *technical* factors that impact the success or failure of optimized health data interoperability design and function.

International Precedent

In 2004, the US founded the Office of the National Coordinator for Health Information Technology (ONC) to establish national standards for health data interoperability (Lipinski and Knee 2019). Since its inception, the ONC has implemented interoperability standards, enacted a broad legislative suite to address the promotion of health data interoperability through legislation that prohibits *information blocking*, mandated patient access to their personal health information, set interoperability certification criteria for health information technology products and established a national health data trust exchange framework (Lipinski and Knee 2019). In doing so, the US recognized that health data interoperability is not a uniquely technical and semantic proposition but must be fully supported by dedicated and harmonized governance, legislation and regulation.

Similarly, the European Union has advanced health data interoperability through the European Health Data Space (EHDS), an initiative aimed to promote optimized health data use across European countries by supporting citizen access and control over their health data, enable cross-border care and drive scientific and economic progress through international data analysis (European Commission n.d.). The EHDS is grounded in the European Interoperability Framework (European Union 2017) that promotes harmonized data governance and public policy through legal, operational, semantic and technical interoperability (European Commission n.d.). It highlights the importance of human factors as a determinant of health data interoperability, citing that "trust" across participating nations will be "a fundamental enabler" of project success (European Commission n.d.).

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Canadian Context

In contrast, a harmonized approach to health data interoperability governance and public policy in Canada has not yet occurred. The Canadian health sector is chiefly composed of sundry, stand-alone service-specific health data repositories between which information cannot be easily exchanged; as such, personal health data remains largely inaccessible to the majority of Canadians (Canada Health Infoway 2022). This is a by-product of the current custodial legislative health information framework used by Canadian jurisdictions that confers accountability and responsibility for health data oversight on health services, without any requirement for the health data they control to be interoperable with other services (Expert Advisory Group 2021). Custodial data legislation functions effectively to fragment the personal health information of Canadians. The problem is further compounded by constitutionally mandated separation of health oversight by province and territory, which has been interpreted as justifying non-aligned jurisdictional approaches to health data governance and public policy.

A 2022 study by the RAND Europe research group suggested that substantial care inefficiencies arise in Canada from regulatory barriers and legal discrepancies in the oversight of technologies and the health workforce across jurisdictions and recommended that these need to be addressed to increase health data interoperability (Hafner et al. 2022). The second report of the Expert Advisory Group (2021) of the pan-Canadian Health Data Strategy stated that the "lack of a common, coherent approach for health data across Canada is contributing to lagging health outcomes for people in Canada, escalating sector costs, expanding health inequities and slowing innovation in Canada's health sector" (p. 4). Furthermore, the "health sector's data governance and management status quo – where data flow is impeded by lack of collaboration and enabling policies – is burdened by subtle but pervasive disincentives to sharing" (Expert Advisory Group 2021: 4). The *Shared Pan-Canadian Interoperability Roadmap,* a national report from Canada Health Infoway (2023), acknowledged that health data interoperability will be difficult to achieve in Canada without legislative and regulatory change and governance co-operation. Together, these observations suggest that Canada suffers from major shortfalls in health data governance, public policy and regulation that impede the implementation of technical data interoperability.

If we accept that health data interoperability is a core – or *essential* – attribute of a quality digital health design, and that the purpose of digital health is to *support bett*er *health*, then by neglecting to ensure comprehensive health data interoperability, Canada is failing to provide *essential digital health*, suggesting that all residents of the country are *underserved*.

Person-Centred Health Data Design

Health data interoperability must be fit for purpose and designed to maximize the quality of Canadian health programs and services and minimize potential forms of harm that can arise from the use, non-use or misuse of health data. This is best achieved by designing health data around the fundamental unit of care, *the patient*, rather than around health services – the current Canadian practice (Expert Advisory Group 2022). The Expert Advisory Group of the Pan-Canadian Health Data Strategy refers to this approach as person-centred health data design (Expert Advisory Group 2021), which entails the health data of each Canadian, following them throughout the course of their care, including across health services and jurisdictions. Achieving this requires the harmonization of data content and technical exchange standards, legislation, regulation and workflow and would only be accomplished through a *co-operative* governance approach. Such co-operation would demand a *willingness to build trust* between health sector stakeholders and jurisdictions – a reimagination of the very *way of being* of the Canadian health sector, where a service-centric culture of care perpetuated by traditional power brokers, including governments, health authorities and physicians, is a transcendent obstacle to achieving systemic health data interoperability. Standing in the way of this necessary cultural shift is a paucity of health data literacy – a health sector workforce, leadership and public who often do not understand the negative impact of health data fragmentation on the health and well-being of individuals, populations and our nation as a whole. Indeed, it is difficult to effect systematic change in a health sector that fails to understand that there is a problem. A clear articulation of all determinants of health data interoperability and the potential harms arising from the ongoing data fragmentation could enable an evidential approach to achieving interoperability success.

Determinants of interoperability

We propose a framework for health data interoperability that includes two broad categories of determinants: technical factor interoperability and human factor interoperability. Technical factor interoperability involves the data content standards and technical considerations required to enable secure access and integration of electronic health data and their transmission across disparate health technologies. The four domains of technical factor interoperability are data content standards, data exchange standards, Internet connectivity and common user authentication. Human factor interoperability involves the system-level relationships that impact the capacity of health sector stakeholders to adopt harmonized health data standards and technology. The seven domains of human factor interoperability are governance, legislation, policy, regulation, literacy, communication and culture. Table 1 outlines the properties of each factor to be considered in designing optimized health data interoperability.

Use of the interoperability framework

This framework provides an outline of determinants to consider when designing comprehensive system-level health data interoperability. The 11 determinants of interoperability in the framework form a matrix that reflects their dynamic and interdependent relationship in a complex health system (Figure 1). To achieve system-level health data interoperability, all 11 determinants should be addressed concurrently. Focusing on select determinants, such as data content or exchange standards, without crafting a supportive legislative and regulatory suite will almost certainly fail to advance health data interoperability. Unfortunately, Canada has a long tradition of doing just that – proposing data standards without mandating them in legislation, resulting in poor uptake and failure of interoperability.

Figure 1. Determinants of health data interoperability

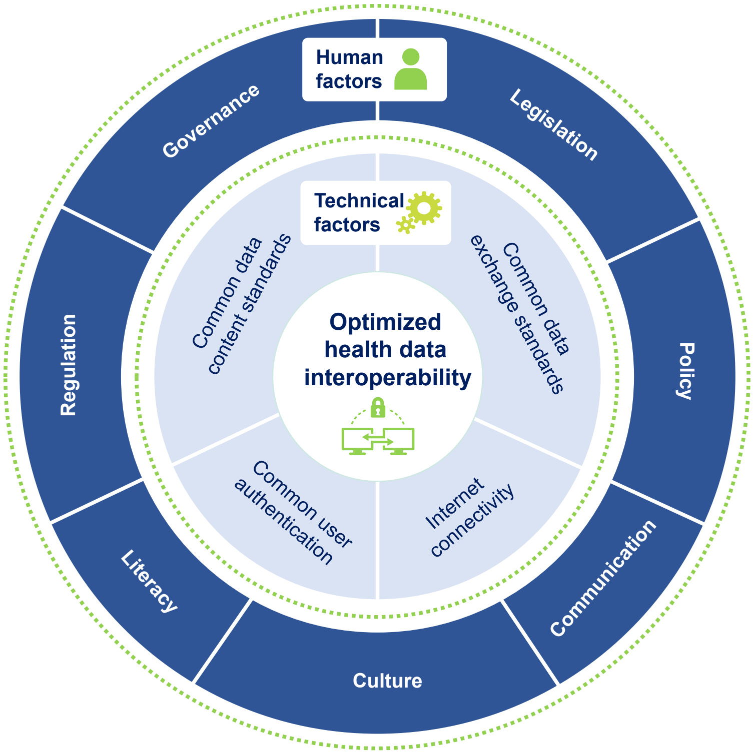


Table 1. Framework of the determinants of health data interoperability

Technical factor interoperability	Consideration
Data content standards	Are there **common health data content standards** that have been set, enforced and adopted across all services and jurisdictions that support health data interoperability?
Data exchange standards	Are there **common health data exchange standards** that have been set, enforced and adopted across all services and jurisdictions that support health data interoperability?
Internet connectivity	Is there **universal Internet connectivity** across all jurisdictions to ensure the capacity for universal health data exchange?
Common user authentication	Are there **common digital identity standards** for providers and patients?
Human factor interoperability	**Consideration**
Governance	Is there a harmonized approach to health data interoperability oversight across services, custodians and jurisdictions that establishes **clear accountability**, promotes quality programs and services and mitigates data-related harm?
Legislation	Does health data legislation uphold a **harmonized person-centric** approach to health data interoperability that promotes quality programs and services and mitigates data-related harm?
Regulation	Is there a **regulatory process** for health information technology that **mandates** health data interoperability, promotes quality health programs and services and mitigates data-related harm?
Policy	Do all stakeholders in the health sector craft and adopt policies that uphold a **harmonized person-centric** approach to health data interoperability that promotes quality programs and services and mitigates data-related harm?
Literacy	Do the health workforce, the health sector leadership and the public possess a **clear understanding** of the current state and value of health data interoperability and its capacity to promote quality programs and services and mitigate data-related harm?
Communication	Is there **transparent, broad and clear communication** between all health sector stakeholders – including the public – about accountability for, and the nature of, health data interoperability?
Culture	Is there a **culture of trust and accountability** to interoperability as a determinant of quality health programs and services that supersedes any jurisdictional, regional, custodial, private sector or organizational agendas?

While some determinants of interoperability – such as Internet connectivity – are easily defined, others – such as culture – may prove more elusive, albeit no less important. The organizational culture of a complex dynamic system like healthcare can have a deep impact on how data are controlled, shared and used, thus influencing the approach to other determinants of interoperability, such as legislation and policy. We suggest that there is a cultural bias in Canadian health service that favours the design of health information around services and jurisdictions rather than around the beneficiary of care or member of the public – a bias that is reified in health sector behaviour and formalized in custodial legislation to the detriment of health data interoperability. As such, human factor interoperability can supersede technical factor interoperability as the dominant category of determinants, recognizing that the relative impact of individual determinants will differ, with variation in health system design and function.

To properly use this framework, the collective design of the determinants of health data interoperability must be accountable to the following two foundational deliverables:

- the promotion of quality health programs and services and
- the mitigation of potential forms of health data–related harm.

Health data–related harm implies damage suffered by individuals, populations or the health system arising from the use, non-use or misuse of health data. Examples include physical damage to an individual due to medical errors arising from missing health information or health sector cost overruns due to inefficient health data exchange. Forms of health data–related harm are listed in Figure 2, which outlines the shared accountability of maximizing quality and minimizing harm in health data interoperability design and implementation.

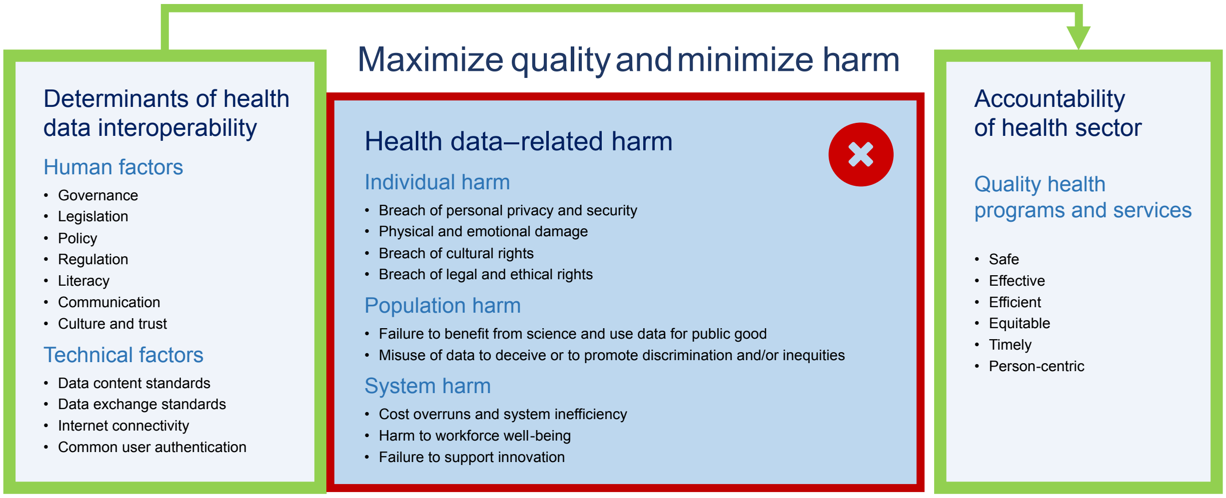
Discussion

Comprehensive health data interoperability will benefit individual Canadians, the health workforce and the overall function of the health sector. Yet a comprehensive and harmonized person-centred approach that considers the concurrent redesign of all human and technical determinants of health data interoperability has been absent in Canada. Such an approach obligates a collective commitment across all health data custodians and jurisdictions to build a common purpose that openly addresses human factors – such as governance, legislation, regulation and culture – that are impeding the capacity for Canada to advance health data interoperability.

The *Canada Health Act* (1985), which is the federal legislation that defines the role of the federal government to provide financial support for provincial and territorial health services, states the following:

> improvements in health will require the cooperative partnership of governments, health professionals, voluntary organizations and individual Canadians; [and]

Figure 2. Relationship between determinants of health data interoperability, health data–related harm and quality health programs and services



> that continued access to quality health care without financial or other barriers will be critical to maintaining and improving the health and well-being of Canadians[.]

It follows that if the fragmentation of health data is understood to be a barrier to "maintaining and improving the health and well-being of Canadians," then the "cooperative partnership of governments, health professionals, voluntary organizations and individual Canadians" in mitigating data fragmentation is a requirement of the *Canada Health Act* (1985).

Human factor interoperability addresses the factors that define our relationship with each other around the design and management of health data: how we choose to govern, legislate and regulate health data; how we educate ourselves in the use of health data; and how we build trust and communicate the value of data with each other. Human factor interoperability suggests that we need to co-operate – across professions, services and jurisdictions – to achieve person-centred health data interoperability and that addressing interoperability as a technical and ontological problem is not enough.

Conclusion

The establishment of comprehensive health data interoperability in Canada is now recognized as an essential element of a high-functioning, accountable and efficient healthcare system (Expert Advisory Group 2022); or stated simply, health data interoperability is a core element of *essential digital health*. Canada is lagging – compared to the US and the European Union – in establishing a comprehensive person-centred approach to health data interoperability, which compromises quality of care, meaning that all Canadians are underserved relative to international comparators. Canada Health Infoway's (2023) *Shared Pan-Canadian Interoperability Roadmap* provides a template to address technical factor interoperability, but participation in this effort is currently optional for provinces and territories. Furthermore, Canada currently lacks a comprehensive approach for addressing human factor interoperability, and without addressing system-level relationships, the capacity of health sector stakeholders to adopt harmonized health data standards and technology will be compromised. The proposed framework of determinants of health data interoperability provides a clear articulation of the factors that Canada needs to address co-operatively to achieve comprehensive person-centred health data interoperability.

References

Canada Health Act, R.S.C., 1985, c. C-6. Government of Canada. Retrieved January 17, 2024. <https://laws-lois.justice.gc.ca/PDF/C-6.pdf>.

Canada Health Infoway. 2022, November 15. *Connecting the Health System: Connected Care. A Healthier Canada.* Retrieved January 24, 2024. <https://www.infoway-inforoute.ca/en/component/edocman/6413-connecting-the-health-system-connected-care-a-healthier-canada/view-document?Itemid=103>.

Canada Health Infoway. 2023, May. *Shared Pan-Canadian Interoperability Roadmap*. Retrieved January 24, 2024. <https://www.infoway-inforoute.ca/en/component/edocman/6444-connecting-you-to-modern-health-care-shared-pan-canadian-interoperability-roadmap/view-document?Itemid=103>.

Cresswell, K.M., H. Mozaffar, L. Lee, R. Williams and A. Sheikh. 2017. Safety Risks Associated with the Lack of Integration and Interfacing of Hospital Health Information Technologies: A Qualitative Study of Hospital Electronic Prescribing Systems in England. *BMJ Quality and Safety* 26(7): 530–41. doi:10.1136/bmjqs-2015-004925.

European Commission. n.d. European Health Data Space. Retrieved January 24, 2024. <https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en>.

European Union. 2017. *New European Interoperability Framework*. Retrieved January 24, 2024. <https://ec.europa.eu/isa2/sites/default/files/eif_brochure_final.pdf>.

Expert Advisory Group. 2021, November. *Pan-Canadian Health Data Strategy: Building Canada's Health Data Foundation: Expert Advisory Group – Report 2*. Retrieved January 24, 2024. <https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-02-building-canada-health-data-foundation/expert-advisory-group-report-02-building-canada-health-data-foundation.pdf>.

Expert Advisory Group. 2022, May. *Pan-Canadian Health Data Strategy: Toward a World-Class Health Data System: Expert Advisory Group – Final Report*. Retrieved January 24, 2024. <https://www.canada.ca/content/dam/phac-aspc/documents/corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries/expert-advisory-group-report-03-toward-world-class-health-data-system/expert-advisory-group-report-03-toward-world-class-health-data-system.pdf>.

Hafner, M., E. Yerushalmi, E. Dufresne and E. Gkousis. 2022. The Potential Socio-Economic Impact of Telemedicine in Canada. *Rand Health Quarterly* 9(3): 6.

Handley, H.A.H. 2014. A Network Model for Human Interoperability. *Human Factors* 56(2): 349–60. doi:10.1177/0018720813493640.

Healthcare Information and Management Systems Society (HIMSS). n.d. Interoperability in Healthcare. Retrieved January 24, 2024. <https://www.himss.org/resources/interoperability-healthcare#Part1>.

Ho, K., O. Adams, A. Sayani and G. Cheema. 2024. Defining "Essential Digital Health for the Underserved". *Healthcare Papers* 21 (4): 5–14. doi:10.12927/hcpap.2024.27276.

International Business Machines (IBM). n.d. What is Interoperability in Healthcare? Retrieved January 24, 2024. <https://www.ibm.com/topics/interoperability-in-healthcare>.

Li, E., J. Clarke, H. Ashrafian, A. Darzi and A.L. Neves. 2022. The Impact of Electronic Health Record Interoperability on Safety and Quality of Care in High-Income Countries: Systematic Review. *Journal of Medical Internet Research* 24(9): e38144. doi:10.2196/38144.

Lipinski, M. and M. Knee. 2019. *21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program Proposed Rule*. The Office of the National Coordinator for Health Information Technology. Retrieved January 24, 2024. <https://www.healthit.gov/sites/default/files/facas/2019-03-22_ONC_Cures_Act_NPRM_IB_%20HITAC_IB_Task_Force_508.pdf>.

Medical Council of Canada. 2022, March. *Clinical Informatics*. Retrieved January 24, 2024. <https://mcc.ca/wp-json/mcc/medical-expert-pdf/?id=8886>.

Public Health Agency of Canada. 2022, May 3. The Pan-Canadian Health Data Strategy: Expert Advisory Group Reports and Summaries. Government of Canada. Retrieved January 24, 2024. <https://www.canada.ca/en/public-health/ corporate/mandate/about-agency/external-advisory-bodies/list/pan-canadian-health-data-strategy-reports-summaries.html>.